Interview 6

Nov. 2, 2017

How are you doing?

I’m good thanks. Everything going well?

Yeah. Thank you very much for agreeing to participate.

Absolutely.

Um, I just…I’ve been asking everybody kind of a set of over-arching broad questions and um, kind of looking for the themes that, um, that appear through the advocacy efforts and what people are saying they’re doing and, and maybe fill in some of the gaps, hopefully, through all the literature and all that that good stuff. So that’s the idea.

Ok, great.

Um, so I guess the first question is just how did you get involved with oncofertility advocacy?

Um, so, um, I’ve been involved in mostly pediatric oncology for most of my career as a either nurse, nurse practitioner, and, um, had a little bit of it but we really didn’t do much with it, um, until this, you know, sort of the AYA movement started around the country. Then I was, um, I had worked with a lot of adolescent/young adults in my career, different diseases, you know, sarcomas, lymphomas, different things like that so I, you know, kind of always had an interest…but um once the AYA sort-of movement started around the country we luckily here at Stanford, um, had people who were interested in starting a program. And so once, um, then I was luckily enough to be able to… to develop it and launch it. So, that’s really how I got involved, was once we started looking at, “Okay, what would be important in an AYA program?” Um, obviously fertility was one of the biggest things. That ended up being sort of the main focus of our program in the beginning, um, and so then I started working with our fertility specialists, um, as well as oncologists and things like that, um, and started really, kind of, reading and researching a little bit more about fertility and then obviously once we launched the program the, the need and the importance got, you know, even more intense as I saw people, started seeing patients, um, and then now it is even moved into the survivorship world as well. So, um, not only new diagnoses but also, you know, for those who—well, for everyone. Even if you did preserve, what do you do in the future? But then also if it never got discussed, really, nobody really talked to you about fertility, then re-educating those patients, you know, “Now what do I do?”

Mm-hm. So why is this coverage important?

So, number one I think, my view on it because of what I just told you is, you know, my view is different from some views. That I lived in this world for a long time as a provider and didn’t understand.

Mm-hm.

Um, because, you know, what the physicians and everybody were saying. Um, that, “For this disease, you don’t have to worry about it. For this disease, you don’t have to worry about it.” Um, and I think it’s, it’s such a need because, um, it’s more than just preservation. Obviously, preservation’s very important, but I think that’s what, um, skews the views sometimes, is that if you can’t, you know, if you’re worried about this disease, you know, let’s not talk to them about it because they don’t have to worry about it anyway, quote, um, and that, you know, I don’t want this to, you know, want to put off their, their treatment. And so I think, um, what I see as the voice of the patients—the voice that says, you know, “You need to tell us about it, because it is our choice, number one, but that doesn’t mean, you know, we’re going to just not listen to you either.” Right? And I think, um, being able to, you know, give the information to the patients I think is what’s most important. Giving them the information—all the information, you know, not just about the disease, not just about fertility, but what does that all mean? And, and also the—it’s okay to say, “We don’t know.” You know what I mean? And I think that’s one of the things that, so, we’re not sure. Um, it doesn’t *look* like this regimen you know, affects fertility but you know, we haven’t followed these patients, you know, long term. And we don’t have a ton of long-term patients-right? You know what I mean? Just kind of being honest about, you know, what is… just like you would be for any other side effect. Um, that you know, that- that we know might happen. We don’t know everything. We know that some people have, you know, heart issues after doxyrubicin, right? Not everybody- some people do. And so, I don’t, you know, I think people getting more informed, um, about it regardless if you’re a patient, a provider, no matter where you are in that field I think that’s what’s really needed. Um, and why is it so important is that you know, these are survivors that, you know, are sort of in a new world, right? We didn’t see this 30 years ago. Um, so we *don’t* know. So I think it’s really important, um, that we be honest, um and allow patients to learn everything they can about it.

Mm-hm. So are you suggesting that the, the, data is limited on certain diseases, certain cancers, and it’s affect on fertility?

Well, there’s studies out there. So for instance, like Hodgkin’s, there’s…Is that what you had?

What was that?

Is that what you had?

Yes.

Okay. So I think that’s a good example then, cuz we can have a good discussion about it. I think many physicians, um, have a-something sort-of in their head about certain regimens.

Mm-Hm.

