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Shared Decision-Making in Squamous Cell Carcinoma of the Anal Canal

Announcer:
You're listening to *Project Oncology* on ReachMD, and this episode is sponsored by Incyte. Here's your host, Dr. Brian McDonough.

Dr. McDonough:
This is *Project Oncology* on ReachMD, and I'm Dr. Brian McDonough. Here with me today to share strategies for engaging patients in shared decision-making around treatment options for squamous cell carcinoma of the anal canal is Dr. Richard Kim. He's a Service Chief of Medical Gastrointestinal Oncology and a senior member in the Gastrointestinal Oncology Department at Moffitt Cancer Center. He's also a Professor of Oncology at the University of South Florida College of Medicine. Dr. Kim, welcome to the program.

Dr. Kim:
Thank you for having me.

Dr. McDonough:
So why don't we start by doing some level-setting, Dr. Kim. When a patient is newly diagnosed with squamous cell carcinoma of the anal canal, why is shared decision-making so critical?

Dr. Kim:
Yeah, thank you. When I meet a patient with newly diagnosed squamous cell anal cancer, shared decision-making is critical because I think the context is a little bit different than many other cancers. Most of the patients come in after some delay of symptoms, which can sometimes be misattributed to hemorrhoids or benign disease. And there's always some embarrassment that keeps patients from seeking early care. In the first visit, when I see the patient, I actually treat shared decision-making as a clinical tool. I use it to establish trust, set up patients for long-term engagement, use it for staging workup for multi-care, and obviously the goal is to potentially prolong therapy.

Practically, when I see patients, I do a couple of things right away. First thing is I set the agenda. I'll explain to the patient what the options are, and I'll ask them what matters most to them. Second, I try to understand their baseline understanding. "What has been told to you so far, and what is your understanding of your disease?" Third, last but not least, I try to clarify their decision, role, and preference. Some patients want headlines; some patients want more details. Some patients want their family involved, so every patient is a little bit different. And we know that in the treatment of squamous cell anal cancer, the early shared decision-making matters because the decisions are not one and done, right? We're often choosing between different treatments, coordinating the radiation and surgeries, and planning supportive care. So I think if the patient's aligned and engaged from day one, I think it works better for everyone.

Dr. McDonough:
As guideline supportive therapies expand to include combination, chemotherapy, and immunotherapy, what approaches have you found most effective for translating complex guidelines and clinical trial data into language that feels meaningful and accessible for patients?

Dr. Kim:
The treatment of squamous cell anal cancer is a great example where currently, we have a new regimen available with a combination of carboplatin-paclitaxel plus immunotherapy that was just approved. But the important thing is that we have to translate this evidence into something that's personally meaningful for the patient.

The approach that works best for me, at least, is that when I talk to the patient, I usually talk about goals rather than the name of the drugs. And usually, I will tell the patient that we are treating it with two objectives in mind: one is to shrink the tumor to relieve the symptoms, and the second goal is to make you live longer. Those are the two goals. And obviously, there are trade-offs with the potential toxicity.

When I talk about the data itself or the trials, I try to avoid hazard ratios, and I instead start with the concrete endpoints that patients can understand. For example, I will tell them the chance of tumor shrinkage until the cancer grows again, some of the plain terms of toxicity, or the long-term overall survival. I'll say something like, “Out of 10 patients, about this many patients will see some shrinkage,” so that the patient understands better. Then I try to bring this data back to life. I tell the patient that this regimen requires a weekly chemo visit. I'll watch for neuropathy; we'll check blood counts for anemia or thrombocytopenia. And if you add immunotherapy, we'll watch for some of the immune side effects that are uncommon but important to call out early.

And also, I discuss the patient's overall conditions. Where do they live? Do they have a caregiver? Do they have baseline neuropathy? Do they have baseline autoimmune history? That will often help me individualize the framework that's given to me. So I think my goal is to make this guideline feel like a personalized plan in order to accomplish the whole goal of trying to improve the patient's overall outcome.

Dr. McDonough:
Now health literacy and emotional readiness can vary widely at diagnosis. So how do you assess what a patient is able to absorb in that moment, and what practical strategies help reinforce their understanding without overwhelming them?

Dr. Kim:
When I see the patient, I assume that every patient has a varying bandwidth at diagnosis regardless of education because they have anxiety and they're shocked by their new diagnosis, right? So I use a very universal approach to communication.

First, I try to understand what the patient wants. So I ask questions like, “Do you want a big picture today or details? What is your biggest worry right now?” That tells me whether to focus on reassurance versus structure versus deep details.

Second, I like to give the patient information in small chunks and check their understanding. I personally rely heavily on teach back—not as a test, but as a test of my own explanation so the patient understands.

