Degendering Symptom Assessment to Appropriately Evaluate for Malignancies

CMEO Podcast Transcript

Don Dizon:

Hello. I'm Dr. Don Dizon and on behalf of CME Outfitters, I would like to welcome you to today's education activity entitled "Degendering Symptom Assessment to Appropriately Evaluate for Malignancies." Today's program is supported by an educational grant from Merck Sharp & Dohme Corporation. And today's activity is brought to you by CME Outfitters, an award-winning, jointly accredited provider of continuing education for clinicians worldwide. Again, I am Dr. Don Dizon, I'm a Professor of Medicine and Professor of Surgery at Brown University, Director of the Pelvic Malignancies Program and Hematology-Oncology Outpatient Clinics at Lifespan Cancer Institute and the Head of Community Outreach and Engagement at Legorreta Cancer Institute at Brown University.

Don Dizon:

And finally, I am director of Medical Oncology and founder of the Oncology Sexual Health First Responders Clinic in Rhode Island Hospital, in Providence. Now, let me introduce our faculty. I am privileged to be joined today by Dr. Ash Alpert, an AHRQ T32 Post-Doctoral Fellow in Health Services Research, based at the Center for Gerontology and Healthcare Research, Department of Health Services Policy & Practice at Brown University's School of Public Health in Providence, Rhode Island. Welcome, Dr. Alpert.

Ash Alpert (they/them):

Thank you. Glad to be here.

Don Dizon:

Me too. Let's start by reviewing our learning objective for today's session. After participation in today's activity, clinicians should be better able to apply efficacious and non-gendered approaches to symptom management. Before we watch our three patient interaction videos, let's take a minute to review some of the concepts and terms that we will use in today's discussion so that we are all on the same page. What's important to understand is that "sex assigned at birth" and "gender" are often mistakenly used interchangeably and it's not appropriate at all to assume anatomy based on gender. It's still quite an important concept because as we know that sexuality and gender are often conflated inappropriately.

Ash Alpert (they/them):

Yeah. In some ways, there's multiple different concepts that are conflated. If we know someone's sex assigned at birth, we think we know their gender. We think we know their chromosomes, their hormonal milieu. And then we also often think that we know who that person will be attracted to, how they'll identify in terms of their sexual orientation, what kind of sexual behavior they're going to engage in. When really we just know one thing when we know one thing. I think there's a lot to disentangle and unpack.

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Don Dizon:

I think that's a really important point. Moving forward, the NIH in ASCO have recently begun to recognize the unmet health care needs of the SGM or sexual and gender minoritized population. Currently the data we have in this group is limited, but we know people in this group have poorer outcomes than the Cisnormative populations. And, Dr. Alpert, is there anything else you want to add on that as well to give it more context?

Ash Alpert (they/them):

Well, I mean, I think that what's really exciting about being alive and being a scholar and researcher and clinician today is that for the first time in my lifetime, large oncology organizations across the US are starting to recognize that the ways that we've often described bodies, identities, and experiences may leave out a lot of us. I'm really happy to be able to be working right now and working with you on really changing the landscape for sexual and gender minority people with cancer. It's a really exciting time.

Don Dizon:

It's incredible to think that it's just starting now. That this movement, which if you just compare it to, say, when gay marriage became legal, has come before the collection of SGM people’s identities in health records. It's just incredible and I think what it reflects are the many barriers that SGM people face to their receiving high quality health care and that includes cancer screenings. These range from the personal to the systemic and it ranges from outbreak discrimination and hostility to activities of implicit bias where, unintentionally at its face, some of the most disheartening and offensive comments can be made.

Don Dizon:

For example, when it comes to cancer screening for cervical and breast cancer among SGM patients, there's a substantial lack of knowledge around the stress that goes with screening and about screenings themselves. And if you look at the data that's been reported, we now are understanding. And it's been seen across multiple data sets that sexual and gender minorities do have lower rates of screening. And that includes with mammography and it includes with pap smears for cervical cancer screening. Dr. Alpert, when we think about the factors that clinicians have control over, we can think about both conscious and unconscious biases; sometimes the unconscious biases called “implicit biases.” The conscious biases are the things we recognize but it's the unconscious or implicit biases that are harder to identify. What do you see are some of the unconscious things we do that discourage SGM patients from receiving the care they need?

