

Charles Ryan:

Hello, everybody. Good evening, good afternoon, good morning, depending on where you are. And it's great to see you all again on this webinar. This is our second Prostate Cancer Foundation webinar on the issues most important to prostate cancer patients. I am Chuck Ryan, I'm the CEO and president of the Prostate Cancer Foundation, and I'm going to just do a couple of introductory slides, then we'll get on with our guests here.

For those of you who don't know, the Prostate Cancer Foundation, the PCF, is the world's leading philanthropic organization dedicated to funding lifesaving prostate cancer research. Our mission is to reduce the death and suffering from prostate cancer. We've funded 28 countries now, 245 leading centers around the world, and over 2200 researchers. We are the global public square of prostate cancer, funding research, leading in communication and education around the disease, supporting patients, and applying discoveries.

And I think we got some really good evidence of our legacy this week. Dr. Carolyn Bertozzi, at Stanford currently, was awarded the Nobel Prize, will be awarded the Nobel Prize, in chemistry. Her and her team developed a very innovative method of creating new chemical compounds and labeling molecules without interfering with biological processes. It's quite a fascinating read, actually, you might want to look it up. And this process has been used to develop multiple new medications. But little less known to many people is that she was actually the recipient of two Prostate Cancer Foundation grants going back to 1999 and 2000. So that is a great piece of our legacy and something we're very proud of, and congratulations to her and her team.

So our topic tonight is not click chemistry, or the Nobel Prize, or even the development of new therapies, but I'm delighted that we have two of my all time favorite conversation partners tonight to talk through the issues that we are facing in the world of prostate cancer, and we're going to start with Dr. Morgans. Dr. Morgans is a genitourinary medical oncologist and the medical director of the Survivorship Program at Dana-Farber Cancer Institute. She's a clinician and an investigator, she's designed numerous analyses and prospective clinical trials that have looked at quality of life, patient report outcome measures, as well as a whole host of factors related to patient experience during therapy for prostate cancer. I've been proud to call her a research partner and a collaborator, and we, collectively, before I joined the Prostate Cancer Foundation, received a Prostate Cancer Foundation Challenge award together, which is looking at cognitive function in prostate cancer. She's been the recipient of a PCF challenge award, as well as a PCF creativity award. So one of our brightest minds in the field now thinking about the many topics facing patients.

So we're going to start tonight with a really important topic called shared decision making, that affects so many men affected by this disease. Alicia, great to see you, thank you for joining us. Tell us a little bit about shared decision making, and just define it for us so that we're all on the same page.

Alicia Morgans:

Sure, thank you. I think shared decision making can have many meetings to many people, but in research at least we define this as the active engagement of patients and clinicians in sharing, bidirectionally, their preferences, beliefs, their understanding of the data, so that they can work together to come to a shared decision, or a decision that they all agree upon as the one that is going to be the best balance of cancer control, sorts of interventions and toxicity, and is going to make the most sense for that individual patient.

I think, importantly, each side comes to the table with his or her own bit of expertise. The physician comes maybe with some of the understanding of the data and the nuances around which patients may benefit more or less from different treatments, and what the side effects might be from different

treatments, but the patient comes, very importantly, with the expertise that only an individual can have about his own body, his own wishes for treatment, his own understanding and wishes for something that he wants to avoid in terms of complications. Those things are things that no one can assume for another individual, and so that expertise is equally important as they all come together to make that choice and that treatment decision together.

Charles Ryan:

So let's divide this into, if it's a shared decision making, we've got two components, right? We've got the physician making the recommendations, and with the experience and the knowledge around various treatments, and then you've got the patient and his family, and other decision makers important to the family. Let's start with the doctors and then we'll get to the patients. With regards to the doctors, what is their responsibility, in your mind, as far as shared decision making in the oncology space or the urology space for this disease particularly?

Alicia Morgans:

Well, I think the doctors need to explain what the options for treatment are, and what the different treatments entail in terms of time commitment, risks, benefits, complication risk. Then of course what is entailed in terms of things that I sometimes call X factors, so the amount of time that one will spend in the hospital versus at home, the needs that that person will have in terms of whether they're going to be reliant on someone else or not, if they might find themselves, if we're talking about advanced disease, in a situation where they're going to be somewhat incapacitated versus fully functional and able to care for themselves at the baseline, pre-treatment. All of that is really important from a physician's perspective.