And that, that—they always say, “The studies show…um, that this doesn’t affect your fertility.” And um, and I kind of question that sometimes, like, maybe there’s one study out there that what? You know, however many people, right? Are they in their 20’s? Are they in their 30’s? You know what I mean?

Mm-Hm.

And so I don’t feel comfortable saying that to patients. I think that, um, you know, giving them the option. And then if you really don’t, you know, like I said, if you, if you, if you’re having symptoms—shortness of breath, and you can’t lie down flat and, you know, then that’s, you know, a reason to start therapy. But I still don’t think the message should be, “You don’t have to worry about it.” You know what I mean?

Mm-Hm.

I think the message should be, “Here, let me tell you everything we know, which is that you’re gonna lose more eggs.” Right?

Mm-hm.

That’s, that’s a given, right?

Uh huh.

For females, right, that’s a given. You’re going to lose more eggs if you get these kinds of chemotherapy, right? Some are going to be more than others. But we don’t know each person’s, you know, what were they supposed to be? What was their fertility track in the first place. Right? We don’t know that! Um, and so, um, you know, giving them more information about what to do afterwards-

Mm-hm.

Because what I hear, when I hear patients and that, “You don’t have to worry- this regimen you don’t have to worry about fertility.” Right?

Mm-hm.

“I mean, I’m not going to worry about it, so what if I don’t have kids until I’m 30-something?” So I don’t start *thinking* about it until I’m 30-something.

Right.

Then it might be too late. Right?

Mm-hm.

So, I think we have to have a different conversation about fertility. It can’t be, “It’s gonna affect you, it’s not gonna affect you.” Right?

Mm-hm.

It’s going to be, “What-you know- what could it look like? What is the important thing about, you know, about going in and, and finding somebody.” Because what I see is that these patients, because of where they’re at in their life, they may not have a gynecologist. They may not be somebody, you know, and it may be til they’re 30 that they even think about it.

Mm-hm.

Um, and so, for some of these chemotherapy regimens, that may be too late. And so, that’s what I think , you know, I don’t know either but I’m willing to say that. Um, and and, that’s where I- I feel like it’s kind of hard right now as a provider doing this advocacy piece, because you are kind of way to the left, in a sense, right?

Mmm.

Um, where we still have a lot of providers on the- way on the other end. And then I think we have a lot of people kind of in between right now, sort of saying, “Hmm, maybe I should…” You know, kind of like that.

Mm-hm.

I think, you know, it’s so important for these people who are these advocates who are a little bit far advanced, um, to understand that it’s okay to be kind of out there by yourself.

Mm-hm.

Um, and that it’s important to be out there by yourself. Because these conversations are what’s been changing things in the last, you know, 5-10 years.

Mm-hm.

Um, and that- but that it is hard, right? Cuz, I know- like I just had this conversation yesterday with um, with a Hodgkins patient and, um, and I think she had already—so, the interesting part is that she hadn’t seen the doctor yet because the doctor was out of town.

Hmm.

But her oncologist locally kind of did everything to get everything set so that she could just- sort of, you know, she could just, you know, go see the doctor and everything you know, she’d have her port, she’d have her bone marrow done, she’d have everything kind of done. She’s got non-Hodgkins, but, which in some ways you would say is even more of a-

Mm-hm.

A, a risk, in my opinion. And so, um, and so she hadn’t seen her and so she had, she works for Google so it pays for fertility preservation.

Mm.

And so she had already gotten ahold of me, um, a week or two ago, so I got her into, um, I got her into see the fertility specialist and she started, you know, her stimulation shots and um, and so when she finally saw the doctor yesterday, you know, she said, “Oh, it’s fine to do that.” But she also said, that, you know, this regimen hasn’t shown, you know, to cause you know, infertility issues or whatever.

Hm.

So it- it was kind of uncomfortable, you know what I mean? Like, like I’m thinking, “Okay, I’m not sure that’s the right-“ You know what I mean?

Mm.

I’m just not sure that’s the right- In my opinion, I guess. But I am also on a different (inaudible). So, if you’ve already started doing this, I mean, I think it’s fine to tell people that, you know, it’s-it’s you know, that there may not be issues but it’s a good thing to have this in case you need it. You know what I mean?

Mm-hm.