Ash Alpert (they/them):

Well, I think even to move out a little bit from the individual clinician, we're all trained to think about bodies in a certain way. And to think that when we see a person we'll know what sort of anatomy they likely have and what kind of cancer screening they may need and we're not taught to think about these things more critically. When a person walks into a room, we're often thinking that we already know what pronouns they might use, what body parts they might have and what health care needs they might have as well. Really trying to unpack that and do things differently first, by asking patients how they'd like to be referred to.

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Ash Alpert (they/them):

And also by potentially doing an anatomy inventory, preferably in written form so that we know what their cancer screening needs might be. And then similarly, when someone comes in with symptoms, not assuming that we know what anatomy they have. In the scenario that we will watch, what happened in the first two versions was that the primary care provider assumed that they knew that the person's anatomy by looking at them. And also assumed that they knew their pronouns and how they would describe their gender. And then in the second scenario, when the primary care provider saw in the chart that the patient was transgender, that changed the care but not in a positive way.

Don Dizon:

Mm-hmm. And if you think even beyond that, there is a term that I've recently come to know and there's this whole notion of being “stealth.” That one is not going to be asked about their pronouns or their gender or their orientation unless it's obvious to the provider. If it's, you are not quote “obviously” gay, if you're not “obviously” trans, they're going to assume a very heteronormative persona applies to you. And I've heard and I would love your comments on this for some trans people, the experience of developing into their own fully formed selves and really seeing their selves recognized is a road that's paved in trauma.

Don Dizon:

And any aspects that could threaten who they are now or bring up those experiences can be considered triggering. And many of these triggering events are occurring in the context of health care. It's almost a relief almost. I'm not sure if I'm using the right word when someone who is trans can pass for Cis because it means they won't have to deal with that. But I think on the other end of it just goes to show that the biases we have, they actually stand in the way of a fully formed doctor-patient relationship.

Ash Alpert (they/them):

Yeah. I would agree that sometimes the ways that our biases become clear to patients do get in the way of rapport and that that can really potentially damage a relationship in the long term, if we can't figure out ways to repair. And in terms of what you were mentioning earlier, yeah, we know that a large number of trans people have negative experiences with clinicians. And that because of those experiences, many people don't seek care even when it's needed. And I think that many of us who are LGBT even those of us who are clinicians experience many microaggressions and traumatic events in the setting of clinical care that make it very difficult to continue to access care even when we need it. Even if it's something like cancer screening.

Don Dizon:

Yeah. And I think it goes back to the point that I'm hoping we will make in this activity, that we should not assume who the person is we are going to see. And that it's up to us to be curious enough to ask them, to tell us who they are using their words and their definitions. Because when it comes to someone's self, the only one person who knows who that person is, is the person sitting in front of you. No one else really knows that. But, Dr. Alpert, just to move on just a bit, can you talk about also the systemic ways that these hostilities might manifest sort of environmentally, environmental cues of unfriendliness, for example?

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Ash Alpert (they/them):

Yeah. Beyond just the patient and clinician sitting in a room together, there's the institution that they're sitting in and that institution likely has non-discrimination policies that may or may not apply to transgender people along with sexual minority people. The other thing that people might notice when they walk into a clinic is what's the situation with the bathrooms? Will I be able to access a bathroom that I will feel comfortable in and not get thrown out of? And then in addition, I think people really pay attention to what's on an intake form. If the intake form makes clear that trans people are invisible in the minds of the clinicians, it's going to be much harder to be out to the clinicians. For example, at an institution that I used to work at the intake form said for women, when was your last period?

Ash Alpert (they/them):

And of course if I'm a man and I'm menstruating, it might be very difficult for me to figure out what to write on that form. And similarly, in our research, we've heard from transgender women who present to an appointment and are gendered correctly but then someone will ask them, when was your last period and might you be pregnant? And at that point, it's very hard to figure out should I lie or should I come out to this person who clearly has not thought about that I might exist as a trans person? And then beyond the walls of the clinic there are laws that vary by state in regard to what services are covered under Medicaid, for example. In a state where gender-related health care services are covered, a person might have a very different feeling walking into a clinician's office than in a state in which that's different.

