Young Adults with Blood Cancers:
Managing Treatment and Beyond

Eric Cohen, RN, BSN, OCN

Slide 42
Gaps in Services for AYAs

Eric Cohen:

Before I get started, I just want to say how proud I am to have my social work colleague and friend Sage here at her first ONS Congress. Sage and I work very closely together, and we run a young adult program, and we're very comfortable with each other. We talk, we do a lot of speaking together. And because of that, Sage may wind up interrupting me during my talk. It's okay, don't be alarmed, I'm quite used to it at this point.

Slide 43
Social Factors That Impact AYAs

So we've made a lot of progress in the last couple of years about raising awareness about the specific issues of young adults with cancer, but we really have a long way to go.

This is a very large age range, 18 to 39, and within that age range, there are many emotional, developmental and social changes and transitions. Young adults tend to be very self-conscious, perhaps even overly concerned about what they look like and body changes. For most of them, this is the first time they've ever really had to confront the idea of mortality. They're also feeling very isolated. Many of them have to leave college and come home to be treated. But not only that, when they come into your clinic, into the infusion clinic, they're usually surrounded by either 10- and 11-year-olds or 70-year-olds. This is a time in their life when they are trying to establish their own independence, and now all of a sudden they're forced to become dependent again, moving back home, and as Nicole mentioned earlier, even medical decision-making. Who's going to make these decisions, can be an issue. And there are financial issues. On the younger end of the scale, they're usually covered under their parents' insurance as long as they're full-time students, and now, of course, they can't be full-time students. And the older end, those are the people that can't navigate work or are trying to go back to work, and many of them may have their own children.

Slide 44
Gaps in Services for AYAs With Cancer

So psychosocial and supportive care is widely available in pediatric settings. It is definitely available in adult settings, but in neither case is it really young adult-specific. And as Nicole also mentioned, we know that a lack of support during treatment leads to decreased adherence to follow-up care later. Also, most physicians don't really think to talk to young adults about prevention and early detection and overall cancer awareness. I also think that there's a lack of nursing school education on young adults, on the impact of disease with young adults. We do pediatric rotations, we do long-term care rotations, but we don't really focus at all on these issues with the young adult.

Slide 45
Young Adults Want Support

What we've learned in our support groups is that young adults really do want support and education, but they want to control how they get that information. They want to get it whenever they want to get it, and they want to go wherever they want to go to get it. They don't want you telling them where to go. And we also know, I don't think anybody would disagree, that young adults are really the leading edge of the technology revolution today.

Slide 46
Technology

One of our young adults, Pat, said in one of our groups, he said, "I've been avoiding the discussion about prognosis with my doc. I really didn't want to know anything at first and then one night I woke up at 2 in the morning scared to death, and I had to talk to somebody who could understand what I was feeling." So what does Pat do? He goes to the Internet.

So today we're going to give you some resources at the end today, of things that you can give to your patients. But again, they're really going to do it their own way. So what are they going to do? They're going to go to Google and they're going to enter the search terms that they want to enter. So what we really need to do is teach them how to search on Google and also how to critically evaluate their results. Same thing goes for wiki's. Probably most of you know how wiki's work, but our young adults probably don't and so we need to educate them about that as well. So a wiki—wikipedia, a dictionary, thank you, Sage. Essentially a dictionary, a source, an encyclopedia. A source of information that anyone essentially can go in and make updates on. So Dr. Rytting could go in and decide to talk about ALL and write definitions for ALL, and then some patient could also come by and write that information. It does get edited, but it's not real-time necessarily, so there may be some false information on there. They need to be aware of that.

I'm going to skip social networking for one second, and say that a lot of our survivors are using blogs. If you do a search on cancer survivorship or cancer patients under blogs, you will see thousands of blog entries, even disease-specific. So if you have ALL, you could go and find a patient going through exactly what you've been through and read their blog, and so they're getting a lot of support that way and also blogging their own experiences.

