Young Adults with Blood Cancers:
Managing Treatment and Beyond

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Keeping AYAs Integrated

Nicole Rosipal:

Good afternoon.

So I'll be talking to you today about *Treatment Adherence and Keeping the Young Adult Integrated into the Healthcare System for Follow-Up Care.*

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Objectives

So mostly we're going to talk about treatment challenges of adherence, and then also the need for long-term follow-up care.

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AYA Developmental Milestones

So AYA patients are still going through developmental milestones, in particular that of independence and also that of developing healthcare beliefs and their own body self-image.

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Compliance vs Adherence

Because of the milestone of developing independence, the word "comply" or "compliance" can sometimes have a negative connotation of coercion, or submission, or even being that of kind of rule-oriented. However, the word "adherence," which is becoming a more popular word in the literature, can have more of a connotation of the patient playing an active role in the responsibility of their own treatment plan.

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Nonadherence

So, nonadherence. Chronic illness in general can have a nonadherent rate of anywhere from 25% to 60%, and patients can actually be nonadherent with their chemotherapy, anywhere from 16% to 100% of the time. And a quarter of these patients aren't communicating to the healthcare professional if and when they experience any kind of illness, such as fever or diarrhea.

The adverse effects of this nonadherence can include increased physician visits, prolonged hospitalizations, drug toxicities and, unfortunately, even relapse.

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Model of Adherence & Persistence

So, this is a model of adherence and persistence, and these are three different factors that can all play a role on a patient’s level of their adherence. First, I’ll talk about the personal factors. What is the patient’s emotional state? Their self-esteem? Are there any psychiatric illnesses that are playing a role in this? Is there substance abuse that’s being included in this issue? What are the patient’s health beliefs? What are their own personal feelings about their disease and their own health condition? What’s their future orientation? Are they making future goals, are they willing to talk about future goals? What’s their socioeconomic status, and do they have a good social support system?

Some of the treatment factors that play a role in a patient having good adherence is understanding the disease and understanding the reason for the treatment of care. Also, if the treatment is very complex, such as the schedule, medications or the plan that they have to require, sometimes those patients aren’t quite as adherent to the plan.

If the treatment plan has more of an urgency or immediacy to it, a lot of times the patients will comply or adhere to the very beginning, but then sometimes that adherence may slack off, especially if they start to see that the benefits of treatment may not be what they were expecting or if they’re having subclinical disease.

Also, if there’s a high cost or out-of-pocket cost, there might not be quite as much adherence to this.

So, interaction with the healthcare system as a whole. Patients that are satisfied or verbalize satisfaction with their providers and the care that they’re receiving tend to be more adherent—and also if they have adequate insurance coverage and convenience to the healthcare system, which makes sense.

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Review of the Literature

So some studies have been done to evaluate some of the characteristics of adherence versus nonadherence. The first study looked at 44 AYA patients with varying different cancers, and what was done is they measured Bactrim serum assays. The patients also then filled out some different psychological measures, and the results showed us that patients that were nonadherent had higher depression scores and also lower self-esteem. It also showed us that mood actually played quite a role. So if the patient was in a good mood one day, they would take their medicine. However, if the next day they were in a bad mood, they might not.

Also, nonadherent patients had a lower survival rate.

Another thing that came out of this study was that adolescents and young adults can actually be reliable sources of their adherence. We don’t always have to necessarily do serum assay levels.

They just need to be *asked*.

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Review of the Literature (Continued)

The next study looked at 50 AYA patients, and prednisone and penicillin serum assays were looked at. Then 38 of these patients, excuse me, 34 of these patients, filled out psychiatric measures also.

Sixteen—this study used the word "compliance"—16 of the noncompliers showed that or verbalized that their side effects were just way too significant to deal with. There was too much interference in their day to day life. And they were also reassured by the absence of symptoms—"If I don't have symptoms, I must not have disease"—and also the increased use of denial.

Compliers, which was 18, talked a lot—were willing to talk a lot more about their future orientation.

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How to Assess?

So how do we assess this as nurses? *Ask* the patient. Assess their understanding of the disease and their understanding of the rationale for the plan of care. Have them report to you the names of the doses and their schedule of their medication. This is an ongoing process.

Unbiased questioning. I'll tell my patients, "I'm not judging you, I just need to know if the tacro level that I get today is because you're actually taking your medicine or you're not taking your medicine," so that way I can determine how to change their medication schedule.

Assess their relationships with their peers, their family, their social support network. Are they receiving good support?

