Scott Redding: Welcome to the Three Ps of Cancer podcast, where we'll discuss prevention, preparedness, and progress in cancer treatments and research, brought to you by the University of Michigan Rogel Cancer Center. I'm Scott Redding.

We're here with Michigan Medicine pediatric oncologist Dr. Emily Walling and University of Michigan clinical social worker Dr. Anao Zhang to talk about the adolescent and young adults oncology program. Dr. Walling is the co-medical director of the Michigan Medicine adolescent and young adults oncology program. She's been at Michigan since 2016 with a research interest on the impact of health disparities and childhood cancer outcomes. Dr. Zhang is the research director for clinical services and patient outcomes for the adolescent and young adult oncology program, and his clinical focus is on care in a healthcare setting and psychosocial oncology. Welcome, Emily. Welcome, Anao.

Dr. Emily Walli...: Thank you so much for having us, Scott. We're really excited to tell people about our new program.

Dr. Anao Zhang: Thanks, Scott.

Scott Redding: Can you tell us, who is this adolescent and young adult oncology program for?

Dr. Emily Walli...: Yeah, of course. So our program is aiming to serve teenagers and young adults with a cancer diagnosis. And the age range that we're really targeting is those about 13 years old all the way up to 39 years of age. And they can be really anywhere in their cancer treatment journey, from diagnosis all the way to completing treatment and entering the surveillance and to survivorship portion of their cancer journey.

Scott Redding: Someone who had a childhood leukemia and is maybe five years out, would this be something they could also participate in?

Dr. Emily Walli...: It would be. I think at that point, we do things on the pediatric side a little differently than they do on the adult side, but it would depend if that patient was already part of a survivorship group already. If not, we would certainly be involved to help transition them to a survivorship group so they can learn about the late effects of their cancer treatments that they need to be aware of and on the lookout for, and cope with life after cancer diagnosis and cancer treatment.

Scott Redding: Why is it important to focus on this age range?

Dr. Emily Walli...: That's a really good question, Scott. So several years ago, a really pioneering pediatric oncologist named Archie Bleyer noticed that people in the age range of adolescents and young adults were not enjoying the same increase in survivorship that their younger and older counterparts were, in terms of surviving from their cancer and relapse rates from their cancer. And he was really one of the first people to point this out, and it's for a multitude of different reasons.

As you can imagine, this age range that we're talking is a time of a lot of transitions. Patients can be anywhere from entering high school to starting a family, to starting their first job, to being in college. And because of this high transition time, there's also a risk of not being insured. All of these things contribute to not being treated at a specialized cancer center and not having access to clinical trials that have been really shown to increase survivability of these respective cancers.

The other thing that contributes to this is that the cancers that are seen in this age range are not replicated at any other time in life, meaning that they're unique cancers from older adults and from children. And so, it really requires people with a specialization in adolescent and young adult oncology to treat these patients.

Two other major contributing factors for this age range are adherence to treatment regimens, and that includes not only taking medications, but showing up for visits. And the unique kind of challenges of this age range, risk taking behavior, experimenting for the first time with drugs, alcohol, sexual health, fertility preservation, wanting to start a family, that might be complicated by the cancer treatment they receive. So there's quite a lot going on in this age range that contributes to their successful cancer treatment.

Scott Redding: To my previous question about the childhood leukemia, someone being about five years out, you mentioned that this is unique patients from someone else. So how would, say, a 25-year-old who's been diagnosed with breast cancer, how would that vary from a 45-year-old who's diagnosed with breast cancer?

Dr. Emily Walli...: So 25-year-olds who are diagnosed with breast cancer, and again, I will tell you this with the caveat that I'm a pediatric oncologist, so I don't treat breast cancer as frequently, but they have higher risk genetics than their older counterparts. So even though we see breast cancer in, certainly, in older adults, as well as the young adult population, their actual cancers behave much more differently. So they may not be responsive to the same treatments.

A lot of the successes that we've seen with breast cancer treatment recently may not apply to this young adult population, simply because of the genetics of their tumor. And we see that reflected across the board with cancers in this age range, that they seem to have a unique genetic profile that can make their cancers more challenging to treat, even if by name, it's the same cancer seen in a younger or older age group.

Scott Redding: Can you explain a little bit more about what makes up adolescent young adult oncology program?