Don Dizon:

Those are excellent points. Thank you very much. Do you want to go ahead with introducing the scenarios?

Ash Alpert (they/them):

Oh sure, I'd love to. In our scenarios, there's a patient named Dominic who uses they/them pronouns who presents to their PCP because they're having back pain and cramping that's been going on for a number of months. There's three scenarios that we present. In the first one, the primary care physician assumes that the patient is a cisgender man so asked about symptoms that the primary care physician thinks would be related and therefore misses what's going on with the patient. In the second scenario, the primary care physician also assumes the patient is a cisgender man but then goes ahead and looks at the patient's chart and realizes that the patient is transgender. And then begins to ask a number of inappropriate or at least questions that don't land well for the patient. And then goes on to assume that the patient is pregnant and refers them to OBGYN.

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Ash Alpert (they/them):

And then you see the patient try to make this appointment and have a great difficulty making it because their name is "Dominic" and the person that they speak to on the phone doesn't believe that they need to make an appointment with OBGYN. In the final scenario, the physician introduces themselves with their name and pronouns and asks the patient to do the same. The physician has already obtained an intake form that has an anatomy inventory so knows the anatomy of the person in front of them. Does a thorough assessment of their symptoms and finds out that the patient, in addition to having back pain and cramping has also had a 15-pound weight loss and becomes concerned and in the end refers the patient for an ultrasound.

Hi, welcome Mr. Bell. What brings you in today?

Dominic Bell:

Hey, I'm having a lot of cramping and abdominal pain.

Ash Alpert (they/them):

Okay. How long has this been going on for?

Dominic Bell:

For months.

Ash Alpert (they/them):

Okay. I see. Where do you feel the pain exactly?

Dominic Bell:

The lower left side.

Ash Alpert (they/them):

Okay. When was your last bowel movement?

Dominic Bell:

Yesterday.

Ash Alpert (they/them):

Are you having any burning with urination?

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Dominic Bell:

No.

Ash Alpert (they/them):

Any change in your ability to urinate?

Dominic Bell:

No.

Ash Alpert (they/them):

Any incomplete emptying of your bladder?

Dominic Bell:

No.

Ash Alpert (they/them):

And are you currently having sex?

Dominic Bell:

I am.

Ash Alpert (they/them):

Okay. Well, I'd like to test you for a urinary tract infection and for some sexually transmitted infections as well.

Dominic Bell:

All right, let's do it.

Ash Alpert (they/them):

All right, Mr. Bell. Everything's negative and since you're a man, I'm assuming that the cramping is unrelated to the back pain, maybe indigestion and that maybe your back pain is something muscle-skeletal. I'll give you some ibuprofen and then I'll see you again in a month.

Dominic Bell:

Okay.

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Don Dizon:

I think if we look at the first encounter, I think it's really striking. It's a striking example to me of this whole phenomenon of being stealth. Someone can walk in, gender is automatically assigned based on appearance and he's referred to as Mr. Bell and then the line of questioning that subsequently follows, which is essentially almost gendered. Wouldn't you think so, wouldn't you say?

Ash Alpert (they/them):

Yeah, it's interesting that you've introduced this word "stealth." The word "stealth" in the trans community refers to somebody who lives their life without people knowing that they're transgender. And in this scenario, I actually do not think the person is stealth. The person is very happy to provide their pronouns and has provided their anatomy inventory on their intake form. But unfortunately, because of the assumptions of the primary care provider in the first scenario, and the second scenario is not provided with an opportunity to give information about themselves including their pronouns, but also their anatomy. And so the physician then ends up making incorrect assumptions that lead the patient to be sent away without any follow up for very concerning symptoms.

Don Dizon:

I think, Dr. Alpert, some could envision that because again, putting in the context of where we want patient engagement to come from, we often will talk of self-advocacy of standing up for what you need from your health care providers. I don't think it would be that much of a stretch for people listening to think if they are trans, they should tell me and not wait for me to ask. What do you say about that?

Ash Alpert (they/them):

Well, I think the difficulty with that I mean, I think there are a number of difficulties with that. And one of them is that there's really no reason that any of us should have to live in a world where our identities are assumed to be "other" and not the default. And so I think it really behooves us as physicians to think about bodies and experiences in a broader way. And secondly, I guess what I would say is that from our research and also from the literature, we know that transgender people often have negative experiences with clinicians. That they experience things like harassment and even assaults in the context of physician visits.