Third, I like to reinforce without flooding the patient, right? So I definitely tend to give patients a short summary or a short red-flag list of the toxicities, such as fever, diarrhea, and shortness of breath, and I try to schedule a deliberate second conversation. Most patients, as we know, have questions after they leave you; many patients will process better after 48 to 72 hours later. So I tell the patient, “Hey, this is step one. You'll come back to revisit, and if you have any questions or concerns, we can definitely address them at that time.”

Dr. McDonough:
For those just tuning in, you're listening to *Project Oncology* on ReachMD. I'm Dr. Brian McDonough, and I'm speaking with Dr. Richard Kim about shared decision-making strategies for treating squamous cell carcinoma of the anal canal.

In addition to health literacy and emotional readiness, cultural norms and stigma can affect how patients experience this diagnosis. With that being said, Dr. Kim, how do you ensure these conversations respect privacy, beliefs, and family dynamics while still reinforcing shared decision-making?

Dr. Kim:
In anal cancer, we know that privacy and stigma are real. And I start at the beginning when I talk to a patient. “Who would you like in the room? Are there any parts of the discussion you want to keep private?” I think that really does reduce the shame and increase engagement. The topic of HPV will come up because we know that it is the number one risk factor for developing anal cancer, but I try to normalize it. And I try to talk in medical terms by telling the patient that the CDC estimates that about 90 percent of anal cancers are thought to be caused by HPV and that HPV exposure is very common. So I try to avoid any language that implies any kind of blame. I tell the patient that this is a very common virus, and our focus is treatment and support.

I think the family dynamics vary from patient to patient. Some patients want shared family decision-making. Others want privacy. And really, the shared decision-making doesn't require one culture model. Every culture is a little bit different. If language is a barrier, I definitely try to use a professional interpreter and confirm their understanding with some teach back. If stigma is affecting care for whatever reason, I try to involve other people on my team, such as the navigators or some of the trusted support people the patient has, to help the patient understand.

Dr. McDonough:
Now once you're past the initial diagnosis conversation and you're discussing intensive or prolonged treatment, how do you encourage patients to articulate what matters most to them and incorporate these goals or priorities into your recommendations?

Dr. Kim:
Once we move from what is it to how do we treat it, I think my job at that time turns to the options that fit the patient. I explicitly ask the patient about their priorities. “What is your goal? Is your goal symptom relief? Is your goal traveling in the next couple months, or are you still trying to work? Who do you live with, or who do you take care of?” And I translate these priorities that the patient has into clinical decision-making.

For example, if clinic visits are major barriers, we try to plan local labs and make the weekly chemo every couple of weeks, for example. If neuropathy is an issue because of their job, we discuss reducing the dosing strategy. And obviously, we also discuss the potential toxicity with immunotherapy that could be very burdensome as well.

I also revisit the priorities because they evolve as time goes on. For example, if the patient prioritizes symptoms at the beginning, a therapy could stop the bleeding and pain, and then the priority may change afterwards. So the point is that shared decision-making is ongoing. And I think by doing this, it's really integrating what matters most to the patient into the decision and not just presenting options.

Dr. McDonough:
Shared decision-making also means setting realistic expectations and acknowledging uncertainty. So before we close, Dr. Kim, can you tell us why it's important to openly address potential side effects, response rates, and evidence gaps with patients?

Dr. Kim:
I'm very direct with patients about the benefits, risks, and uncertainty because it's essential for informed consent for safety. If the patients don't understand the response probability or side effects, I think they're more likely to stop the therapy prematurely, ignore red flag symptoms, or lose trust when something happens.

So I try to discuss response rate and disease control in plain terms in a very straightforward way. Then I try to pair it with a toxicity plan. Usually for anal cancer, we give a combination of chemotherapy and immunotherapy. So therefore, we discuss immune-mediated toxicity, which can be serious but is often very manageable when found early. We give patients clear instructions on what to report and when.

I also acknowledge that there is some gap with evidence, right? For example, what's the optimal sequence after progression? As I mentioned, first-line therapies include a combination of chemotherapy and immunotherapy, but after progression, what do you do? There is a gap there, right? So I frame this uncertainty as part of shared planning. I tell them, “Here's what we know, and here's what we don't know.” And sometimes we'll say that in the future, we'll have to make the decision together to see what's in your best interest. And I think this approach builds credibility and keeps patients engaged in the long term.

Dr. McDonough:
It makes a great deal of sense. With these insights in mind, I'd like to thank my guest, Dr. Richard Kim, for helping us better understand the importance of shared decision-making in caring for patients with squamous cell carcinoma of the anal canal. Dr. Kim, it was great having you on the program.

Dr. Kim:
Thank you for having me. Appreciate it.

Announcer:
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