But, I don’t know. I don’t know. It felt really kind of—and then I felt like I needed to go back and talk to the doctor at some point, you know what I mean?

Mm-hm.

And try to educate them in a way. But then, you’re talking to somebody who’s sort of like a world-renowned specialist in lymphoma! You know what I mean?

Mm-hm.

Um, and so, I-I don’t know, I think just, it’s really interesting.

So it sounds like that patient navigation component is really critical, at least in the clinical setting.

Yeah and I guess um, yeah that’s where I feel like right now—it’s still where, like I think of that, like, people you know, on both ends and somewhere in the middle. I feel like that’s still really where everything is—that we need to get everybody on the same page in a way.

Mm-hm.

That will make it easier for patients. Cuz I think it’s hard…I think it’s hard for females especially, right, because males, you know…

Mm-hm.

It’s a lot easier. Um, per se…

Haha.

Um, plus cheaper, right? So I think for females, if we’re kind of on a different page, imagine where, you know, (removed) imagine where they are!

Mm-hm.

They’re coming into this with no knowledge, um, and of course if you look on the internet, you’re gonna get any-everything else from all ends of the, you know, spectrum!

Right.

So, I-I feel like we owe it to our patients to sort of, have these conversations and come to a, you know, like a…and come to a concensus of where we can help and support these patients.

Mm-hm.

Um, not having such a stand on, you know, on maybe how we feel, but more about what’s the best thing for this patient. Because I think in this opinion, if you have insurance, they cover it. And if there’s a chance, why—and if it doesn’t interfere with your treatment…

Mm-hm.

You know what I mean? Why even question it, I guess? In my opinion. But-

Mm-hm.

Um, but I think this-

So if you-

This is a conversation that we have to have.

So if you were able to, you know, achieve all of these goals and all advocacy efforts were successful, how would the policy landscape differ from the way it is now?

I-I think it would be a policy that *all* patients, um, get a fertility consultation. Meaning that they get the whole spectrum, not just jaded- you know what I mean?

Mm.

I’m not saying that the doctor can’t say the research, right? And they can’t, you know, of course—that’s what they do, and that’s what they’re supposed to do. Right? Even in this disease, they do that, right?

Mm-hm.

So, you know, “We’ve done this, we’ve studied this…” Blah, blah,blah. But, I don’t know that we have a study with thousands of patients- you know what I mean?

Mm-hm.

With every regimen, um…to make a really-a really good, you know, sort of thing. But I think the policy would be that every patient gets a discussion whether or not they preserve. You know what I mean?

Mm.

That- and that it’s documented, and that the patient has been able to ask questions and has been able to sort of explore that whole, sort of, side of things.

Mm-hm.

Um, before, they get treatment. I think we have a long ways to go, right?

So, yeah, and what could that look like across different types of insurance, because as of now it's only private- private insurances that are benefiting from any existing legislation.

Um, I think they, you know, obviously um, in my opinion, it needs to be covered just like an echocardiogram is covered to monitor your heart, um, before you know, we give doxorubicin. I think insurance companies- or there has to be some way- that it’s covered, and that, um, it seems like such a small cost and such a huge, you know, what you get on the other end, that I think the insurance companies or, some kind of payment for this, you know, has to come. Obviously, you know, this isn’t issue. Obviously under universal health care this is covered. Um, it’s funny- I think when we look at it and how far we are from, you know, how hard it is…one patient can get it covered and the other who has the same exact disease and you know, same age, same everything, um, you know, has- doesn’t have that option.

Yeah.

Um, it seems, you know, really unfair. Um, and so I think we have to find a way that this is covered as an oncology, cancer issue, not- not an infertility issue.

Okay.

Um, because these patients don’t have infertility- they’re not infertile at this point. And so, that, you know, is a, oviously another issue. Um, and I think though, if we start having these conversations like we talked about in the beginning and everybody gets on the same page, that piece becomes easier as well.

Mm-hm.

Um, you know, because if I’m an insurance company or I’m a whatever, and I’m hearing some doctor say it’s, you know, it’s not a, you know, an issue for a lot of these medications and that we don’t see issues, dah dah dah…I’m not going to be as, you know, apt to listen either. Um, and so I think having, you know, being on the same page as a- as, you know, advocacy and for people who take care of these patients, we have to be on the same page in order to make that happen in the legislation as well.