Ash Alpert (they/them):

And so if somebody is assuming that someone is not trans and makes that clear in their language, it may be very difficult or possibly even not strategic to come out to them. Because coming out to them may cause the patient to not be safe. And so in some ways, patients are navigating very difficult choices because on the one hand, as in these scenarios, physicians may not have all the information they need for clinical problem solving. If the patient doesn't come out or doesn't talk about things that are relevant for the clinical visit. And on the other hand, if patients come out, then they're potentially facing things like harassment and even worse. I think it's a very difficult situation for patients.

Don Dizon:

Yeah, and I think all of this comes down to the concept that this all could have been avoided. As this patient has alluded to, it's important not only to understand that patient by talking to them but it's really important that we are the ones to guide the queries. And this includes getting into sexual orientation and gender identity or SOGI questions. And I think as you just beautifully explained, it's like this whole notion that the patient before you reflects their orientation, reflects their gender expression, reflects everything about them is an incorrect thing. And you don't have to look gay or lesbian or trans to prompt those questions. I think that's such an important point. But, Dr. Alpert, you want to take us into the second encounter?

Ash Alpert (they/them):

Sure. In the second encounter, I think I may have mentioned this earlier. What happens is the patient walks in, the physician assumes that they are a cisgender man. And then the physician looks at the chart and finds out that the patient is transgender and then proceeds to ask a number of questions about that.

Hi, welcome Mr. Bell. What brings you in today?

Dominic Bell:

Hey, there. I'm having a lot of lower back pain and some abdominal cramping.

Ash Alpert (they/them):

How long has this been going on for?

Dominic Bell:

For months.

Ash Alpert (they/them):

Okay. Let me take a look in your chart quickly. Oh, I'm sorry. What is your sex?

Dominic Bell:

Legally or assigned at birth?

Ash Alpert (they/them):

Your biological sex?

Dominic Bell:

Female.

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Ash Alpert (they/them):

When was your last period?

Dominic Bell:

I don't get periods.

Ash Alpert (they/them):

We should do a pregnancy test.

Dominic Bell:

But I'm not pregnant.

Ash Alpert (they/them):

Are you currently sexually active with a man?

Dominic Bell:

I am, yeah.

Ash Alpert (they/them):

Okay. We should do a pregnancy test.

Dominic Bell:

Okay.

Ash Alpert (they/them):

Your pregnancy test came back slightly positive. Let's put you on a prenatal vitamin and send you to obstetrics and gynecology. I'm glad you came in today.

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Don Dizon:

Yeah. There are a bunch of issues that this does bring up. But I can also see the dilemma that we are actually trying to address in some of our outside work, which is preparing the clinical team to sensitively and equipped with knowledge, how to address these questions that are so inherent as to one's identity and one's idea of personhood. I think there are challenges to so much of this. And I think one of the things that I hear about from the clinicians is this will come up rarely in their clinics. And it seems strange devoting this much time to that one-off patient. And I think as we've discussed in the past the assumptions, even in a statement like that are pretty incredible. That if you think it's rare and what's the harm in hurting one person since 99 people are going to feel just fine about it? Really goes against all of these concepts that we have and are working towards. Equality and diversity and inclusion. All of these big concepts in health care today will never be realized unless we address SGM people as well.

Ash Alpert (they/them):

Mm-hmm. Yeah. I mean, the reality is that most oncologists are seeing trans people, whether they know it or not. And I think the whether they know it or not is really important to consider because I think that the more you think you're never going to see lesbian, gay, bisexual, transgender, queer and other non-cisgender and non-heterosexual patients, the less likely it is that your patients are going to be out to you. And the less likely it is that you're going to know that you're seeing sexual and gender minority people, whether or not you actually are.

Don Dizon:

Right. Dr. Alpert, I think one of the other things this kind of brings up is what might have tripped up the physician, him or herself at that time or themselves even is the way you ask the questions around sexual orientation and gender identity. So much of our forms that aren't asking "assigned at birth" versus "what is your current gender?" It literally says, "What is your gender: male or female, other or write in?" But you actually need to contextualize that because as you so clearly stated, when you ask someone about their sex, which by the way, you should probably say "What is your gender?" That can have very different connotations. Do you want to expand on that a little bit?

