

Mayo Clinic Q&A - Adolescent _ Young Adult Cancer Awareness ...

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SPEAKERS

Dr. Halena Gazelka, Narrator, Dr. Allison Rosenthal

N Narrator 00:01

Coming up on Mayo Clinic Q&A, a cancer diagnosis can be a frightening experience for anyone, but for adolescents and young adults that experience can also bring some unique challenges. Some receive care in pediatrics, but the majority are cared for in adult cancer systems with many facing issues with access to appropriate care. Today, we'll look at the adolescent young adult program at Mayo Clinic and learn how these individuals are being supported and treated throughout their cancer journey.

D Dr. Allison Rosenthal 00:30

With this being an underserved, under-recognized under-diagnosed population for the most part, they really are the poster children for facing disparities when it comes to their diagnosis and care. And so, one of the biggest issues that we have to overcome here is that a lot of young adult patients have delayed time to diagnosis. And with delayed time to diagnosis when it was more advanced stage disease, you end up with different treatments being needed and more long-term considerations.

D Dr. Halena Gazelka 00:56

Welcome, everyone to Mayo Clinic Q&A. I'm your host, Dr. Halena Gazelka. April 4th through 10th, is adolescents and young adult, or AYA Cancer Awareness Week. It's an excellent time to discuss the unique challenges faced by people between the ages of 15 and 39 when they experience a cancer diagnosis. While some AYA people with cancer receive care in pediatrics, the majority are cared for in the adult cancer systems, and sometimes people in the group don't fit well with either patient population. Here with us to discuss this is Dr. Allison Rosenthal.

Dr. Rosenthal is a Mayo Clinic hematologist and oncologist who is developing a program at Mayo Clinic Cancer Center to meet the unique needs of AYA patients. Welcome to the program, Allison.

D Dr. Allison Rosenthal 01:47

Thank you so much for having me, and I'm really excited to be talking about this topic as it's something I'm really passionate about.

D Dr. Halena Gazelka 01:53

I can imagine. What a really interesting topic, and what a difficult time for someone going through life. How is it different to be an adolescent and young adult or an AYA individual who is going through a cancer diagnosis?

D Dr. Allison Rosenthal 02:07

Yeah. So, I think that's the really important thing that we have to start bringing to light and educating people on is that it is different, right? It's not the same as if you are diagnosed as a child or even as, you know, 10 or 12-years-old, it's not the same as if your diagnosis is at 55, or 65, or a 75-year-old. And if you think about the kinds of things that people in this age group are going through, there's a lot of life transition happening there. So, this group really has a lot of unique needs as far as psychosocial development, you know, what they're going through as far as trying to find their independence, financial independence, some of them are still in school, some of them are trying to start families. And so, it's just, you know, there's never a convenient time to be diagnosed with cancer, but particularly inconvenient in this group. And they often get overlooked because I think people just don't recognize that cancer is really common in this age population as well.

D Dr. Halena Gazelka 02:59

Are the cancers that are experienced in this age group different than what older adults or young children might experience?

D Dr. Allison Rosenthal 03:06

So, people of any age can get any kind of cancer, but you're absolutely right. There are some cancers that are more common in this age group. And while the numbers change periodically, I think the ones that are most common at this point end up being thyroid cancer, breast cancer, melanoma, blood cancers. And there's been a rise in the incidence of GI cancers in this group as well, for reasons I think we're still trying to sort out. But it is a little bit different. And so, that goes, you know, in the same vein as, you know, we have to educate people and have better awareness as to what affects this group.

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Dr. Halena Gazelka 03:39

So, if these individuals might be experiencing the same cancers as someone who is older, are the treatment strategies and approaches to how to care for them different?

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Dr. Allison Rosenthal 03:48

It can be. So, as you alluded to in the introduction, some of these patients do get treated in the pediatric setting. And so, that's largely our later teenage patients. However, there are some pediatric programs that are really comfortable taking care of people even up to the age of 25. And I specialize in lymphoma. So, what I know the most about are blood cancers and the differences in treatments there. But there is a huge difference in what would happen if you were 18 with let's say, Hodgkin lymphoma, which is common in young people, and you get diagnosed and treated at a pediatric center versus if you come to an adult center. And because those treatments are designed differently, and the toxicities are different in the short and the long-term, one of the real issues we have with this population is that sometimes we don't speak the same language, you know. So, if a pediatrician or a pediatric oncologist calls and says, I have this patient, here's what I'm thinking, what do you think? I have to look up the regimen they're talking about because we just don't talk the same. And so, one of the things we're hoping to accomplish with having this group and having better coordinated comprehensive care and transition from peds to adults, is making sure that we are all on the same page and understanding, you know, what we think might be the best treatment for them no matter what age they are.

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Dr. Halena Gazelka 05:01

Allison, here at Mayo Clinic, we are very aware that disparities exist in health care and that they can really affect the treatment that an individual receives. And we are working hard to diminish those disparities and resolve them. Are there disparities that are that are present in this age group when they're going through cancer therapy?

