

*Young Adults with Blood Cancers:
Managing Treatment and Beyond*

Sage Bolte, MSW, LCSW, OSW-C

Slide 50

Survivorship Issues Facing AYAs

Sage Bolte:

Hi, there. So good to be here amongst friends and colleagues, and I'm glad to be the lone social worker, I think, here, and just honored to be in the midst of you all.

As Eric said, we tend to interject on each other, so he may chime in on the things I'm going to be speaking on.

So some of the things we've talked about, I'm going to wrap up what we've been talking about in general, and then go on to what we can do about it.

Let me first mention that the reason I asked "what's a wiki?" is because I know there are many people in this room who have probably not heard about Wikipedia or Facebooking or MySpace, and that's okay. You're not part of the Stone Ages, it's okay that you haven't, but let me tell you that if you are working with young adults, which all of you will at some point in your nursing career, I'm sure, you need to know what these are. So you need—I just want to challenge you and charge you to go get educated. What are the things out there that are attracting young adults to stay connected? Because that's the only way, for this age group, that you're going to connect with them and keep them engaged in treatment. You need to be in the know. We can't kind of fly by the seat of our pants with this population unfortunately. We really need to be in the know—then they take us seriously and they stay connected. Whether you are 25 or whether you are 75. We were talking earlier about the woman who runs the young adult group or the teen lounge at MD Anderson, she's in her upper 50s and has an amazing connection with these adolescents and young adults. Age doesn't matter. It's all about you staying in the know.

Slide 51

What's So Unique About AYAs?

So what's so unique about this? We've talked about some of this already. They're going through so many normal developmental milestones, and then cancer comes in and smack, flips their life upside down in so many ways. It interrupts high school or high school graduation, it interrupts college, or they may have to move back home. And if we just think about that from a psychosocial perspective, yes, it interrupts college and yes, they can come back, but I want you to think about being 21 and just about to graduate college, getting ready to start your own career, maybe you're in a serious relationship or you're just starting to explore those relationships, and now suddenly you've been diagnosed with cancer and you have to move back home. You've already started to separate and you've built this autonomy and this sense of self on your own. Maybe you have a sexual relationship with your partner, maybe you have begun dating more

frequently. And now you're back home under your parents' roof, and now your parents have started to become your parents again, telling you what to eat, how you should get up, when you should get up, make sure you take your medicine. It's going to cause a lot of conflict and a lot of strife, and it also is very confusing to the young adult because you will see some regression behaviors. Kids will regress. I know *I* regress when I go home, and I'm 31! It's very common. So when you complicate that by now they actually are having a role reverse, where the parents are having to care for the child, it can be very, very challenging. So that's one milestone that definitely gets interrupted.

Thinking about starting and developing a career. If you're at the very beginning of your career and you're diagnosed with cancer, how does that shatter or shake your sense of self and your confidence in what you have to bring to the table? Are you someone that that employer is going to keep on? If you start your job and three months later you're diagnosed with cancer and you're going to have to be out for a number of days, 90 plus days, you may worry about that job security. That in and of itself, again, is unnerving and scary.

And as we talked about before, it really rattles this sense of immortality. I think this age group in particular has a sense of invincibility and immortality, and getting cancer changes that.

Slide 52

What's So Unique About AYAs? (Continued)

So some of the challenges with this population is, again, they're usually the most underinsured and financially unstable. There is that sense of invincibility. They are hard to follow up, as we've talked about. But the biggest challenge, I think, from a psychosocial perspective and what we as nurses and social workers need to be more aware of, is there is just an enormous amount of loss. *Enormous* amount of loss with this population. Not only are they having to move back home, or maybe they're newly married and their wife is having to take on the role of breadwinner and now this young man, who was looking forward to being the man of the household, is now home, feeling really crappy, weak, not able to perform as what he feels he should be able to do. He's not able to sexually engage with his partner. There's a lot of things—that is loss after loss after loss after loss. Add on top of that the loss of fertility possibly, so the loss of maybe future planning of children. You might hear, at least we do in our group a lot, this loss or sense of loss around “Nobody will ever want me, I'm damaged goods, who's going to want me after they know I have cancer?” Who's going to want me now that I can't breathe when I walk up a flight of stairs, I can't play basketball with my buddies, I can't keep up with my 3-year-old, who's going to want me? That's a huge question for this population. And again, developmentally appropriate, because they really are starting to explore and invest in long-term relationships, and cancer devastates that.

Our role is to give them hope. That's my feeling.

Slide 53

Highest Identified Needs

Brad Zebrack, who I adore and idolize and put on a pedestal, does a lot of research in this area.

He did a study recently in 2006 that had some really great information I thought I'd share, just quickly. Some of the things that they found when they interviewed over 200 young adults is that what they identified needing in treatment is they obviously need adequate health insurance. They want a multidisciplinary approach to the delivery of oncology care. So they don't want *just* the physicians or *just* the nurses or *just* the social workers giving them information. They really do want a team approach. So as nurses, *use* us social workers beyond just financial needs and discharge planning. We're trained in other areas, *use* us. You don't have to get a psych consult all the time. Use us social workers, we're already integrated in the care team, *use* us.

