Charles Ryan: All right, so we're going to transition now in a different, but I guess related topic, when we think about wellness for men with prostate cancer, and that's mental wellness and clearly a topic that has not gotten the attention that it deserves. I would say that perhaps at Memorial Sloan Kettering where Dr. Roth works, it's an area that maybe it's getting the attention that it does deserve. So for those who don't know, I did my own training in oncology at Memorial Sloan Kettering and I remember Dr. Roth way back then as somebody who we could call and he would come in and talk to our patients. And he had gone on and developed a significant practice as a psychiatry liaison to the Genitourinary Medical Oncology program at MSKCC. And he's had that for 28 years. He is a psychiatrist. He's been the training director of the MSKCC New York Presbyterian Weill Cornell Fellowship and Psychosomatic Medicine for 12 years.

And he's had numerous contributions to the field, including the development of the Distressed Thermometer, the Memorial Anxiety Scale for Prostate Cancer, and conducted an NCI funded double blind randomized placebo-controlled trial using methylphenidate for fatigue in men with prostate cancer, and that's a therapy that we should talk about because I've used it in some of my patients. And most recently designed a geriatric specific psychotherapy for older prostate cancer patients. He's published extensively including two books. The first is Managing Prostate Cancer: A Guide for Living Better and Psychopharmacology and Cancer Care: A Guide for Non-Prescribers and Prescribers.

As one might imagine with a CV like that, he's received numerous awards including the American Psychosocial Oncology Society in the Jimmy Holland Award Lifetime Achievement Award, which is a very prestigious award, as well as a number of other awards. And I'm delighted to catch up with you. Dr. Roth, it's great to see you again and thank you so much for joining us tonight. I know there's a lot of patients out there who are eager to hear your background and the topics you confront with patients. So I guess I'll start right there and just say what are the main topics you confront with patients with prostate cancer today?

Andrew Roth: It's very interesting, Chuck. First of all, thanks for inviting me here. I think not everything that looks psychiatric in the world of prostate cancer is psychiatric. And that's one of the biggest issues is that men have a lot of worry. They might have a lot of mood changes, especially for those men who have more advanced disease and they might be on the antigen deprivation treatments. And you mentioned before these medications when they're decreasing someone's testosterone, they can have a lot of effects on the whole body. They can cause weakness, they can cause fatigue, they can cause men to start crying at the drop of a hat, even if they're watching a baby diaper commercial.

And so what often happens is I go into our clinic waiting room and I expected to see one person, Mr. Jones, and I go out there and I say, Mr. Jones, and two people stand up. It's the partner and it's Mr. Jones. And I get introduced to the partner and then I start walking back and I look over my shoulder and there are two people following me. And I say to Mr. Jones, Do you want them to come in? And Mr. Jones will usually say, Sure, the other reason I'm here, or we have no secrets, or this is something that's been impacting all of us. And very often if someone is having irritability or mood changes or anxiety because of their treatment, it could be chemotherapy. Sometimes when men are getting chemotherapy, they're also getting a steroid with that, a dexamethasone that can cause some emotional changes too.

And so the family's coming in saying he's depressed or he's got an anxiety disorder. And that's where I think it's very helpful to have someone who is a psychiatrist who can try to distinguish what is a symptom of the medication and what is a psychiatric syndrome. And so very often, many of the men that I see don't need to get a psychiatric medication, which is not a bad thing because many of them don't want to a psychiatric medicine. They don't want to be considered, Oh not just do I have prostate cancer, but now they're telling me I'm crazy too and they're not crazy at all. But this is difficult stuff. And being able to tell someone those tears, you're having that irritability that is related to the hormones and

it's related to the hormones because you've got the courage, you've got the courage to take this medicine to save your life. And when you reframe it that way, men and their families might be a little bit less upset about it and then I could start teaching them how to deal with it.

Charles Ryan: It's a fascinating insight and I agree with you. We understate, or underestimate, or appreciate perhaps the courage that our patients take on as they take on these therapies, which alters their physiology, as I said before. And the goal of understanding that is why we're here tonight. And you've talked a little bit about exercise as part of your prescription pad for patients experiencing anxiety and other components of the emotional anguish that they go through with prostate cancer.