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Dr. Allison Rosenthal 05:27

Sure. So, this is really important also. And some people who are studying this age group, in particular young adults who get diagnosed with cancer, are really looking at this now and how to improve this because with this being an underserved, under-recognized under-diagnosed population for the most part, they really are the poster children for facing disparities when it comes to their diagnosis and care. And so, one of the biggest issues that we have to overcome here is that a lot of young adult patients have delayed time to diagnosis. And with delayed time to diagnosis, you end up with more advanced stage disease, you end up with different treatments being needed and more long-term considerations. The other thing is that there is a really big gap in young adult patients with cancer having access to appropriate care. And that means both age-appropriate support for what they're going through, but also centers, you know, there aren't a lot of centers or there isn't a good way to find a center that has expertise particularly in taking care of this population. And then I guess the third thing that ends up being really important is that this population really experiences some challenges with being insured properly, right? No one ever plans for cancer. Nobody ever thinks I'm going to get this plan so

that I can have good coverage if I get cancer. But one of the things that happens in this age group is they age out of being covered by their parents, or maybe they've already gotten married and started a family. And so, now they're on their spouse's insurance or something. And so, one of the other disparities they face is being under-insured or inappropriately insured. And so, if you lump that all in with all of the social determinants of health that we've all been talking about, you know, recognizing as being barriers to good care, you take the racial, the ethnic, the socio-economic challenges that any patient with cancer may face, and then put it together with all the challenges this unique population faces, they really have, you know, a lot of disparities that they face. And so, we have a lot of work to do in this space.

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Dr. Halena Gazelka 07:22

Wow, that is a lot, Allison. So, how does the adolescent and young adult cancer center program that you're putting together for Mayo Clinic help meet some of those unique needs?

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Dr. Allison Rosenthal 07:36

So, this is really exciting that we finally have gotten the attention of enough people to understand that they have unique needs and that a program needs to be built around those needs. And so, kind of the holy grail or the perfect, the ideal program that we're hoping to put together keeps all of that in mind. So, it combines what we do well at Mayo Clinic, which is multidisciplinary, you know, state of the art comprehensive care for cancer patients, and then pairs that with things that this group needs. So, ideally we'll have a nurse navigator that all the patients will meet as they come in to the system, a social worker dedicated to AYA issues and needs, health psychologists. It will take some time to build all this up and have all the right people in place, but we'll also need things like financial counselors, people to help with the insurance concerns, vocations counselors, so as people go back to school, or have school interrupted, or trying to find a job. And then of course, we'll have to make sure that what's built into this is a very clear, concise, and coordinated transition from pediatrics to adults. Because that's one of the other challenges we face here is some of these kids will be diagnosed at the age of 16, or 17, and they'll need adult care soon. And so, we have to make sure that we're doing everything they need in the short and long-term to transition them to long-term care and follow-up as well. And the one thing that I left out of there, that is probably also, you know, one of the most important things is having survivorship care that focuses on the needs of these patients as they move forward. We're really fortunate that the majority of young adult patients who get cancer care are going to do well in the long-term, there's going to be a lot of long-term survivors. But if we aren't paying attention to the long-term treatment side-effects and the monitoring and maintenance of health behaviors and such that happen after a cancer diagnosis, then we aren't doing, you know, the full service for these patients that they really deserve.

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Dr. Halena Gazelka 09:26

What role will clinical trials play in this?

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Dr. Allison Rosenthal 09:30

Clinical trials are going to be critical to the success of this program and mainly to help improve outcomes. So, one of the things that got the AYA group kind of into the spotlight as needing more attention and more dedicated attention is that the outcomes for cancer care in the young adult population haven't improved nearly as fast as they have in pediatrics and older adults. And so, clinical trials are really, you know, the optimal way to improve outcomes. And one of the challenges, the big hurdles with this group has been that their participation in clinical trials has been really poor, and that's for a couple of reasons. One, there aren't a lot of clinical trials that address this entire age group. They happen in pediatric programs, they happen in adult programs, but there's not a lot of crossover in making sure that there are trials that encompass the whole group. Education, so these patients have, you know, varying ideas about what clinical trials are for and what they mean to them. And then access to centers that are running them. Unfortunately, that's all changing. So, there are a lot of cooperative groups that are getting together now, both from the peds and adult side to say, look we really need to study this better, both from finding new treatments, new combinations that are less toxic, but also looking at things like behavioral interventions and, you know, physical activity interventions and ways to help manage some of the psychosocial effects that this has on people. So, absolutely, clinical trials are going to be critical to the success of this program. And we're really looking forward to building that out as this program takes off.

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Dr. Halena Gazelka 10:56

What an exciting program. I just loved hearing about this today, Allison. It's incredible solutions that you're looking for to some common problems for people in this situation. When will the program be up and running?

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Dr. Allison Rosenthal 11:10

So, it's in its infancy now. We're up and running with the people that we have identified as kind of being champions in this space and interested. It's important, I think, to recognize that this program isn't going to take the place of anything that's already happening. It's going to serve as kind of a complementary support system really for these patients. So, they will continue to get all the excellent care they're getting in their disease directed groups. Now there are disease specific groups now, but this will be an added layer of support, you know, mainly focused on, you know, what the issues are specifically with this population so that things aren't falling through the cracks. And ideally as everybody comes in, there's a needs intake assessment, so they get connected with all the right resources right from the get-go.

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Dr. Halena Gazelka 11:54

That's wonderful. Thank you for sharing this with us today, Allison.

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Dr. Allison Rosenthal 11:58

You're welcome. Thank you for having me. I'll talk about this all day long any chance that I get.

D Dr. Halena Gazelka 12:02

Our thanks to Mayo Clinic hematologist and oncologist Dr. Allison Rosenthal for being here today to talk to us about adolescents and young adults with cancer diagnoses. I hope that you learned something. I know that I did. We wish each of you a wonderful day.

N Narrator 12:20

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