Dr. Emily Walli...: Yeah, absolutely. So we really want to be a umbrella over the already excellent oncology care that patients are receiving at Michigan Medicine. What the tenants of our program is that we are ... I'm, again, a pediatric oncologist. I'm partnering with Dr. Rashmi Chugh on the adult side, and so, she is the other medical co-director. So our group has expertise in both pediatric and adult oncology, which is critically important.

We're a patient-centered program, even within the discrete age range of 13 to 39. As you can imagine, patients have a huge variation of needs within that range. A 13-year-old certainly doesn't have the same needs as a 39-year-old. So we want to design our program to meet the specific needs of the discrete age ranges of these kids.

And I'll just give you an example. One thing that's pretty unique to our program is that we've partnered as well with adolescent medicine, and they will be available to see patients from the ages of 13 up to 25 and do the usual primary care that adolescents in this age range really need. Access to sexual health conversations, risk taking screening in terms of drugs and alcohol, mental health screening that our adolescent medicine providers are really experts at and that can sometimes fall by the wayside when they're simply being seen by an oncologist. And their cancer treatment takes center stage.

So our program is going to be composed of clinical services partnered with a research component. And that is what Dr. Zhang is really in charge of. And we're so lucky to have him help us with this, because along with a high clinical need of this patient population, there's also a lack of research on this patient population. So as far as the clinical services, I already talked about adolescent medicine and the important work that they're going to be doing.

We will also be able to streamline our process for fertility preservation for these patients with our partnership with reproductive endocrinology. We have access to psychologists that specialize in both the younger age range of this age group and the older age range. We'll be able to collect all the clinical trials that are available for patients in this age range.

What's been really shown to be lacking is that current clinical trials have a lack of representation of patients in this age range, and that's not only important for the individual patient, that they're not receiving the treatment offered on the clinical trial, but that also means that we don't have biologic specimens of their tumors. And that's really a big deal, because as I talked about before, what we see in other cancers, in some cancers that hit this patient population, is that they have a completely different biologic profile than their younger and older counterparts. So that's really critical information that right now we don't have robust access to.

Scott Redding: So, as it relates to clinical research, it's sounds very similar to what we hear a lot about when it comes to minority populations, that we don't have enough information from those populations to understand how their tumors react, and it's the same for this younger teen and a young adult population?

Dr. Emily Walli...: That's exactly right, and that's a great analogy. They're, as far as underserved patients within oncology, this is really the age range that would qualify as underserved patients.

Scott Redding: I know that there's research out there that once a patient is done with their oncologic care, that there seems to be a lag or some lack of information from that handoff from the oncologist back to the primary care for general future care. By having adolescent medicine as part of that, will that maybe help with that handoff as time goes on?

Dr. Emily Walli...: I certainly hope so. And that's another really good point, is that our program wants to be present for patients as often as they need, but we know that we will be present, our hope is that we're present at critical times of transition. And you hit on one, that's exactly right, that when they're completed treatment and they need to go back under the care of their primary care provider, it's so important that the patient not only knows what they went through, but that their provider knows what they went through. So the completion of therapy is a key component that we want to help with that transition.

The other major transition in a patient's life is at their diagnosis, right? And that's when we're hoping that we'll capture a lot of these patients, that once oncologists are aware that our program exists, their patient will be referred to us right at diagnosis and we can plug them in with our program and keep them on our radar for needs as they arise.

And then, the third transition is, even after the completion of therapy, typically oncologists will follow patients for many years. And the purpose of that time period is for really disease surveillance. Our hope with our program is that we start talking about survivorship early and help patients understand what they went through, what they need to be on the lookout for in the future, what possible late effects of conflict of treatment they could have.

And so, then that third transition is really the transition then from the surveillance period to a survivorship program, and survivorship programs typically follow for many, many years. And really their focus is the late effects of treatment. But our hope is to start that conversation early and arm patients with the information that they need.

Scott Redding: Anao, can you talk a little bit more ... I mean, obviously, we've heard a lot about the clinical side aspect. Can you talk more about what the research side is and what that might look like outside, I mean, we just talked about clinical trials, but explain a little bit more about how this all fits in?