Andrew Roth: Yeah, I was really happy to hear Dr. Kenfield speak about her work because no one leaves my office, certainly a new patient without hearing a few different things. One is I usually ask, "Do you exercise?" And many men will say no. Before the pandemic, they may have gone to the gym, before the cancer, they used to work out. Now they say no. I say, Do you walk? And they say, "Yeah, I walk." I said, "That's exercise." Because we know that even walking 20 to 30 minutes most days of the week, not immediately, but after four or five weeks is going to increase mood, it's going to decrease anxiety, it's going to improve sleep, improve concentration, it improves a whole lot of things, improves energy.

So I think I want the patients that I see to be more active and sometimes we have to really start from square one, which is, okay, you used to run marathons, now you could barely walk two blocks in Manhattan. Let's start with a half a block and let's build up. And sometimes that old saying, the Nike saying of just do it is very important because with the lethargy that some of these men have from their treatment, they feel like I don't have the energy to do that. But they don't realize that they're going get these gains back if they're able to do this somewhat consistently.

Charles Ryan: There was a randomized trial in Canada several years ago that I quote about. It was exercise in men on hormone therapy. Men were coached to exercise three times per week, resistance exercise. Its similar to what Stacey was talking about. And what they found was that people not only had better quality of life, who exercised, they had more energy. So if you're tired exercising, some might think, Oh, I'm going to feel more tired, but you're actually going to feel less tired. And I think that's a key part of all this. So can't underscore the importance of physical exercise, especially in men who are receiving hormonal therapies of one type or another. Could you tell us a little bit about the Distress Thermometer, and the anxiety scale and perhaps men listening, patients listening are not in a practice where this is routinely measured and how they should think about it and whether they should talk to their doctors about it, perhaps even.

Andrew Roth: I think when we developed the Distress Thermometer, it was maybe 24 years ago and we thought if we ask men, are you anxious? Are you depressed? Some of them might not even know what we're talking about because they don't identify as feeling depressed or anxious. And so we came up with the word of distress. We have a visual analog scale of zero to 10. It looks like a thermometer. So we made it very medical that no one would assume, Oh God, they think I'm a psychiatric patient. And it became a very good algorithm because our Distress Thermometer, which was just the zero to 10, was then adopted and adapted by the National Comprehensive Cancer Network and the American Cancer Society. And they added something really nice to it. They added a problem list.

And the problem list included spiritual issues, it included social issues, it included emotional issues, it included even the patient's own list of physical problems so that if someone filled this out and they gave it to the oncology team before their visit, these were things that could help the oncology team triage and make a referral and say, this person might benefit from seeing a chaplain. This person may benefit

from seeing the social worker. And even if they only got the business card of the social worker and they said, I don't really want to follow up now even though my score was relatively showing that I was very depressed or distressed, these folks would then be able, if they've got worse, if they start to feel worse, they had a place to go. They knew there was something in the system where they can check in.

And I think that was very helpful for the oncology teams because when I first got to the clinic, the nurses, the fellows, the attendings were getting lots of phone calls, lots of distress from patients, from families, my PSA went up this much, I think I'm going to die. And they're very worried about different kinds of numbers. However, they weren't really sure what those numbers might have meant. And so if we could not say which is the usual reaction from a loving family member to someone who's anxious is, don't worry, everything's going to be okay. And it's like the pink elephant issue. The more you tell someone not to worry, they may say, Well, how do you know there's nothing to worry about? Worry more.

Charles Ryan: Right. As you know, it's an important, probably a vital sign, and I'm sitting here reflecting on when my patients check into the clinic, they're always asked the blood pressure and heart rate and everything and they're always asked, Do you have pain? Which is a very important question. And it was actually a substantial moment in oncology when we realized we were underassessing and undertreating pain. And so now we made it a vital sign, Are you in pain today? Yes or no? And I would think that, are you in distress today is a potential vital sign that we should be thinking about. So there's probably a little bit of implementation, research and work we need to do there to get that into standard practices. And so that's a challenge ahead. And maybe you have some thoughts on how much this has been disseminated into practices around the country.

Andrew Roth: Well, I think actually Canada has made distress another vital sign. And so it is very much focused. And a number of years ago when the Institute of Medicine came out with their care of the cancer patient, they did recommend that all major cancer centers have some screening for distress. It didn't have to be our Distress Thermometer. And frankly, many different centers have different ways of screening and using tools to be able to ask patients, How are you doing? Essentially it's how are you doing over the last week or so? And it may just be that someone's really frustrated because they couldn't find a parking spot or there was a lot of traffic. But very often we're seeing things come to the top that indicate someone might be having a more difficult issue and we usually have the resources to hook a patient or a family up to. And that could be very relieving for a whole family system.

