

Speaker 1:

Welcome to The Eye on the Cure Podcast, the podcast about winning the fight against retinal disease from the foundation Fighting Blindness.

Ben Shaberman:

Welcome everyone to another episode of The Eye on the Cure podcast. I am Ben Shaberman with the foundation Fighting Blindness and very pleased you could join us. And I'm especially pleased today to have with us Sylvia Sorenson, who's going to have a conversation with me about mental health and low vision. It's a topic that we don't cover a whole lot at the foundation. We're obviously focused on treatments and cures, but it's a really important topic, and I'm glad that we'll be covering it. And Sylvia, welcome. Glad you could join us. And just to give our listener some background, Sylvia is a PhD. She is associate professor at the University of Rochester in the Department of Counseling and Human Development with co appointments in the departments of psychiatry, Ophthalmology, and the Center for Community Health and Prevention. It sounds like you cover a lot of territory there at the University of Rochester.

Sylvia Sorenson:

Intersecting circles.

Ben Shaberman:

Right. So on that note, tell, give us a little background on your work and how it relates to people with vision loss.

Sylvia Sorenson:

Yeah, so I want to qualify all of my answers first of all by saying I'm neither an eye doctor nor a clinical psychologist.

Ben Shaberman:

Okay.

Sylvia Sorenson:

And I think that's important because I come to this originally as a researcher and my background is in human development and gerontology, but I have a special interest in underserved populations, and people who have vision loss are one of those groups who are underserved medically and also in terms of mental health.

So the project that we're completing right now, we offer a resilience building program to older adults, people over 55 with any kind of vision loss. And because we were interested in engaging minoritized populations, so African Americans, Hispanics, Asian Americans, we also did not limit either the conditions or the type of vision loss. In this project, what we offer is a program that consists of four group education sessions in which people learn about different aspects of vision loss.

Like for example, the medical aspects or the socio-emotional aspects of vision loss, and also different ways to actually deal with everyday issues that you run into when you lose your vision. And after those four group sessions, we offer one on one individual coaching sessions, and we call them resilience building coaching. They're an adaptation of problem solving therapy, but they're not therapy. There

really are more identify a problem, work through the problem, and learn the technique of being systematic about dealing with your problems. So that's the latest project that we've been working on, and we are researching how well that can be implemented in community settings.

Ben Shaberman:

Interesting. So what do you observe in your research as being the most significant mental health challenges for people with vision loss? Obviously there are the numerous practical challenges, but emotionally, what do you think people struggle with?

Sylvia Sorenson:

Well, a third of older people who have vision loss develop depression at some point. So that's a really high number. And even if you don't have clinical depression, you might develop depression symptoms, which really put a dent in your quality of life if you're having depression symptoms a lot. Another thing that we see is anxiety, sometimes panic attacks, and sometimes just worry and anxiety about the future. And that is also something that affects younger people a lot. So young people with vision loss for example, worry about finding a mate and a life partner. And whereas older people may be more worried about how are they going to remain independent? And then the other issues that come up that contribute to that contribute to mental health problems, although they are not diagnosed mental health problems are loneliness. So a lot of times people who lose their vision start isolating themselves or becoming more isolated, because they're less mobile.

And loneliness we now know is associated with all kinds of difficulties, both mental health and physical health problems. Low self-esteem is something that happens a lot. People feel like nobody really wants to be with me anymore if I have vision loss. Fear of falling is really important for older people because they stop doing the necessary exercise and movement that they need. And then losing valued activities, that's one of the important things that lead to depression in a lot of people. So if you were a musician all your life and now you can't read music, then that can be really, really frustrating. And oftentimes is sort of the in between variable that then later leads to depression is that you are losing things that you really love.

Ben Shaberman:

Sure. That's a wide range of potential challenges. And as you were giving that overview, I was thinking that the pandemic that we're in the middle of right now is just exacerbating all that stuff, because even those of us with relatively good vision are struggling with some of those issues. I can imagine the additional challenges if you have vision loss. So obviously people can try to seek therapy as one way to address these conditions. Can you give us a little more information on what you think people can do in their communities to deal with these issues?

Sylvia Sorenson:

So I think the first step is oftentimes just education. So people learn about their vision condition from an ophthalmologist, and an ophthalmologist is usually not trained to impart that information in a way that allows them to take it in and process it. So oftentimes people will come to us and say, "My ophthalmologist said you're going to go blind and there's nothing I can do about it." And that feels like a death sentence to them.

And so I think the first step is really to learn about what is really my condition. What is you're going to go blind really mean? Because if you're legally blind, you still see something. And if you have macular

degeneration for example, that is a long process. It's a decade long process. It doesn't happen overnight, usually. And so educating yourself about the condition that you have and really what is the timeframe, and then educating also others around you about your condition is really important.

