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Case Discussion: Addressing Access Barriers and Social Determinants of Health, Part of the Focused Sight Initiative: Quality Improvement Interventions in Retinal Disease

Dr. Chin Yee:
Welcome, everyone. Thank you. We're here today to do a case review: Focused Sight Initiative: Addressing Access Barriers and Social Determinants of Health in our patients in the retina field. I am David Chin Yee coming to you from Atlanta, Georgia, with Georgia Retina, and I have joining me 2 amazing technicians from my office in Stockbridge, Georgia.

Here we have Ms. Amber Maxis and Nicholas Post, and we're going to go through a case scenario and have some discussions on some of the patients that we see on a day-to-day basis. Looking at some of the barriers or issues that we face on a day-to-day basis and how we kind of overcome and divulge that to the retina community and our patients as a whole, to let them know how we can hear them out, listen to them, and address any concerns that they may have.

So to kick things off, we have a classic case scenario here. Maybe one of the patients we saw earlier today in clinic here is a middle-aged Black man with recent onset of proliferative diabetic retinopathy. Unfortunately, he was referred late from an optometrist. Can't say it's the optometrist's fault; we will go through that.

But patient presents with significant vision loss at this point in both eyes and honestly said, you know, Doc, I've delayed seeking care because of my own personal fear. You know, I have friends that they've told me getting a needle in the eye is what you need to get done to get this treatment, and to be honest, that didn't sound like a good idea to me. In addition to that, the patient at this point was not seeing well and so was not able to drive. And so there's transportation challenges, right? Being able to be seen and getting this addressed and taken care of was not easy.

Lastly, the patient also noted, Hey, I don't have vision insurance. The patient only had medical insurance and was under the perception because he was having difficulty seeing that he didn't have vision insurance, so how would he be able to afford this? So he was unclear, lacking insurance, clarity and coverage.

So we're going to touch on some of these barriers just being set up from this patient scenario and see what you guys think. How do we address it? Some of the first barriers I'd like to assess is, how do we see systemic and personal barriers compound over time and lead to our patients having difficulty getting care?

Who wants to take this one?

Mr. Post:
I can speak on this one. So oftentimes we do see patients that experience financial difficulties. Oftentimes they don't have what you would consider the most optimal insurance to cover the treatment that we provide here in clinic. So with that, they oftentimes find difficulty because the treatment regimen that we have for diabetic retinopathy, it is on a fixed or it's on a restricted interval, let's say. So begins every 4 weeks and hopefully we can extend that interval from there, but coming every 4 weeks can be strenuous on patients that are already tight, with their budget, because then they have to take off work every 4 weeks.

And if they delay that treatment, then their vision gets worse. And then they have difficulty even just getting back to work, right? Because obviously you need your sight to do your job effectively. So we see that just kind of snowball into, "I don't have the money so I can't make it into the visit." So they don't make it into the visit, but then they can't work.

And then also they find it difficult to get transportation not only to the clinic but also to work.

Dr. Chin Yee:
Yeah, and we know these patients, unfortunately, they're not only coming to see us, they have other doctors that they're trying to get into, right? Controlling their diabetes in and of itself, whether it be diet, nutrition, and that costs money in and of itself, right? To see the other doctors to pay for medication. And so we can see how one, the financial burden can kind of snowball, as you said, and kind of lead to more difficulty, you know? And then there's these systemic issues, right? The patients even having trust with the healthcare system, right?

They've had previous examples where they went in, they went in to see an eye doctor, which was maybe someone like an optometrist that would only take vision insurance and they're saying, Hey, I don't have vision insurance, how can I be seen? And so again, delaying the care, like in our patient, made the difficulty where the vision was even a lot worse and kind of continued to compound.

And as you said, we know that these things unfortunately can get additive and lead to more problems and we need to acknowledge it and address it to be able to see how we can avoid those things. You know, moving on, I would say some other barriers that I think we need to always address is, we're always worried that patients don't, follow up, right?

Especially in our diabetics, we know that part of the problem is they're not compliant or as well controlled with their regimen for their sugars, and therefore we worry of them not coming and following up.

Amber, are there some patient patterns that you like to clue into that make a special note that say, Hey, we're going to be concerned with them following up?

Ms. Maxis:
Yeah. So to touch on what you both said earlier, there are some patients that I've noticed that we typically are more likely to lose to a follow-up. Patients of course, with worried about those financial costs, you know, maybe they have insurance, but they're underinsured. Maybe have no coverage at all or just uninsured, those kind of patients we might not see back.

Also, patients, of course, with transportation issues. Maybe they don't have a family member or a friend who's able to bring them in and they might not also be able to pay for their own transportation to each appointment. So we might not see those kind of patients coming back. Other patients we also worry about losing to follow-ups can also be patients who are just not only fearful of getting treatment, but they could also just have fear about how long they'll be on treatment, maybe they've had poor or bad previous experiences with other providers and are scared to come back.