They're also using YouTube. There is some cancer information, education, on YouTube, and I'm sure that we'll be seeing a lot more of that in the future.

And then social networking. So everyone is using today Facebook. My mother is on Facebook. I have an 85-year-old aunt who's on Facebook. So everybody is using Facebook, and there are many cancer support groups on Facebook—thousands actually—with hundreds of thousands of people involved in these groups. And these groups are also usually not monitored. There is no professional looking at these groups and saying—looking at the information that may be given out in these groups, but that is what they're doing.

And then I also think that there's a very practical application for Twitter, especially for young adults. We just started, *Life with Cancer®*, just started to Twitter. I do one tip on managing side effects a day, which they can get on their cell phone. So I do think there are some opportunities there for us as well.

Slide 47
Fact-to-Face Support

But we'll never replace face-to-face support. Our patients find it really validating to be face-to-face with someone who's been in their shoes. I had a patient come in to a young adult support group that I was leading—she was a new patient. And in that same group, this particular night, one of our long-term patients in that group was having a rough time. She is a hereditary breast cancer patient, she lost her whole family essentially, and on this particular evening she was really feeling that. So it was a quite intense group, and I was really concerned about this new patient in the group, that it was just going to be way too much for her and I'd never see her again. A couple of days later, she called me and asked me a couple of questions and in it I said, "I was really concerned about you the other night, I thought maybe it was too intense, maybe that group was too intense." And she said, "You know, Eric, sometimes intensity is good, I'm always having to put on a strong face for my family and friends and the group is the one place that I can be real." So we'll never replace those groups.

We have a support group now that's running about 15 years and I think that the success of that group in large measure is due to the fact that this group also meets on their own once a month for happy hour. No facilitators, they just do it themselves. They organize it themselves, they go to a different restaurant. And I think that really keeps the group connected. They don't always come to the dinners, the happy hours, and they don't always come to the group, but they shift back and forth when they need to, and that is also very, I think, very successful.

So now there's a group called imtooyoungforthis.org, I2Y.org. They are setting up happy hours across the country for young adults with cancer. I think that's a phenomenal thing.

There are also retreats available for young adults. Planet Cancer. Camp Māk-A-Dream. Both have excellent retreats, so if there aren't young adult programs in your area, they can go to these things and they can get actually scholarship money to go to those camps.

Slide 48
After Treatment Ends

And then after treatment ends, again, we are really losing most of our young adults or way too many of our young adults to follow-up care. So Judy, who came to us recently, said, "I had cancer 10 years ago when I was living in Michigan, I moved here a couple of years ago, and this year my primary care doc asked if I'd had a baseline mammogram. I hadn't, so I went. When they told me I had breast cancer, I thought how can this be? I already had cancer." So again, an illustration that we really aren't doing enough education on late effects and the difference between long-term effects and late effects. I think we need to do better that way.

As Nicole mentioned, survivorship care plans I think are really a must for this age group. This is a very transient age group. They are definitely going to move out of the area at some point, and they need something to be able to take with them that they can give to medical professionals to see what they've been through and what they've had.

There are also survivorship clinics now that are starting to come of age, thanks to some support from the LiveStrong and Lance Armstrong Foundations, but again, they're very few and far between and really not enough.

Slide 49
Community Service

The other thing that our young adults tell us and really helps with the success of our group is community service. They have a very strong desire to give back. I think it helps them make sense of their circumstances, of their journey, their cancer journey. So we really encourage them to do something as a group together. They've done Team-in-Training together as a group. There are other community-sponsored fundraising events that they can do. It's a great thing for the group, and it really helps them stay connected to each other and stay connected to the healthcare system.

Then the other thing is college campus programs, I think it is a great thing to send young adults back to colleges, to do programs there. Our local university, George Mason, is doing this year a Testival, and so they're going to raise awareness on testicular cancer for men, and our young adults are going to participate in that as well. I think that's a great thing.

That's it for me. I'd like to introduce Sage Bolte.