Mm-hm. So how do you see this, um, as a quality of life issue for patients— or do you see it as a quality of life issue?

I definitely see it as a quality of life issue. They may not know that right now, um, they may, um, I mean I think they think about it- I take care of a lot of young patients as well, um, and uh, so I-I-I see patients in their teens so obviously for them at that point it doesn’t seem like it is, but it’s going to be.

Mm-hm.

Um, at some point in their life. Even if they choose not to have children, or can’t, um, that’s a discussion or decision that is made by them because of their cancer not, you know, necessarily what they would have…

Mm-hm.

…um, decided on their own. And so anytime you do something like that, obviously it’s a quality of life thing. You’re making decisions based on things that have happened, and um, are out of your control, which makes things—this, you know, issue difficult, and you have to make choices different than you would. And that’s- that affects your quality of life. Um, and I think for many people being a parent is something, you know, everyone thinks about or expects or assumes, um, that they’re going to do.

Yeah.

And so when cancer comes along and takes something like this away, um, it definitely is a quality of life issue. And I think we need to see that as- as people, you know, who are trying to fight for these patients, and anybody who takes care of them, that, you know, this is just as big as every other, you know, quality of life issue that happens because of cancer. Um, and I think because patients are telling their stories and talking about how they feel about this, um, that’s starting to change. Um, but, um, I think it needs to continue. Like I think that, um, going back to the beginning of our conversation, that this has to, you know, we all have to be on the same page. Um, and we all have to, to advocate for all patients.

Mm-hm.

You know, um, and I think most importantly, be okay saying, you know we still have to figure this out. We’re not where we need to be. Um, because obviously it’s affecting patients’ quality of life more than anybody sees it, any one person sees it. And I think the more we have these conversations, the more we bring this topic up, the more we are going to see how it affects quality of life.

So do you think that the- the status of the policies around this dictate the conversations that are happening in the hospital?

Yes, yes I think so. Um, because I’ve even had conversations with people who are, you know, in similar—similar visions of, than I’m in, um, around the country, and because of, um, cost, even…

Mm-hm.

They have a hard time offering this to patients because of cost. Um, and when we’re having those conversations, that’s really sad, right? Because, um, if we’re sort of—and I can understand what they’re saying, right? Like, if-if, you know, if it’s gonna cost thousands of dollars out of pocket, why are you going to offer it to them? But that’s-right- that’s the wrong way to see things because then you’re just taking away what, you know, information, um, and like the patient needs to know everything regardless of what the cost is. And it is unfortunate um, but if we shy away from that, we’re never gonna get this paid for. You know what I mean?

Mm-hm.

So, I think we have to discuss those uncomfortable conversations and this is why it’s so important—because we even think like that! Right? Like, “Why even offer this to somebody because the cost?” That’s awful. Should we think of that discussion…but that’s where we are and I think that’s why, um, why these conversations are so important and definitely drive policy because if- if it’s already a small portion of the population that it effects, um, then you know, people aren’t going to understand how this affects quality of life and what it means for- for these cancer patients if we don’t have these conversations and we don’t have, you know, policies, and we don’t have things like this that are going to, you know, drive and help drive, um, legislation and um, and advocacy.

Right. Well (removed), thank you so much I really appreciate it. Your perspective is really unique on this, so I was really grateful when you agreed to talk to me.

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Absolutely, absolutely. Um, and like I said, when we have these people doing this for 10 or 15 years, it will make the research look different. You know? And- and the other thing is that, you know, so what if you never use it? Um, that’s great—if you never, right? If you never have to use this because you are—you remain fertile.

Mm-hm.

But, having the choice and having that piece that you don’t have to worry about…you know, at least you can put that to the side, you know what I mean, as you go through and beyond this, um, that in itself should be—you know what I mean? A reason for, for having this, a reason for discussing this. It shouldn’t matter that, you know, what happens. It’s at the time—if it’s potentially going to affect you, you should have it, you know, an option to protect that. So, um…

Yeah.

So I think it’s great that you’re doing this and um, like I said, more things like you—more, you know, more projects like this are going to continue to bring more people and more people listening to the conversation.

Absolutely. Yeah, that’s the intent.

Definitely.