Dr. Anao Zhang: Yeah, definitely. So as you said, Scott, in addition to their clinical trial enrollment, we're also looking at many other psychosocial-related needs of those adolescents, with the ultimate goal that we can provide better care for them. So our research aims are primarily focusing on, first of all, understanding the needs of those adolescent and young adult survivors. And also, second, trying to figure out what are the best and most effective strategies to engage them throughout the care process, as Emily described, from when they're receiving active care treatment, as they transitioning to the survivorship care. And finally, we're also looking at the implementation of some of the psychosocial services that can be sustained, not only at the University of Michigan, Michigan Medicine, but also at the state and national level.

Scott Redding: What exactly are the psychosocial services that you're describing?

Dr. Anao Zhang: Definitely. So really, I think it goes back to what Emily says. Consider our program as an umbrella, on top of a patient's oncological care at Michigan Medicine. So our role is really ... We are initiating this today under this program is to get a broad understanding of, what are some of the current needs of those AYA survivors, right? So we plan to do a survey, hopefully of all the AYA patients and survivors who are receiving oncological care at Michigan Medicine and trying to get a better understanding of how we can provide support for them. Is it to get them better appointment, in the sense that, a more timely appointment? Or is it to provide them more peer support? But that is what we're doing now.

And in the future, what we're really hoping is that based on their feedback would then inform the further development of our clinical service. That is, we are going to prioritize those areas with critical needs that those AYA patients and survivors will feel comfortable and come to seek for those services. So one thing, as Emily has already mentioned, is that we're going to connect them with adolescent medicine. So it's like as the gatekeeper, if you may, they're going to do a comprehensive evaluation from medical to psychosocial, and then starting from that point, the program are going to refer them to different services that may compliment to the oncological care.

Dr. Emily Walli...: That's exactly right. What we know from the research is that when we talked to survivors who were diagnosed in this age range, that they report a lot of unmet psychosocial needs. And I can tell you as a practicing pediatric oncologist, of course, everyone tries their hardest to address the psychosocial needs, but really, the medical treatment often takes precedence. And I think there's a lot of room for improvement in that area.

And so, what Anao describes is that we really want this program to be patient-driven and patient-centered so we know that we're actually meeting the needs that they have. I can come up with all these things that I think are lacking, but there's no better source than asking the patients. And so, part of what we'll be doing the first two years of initiating this program is also running a pilot study, where we'll be assessing for acceptability and success, really, of the program from both oncologists, both treating oncologists, and from the patient population to see, what do we need to tweak? What could we be doing better?

So one of the first studies that we're running through the research arm of this is we're looking into acceptability of our current methods for fertility preservation and how we address that. And really, our questions are, first of all, do patients understand why their fertility might be at risk or that their fertility is even at risk? Why do some patients accept fertility preservation? Why do some patients refuse fertility preservation? These are the things we're trying to get at the heart at to better serve this patient population.

And something that I forgot to mention earlier when we were talking about the clinical structure of this, is this aspect melds with the research structure of it, but we are also going to have a patient advisory board. The really goal will be to dictate the services that we run from this program. And so, this will be a group of patients that, from both the pediatric and the adult side, who meet on a regular basis and help guide our program needs.

Part of that will be the plan to develop a patient mentorship program for our patients, so meaning patients who are newly diagnosed could potentially, if they're interested, be paired with someone who has already been through the process, who had a similar diagnosis. And then, we really hope to form more specific support groups. So, right now, there's an adolescent and young adult support group, but it serves patients when a really wide age range. And as I was talking about earlier, these patients have very different needs. So we hope to form a support group for, potentially, new parents, patients in high school, patients who just started college, that sort of thing, to make it more of a group of their peers who patients can lean on and learn from.

Scott Redding: And I have to assume that a 15-year-old leukemia patient has different needs than a 23-year-old testicular cancer patient.

Dr. Emily Walli...: Yeah, exactly. You got it.

Scott Redding: Even if they're both males, but they would still have different needs and different issues and concerns.

Dr. Emily Walli...: That's exactly right. They were treated on completely different treatments, so they have different risks going forward. And so, it's not enough to say, well, they're the same age range. And like you said, they're both men and they both have cancer. Right? That's not enough.

Scott Redding: Both of you mentioned this as an umbrella program. So this is, for lack of a better term, virtual compared to an actual clinic setting?