Maybe they've heard some horror stories from family and friends. We also worry about patients, especially our diabetic patients, maybe they're on dialysis and they're trying to schedule their appointments with us around that. Maybe they're not feeling too good afterwards and aren't able to come in.

So those are typically the kind of patients, I've noticed we lose to follow-ups.

Dr. Chin Yee:
Yeah, and you can see that that's a long list. You hit on at least 5 to 6 different issues that we see on a daily basis. Not one is more important or less important than the other. And we even have patients that have all those combined together and we don't acknowledge and face that fact.

There's no question these patients will have suboptimal care and outcome like we want to achieve. And you kind of touched on one of them, and I want to hit home on that a little bit more. You know, how do you think we approach these patients who maybe distrust the healthcare system in general in the US?

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Ms. Maxis:
Yeah. So with these kind of patients, I typically always approach patients more so, and try to connect with them. Tell them, Hey, I have family members who are going through the same thing that you're going through, who have also gone down this path and had to get treatment, had to get injections, and this is how it was for them.

I'm just trying to be encouraging, and just really just educate our patients and let them know what the diagnosis is, why are they here, what it looks like, and how we go about treatment just to help with that fear level, especially with patients, you know, it's their first time getting an injection.

Most of the time when patients think about getting injections, they're thinking more so like an injection in the arm. You know, not a lot of people think that we do treatments and do injections in the eye, so they might have fear about that, just encouraging them saying, Hey, the treatment shouldn't be painful at all, we do a lot of numbing, you might feel a little bit of pressure, but it shouldn't be painful at all. Just reassuring them to try to lower some of those stress and fear levels.

Dr. Chin Yee: I think it's important. You kind of mentioned that for us to be on the same page, right?

It's not only coming from the doctor; it's coming from you guys as well. The technicians and staff, the ones that are seeing them when they're first coming to the door, meet them and, you know, addressing what are their first concerns. And if we have that consistent message right, where we're saying you do need treatment, you have this problem, that consistent communication and message helps to maybe allay any fears and build that trust. A lot of times, trust takes time and experience, and we tell them, Hey, trust, give us a chance, right?

Test us out, see how things are going. Let me prove to you that as a team we can get your vision better to get you back to work, and that can maybe help to allay some of those other problems even though they may have had distrust in other areas of their life, in other doctors, we want to maybe nip that in the bud and address that so we can move forward.

You know, one other barrier, Nick, I'll throw it to you. What role do you see images, analogies, or even community liaison staff play in the educating process to make sure the patients understand what's going on with their disease?

Mr. Post:
I actually think those things are very important. Extremely important because I think the general population, when it comes to vision loss, they associate that with glasses, you know, I can't see so much, so now I need to go get glasses. And they're not too familiar with what a retina is.

Some haven't even heard of the term retina in general. So when they come in, showing them, like, we have a model in every exam room that you often refer to so that you can show them exactly what it is that's occurring in the eye. And then you also use many analogies of your leaky hose that you often refer to.

We'll just help patients and kind of bridge that gap so that they understand what's going on in the eye and also how the treatment is helping. Because a lot of times they just hear an injection and they don't exactly know why am I getting the injection? But when you explain what it's treating and how it's preventing further vision loss, I think that's, yeah, integral and the coming back and getting the continued treatment.

Dr. Chin Yee:
Amber, any thoughts on that as well? Like images, how that plays a role?

Ms. Maxis:
Yeah. To touch on with what Nick said earlier, I think a visual representation is also really helpful for the patients. You always show a patient, you know, this is what your retina should look like and this is what yours looks like.

Just trying to show them the difference and help them to understand that maybe there's some swelling going on, some leakage going on. Just giving them that visual representation so that they can see for themselves that something is going on and why it needs treatment.

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Mr. Post:
Right. And I think also when they see those images and they see the comparison from before and after, and they see the progress that they've made, it only makes them more inclined to come back because they've seen, okay, this is working. I'm not just getting this for no reason.

Dr. Chin Yee:
And you know what? Finally when their vision actually returns or they start seeing better, that's the golden ticket, right? That's where they develop that trust when they see the results. I want you guys to share on any success stories that you have seen that has helped to reduce some of these access to disparities that we see on a day-to-day basis.

Anyone want to throw out any specific success stories before we move on on the case?

Ms. Maxis:
Sure. I've seen a lot of our patients, especially who have those issues with finances, some of those financial burdens, you know, we have patient assistance program for the patients who have no coverage, who are underinsured or uninsured, just to help them get free medications.

So they don't have to deal with those costs when they come in for their appointments. You know, we also do the copay assistant programs for our patients with the commercial insurance to help lower their costs as well when they come in. And that's helped a lot. And that, to me, has—I've seen encourage and motivate patients to come in even more for their appointments when they're not having to worry so much about the finances.

