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ReachMD
www.reachmd.com
info@reachmd.com
(866) 423-7849

Case Discussion: Missed Diagnosis, Part of the Focused Sight Initiative: Quality Improvement Interventions in Retinal Disease

Dr. Kim:
I'm Dr. Kim. This is the Focused Sight Initiative: Quality Improvement Interventions in Retinal Diseases. I'm here with my practice team to discuss a challenging case and how we were able to help the patient overcome some barriers to treatment.

So I'm actually going to discuss one of my patients. He's up in our Fullerton office. He has a little bit of a background. So he used to see a different retina specialist many, many years ago. Then he ended up seeing one of the partners in our practice for about 3 years. And then most recently he had seen another retina specialist, prior to seeing me, who performed one injection in his eye, but then he felt his eye was, quote, never the same again. And so I was then seeing him for the first time, this is about a year and a half ago, with acute loss of vision in his left eye, and that appeared consistent with a vitreous hemorrhage in the setting of proliferative diabetic retinopathy. So when I see a patient like this in my practice, I'm already getting a couple of red flags.

So, Dr. Nguyen, you work closely with all the different retina doctors, and in fact, you're the first line of defense. You see the new patients before the doctor comes in, and you always do a really great job in terms of giving me the background, not only diagnosis and treatment strategies, but, “Hey, this patient had trouble understanding this,” or “I think this will be a difficult one,” or “His understanding is not quite there.”

So for me, there were already several red flags that might indicate compliance may be an issue with this patient. First of all, the doctor hopping, right? And I think a lot of that was not necessarily that he was not getting good care, but it just really stemmed from an inadequate understanding of his disease and just not being fully on board with the doctor's treatment decisions, not really weighing in and understanding why things were being done.

And then second of all, having had these periods of being lost to follow-up. So prior to being seen here, there were gaps of over a year in between visits, and he really only re-presented when he noticed that significant loss of vision, more often than not due to vitreous hemorrhage. Then finally, the third red flag for me was just the way that he thought that certain treatments were what made his condition worse in the past.

So, Dr. Nguyen, I just wanted to start with you. What are some ways that you might approach this first visit with this patient given his particular unique situation and perspectives?

Dr. Nguyen:
I think that's a great question. So typically when I see a patient like that, that's been to multiple doctors and that's been kind of like doctor hopping, I think a lot of it is just kind of lack of understanding on the patient's perspective.

So usually when a patient comes in, I always like to ask them to tell me instead of telling them what's going on. So I want to hear their perspective first. So that way, they feel seen and understood. So I always try to put myself in the patient's shoes, and once they give me their perspective, then I’ll give my perspective as well, too, on it and I'll try to kind of mesh the two together. So usually I'll tell them I know that this is what they've done at other practices, and I apologize about lack of communication or maybe lack of understanding, but this is what's going on with your eyes and I want you to see the big picture of what's going on.

So I usually like to take it back about two steps, just to let them know we understand what's going on. We want to do everything we can to help you. This is how we're going to help you. So I usually try to go step-by-step with the patient.

Dr. Kim:
I think that's great. I think that's also great that you start open-minded. I think a lot of times doctors come in hot, you know, we have our ideas and our plans, and we're just kind of telling the patient as opposed to having that two-way conversation. And that helps us unravel a lot of these underlying preconceptions and misunderstandings, perhaps, that they come in with before we even have said a word.

Miguel, so you've been with Orange County Retina for several years, you're an aspiring doctor. You've worked with us in the capacity as not only a scribe and a back-office tech, but now heavily involved in clinical trials. Sometimes, especially when you're numbing a patient or there is sort of that downtime or you're checking them in, I'll see patients having these side conversations with you.

Have you ever found that patients sometimes confide something to you or relay some comments that they may not necessarily feel comfortable sharing with the doctor?

Mr. Llerenas:
Yeah, I think it's pretty common. I feel like when you're talking to the doctor, sometimes they're not as comfortable. It's the first time meeting; it's a lot of pressure. And then, obviously there's also a language barrier. That also contributes to the fact that they don't feel comfortable asking questions, you know? So then spending a lot of time with the patients, prepping them. I start asking more personal questions and they get comfortable and then that's when they start slipping in little key details like, "Hey, actually I also have these symptoms." And I'm like, "Oh, okay, that's good to know." I'm going to go tell the doctor this because that could be pretty important, you know? So there's definitely a lot of instances where they open up a little bit more when the doctor's not in the room.