Then on top of that, that individual needs to explain, what are our expected outcomes in terms of disease control, which is going to be so important to so many patients, as for many this is going to be their top issue, and then what is going to be the expected complication rate and what do those complications look like short term and long term? For many patients, this can be equally if not more so important than the cancer control rates.

Charles Ryan:

So where do physicians fail as participants in this process and how could we be better?

Alicia Morgans:

Yeah, that's a great question. You did not prep me for that one, so thank you for that. I think that physicians fail when we don't communicate in a way that is really clear and on the level of understanding of the person that we're talking to. Sometimes, especially when things are complicated, we talk at a high level that even other physicians who don't practice in that specific area may be a little confused by or a little off put by. Part of that is that it's harder sometimes to explain something, and the nuts and bolts of something, in a way that everybody can understand. It does take an extra minute or five to go into something a little more detailed and not just gloss over it. And I think that sometimes because of time pressures, or perhaps because we have just maybe not even the understanding that our patients are not understanding us, we gloss over certain things. I think that's the biggest thing.

The next biggest thing is that physicians fail when we don't listen, and we don't actively engage in that second part of shared decision making, which is not just us telling the patient what the options are, but really listening and then actively eliciting the patient's preferences, their understanding, their wishes, their needs, their restrictions, their childcare situation, or the fact that they need to take care of their

sick wife or partner, or whatever those things are. So we have to not just communicate to the patient, but we have to actively engage that patient and pull information out even when patients are less, I guess, inclined to share that back and forth with us.

Charles Ryan:

Yeah, no, I would agree. I think, when I think of the mistakes I've made over the years with regards to decision making, it always stems from not knowing enough about who you're talking to. And that is the biggest challenge of course in all of this, which is, as you point out, the time pressure. Then there's also a challenge, and I will put this on the patient's side in a minute, which is eliciting from the patient and their family, these key factors, the key most important decision factors.

As you were talking, I was thinking about certain individuals don't want to take particular therapies, now we're talking about more intense therapies, probably for more advanced disease, because they don't want to be a burden to their family, or there's a financial thing in the background that you don't know about or something like that. So that's always a challenge because you can listen, but there has to be a two-way street.

So we physicians, we fail sometimes, or we don't reach the perfection that we think we're capable of in this process. Anything systemically, anything the system can do, or that you could recommend to us physicians as aids to helping with shared decision making, whether it's asking patients to put down their goals of care before they come and see us, or to follow up with phone calls, how could we do better?

Alicia Morgans:

Another great question. I think one of the things, where I currently practice, we have a system where every patient who comes in with localized disease is seeing a medical oncologist, urologist and radiation oncologist. And I don't think that most systems have the bandwidth to do that. We have about 20 medical oncologists in our group, which is not the norm in the majority of centers, which means that all the medical oncologists can see these patients with localized prostate cancer. It's just the way that we have grown up. But that allows every patient to get a radiation oncologist view, a urologist view, and then a medical oncologist to put things in context, and also offer things like genetic testing, maybe PSMA PET scans, if it hasn't already been discussed.

And it also is that point person to pull together the other opinions. Although, I would say that I'm really fortunate that our radiation oncologist and urologist, when I see the patient before them, they serve in that role to pull all those opinions together. So that is something that I don't know if that could be scalable in large terms, and I actually assume that it's probably not going to be scalable in large terms.

But encouraging our patients to see other specialists, even if it's not standardized within our system, even if it's just a urologist recommends that patients always see a radiation oncologist, a radiation oncologist always recommend a vice versa, to see a urologist, I think that can be really, really helpful, just so that everybody has an understanding of both sides of the coin. Because it is, for some patients, it can be off putting. The person that's doing my surgery is only telling me about surgery, for example. That can be off putting for some individuals. But having the balance I think can be really helpful.

Charles Ryan:

I've had a recent patient encounter where they said, "I had the best of all of this because I think it was a radiation oncologist who told me I should have surgery, or might have been a urologist who said you should have radiation." Which is, if somebody goes against what is perceived to be their best interests, that is felt to be the highest form of sincerity perhaps, I don't know. I would like to think that we don't have to go that deep, that we should just always not be advocates for our modality, so to speak.