Dr. Emily Walli...: Yeah, that's exactly right. So I think what's important to know, that I really want to stress, is that patient care will stay within their oncologist, who they were referred to, who diagnosed them, so really, the disease specialist. And we think that's really important for the reason that I mentioned earlier, is that these patients really have quite a range. So you can't really just say, I'm an adolescent oncologist, because that composes breast cancer to leukemia, and those are treated very, very differently, obviously.

And so, patients' oncologic care and treatment will stay within the purview of their treating oncologist. But our hope is that their oncologist will refer them to our program and then we can plug them in with adolescent medicine and these other services that we've described going forward. And we can be involved at these key critical transitions as well. So we'll be in the background keeping track of these patients and available to these patients and intervene as needed, but also at these critical transition points.

Dr. Anao Zhang: And I just want to add very quick that, similar to what Emily described, our role, I think, is really as to filling the gap of our patients' care experiences. So we're not necessarily actively intervening anything, but when they feel that there is an unmet needs, that we are really just there for them. So if that is whether, if they wanted an appointment with another department or that it's just they want a peer that they want to speak to. So it's really that we're filling, we're being there and filling the gap.

Scott Redding: This is a pretty comprehensive program in offering a lot of different, extra resources and tools for these patients. Can this be found at other cancer centers here in the state, in the country, or are there other programs similar to this?

Dr. Emily Walli...: Yeah, there are. We are really, really lucky to be partnering with an organization called Teen Cancer America. Their full name is Who Cares, Teen Cancer America, and they are funded by the stars Roger Daltrey and Pete Townsend of The Who. And what this incredible organization does is they help hospitals develop these type of programs. So basically, they've recognized that there are a lot of unmet needs in this patient population and they help fund for those to implement these programs. So we are joining a huge list of hospitals around the country that, these are really popping up. So for example, Children's Hospital of Philadelphia, Children's Hospital of Minnesota, Memorial Sloan Kettering, Children's Hospital of Stanford. So really, across the country, these are starting to pop up as people realize that there's significant unmet need.

Scott Redding: I know we've talked about the research goals of the program. Has there been any research that we've been involved with, that you've been involved with leading up to the launch of this program?

Dr. Anao Zhang: Yeah, absolutely. So because we have this unique platform to harnessing the expertise of adolescent and young adult cancer researchers across the University of Michigan campuses, we are actually, during our still pretty young phase of the program, we've already secured an external grant funded by the [inaudible 00:22:15] Foundation for Pediatric Cancer to conduct a pilot trial at delivering computer-based cognitive behavioral therapy for adolescent and young adult cancer survivors to measure health outcomes.

We are also secured an internal grant from the University of Michigan School of Social Work to establish a pre-doctoral fellowship with a specific focus on health disparity among AYA cancer survivors. We're also in the process of submitting, and some of them are now being under reviewed by the National Cancer Institute, for randomized control trials to improve the biocycle social outcomes for adolescent patients and survivors.

Scott Redding: What about clinical trials?

Dr. Emily Walli...: So we have not, as of yet, developed any clinical trials, but I see a great opportunity to do so in the future. My hope is that we can develop, start with institutional clinical trials, potentially expand these to regional cancer centers, of which there are several in the area. I'm also hoping that we can do joint tumor boards with the medical oncology department and really just develop a more robust partnership for this patient population.

Dr. Anao Zhang: As we wrap up, is there anything that you want the listeners to know that we've not maybe covered?

Dr. Emily Walli...: I think we could end with a quote from the great Archie Bleyer, if that would work. I love this quote. I wish I could have said this that eloquently, but he said in 2007, "The greatest difference in the management of adolescent and young adult patients is the supportive care, particularly psychosocial care that they require. These patients have special needs that are not only unique to their age group, but also broader in scope and more intense than those at any other time of life." And so, recognizing that is something that these adolescent and young adult programs have done, and that we are hoping and trying to address with our program at Michigan Medicine.

Scott Redding: Well, I think that sounds great. I really appreciate the time, Emily. And Anao, thank you again.

Dr. Anao Zhang: Thank you.

Dr. Emily Walli...: Thank you, Scott.

Scott Redding: Thank you for listening, and tell us what you think of this podcast by rating and reviewing us. If you have suggestions for additional topics, you can send them to cancer center at med.umich.edu, or message us on Twitter at UM Rogel Cancer. You can continue to explore the Three Ps of Cancer by visiting Rogel Cancer Center.org.