Dr. Kim:
Definitely. Yeah, those are great points, and you obviously don't tell them that you're going to tattletale to the doctor, but these—only things that would be helpful for their overall care for us to know.

But, Dr. Nguyen, when you hear a patient maybe sharing something that isn't necessarily true, like, for example, the injection definitely made my vision worse, in those particular situations, but also perhaps if they are very scared to the point of being noncompliant, how do you usually balance that empathy component with urgency and also just balancing perhaps the patient's wishes with your wishes and recommendations, which for the most part are aligned but sometimes can be at odds, especially for these tough diabetic patients?

Dr. Nguyen:
So I think that's a great point. We deal with that on a daily basis here. So usually, again, it goes back to listening to the patient before I give my defense on things. And so usually when I listen to the patients, I'll be like, okay let's talk it out. Let's figure it out together.

So I usually listen to them first and I'll say, "Look, what's happened in the past, unfortunately, I'm sorry that happened to you, but I can't change that. But we're going to do everything we can to fix what we can now." And my favorite line is to tell patients that our job is to preserve the vision that you have right now for the rest of your life, and this is how we're going to do that. And usually, I'll try to let them see the big picture, that even though maybe they're coming in now, we want to get them better now. That way it doesn't get worse in the future, because it can get worse in the future if they get lost to follow-up and things like that.

So it's a good balance of being understanding with them but also letting them know that this is very serious. Eyesight is so important and we're going to do everything we can right now to fix what we can right now.

Dr. Kim:
Yeah, so your strategy is I am empathizing with you in the present, but our goals are really working towards the future, and hopefully by bridging the current situation with our obviously mutually aligned goals of preserving vision for the future, we can come to a common understanding to make a treatment plan.

So with my particular patient, I'll call him Mr. V. I think that he has been particularly challenging for me because he has very specific desires. So he got a vitreous hemorrhage. Thankfully the most he's gotten lost to follow-up with me was like a 4-month period, but for the most part he's been very, very compliant with his injections and I always feel very grateful for that. But his vitreous hemorrhage was very dense and it was not fully clearing. It was clearing to where he got some vision back, but not fully. And he actually developed ghost cell glaucoma, because obviously the red blood cells had dehemoglobinized. His pressure was like 35. You know, I'm having to put him on all these multiple eye pressure-lowering drops, and it was one of those, like, "Hey, Mr. V, I really think we should probably think about surgery." You always want to couch it in a way that doesn't sound scary and like an emergency, but sort of a firm recommendation. With him, he was just flat out like, "I don't want surgery." He's very busy, he's working all the time, and he's like, "No, no, my vision's clearing. I don't think I need surgery. I'm doing fine with the drops." He's been fairly compliant with the drops and the pressures have been great. So we've agreed to disagree and just meet in the middle. I think if it were ever a situation where he was going to lose vision imminently or like pressure's not controlled, I would more strongly word my recommendation, but I would rather keep the status quo and maintain a

relationship and trust than try to push something on him that he doesn't feel comfortable with yet.

So I still view it as rapport building at this time. But every time I see him, I get to learn a little bit more about his life, his family situation, his work situation. And I think that helps him to lower his guard and then to trust my recommendations. And again, I'm just really grateful that he comes back and he's been overall very faithful with his injections.

He's trusted me with fluorescein angiograms and lasers, which he's refused other doctors in the past. So it's like having a kid that you want to encourage but not make them feel so pressured that they don't even want to keep trying.

Dr. Nguyen, what are some perhaps nonobvious reasons that you've encountered for why a patient may want to refuse treatment? Like the obvious ones perhaps are, oh, I have a busy work schedule, or I have travel coming up. I just don't have time to deal with that right now. But are there some things—and I think Miguel brought up a great one before, which was language being a barrier and just not feeling comfortable.

But have you encountered things? And then I'll circle to you as well, Miguel, after that.

Dr. Nguyen:
I think going back to the language barrier, I think a lot of it is also—I haven't seen it too often—but like a cultural barrier. I know sometimes it's hard for them to understand that. And when you say, oh, the injections inside the eyes, it's pretty scary too. I think listening to them and trying to explain it to them on their level. That way, they understand it.