So for example, if you have macular degeneration, your central vision is affected. So you may not see or recognize somebody right in front of you, but you might see that tissue on the floor out of your peripheral vision. And the people around you might say, "Well, you're not really blind if you can see that." And so educating them about what your condition is like, what you have learned about the prognosis, is really important.

The other thing I think, is to stay on top of the newer developments. So it takes about 15 years for some new development to actually hit patient use. And so whatever was started about 15 years ago may finally become available now. So that could be sometimes stem cell research that might actually have applications now, or it could be implantable telescopic lenses, things like that. So trying to stay on top of that and checking in with your doctors about what some of the newer available treatments are, I think is really helpful. So education.

The next thing is support. You need to garner support and also communicate how much support you do or don't want. So a support group is really good, because they're all people who have similar issues that you have. And so you can exchange ideas and you can do things together and not feel like you're standing out because you spilled something on your shirt because you didn't see it. But also your family support, sometimes people over support you and they do everything for you, and people get really angry about that. And so communicating in a calm way before that happens to somebody that I'd like help with this, but I don't want you to do this for me because I feel like I can still do that myself, and it makes me feel better if I do those things myself. So that's another important thing.

Education support, vision rehabilitation. I think that is huge and it's totally underutilized, and it's also not well-funded by Medicare or Medicaid and those organizations. So if you are younger and the vision rehabilitation can contribute to your work ability, then usually you could get it funded in ways. If you're older, Medicare does not cover it or only parts of it, but it's an incredibly important tool. And actually in our four education sessions, we have two professionals who do vision rehabilitation. One for sort of indoor, immediate everyday activities and the other one for orientation and mobility. And they talk to our participants in our programs, because if the participants can't access that rehabilitation, at least they can get some of that information from us. So that's vision rehabilitation.

And then the fourth thing, you mentioned counseling. And so our program is instead of counseling in a way, because we are really focusing on a less sort of therapy, think about your childhood and how that's contributing to your current situation. And more about how do you solve problems right now, and how can you do a better job of solving problems to make yourself feel better? Because usually feeling down is an indication that some problem hasn't been addressed. And so we try to work through that. So that's the fourth component, is to find some way to either go into a program where you learn problem solving or get some kind of therapeutic or counseling intervention. And I do think a lot of counseling in those situations, I think that even having six sessions with a counselor and just working through some of the emotions that you're feeling as a result of the vision loss is really helpful. And we refer people after our program sometimes for continued counseling as well.

Ben Shaberman:

I really like that review of many practical suggestions that you provided, practical things that people can do. And just a little plug for the foundation Fighting Blindness, we have a chapter network throughout the US where people can get involved in their local community and meet other people who are dealing

with the same challenges of low vision, progressive vision loss. And at the end of the day, often it's just nice to have somebody else to talk to and commiserate.

For people in their communities, are there organizations or types of therapists they can reach out to to maybe get some counseling? Is there a certain kind of group that you would recommend?

Sylvia Sorenson:

Yeah, so I was thinking about that. And I know that for example, here in Rochester, we have a Deaf Health Center. So we actually have a center that's very interested in people who are hard of hearing or deaf, and providing them with both physical and mental health services that are accessible to them. There is no such parallel for vision impaired people, but a lot of cities have an association for the blind, or there are state associations for the blind. And I can send you some resources that I've put together about that for different states and cities, just to give you an idea. But those associations oftentimes have social workers. And the social workers there are specialized on vision loss. And so they are experienced in talking people through the issues that they might be encountering.

One of the recommendations I have on a systemic level, not on the personal level, but people may want to advocate for that, is that any larger vision clinic should budget for a social worker and have that social worker not just help people get to appointments or pay for appointments, but also actually provide some counseling assistance for people who are struggling. And if that is part of the normal all round eye care, then people will take more advantage of it. Right now, mental health is a little stigmatized, and so if you say, "Well, you should talk to our counselor," people might not feel comfortable with that. But if that's a normal part of your intake, for example, that would make a world of difference in getting people access to some sort of mental health assistance.

Ben Shaberman:

I definitely agree, and I think your comments about low vision rehabilitation are really important because it's a very practical step that people can take to improve their quality of life. And each community has its own low vision resources and rehabilitation services, but I would think those places might also know about where somebody could get some mental health support as well. Do you ever work with groups, the bigger mental health organizations? Like I'm thinking of NAMI. I'm not sure how you pronounce it. National Association for Mental Illness or other groups like that?

Sylvia Sorenson:

I have not actually. I've worked with them or were representatives of them in other contexts, but not in the vision loss context specifically. I think that vision loss seems to be still in the provider community, one of the really underserved group, because people don't know exactly how to adjust their approach to match people who have vision impairments. That's a great idea actually, is to do a collaboration with NAMI, specifically for people with vision loss.