But you bring up another point, which has been, I think, a real challenge, and I've had it in my career as well, where people come to me to break a tie between radiation and surgery. The typical medical oncologist out there in the world isn't really equipped to do that, because it's not part of what they see on a daily basis. I'm talking about community oncologist, and you're in a very special place, which is a highly focused one, major academic center, et cetera. So that, perhaps, is a challenge that we have as a workforce, that we have to think about, and we need to perhaps make resources available to our oncology colleagues to help in that process.

Alicia Morgans:

Just a comment there. I think that sometimes we are most helpful, not necessarily in our nuanced understanding of these treatment modalities, but just in our ability to say, here's the big picture, what's most important to you is what's most important in making this decision. Because ultimately, the cancer control outcomes, or how well each of these different modalities cures the cancer for a majority of patients with localized prostate cancer, it's equal. So even having the medical oncologist really elicit, again, those patient preferences and those barriers. Maybe the patient lives two and a half hours from that radiation facility, and Monday through Friday travel for six weeks on end is actually going to be a major barrier for that individual who's also eligible for surgery. So talking that through, what does that look like? Helps people to make those decisions. So even if we don't have the nuanced understanding, I think that medical oncologists are expert in pulling out what's most important to patients.

Charles Ryan:

Yeah, agreed. We're going to switch now and think more about the patient role in all of this and advice that we have for patients. So you're standing outside of an exam room with a patient, he's about to go in and see his doctor, and you're going to give him three pieces of advice on shared decision making. What are you going to say to him?

Alicia Morgans:

Wow, these are zingers today, okay. So, what he should do with his doctor, I would say know what's most important to you, what you want, and then I'm going to say the second thing, just to have another thing there, what you don't want. And know the order in which these things lie, because a lot of times we get some of what we want and we accept some of what we don't want and somewhere in the middle is where we end up. So know both what you want most and what you definitely do not want. Then the third thing would be talk, say these things to your doctor, ask questions.

And actually, I'll add a fourth one. It's okay for most patients to take a little time and to think it through. I have a lot of patients who by the time they're finished we're talking and they say, "I just need a little bit of time." I certainly don't want them to take six weeks, but I often will have my nurse call them towards the end of the week, or early the following week, and the patient can take that time and speak with loved ones, caregivers, others, and put those things in perspective and then make a decision.

That is one luxury we have in prostate cancer, even with high risk prostate cancer, at least, usually, we have a few weeks where we can have that ability to take everything in and make the best decision for that person without the rush that we sometimes see in other in other cancers. Breast cancers are diagnosed on a biopsy and then by the end of the week they're in surgery. I mean, it's a very different situation, and I'm grateful that we don't have that timeline in prostate cancer. We are urgent, but we're not emergent in our decision making.

Charles Ryan:

Right. All four of those were great. I would say just a couple of simple things, I would say take a pad of paper with you, and a pen, and write down your questions. I love it when I have a patient who's got a family member who's taking notes. While I'm having a conversation with the patient, somebody else is taking notes. How do you feel about patients recording their conversations with their doctors?

Alicia Morgans:

I'm always okay with that. I mean, if they hear something on playback that they don't understand, I'm also always okay with trying to sort something out if there seems to be conflict on that. That doesn't usually happen, but I would be, if that ever did happen. I think you're going to be talking to Matt Cooperberg shortly, I think there's been some work that's happened at UCSF looking at patients recording conversations and cancer care, and trying to understand how that can best be leveraged to optimize the patient experience, so maybe he has some insights. I know it wasn't him, I think it was from the medical oncology group and one of the of the junior faculty working with maybe Rahul Aggarwal, but really interesting work looking at recording and how that can benefit us. I'm always okay with that.

Charles Ryan:

Yeah, good. Yeah, I am as well. A couple of other things that I think patients can think about, which is, for example, what I like to do when I've had a really complicated visit with a patient and I'm going to write my summary, I will sometimes dictate in front of them so they hear what I'm saying about them into the chart. I think that that can help because there's always questions. After I've summarized, the patients, almost uniformly, will say, "Oh, I want to add this", or, "Now that you say it like that, I think about this", et cetera. So there's all kinds of little tools I think that patients can ask for. They can ask their doctor, "What are you going to put in my chart?" Then of course patients now have access to what we write about them, which I think is a good thing, because you get feedback from what you say and it makes you choose your words maybe a little bit more carefully. So that has created a whole new situation around shared decision making, I think.