And then also, are there any underlying psychiatric factors? Include psychology, psychiatry as needed.

And then what is their own evaluation of their disease, their own evaluation of the risks and benefits of the medications and treatment plan?

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Predictors of Good Adherence

So what are some good predictors of good adherence? So these patients have realistic conceptions of their illness, prognosis and vulnerability. They have consistent social support network, and they have a good understanding of abstract concepts, such as subclinical disease. And they're able to endure the side effects more easily.

As I said before, ability and willingness to plan for their future.

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Predictors of Poor Adherence

Predictors of poor adherence, some red flags. Missed appointments, unfilled prescriptions, verbalization of poor relationships and mistrust of the healthcare system. Adverse effects are viewed as just being too significant. Depression. Use of denial. And lack of understanding of the abstract concept of subclinical disease.

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Interventions for Nonadherence

So what are some interventions that we can do? Trying to ensure that we're as accessible as possible and trying to make their medication and treatment schedule as convenient as possible. Collaborate with your families on timing, etc. Medications, simple schedules. I've also listed two Web sites here. These are free Web sites to patients. They're able to make their medication schedules with the assistance of nurses. It also shows pictures of the medications. And then they can actually get free text messages on their cell phones that help remind them to take their medicine—and it's free.

So ensure that they're getting all the education they need to help them improve their understanding. Encourage their social support. If they're in college and living with a roommate and they approve, get the roommate involved with their healthcare and have their roommate understand what's going on, too.

And support the AYA to be an advocate for themselves. Collaborate them as much as possible.

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Long-Term Follow-Up

So, long-term follow-up. I often hear, "But I thought I was done." So 1 in every 168 Americans between the ages of 15 and 30 years of age will develop invasive cancer. Fortunately the number of pediatric cancer survivors is increasing. There isn't a lot of information on the 30 to 40 age range. However, three fourths of these survivors will develop a chronic health condition, and about 40% will develop a very severe chronic health condition. Unfortunately, all systems can be affected—any system can be affected.

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Rationale for Long-Term Follow-Up

So what is our rationale for long-term follow-up? We want to improve the quality of life. For example, patients that are at risk for cardiomyopathy should be receiving regular screening of their echos and also risk counseling. That way if they need management earlier, it's better than rather than later.

We want to also understand, is the aging process being altered by radiation or chemotherapy?

Things such as skin cancer, or also what has been brought up is, are some of these people going to hit dementia earlier or have a higher risk of dementia. We don’t know. What about common adult health problems, such as osteoporosis, like Dr. Rytting was speaking about.

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Types of Adult Survivor Medical Visits

So this graph shows findings from the Childhood Cancer Survivor Study. Survivors continue to have some form of healthcare, however, the likelihood of a visit related to their cancer history, whether it be at a cancer center or with their general practitioner, decreases drastically over time, as you can see with the red bar and also the blue bar. A minority of the survivors are following up at an actual cancer center and having survivor-based medical care provided to them.

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Cancer-Related Visits (CCSS)

This graph shows that this is also true amongst patients that have high risk cancer. They’re not receiving survivor-focused healthcare, and it decreases with time.

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Chronic Health Conditions

And finally, this graph shows that as the cancer survivor ages, which is the yellow line there for you, the incidence of chronic conditions increase. However, the percent of survivors going to a cancer center for follow-up decreases drastically. So there’s obviously a huge discrepancy here. So their health conditions are increasing in number or worsening if they’re not seeking help for these.

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Optimum Care

So what does optimum care consist of for follow-up? Optimum care consists and begins at diagnosis and should continue until the end of life. Plan of care should include and take into account the patient’s cancer history, including their treatment plan, any genetic predispositions, their lifestyle behaviors such as smoking, and other health conditions that the patient may, or survivor may actually already have. Survivors also need a medical home or a single provider that is coordinating their services.

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Optimum Care (Continued)

This care should also include anticipatory guidance and health promotion and disease prevention. There should also be a multidisciplinary team approach that includes a primary care provider, pediatric specialist and adult specialist and any ancillary services, social work, financial services, psychology, etc. Also, the survivor should be empowered to advocate for their own healthcare needs. The way that we empower our survivors is by educating them on their potential late effects, so that they know what to advocate for. And research, so we can continue to learn about what their needs are.