Ash Alpert (they/them):

Yeah. I mean, what we know is that the word "gender" means a lot of different things to a lot of different people. When physicians ask about gender, what they actually might mean is sex assigned at birth or they might be trying to ask about a whole variety of things. Sex assigned at birth, current anatomy, hormonal milieu, but not really have the words to ask more nuanced questions. Whereas "gender" usually what it actually is usually about is someone senses themselves as a man, a woman, a non-binary person, or something else. But since many people are using that word in a different way, it becomes almost impossible to know what someone means when they ask the question without more context.

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Don Dizon:

I think that's brilliantly stated. Shall we go into the third encounter?

Ash Alpert (they/them):

Oh, sure. In the third encounter, the patient walks in. And the first thing that happens is the physician says "hi," provides their name, and tells the patient their pronouns, which happen to be they/them and asks for the patient's pronouns. The patient then states their name, which is Dominic, and their pronouns, which are also they/them and then they go on to talk about symptoms.

Hey there, I'm Dr. Alpert. My pronouns are they, them. What is your name and what are your pronouns?

Dominic Bell:

Hey, there. My name's Dominic Bell and they, them pronouns honor me.

Ash Alpert (they/them):

Okay. Great to meet you. What brings you in today?

Dominic Bell:

I'm having a lot of cramping and lower back pain.

Ash Alpert (they/them):

How long has this been going on for?

Dominic Bell:

For months.

Ash Alpert (they/them):

I see. Did you have an injury that you remember?

Dominic Bell:

I did not.

Ash Alpert (they/them):

Where in your back does it hurt, exactly?

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Dominic Bell:

The lower left side.

Ash Alpert (they/them):

And what does the pain feel like?

Dominic Bell:

It's very sharp.

Ash Alpert (they/them):

Okay. Has it been getting worse, better, or staying the same?

Dominic Bell:

It stays about the same.

Ash Alpert (they/them):

Okay. Does anything make it better or worse?

Dominic Bell:

I've been using heating pads but I don't know if it makes it any better.

Ash Alpert (they/them):

Okay. Does the pain radiate anywhere else in your body or does it move around? Do you feel it anywhere else?

Dominic Bell:

No.

Ash Alpert (they/them):

Have you had any changes in your weight?

Dominic Bell:

Yeah, I lost about 15 pounds.

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Ash Alpert (they/them):

Okay. Were you trying to lose weight?

Dominic Bell:

I was not, no.

Ash Alpert (they/them):

And how long has it been since you lost that weight or over how long of a period did you lose 15 pounds?

Dominic Bell:

Roughly two months.

Ash Alpert (they/them):

Okay. Any night sweats?

Dominic Bell:

No.

Ash Alpert (they/them):

Any fevers?

Dominic Bell:

No.

Ash Alpert (they/them):

Any new lumps or bumps anywhere?

Dominic Bell:

Yeah, at the left side of my groin.

Ash Alpert (they/them):

Huh. And when did you first notice that?

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Dominic Bell:

A couple of months before the pain started.

Ash Alpert (they/them):

Okay. And you mentioned that you've been having some abdominal pain?

Dominic Bell:

Yeah, I've been having abdominal cramping.

Ash Alpert (they/them):

Okay. Just reviewing your intake form based on the anatomy here, it seems like this might have to do with some of the anatomy in your abdomen and pelvis. How would you feel about doing an internal ultrasound?

Dominic Bell:

Okay. Let's do it.

Ash Alpert (they/them):

Hi, Dominic, how are you doing today?

Dominic Bell:

I'm doing well. How are you?

Ash Alpert (they/them):

I'm good. Thanks for asking. Is it okay if we talk about your test results?

Dominic Bell:

Yes.

Ash Alpert (they/them):

We noticed a mass on the ultrasound and I'd like to send you to a specialist to do some more testing. Somebody from our office will give you a call with an appointment time.

Dominic Bell:

Okay.

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David:

Hi, Dominic. This is David calling from the doctor's office. I'm calling to schedule an appointment for you.

Dominic Bell:

Great. Thank you.