And besides being cultural, a lot of it is, I think, psychological as well, too. Some patients, if they've had a lot of personal things going on, in their head it's kind of two spectrums where they think—if they think they see pretty well, sometimes they're just like, oh, well, I'm not going listen to this doctor. I see pretty well; nothing is wrong with my eyes. Or the other perspective is that sometimes I'll meet some patients that are just going through so much personally, just with mental health issues and things like that. They kind of don't see the purpose. They don't have that drive to go have their vision get better.

So those are just a few examples of nonobvious reasons why I've seen patients not be more compliant with their follow-ups.

Dr. Kim:
You mean life isn't just this? I think we forget the rest of the body, the rest of their life happening, the fact that they're caregivers, that they have other lives, comorbidities—psychological, mental, physical—going on. That it's easy for us to get so microscopically focused here that we often forget these other factors.

Miguel, did you have any ideas or any reasons why there might be some—those nonobvious reasons why patients may refuse treatment?

Mr. Llerenas:
I think you guys summed it up, but I could say changes in insurance. Sometimes patients are paying out of pocket and it's like, okay, I can't really afford injections, so I'll give you guys a call back whenever I have the funds for them. Or no transportation. And sometimes they just can't take time off of work. I've seen it a lot when I volunteer at free clinics, where patients are uninsured and it's like, okay, I took 30 minutes out of my lunch to come to this doctor appointment. I'm not going to get a lunch, but at least I'm getting a doctor visit, you know?

So it's really hard to give treatment to these patients although they want it, because their overall life, they can't take the time off or there's other social factors that contribute. So it's good to know the person as a whole and get to know them and it's more than just the eyes.

Dr. Kim:
And I guess, to turn it around, because we know these things exist, what are some ways that we can mitigate some of these barriers for patients and make it easier for them to comply not only with doctor visits but also with their treatments? I liked the thing that you mentioned, Dr. Nguyen, about the cultural barriers. I think one very tried-and-true strategy is to have a patient bring a family member. Sometimes it could be an older person who's very stubborn, who's very set in their ways, but a younger son or daughter will accompany them and be like, I got you, I got you, right? And they'll be that mediator to explain the rationale for things. But also, they'll let us know normally they don't do X, Y, Z. Or for older men, this is a very embarrassing situation. Or he used to be very independent, so it's very hard for him to accept these things coming up. So I think it's very helpful to have that middleman to mediate for those situations.

Are there anything that come to mind for either of you in terms of ways that we can help minimize these barriers for our patients?

Dr. Nguyen:
We obviously have a high Spanish-speaking population here, so sometimes we have these educational pamphlets. The majority them

are English, but the national retinal association has a Spanish translation, so we'll do that as well, too. And usually, if we're fortunate to have Spanish translators from our workers here, or even not Spanish—sometimes other workers here speak other languages—that does help a little bit as well, too.

And sometimes they'll, you know, a son will bring in the mom or the dad or vice versa. And a lot of times I've noticed that people will speak to the person that speaks English, which is not the patient. And so a lot of times I'll talk English to the patient, and I'll usually let their daughter or son know, hey, I'm going to talk to your parent. But you can listen to me and I'll try to do it at a pace where I take a break and that way they can translate in between. And with that, I noticed that they appreciate that even if they don't really understand me. Because it's just like a sign of acknowledgement to the patient.

Dr. Kim:
Yeah. And then just before we wrap up here, Miguel, I was going to speak for you. One, I think, tangible barrier is getting involved in clinical trials, right? Because a lot of these patients can get involved for free, but all their treatments are provided for during the entire duration of the study; they provide transportation. So for patients for whom the cost is a barrier, transportation is a barrier, insurance is a barrier, those are another great strategy that we use here at Orange County Retina as well.

Before we wrap up, just a final take-home message. Patient hesitation is common but often addressable, right, with the right communication tools, which we've discussed some strategies for today. I think practical implementations, texting reminders about appointments, those things are important, but also the subtle things that you brought up, Dr. Nguyen, interfacing with the patient directly and helping them feel empowered, feel respected, I think, is also very important. So we really seek to emphasize this training for every team member so that we can maintain that consistent, empathetic messaging here for every single one of our patients.

That's all the time we have for today. I really want to thank my amazing staff, Dr. Nguyen, Miguel Llerenas, for joining us and thank you to our audience for listening in. So hope you all learned something and take care.