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Model of Potential Barriers & Enablers

So this is a theoretical model that was done by Oefinger et al. This looked at the potential barriers and also the enablers of the care of the cancer survivors. So the primary goal here is risk-based care, which is the center triangle there, and all of these factors play a very key role in this, in attaining risk-based care. First and foremost is at the top, trying to understand the patient's cancer experience. Healthcare providers must be sensitive to the survivor's cancer experience through which they will interpret their current health and any potential illnesses. This can be any psychological factors, knowledge deficits.

Next is the core health beliefs. And affecting core health beliefs are internal and external modifiers. That's including their cultural background, their cultural beliefs, and then also any social norms.

Core health beliefs also include their own personal beliefs of the vulnerability to their late effects. Some patients believe, or survivors, "I'm done with this, I don't need this, I'm invincible to these late effects," whereas others want to be screened every two months. All of this information goes through their own health locus of control. Some survivors say, "I don't even have control over my own health anyway, I didn't have control whenever I got cancer, so I'm not going to follow up because I don't have control if I'm going to get a late effect." Others say, "No, I have control over my own health and therefore I need to be able to follow up on the late effects as much as possible."

The next factors are provider-related factors. There are some healthcare providers that minimize the risk of late effects, whether it be outside in the community, and some of the community physicians only have two to three long-term cancer survivors in their practice, so there is a knowledge deficit among some primary care providers there. Also the time factor. Long-term survivors require quite a bit of time to ensure that all of the care that they need is addressed, and some just simply don't have this time.

And then also there needs to be a core belief of wellness and prevention instead of just relapse-focused.

The last factor is the health systems-related factor. Unfortunately, there can be discrimination amongst medical insurance companies with healthcare survivors—excuse me, with cancer survivors. Also, there can be inadequate coverage for their screening. There isn't a lot of evidence-based practice—there is becoming more information on that— for which healthcare policies need to be made. And then also the patient's feelings about the healthcare system. Did they have a good experience with their cancer experience and want to continue to follow up in the healthcare system, or was this not such a good experience and they want nothing left to do with the healthcare system?

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Enhancing Long-Term Follow-Up

So what are some interventions that we can do to enhance the long-term follow-up? So education to the patient and communication of their long-term follow-up plan, and educate the primary care team. If that primary care team happens to be an outside primary care provider, definitely providing summary letters. What we do is we—post-transplant—is I write a letter to the primary care provider that includes their cancer, the chemotherapy, the treatment, any radiation they've been through, their short-term risks, and then also we try and work with the long-term follow-up team to work on what their long-term risks are going to be and what their screening needs to consist of.

And introduce the concept of long-term follow-up prior to the completion of treatment. If at the very end of treatment, on your very last day, you say to the patient, "Okay, well, now you're cured, but we need you to follow up for the rest of your life," that might not be taken quite so well. So, as soon as the patient becomes more stable, it's a good time to talk to the family or the patient, whomever, about the fact that they will need to be followed up.

And again, empowering the survivor to be their own advocate.

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Models for Center of Care for Survivors

Then finally, what are some models for the center of care for the survivor? So there is the cancer center, so you can either do the primary oncology team, or there are sometimes a long-term follow-up program within the center. The benefits of this is that it's usually comfortable for the patient, there's continuity of care, and there's also expertise with this. Some of the disadvantages are the fact that sometimes this can be more relapse-focused. Then also sometimes the survivor wants to move on or wants to literally move. There's also young adult transition centers. This is a good idea because it helps with multidisciplinary team approach and also helps to continue with research. The disadvantages, though, are that it doesn't include a primary—sometimes doesn't include a primary care provider, which definitely needs to be a part of it. And if it's not geographically convenient for the patient, patients might not follow up.

Final approach is the combined approach, and this is the one that is endorsed by the Institute of Medicine. So what's recommended is that the patient first follow up in the cancer center, either with the primary oncologist or with the long-term follow-up team, to develop a plan. Then there's a transition to the primary care provider and an actual conversation with the primary care provider about what the patient needs. This helps with the partnership between the cancer center and the primary care team and it also helps—because it's more of a wellness-based than relapse-based—and this also continues to help with the access to a cancer center. Some of the disadvantages are that the PCP, the primary care provider, needs to stay up-to-date on the latest and greatest of oncology care, which can be difficult.

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Resources

Finally, here are some resources. This information about the Childhood Cancer Survivor Study, and then also Children's Oncology Network, Institute of Medicine, and then there's the Robert Wood Johnson Foundation that again is studying the enablers and barriers to long-term follow-up.

I'd like to introduce Eric now. Thank you.