Charles Ryan: Yeah, I think we should in a way try to put mental health and anxiety and depression in the context of the disease states, if you will. One of the challenges I think is the treating physician sometimes to have the context of the world the patient is coming from. I might see a patient on... The first patient I might see might have metastatic disease and actually be in pain and be experiencing resistance to treatment in a very different situation, and then I might see the next patient who just had surgery a year ago and now his PSA is rising and it's 0.5 and there's a lot of options for that patient and the anxiety in that second patient, maybe higher than it is in that first patient. Right. Because the disease extent is not always proportional to the anxiety that the patient may be feeling. In fact, some of the most anxious moments I think in the life of a prostate cancer patient are that first diagnosis. What kind of treatment should I have? Even early stage disease for sure.

Andrew Roth: Yeah, I think you're right. And we did develop another instrument called the Memorial Anxiety Scale for Prostate Cancer or MAX-PC for short. And we had three subscales, prostate cancer anxiety, the PSA anxiety subscale, and a fear of recurrence. And we thought for sure that that middle

subscale of PSA anxiety was going to go off the wall. And interestingly it didn't in our first study. And so what we did was we went back and looked at not just one PSA correlation with anxiety, but three PSAs in a trend. And we found something that was quite interesting. Change, uncertainty is very important in terms of anxiety. And so if someone had a PSA that was going up, yeah, that's a no brainer. They were going to have more anxiety. If it was going up, down, up, still high anxiety. If it was going down, up, down, high anxiety.

And even for those guys where it was going down, there was high anxiety. If there was stability in the PSA, whether it was here or here, there was less anxiety. And I think everyone knows that anything that can go down can go up. And that's where a lot of men are focused on. They're focused on the future and therefore every PSA is a totem of life or death even though what I know you explain to your patients and our oncologists explain to their patients is that it's a signal. It's a signal. And what you do really well is try to distinguish noise from a signal and if there's the real signal, you know what to do about it. And that's in your toolbox that I think can help patients deal with the anxiety. But most guys want to know, I got the one and done. I got the definitive treatment that worked.

And recurrence or potential of recurrence is very scary because it means for many men, Uh-oh, if I'm not cured, I'm going to die. And that's a lot of the work that I get to do with men is how to help them understand that they have a lot of life to be living and don't just get ready to die. Maybe I could say especially with prostate cancer, but we know there are aggressive forms of prostate cancer, but once someone gets in their head, I might as well get ready to die, they stop doing things that are very life enhancing, like hanging out with their grandkids, hanging out with their friends. And that really sucks a lot of the life out of them.

Charles Ryan: Very important point. And not everybody who undergoes curative-intent therapy and then experiences the relapse is going to die of prostate cancer. It's a very unique disease from that perspective. I call this the existential moment that my patient goes through when he's had surgery, he's had radiation, and those are both curative-intent therapies, and now he comes to me and I'm an oncologist and I don't say that I can cure your disease except in rare instances with hormonal therapies or other therapies, but that does not mean that you're dying of this disease. It means that we're going to manage it. And I try to put in the context of if you've just been diagnosed with diabetes, we're going to sit down and we're going to talk about how to manage your diabetes and help you live well with it. And for many patients, the timelines are decades after even a recurrence of the disease. So I think that's a really important key point to make.

Andrew Roth: Yeah. Chuck, that comes back nicely to the exercise discussion we were having before with Dr. Kenfield. There are some of our patients who come in and say, I exercised all the time and I still got this prostate cancer. What was the point of that? And I usually have the discussion at that point that if you weren't exercising really well, maybe you would've had a heart attack already. You could've had a stroke already, your quality of life might be much worse. And in fact, if you're in decent shape and can stay in as good a shape as possible, you might be able to deal with whatever treatments are coming at you from the prostate cancer side as well as the other things that are naturally going to happen as we all get older. And so why not be better able to deal with those things by being in better shape?

Charles Ryan: I think you've referred to this as... Is this what you referred to as sort of all-or-none thinking, which is, it's all bad, now that I have this cancer and it's recurred and it's now you're trying to pull the patients back from that sort of trap of all-or-none thinking?