Alicia Morgans:

Yeah, so one comment I would have there, I actually write my notes in the same way, because I view my notes as a mode of communication to other healthcare professionals, and I'm always happy to answer questions, and I'm happy to have those notes released to patients, but they're written in medicalese, because I am trying to communicate to other doctors. So I'm always happy to interpret, but again, patients haven't usually had any comments on that part where we're really trying to give instruction to other doctors.

But one thing I would say to patients, I'm all for actively engaging in that shared decision making process, but one of the things that's happened as now all of our records are available to us, pretty much the moment the attending physician signs the document is that you may find that your gateway tells you that your pathology has come back, your genetic testing has come back, your PSMA PET imaging has come back, or other things, and you may know before your doctor knows. That can be challenging because those, just like I mentioned with my notes, those are all written in medicalese, because it's meant to communicate to doctors. There's not really a translation for people who are not trained for years and years in how to understand those, and that can be really stressful.

So I would caution patients, yes, it will be out, but what you may want to do is, what I usually do with my patients is, I have a test coming back within a day to a day and a half, I have an appointment where we are going over those results, because the report itself can be stressful and written in ways that does not make sense. Something that's a completely benign finding, or non-cancerous, non dangerous finding

can sound like the end of the world when we write it in medicalesse. So just to be aware of that, when you're trying to engage in shared decision making, make sure you include your doctor in that process, because sometimes it can be really stressful to read those results without that collaboration with your doctor.

Charles Ryan:

I think one of the major problems patients face is they get overwhelmed. You're talking about medicalesse, and you're talking about patients going through their medical records, and let's say it's a 45 minute visit where you've presented three different options for treatment, whether it's for localized disease or you're talking about starting somebody on radioligand therapy or chemotherapy. I think this is a key point, which is enabling the patient to have the time and the space to digest things and come back. One possibility is to have, and I've seen this done, and I sometimes will do this, have a two visit decision making visit. And here are your options, go and think about it then come back.

So let me just, in the last few minutes we have, let's just troubleshoot some problems that come up with regards to patient decision making. One is, I think the doctors, sometimes we put too much of the burden of the decision on the patient. We talked about this as we were preparing for this, if you go back two generations and before that, medicine was a very paternalistic thing. You didn't really talk to the patient just because they couldn't understand it, that was the idea, and so you just recommended something and that was the way it was, and you were the doctor and there was no questioning.

I think medical education now is swung the other way, which is saying the patient is the most important decision maker in the process, and I would agree with that statement, but it does lead to patients getting overwhelmed sometimes. So what we were talking about is sometimes I think it's just okay to say, "Look, I'm the doc...", you don't say look, but you say, "I'm the doctor and I think you should do this." And defend your position. Have an opinion, be firm about it and defend it. How do you respond to that?

Alicia Morgans:

As you said, we talked about this before. There are things that I can recommend, and there are things that I won't know for any individual. I will be imposing my own preferences and beliefs if I don't elicit those from the person. So when I find myself in a situation where the patient that I'm working with and supporting is clearly stressed by the decision, and people usually will say, "Well, I just don't know. You're the doctor, please tell me what to do." Or they respond by just not making that decision, which can be just a more passive way of saying, "I just don't know how to make this, it's overwhelming, this choice."

What I do is, again, actively elicit their preferences, what they most want to happen, what's most important. For some people maybe it's not, "I want to be alive for the most amount of time. I want to avoid a wheelchair. I want to avoid being sick for half of my treatment course. I want to avoid..." Whatever it is. They may have their preferences. Then I also try to actively elicit, what are you trying to avoid? What is the worst thing? What is the worst thing that you can imagine? Maybe for someone with localized disease, it's incontinence. And then we have these stakes in the ground where we can say, "Okay, this is what you want", and we talk it through, "This is what you want, this is what you absolutely want to avoid. Here's, from my perspective, how you put those together best."

Charles Ryan:

I love that.

Alicia Morgans:

And so I do try to tell them, because it's ultimately, I'm not going to say, "You're 59 and you should have surgery for your localized prostate cancer", because for 85%, 90% of guys, maybe that's true, maybe that's what they want, it's the best mix of their preferences and their wants and their wishes. But for that 15% it is not, and it is not for me to say that for everyone. But I do try to understand what they want, what they don't want, and then I give them a recommendation based on that. I always say, "If that doesn't resonate with you, let's go back, let's figure it out. Because we have the luxury of, we can, like you said, we can have another visit, we can have another conversation, we can work this out." We have to make a choice, and I usually give people a deadline, "This is when we need to figure this out, but we can have multiple conversations until that happens, let's make that together."