Dr. Chin Yee:
Well said. I mean, and they see that we're jumping over barriers, right? Going the extra mile to be able to help them to get the treatment that they need. I think, again, that helps to build, that trust that we want between us as a healthcare team and the patient.

Nick, how about yourself?

Mr. Post:
So there're often a lot of patients that come in, they're very concerned about the injection. So just that fear factor, explaining to them exactly what to expect, not only long term, and like coming back every four weeks, but also in the immediate following the injection. You know, you may have a few floaters, pressure may increase slightly, you may get a subconjunctival hemorrhage, but just nipping those in the bud before they become an issue. So when it happens, the patient sees it and they're not too alarmed. And we also ensure we gain their trust by letting them know that we do have a call center that they can reach out to anytime that they have a concern, small or large, that we will call back and address the concern. That way, you know, they feel comfortable with everything that's going on.

Dr. Chin Yee:
Well said guys. You know, last question I'll point to you guys and I'll wrap the case up is how do we balance that empathy feeling that the patient's being heard, but also driving that urgency message that hey, you need to come in, you need to get treatment.

How do you go about doing that to kind of help me and my partners and everyone in the office to get that understanding to address barriers? Any thoughts on that?

Mr. Post:
So oftentimes, I know you emphasize that ultimately it's the decision of the patient, but letting them know that the sooner that they get the treatment, the better, the outcome would be, right?

We want to address the issue before there's further vision loss, before there's further irreparable damage, so just letting them know that we are acting in their best interest, that we wouldn't have them in here. We wouldn't propose a treatment if you truly didn't feel like there was any positive benefit to that.

But again, ultimately it's the patient's decision, but you can let them know what you think would be best.

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Dr. Chin Yee:
You know, I put fun and joke aside. I always tell you, and it's true. It's a team effort. Every time we do an injection the staff help to numb the patient up. And I usually put the blame on if the patient feels the needle, we say, Hey, it's the technician's fault. But if you don't feel the pain or the needle, I get the credit.

But again, it's these things to kind of reassure we're all on the team to make your fear and the concerns addressed. So we're going to go back to our case scenario. And some of the fears, or some of the objectives or barriers that were noticed was, Hey, we need to address the patient's fear with the needle in the eye, right?

They're worried about the fact that it's going to be painful, it's going to hurt. And what we did is you guys shared your own personal experience with your own family members. With previous patients addressing and reassuring them, Hey, yes, the thought of a needle in the eye is horrible, but we promise we're going to numb the eye so it doesn't hurt and address any of the concerns as you mentioned, Nick, ahead of time, you may not floaters, it may feel scratchy, but hey, by tomorrow it's going to be fine. And then guess what? If there's a concern, give us a call. We're here for you so we're not abandoning them. And we give them a call to check up to see how they're doing to make sure they know they're cared for and they should not have any concerns or fears in regards to the needle in the eye. We've also got to tailor the education, you know, everything. Even though we may say generally patients do well, we tailor the treatment and we tailor the message and the discussion, and we do that by using analogies.

We use illustrated pamphlets and we make things simple. As I said with analogies, likening, the anti-VEGF medications we use for treatment like incident for the eyes, right? So however we can get these patients to understand and buy in and know why they're getting the treatment, it breeds jumping over these barriers and compliance in maintaining the treatment that we want.

Now, Amber, you kind of hit home on this and that you do a lot of the financial assistance for us, but the patient was concerned. They did have insurance, but they needed assistance with a copay card. You were able to get this patient copay assistance and be able to then get not only their medication taken care of, but also their copay visits.

So their out-of-pocket is practically nil, so they're getting treatment, getting better outcomes, and also not having that concern and fear of cost. We did reach out to family members in the beginning for this patient because guess what? They could not drive. Their vision was too poor to be able to get themselves in here, and you both took time to reach out to the family member, specifically his sister, to get him in and say the importance of help him out in this instance until we can get him back on his feet, to maintain his independent, to be able to go back to work. And that's what we were able to achieve. So patient testimonial says a thousand words. This is a picture on OCT showing where the patient had significant swelling, we improved the swelling and the patient's vision improved. And what the patient said was, at first I was afraid of the needle and specifically the aftercare limitations.

However, the staff, you guys, spoke to me like family. Explained everything with pictures and also involved my daughter in the process. And because of that, now I can drive, maintain my independence and continue working to provide for my family. So these are the impacts we want to allay to all our patients.

But this one test testimonial sends, a picture of how we're able to address barriers and overcome these challenges. So to wrap things up, what does all of this mean? We know patient hesitation is common, but very often addressable with the right communication tools, addressing empathy and addressing their concerns.

We do know there are many social determinants that aren't just patient problems. They're practice challenges too. And although we can't change the world, what we can change is what happens within the 4 walls of our office, and I thank you guys for helping to participate in the care of our patients, to get them what we want to achieve.

Thank you all for joining and we hope this was helpful to you all.

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