Andrew Roth: And it's hard to do that. Again, if I just say, Oh, you're getting into all or none good or bad, they might say, Well, tell me what part of that I could die is good. And then we have to have the other discussion. I need to hear from them what else is going on in their lives, who else is in their lives? What do they have as goals for the future that they would like to work towards? If they used to spend hours with their grandkids and now they don't have the energy to do that, I'm going to guess there may be more of a likelihood of depression when they say, I don't want to see the grandkids anymore. But the guys who are saying, a half hour with them still makes my face shine up, my smile its wide. That's what we want to focus on.

Charles Ryan: Living with the recurrent prostate cancer, not focusing on the dying of it because in many cases you're not going to. I've been studying prostate cancer for 25 years now, and I've come to respect it as an enormously diverse disease and getting into this idea of all our non thinking, we the physicians taking care of these patients really need to help put our patient's disease in the proper context. If you have low risk score, low Gleason score, slowly recurrent disease, that's a very different thing. And somebody who's has metastatic disease and somebody who has metastatic disease with this or that mutation may have a very different story to the person sitting next to them in the waiting room. So I think that's incumbent on us as the treating community is to understand and respect and communicate this diversity, the diversity of prostate cancer biologically and clinically for our patients.

And this brings me to a point that I think is also important with regards to mental health, which is in particular in the early phases of this disease we the physicians, I think, put too much pressure on the patient to make decisions about their care. We say you've got early stage disease, you could do active surveillance, you could have a radical prostatectomy, you could have radiation therapy, you could do focal therapy, et cetera, et cetera. People will go through all these different things and we say it's your choice. And of course it is their choice, but it's also putting an enormous burden or pressure on them to make these decisions. That happens less, I think, in more advanced disease where there are, to be quite honest, there's a little bit more certainty about the way things work and should go. Do you see this as a really important problem in patients who are facing a diagnosis of prostate cancer and making decisions?

Andrew Roth: Yeah, I see it from the folks who have more early stage disease. So a number of the folks who get referred to me from the urologists or the radiation oncologist, they've already... Not only do they have one second opinion, they might have four or five second opinions. They've seen a couple of urologists or surgeons, they've seen a few radiation oncologists, and then they come to see the medical oncologist as sort of the tiebreaker. And the tiebreaker can't really be a tiebreaker either. But very often what the medical oncologist can do is synthesize some of the arguments both ways. And everyone is always looking for someone who's going to go against their profession. So if the radiation oncologist says, I think you should do surgery bonus points [inaudible 00:21:27] goes the other way.

But I think you're right. In our consumer oriented society, patients want more control, but I don't think they ultimately want their total control. They really need to hear information from their doctors. And what's interesting about prostate cancer is you can get 10 prostate cancer experts in a room and you might get 12 different opinions on what to do. And that's from people who really understand the disease. But we are all different individuals and our patients are individuals. And some people will say if the recommendations are leaning towards active surveillance, there are some guys who say, I can't live with a tumor inside of me.

There are people who are being told that maybe surgery is a better option than radiation for them, but they say the chances of erectile dysfunction are greater with that than with the radiation. Although with

the radiation, it might be further down the road. And so they can get very confused. But my being able to talk with them about what their goals are, what do they think they might be able to live with in terms of the side effects if they happen, and what might they have a really difficult time living with. And what goes on in their head, maybe from past experiences, others they've known with prostate cancer or other cancer and the treatments they got and what is getting in the way of them making a better decision right now.

Trying to take away some of the potential guilt, the buyer's remorse of any decision is very important because if a treatment goes well, people say, I made the right decision. If it doesn't go the way they want it, they got a lot of side effects or the cancer came back, they're going to perhaps feel like, Oh, I should have done the other decision, the other treatment. And that's false thinking.

Charles Ryan: A well known entity in prostate cancer is treatment regret. And that's actually going to be our topic next month on this very webinar with Dr. Matthew Cooperberg, a urologist from UCSF who's studied this over the course of the last many, many years. And it is an interesting point you make about our consumer mentality where we give them... We the medical profession, want to give our patients a menu to choose from when really what they want to say is what I think you should do is you should do this. And I try to do that when I really think it with a patient. I try to say, Look, taking everything into consideration, I hope I'm taking everything into consideration, recognizing that I may miss things. I say, I think you should do this because of X, Y, Z reason. And then may acknowledge that there is some ambiguity in all of this process and that there may be one or two correct decisions. But the patients should know.