And I hear you when you say that we can't be paternalistic, at the same time, it is so important to understand our patients and we can't assume, based on what we think is best or worst, that we know what's best for any other individual. So I do try to really pull them into that decision as much as possible. I will take responsibility for the decision if that's what they need, in terms of, "This is what we chose", and no matter what, we can't always account for cancer, we don't always know.

Charles Ryan:

You said the really most important thing I think that people should take away from this, which is you the patient need to go into the doctor and be ready to verbalize what is most important to you.

Alicia Morgans:

Yes, yes, yes.

Charles Ryan:

A lot of people, when I ask that question, they'll say, "Well, I don't want to die of prostate cancer." Well, of course, but with a little bit more granularity in terms of treatment, side effects, time, distance, travel, burden to family, et cetera. There's so much more that we could dive into on this. We haven't even really talked about how to integrate your spouse or your caregiver and others into the decision making. Last couple minutes on that point though, how can we enable our patients to be really a team of decision makers?

Alicia Morgans:

I think it's interesting that, in my clinic at least, a majority of patients and their either spouse, partner, loved one, whoever, adult child, people come in as a team. This has been something that has lately come back, and I'm really grateful for that-

Charles Ryan:

Post-Covid, yeah.

Alicia Morgans:

... because during the pandemic people were on their own in the clinic.

Charles Ryan:

That was terrible.

Alicia Morgans:

And that was devastating. There's only so much you can do by having someone on a telephone listening in, sitting on the table. So they are back, and people do, they talk to each other in the room. Sometimes I will pull out the comments from the caregiver, the loved one, the spouse, whoever it is, and just say, "Oh, that's really interesting. What do you think about that?" To the patient. But having people in the same space again, I think really has helped that whole process. And if patients are coming into this, luckily most people are not on their own, and so they do bring people in pretty naturally, but I do try to help facilitate that when I can.

Charles Ryan:

Yeah, this is a wonderful part of being a physician, is dealing with, at least from my perspective, dealing with families and making these complicated decisions. However, it's also very challenging, because I've, I'm sure you have too, mediated disputes between dad and the adult children, or husband and wife, or whatever, about whether treatments should be done. In some cases you find yourself helping to mediate the challenge there, so your thoughts on that?

Alicia Morgans:

That is true. I had one just a few weeks ago. It wasn't necessarily surgery versus radiation, it was do you want to get treated at this center or do you want to get treated closer to home? This was metastatic disease, this was going to be a long term engagement, and patient wanted to be closer to home. And actually, that team, they were doing a great job. I reviewed all their records, they had it down. They were offering the latest triplet therapy, they were doing all of it, but the spouse really felt like, "I really want to have him at this academic center, and I want him to be here for as long as he can be here." And that was her driver. So you could see both sides, and they did not work it out before they left the clinic room. And I know they're going to get another opinion and that's good, I can't solve that problem for them.

Charles Ryan:

No.

Alicia Morgans:

But these things happen and we just need to support people as they work through them in the best way that works for them.

Charles Ryan:

Yeah, but you also pointed out another really important role that we can play is sometimes we're just the platform, we're just the table around which people sit to have this conversation.

Alicia Morgans:

Yes.

Charles Ryan:

And sometimes our job is to get out of the way.

Alicia Morgans:

Yes.



Charles Ryan:

All right, well I wish we had more time to go through this, we could probably talk for hours on this. And there are so many challenges with patient communication and with shared decision making, we really didn't get into the situation of what do you do when you just disagree and you think a patient's going to do something that is harmful to them? And this comes up a fair amount, where patients read about something on the internet or something like that, that they want to go after, and they want you to share in that decision making, which is hard. But I suspect I know how you would approach that.

But I want to thank you for your time and thank you for all of your great research and effort, and you're really a leader in the field in helping us to determine what matters most to patients with this disease as they go through the journey of treatment, whether it's localized disease, recurrent disease, metastatic disease, or whatever. So thank you so much for joining us and hopefully we'll have another conversation sometime.

Alicia Morgans:

Well, thank you so much for having me. It's been a pleasure.