Don Dizon:

And I think one of the other things that it does stress is that sexual orientation, gender identity data can be very sensitive. Not only to the person answering a form who may have questions of what are you going to do with this information? How is it going to be stored? Who's going to have access to it? But for the clinicians. It wouldn't be fair to admit to some discomfort on how to ask the questions, especially when it comes to things like an anatomic inventory. Because not everyone who is trans is going to have the same journey to their own gender identity. But not to ask the question's going to have such ramifications into the screening realm and also as we go about our differential diagnosis and approaches to treatment. What I think this nicely shows is that having the patient answer an intake form privately or at their own time, and know that information is going to be looked at can be a very useful thing for both to help preserve and might I say even foster a doctor-patient relationship.

Ash Alpert (they/them):

Yeah. I really agree with that. That providing patients with the privacy to fill these things out on their own and providing clinicians with the information they need for clinical problem-solving really probably does provide some comfort on both the patient and clinician side and lead to a better relationship and more rapport.

Don Dizon:

Mm-hmm. And especially when it's not guided as in this case, by an assumption of what is already going on. That oh, it's your bladder or it's definitely your colon. Because you're a woman it's clearly IBD. I mean, we still see these sort of characterizations of diseases being gendered, which you and I have spoken about quite a bit that diseases don't have genders. Diseases are some things that everyone experiences and it doesn't respect lines around that.

Ash Alpert (they/them):

Yeah, definitely.

Don Dizon:

Well, I think as we look at the conversation that was had, a big word that comes up is this very important consideration of respect.

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Dominic Bell:

Respect is a huge thing for me and I would want my doctor to be respectful of who I am as a person, when they're doing an examination and to not make assumptions. Also, it's important for me that clinicians be direct with their questions and ask what they want to know. For example, do you have ovaries or do you have penetrative sex instead of what is your sex and are you having sex?

Don Dizon:

And that all of our patients deserve our respect and it need not be confined to any one category of person that in order for us to achieve equality in health care. And would that be equity in the choices that people have when it comes to their treatment, we need to show a little bit of cultural curiosity and get to know people. Not by assuming who they are but by asking them questions and giving them the opportunity for them to tell us. Dr. Alpert, as we go forward, can you review some of the key communication concepts that open the patient-doctor relationship and lead to high quality care, particularly as it relates to cancer screening?

Ash Alpert (they/them):

Absolutely. I think one thing that I really love about this set of videos is that the actor in the video actually does a debrief where they talk about what's really important to them in clinician patient encounters. And they mention just like you said, how important respect is for them and the importance of clinicians asking direct and specific questions.

Dominic Bell:

It's always a good idea to introduce yourself with your name and pronouns and then ask what the other person's name and pronouns are. If it's in a returning patient, it should be in the chart somewhere where the physician can review.

Ash Alpert (they/them):

For example, "Are you having sex?" is a very vague question because there's lots of types of sex. And "What is your gender?" or "What is your sex?" may also be very vague and unclear questions. Asking questions that are much more specific and then also ensuring that you introduce yourself with your name and pronouns and ask the patient to do the same so that you can refer to them in a respectful way. And the last thing that the actor in the scenario brings up or the patient in the scenario brings up is that oftentimes they've had the experience that clinicians assume that the cause of symptoms or disease are hormone therapy when that's often not the case.

Dominic Bell:

When it comes to conversations with clinicians, the one thing that always comes up is hormone replacement therapy. Often, clinicians assume that testosterone is the cause of my symptoms when that isn't really the case.

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Ash Alpert (they/them):

And so really trying to keep that in mind when you're thinking about what's going on particularly for a transgender person on hormone therapy and how your biases against hormone therapy might influence your differential diagnosis, I think can be really useful.

Don Dizon:

Well, thank you, Dr. Alpert, for that very interesting discussion. Let me close out this portion of the program with some SMART goals. SMART meaning "specific, measurable, attainable, relevant, and timely." One of the first things is to create a physical environment that is gender-neutral and which will be seen as inclusive of SGM patients and their loved ones and caregivers. To approach and speak to all patients without any assumptions about their own gender and anatomy. And that includes using your pronouns as a way to ask them for theirs. And then addressing cancer screening in particular, through the relevant anatomical needs of patients, not based on the presumptions you make about their gender.

Don Dizon:

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