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## Why QoL Measures Change TED Management

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### Episode 3

#### Dr. Subramanian:

Hello, I'm Dr. Prem Subramanian, and I'm here today with my friend and thyroid eye disease expert, Dr. Kim Cockerham. In our last episode, we discussed how CAS, EUGOGO, and VISA are great tools for assessing inflammation and visual function in thyroid eye disease, but Kim, what tools do we have that can help us to assess the psychosocial burden of thyroid eye disease?

#### Dr. Cockerham:

Well, that's what's exciting is we now have validated quality of life tools specifically for thyroid eye disease that look both at the visual function impact and also the alterations in activities due to appearance. And these are very, very helpful. And when you have patient-reported outcomes, it improves treatment selection and it gives you shared decision-making, which is so important with these patients to help them with their journey.

There's both informal and formal quality of life tools that you can talk with the patient and their family and identify what's the therapeutic intervention timing, type, what's the best next step? It allows us to partner with our patients, their support systems, and the other healthcare providers involved in their care. So very exciting that these quality of life tools have come forward and been utilized so much more as part of the clinical trials, but also now clinical and real clinical life.

So an example: thyroid eye disease severely impacts quality of life. And so we did a survey of 100 patients with chronic thyroid eye disease. So again, that measured patients probably with lower CAS scores, much longer duration. These patients' mean duration was almost 6 years, mean inactive, which means CAS score very low, of greater than 3 years. And you see that their quality of life is very low, so their scores are diminished. So a lower score—100 would be good, 60 is low—and that is because of their vision impacted them, but also their appearance. So it's dual-fold in terms of the impact on these patients due to the quality of life tools.

And here you can see low quality of life is associated both with symptom burden but, surprisingly, surgical intervention. The more surgical intervention the patients had, the more they identified as having a poor quality of life, which was kind of surprising to me.

In terms of these patients, it's because they've interacted with so many healthcare professionals. So every time they have surgery, every time they're admitted, or they have IV steroids, or they have a surgical intervention, it impacted their mental health, it impacted their ability to be employed, and it may not help their pain, their blurred vision, or their double vision. Because it's not unusual that a patient undergoing, for instance, a decompression for proptosis or optic nerve decompression, they get worse double vision, which can impact their quality of life even more.

So we need to continuously assess these patients' signs and symptoms but utilize this quality of life information while considering when

and how to treat the patients in the best possible way.

**Dr. Subramanian:**

You brought up some really important points here, Kim, and I think that this highlights what has been covered over the past few episodes, which is that as doctors we're always looking for things to measure. And we measure our patients' proptosis and their eyelid fissures and even the magnitude of their diplopia in terms of their strabismus, but it doesn't always capture those key elements of how they are perceiving their disease.

These are people who are often getting a disease for the first time. They may have been previously healthy, and the impact that this has on them psychologically is often underestimated. I know that there are studies that show that too.

So I really appreciate how you have tried to integrate our measures of what the patient is experiencing and what the patient is reporting, and how our interventions that we think are aimed at helping them get better in the short term might even make them feel worse. And keeping that in mind and helping them to understand that we're together going to a final goal and an outcome that we want to be best for them that can really help them along on that journey in their thyroid eye disease.

So I want to thank you again for appearing on this episode, for sharing these thoughts with us, and thank our listeners for being here. And stay tuned for the next episode as we continue talking about thyroid eye disease.

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