That's also challenging for the doctors to sort try to weigh all these different factors. But I certainly think we as a medical profession, and you've been involved in medical education and I have as well, which is we want to be deferential, we want to lay out all the options, but sometimes it's easier if we really feel there's a right path, we spell it out. And I have throughout my career treated testicular cancer where pretty much every step you make for testicular cancer care is well established with data and you can just say, this is how you should do it. And there's not really a menu of options. This is how it's done if you want to be cured to this disease. So really fascinating. And another reason why prostate cancer is such an interesting and challenging disease to treat.

Final couple of minutes here. Tell us a little bit about how the patients listening can interact with a psychiatrist if they're seeing one on the assumption that they aren't fortunate to be at Memorial Sloan Kettering where they have somebody with 28 years of prostate cancer psychiatry experience at their disposal. Who should ask to see a psychiatrist and how might they help their psychiatrist help them out from a prostate cancer perspective?

Andrew Roth: Whether it's a psychiatrist or a psychotherapist, a social worker or a psychologist, I think if they or the families are noticing trends, and trends that are... And it's not just that someone has a good day and a bad day or a couple of good days and a couple of bad days. But one of the ways I like to try to distinguish if someone has a significant depression... But we know depression can be impacted by pain, it can be impacted by fatigue. And so I might ask a man, so if I had some magic pill to give you that would improve your pain or improve your fatigue, what would you like to do? And the guy who's not in a major depression is going to tell me, I'd love to hang out with my kids or my grandkids. I'd love to even try golfing again. I'd like to do this.

The person who is much more depressed is maybe just raising their arms saying, I don't care. I don't really know. And so when the oncology team picks up on these kinds of things, someone is less interested in getting the next treatment. And that doesn't mean they're depressed. They might feel

conflicted of, I went through this stuff, I had these side effects and I didn't get what I really wanted. Why would I do something else that might have more side effects? And that's a reason... And so sometimes talking with a therapist could help someone gain some clarity about what they want to do, what is important to them, how they get back to living instead of dying.

And it is difficult if the oncologist says, Hey, maybe you should see a psychiatrist down in the community, because not every psychiatrist or therapist in the community has experience with cancer. But a good therapist can handle this stuff very well. And I'd rather someone be talking to someone or getting some kind of input or medication if they need to. But even with some of the newer antigen deprivation treatments we have, some of them can interact with some of the psychiatric medicines. So I've consulted with people who are in private practice to let them know where I think medications can be helpful or they need to watch out for rising levels or decreasing levels or changing things in the cancer.

Charles Ryan: I was just going to say, we've been talking for 29 minutes and haven't talked about antidepressant medications, we haven't talked about anti-anxiety medications. And that of course is a decision that has to be made in conjunction with a mental health professional and not something we can make, I think, blanket statements about. Do you want to close on with any closing thoughts on that statement?

Andrew Roth: Ryan, I think a lot of people come to me and the patient saying, I definitely don't want a medicine. And I'll ask them right up front. When your doctor referred you to me, were you thinking, I hope he does talk therapy, I hope he doesn't do that talk therapy, I hope he gives me a medicine, I hope he doesn't give me a medicine? And then I do my assessment to see how much a medicine may help and which medicine might help. When we did that fatigue study, we found that even though fatigue was such a big problem and very prevalent, a lot of guys didn't want yet another medicine, a psychiatric medicine like a stimulant to deal with it because they were afraid side effects.

Charles Ryan: Yeah. Well, I can't thank you enough. It's been a great half hour. I think I could keep talking to you more and we could get into some deeper issues and some more complicated issues because there are many, as I said with this very diverse and complicated disease. I want to congratulate you on a wonderful career at Memorial. And I recall seeing you and admiring you as a fellow back in 2001 or so when I was there at that time. So it was really great to catch up with you and hear about the field and all the work that you've done.

And I think I'll wrap up the webinar with just a quick couple of messages here. And I want to thank everybody for joining us. Again, look at pcf.org/pcam22, and we have resources there about living well beyond cancer, resources for African American men, nutrition, et cetera. A really great resource. And we hope that this has been helpful for all of you and that this becomes one of your resources in the form of a monthly tuning into this webinar. So Dr. Roth Andy, great to see you as well. And goodnight everybody, and thank you.