I think that sometimes people don't want to actually admit to vision loss, because they fear they're going to be taken advantage of, or for older people that they might feel like people will want to take away their independence, which people I've talked to have told me that I really don't want to let my kids know that how bad my vision is, because they're going to say, "You need to move to a nursing home," or something like that and that they don't want to do that.

So that's sometimes tricky in terms of getting an organization like NAMI involved because they don't want to admit to the vision loss, and they certainly don't want to admit to any kind of mental health issue. So that's why we frame our work actually not as a mental health program, but more as a resilience

building because we want to say, "You may or may not have depression symptoms, but we want to make sure that in down the road you might be able to prevent that." And we've had some success with that.

Ben Shaberman:

Thanks again for sharing that. And again, I appreciate your practical perspective on trying to deal with the mental health issues. If somebody can be a little more independent and do the things they like to do by translation, you would think that would improve their mental health.

Sylvia Sorenson:

Yeah, so for young people, it might work if they learn braille early on, for example, to have all of your materials available at braille and that sort of thing. For older adults, learning braille is a long shot. Some do. I've talked to people who are actively learning braille so that when they lose their vision completely, they have that option. But I think even braille is still underutilized. And so we really have to think about alternatives to braille. And so for example, all of my materials are large print, and we have super large print stuff for some people, because they have difficulties.

One thing that you mentioned earlier was the pandemic, and our program was all in person initially, and we have tried to adapt it to Zoom for the pandemic, and that's been mildly successful. Some of the one-on-one sessions, actually, it worked very well because we could use the screen for those with not so severe vision loss to lay out things that otherwise might be hard to see. The group sessions were hard on Zoom, especially anything like orientation and mobility. So we were trying to adapt what we were doing to this new format with mixed success.

Ben Shaberman:

Right. And yeah, Zoom can be a little challenging again for those of us with pretty good vision. But I want to get back to one other thing as we kind of wrap up, is that I think technology can really help people quite a bit. I know I have colleagues who are so proficient with voice technology, screen readers, it's amazing the things they can do with their iPhones and their smartphone.

Sylvia Sorenson:

Yeah, I think that you raised a really good point that I forgot to put in my notes, but there is a YouTube series by a gentleman. His name is Sam., it's called The Blind Life. You may be familiar with it, which I recommend to people because he's amazing. He reviews all this technology and really I think that that's a new frontier in some ways that we should be trying to pursue further. But cost is a real big issue for people with a fixed income and people with low income in general. And so how can we make the technologies that maybe allow people to work and be active and do the things they love available to people who can't afford a \$3,000 reader or something like that.

Ben Shaberman:

And coincidentally, we had a national webinar a few weeks ago on low vision, and Sam was a guest.

Sylvia Sorenson:

Oh, wonderful.

Ben Shaberman:

And so he was wonderful. He's got a great attitude, good sense of humor, a really cool beard as a beard guy. I appreciate the long beard. But yeah, he's a great resource. That, again, is called The Blind Life.

So Sylvia, this has been a really excellent discussion about mental health. And again, I appreciate your suggestions for things people can do to try to improve their quality of life. And I think at the end of the day, mental health challenges, you need to find people you can talk to, commiserate with, and look for resources in your local community to help with low vision, to help you do more of the things you like to do.

Sylvia Sorenson:

Maybe one more point that I want to make is that the anxiety that sometimes comes with looking into the future, you can ameliorate that a little bit by using your problem-solving strategies for future problem solving. So you can think about what may I have to change when my vision gets worse and start preparing for that. And that might actually make it easier then to make transitions.

Ben Shaberman:

Good advice. Good advice. I'd like to remind our listeners that if you have questions down the road, you can send an email to podcast@fightingblindness.org. That's podcast@fightingblindness.org.

Sylvia, again, this was a wonderful talk. Thanks for taking time out of your day to interview for this podcast. Any final thoughts or observations?

Sylvia Sorenson:

Don't give up hope. Don't give up hope. I think that that's really important that just because you are losing your vision doesn't mean you're losing everything else. You can still find ways to do what you love.

Ben Shaberman:

I agree. And sometimes we have to keep in mind we can't fix everything overnight. Sometimes it's just baby steps to get to your destination. I know, I employ that philosophy in my life. So Sylvia, again, thank you for joining us for the Eye on the Cure Podcast. And thanks to all our listeners for joining us, and please stay tuned for the next episode. Bye, Sylvia

Sylvia Sorenson:

Bye-bye.

Speaker 1:

This has been Eye on the Cure. To help us win the fight, please donate at foundationfightingblindness.org.