The treatment decisions that account for risks to the successful achievement of developmental tasks facing the population such as education, family planning, career development, employment, they want that information up front. And they want to know about the clinical trials and state-of-the-art treatment protocols that are out there, that are designed for adolescents and young adults. And again, these needs continue long after treatment ends.

Slide 54

Highest Identified Needs (Continued)

For in-treatment what they talked about, their counseling and supportive needs, while they're going through treatment, not survivorship issues, but while they're in treatment, they want individualized information about disease, treatment, side effects and late effects. And Eric had mentioned that they want it on their own time and at their own pace, and that's absolutely true. So give them the resources and the tools and the know-how of how to find that information when they want it.

They want information on resources that are appropriate for developmental stages. So please do not give them a packet that has a kid on the front of it. It's *so* not helpful, and it really ticks them off, quite honestly. If you don't have a packet without a kid on the front of it, tear the picture of the kid off and give them the information or Xerox it or rewrite it. It is very unhelpful to give a 19-year-old a pamphlet with a 13-year-old face on it. Information resources that are appropriate.

Opportunities to meet other young adults. We talked a lot about that. Give them opportunities to meet other young adults. There are ways to do this that are HIPAA-friendly and HIPAA-appropriate, and you can connect them randomly on the hall as they're walking there and doing their laps. There are ways to connect them.

And then they really ask for support from family and friends, and we'll talk a little bit about how you get them engaged with that.

Again, these needs continue.

Slide 55

Highest Identified Needs (Continued)

After treatment, so once they're done with treatment and looking at survivorship, what they said they need from the healthcare perspective is they need insurance, as we've talked about. They

need ongoing medical and monitoring for long-term effects. And how they go about doing that—so a lot of these 19-, 20-, 25-, 30-year-olds who are out in the community or away from home, don't necessarily know how to go about getting connected with a primary care physician who can help follow them for their late effects, so we need to be facilitating that.

Assist them for transitioning care, as I just said, and then evidence-based guidelines for long-term follow-up care.

Slide 56

Highest Identified Needs (Continued)

As far as what they need psychosocially, this is what they say, and I'm going to focus on a couple of these. Obviously they want individualized information about some of the risks and then therapies that are available, psychosocial therapy. They want to know information—this was their top two requests—they want information about sexuality, fertility and reproductive risks. It's not going to scare them off. *It's not going to scare them off.* It's not going to make them feel worse. They *want* the information. And as we talked about earlier, information and education is empowering to them. They want this information up front. And that doesn't mean just put on a condom 24 hours within treatment. It's not just that sex talk. It really is talking to them about sexual function and sexual dysfunction and the sexual self. So thank you, Mary, if you're out there, for having that talk earlier. So glad, this a topic that's really close to my heart, I'm really glad that's getting out there.

They want opportunities to meet other survivors after treatment, to stay connected and engaged. Most of the time during treatment they don't have the energy to be part of a group. Many of our patients kind of come in and out during treatment, but it's after treatment where they really want to be engaged because that's kinda when the stuff hits the fan. It's not during treatment, it's after, and they wake up in the morning and go, "Oh, my gosh, I'm a cancer survivor, I just had cancer, what does this mean for my life?" That's when they really need our support.

And they want to find people where they can have the ability to express and cope with feelings about cancer, including the desire to return to normal, or as we talk about in the cancer world, the "new" normal. And that's a part I think we can do better as nurses and social workers, is at the very beginning, start normalizing, that normal may never be normal again. That their normal may be a new normal forever. The more that we can normalize that and acknowledge that it's a loss, but that it's okay, they have the control and power to redefine what that normal looks like. That young adult is going to feel more in charge of their ability to make choices, to make their normal look however it's going to look.

Slide 57

Common Concerns

Some of the common concerns that the young adults raise are these questions. Do I have to tell my cancer history, not only to someone I'm dating, but to an employer, to friends and family who I meet later in life? I guess you wouldn't meet family later in life, but friends later in life. Can an employer not hire me because I've had cancer? This one we hear a lot. My job sucks. I

took it, it was my first job I got out of college, I took it because I needed a job and now I'm stuck because I feel like nobody else is going to hire me if they know my history and I'm not going to be insurable. How long do I have to see the doctor? What if I want to move, then what? Which we hear a lot. I'm almost scared to move because my oncologist and my network of support and strength is here. When do I tell someone I've had cancer? Especially around the dating issue. Will I ever be able to have children? My friends don't get it, and I love my parents, but it sucks being home. This one we hear a lot, too. "Sucks" is a big word in the young adult world.

And then the theme of loss, which is probably a topic that comes up in every single group we have.

Slide 58 **Instrumental/Practical Issues**

How does this go about in the kind of practical issues? We know that the interruptions to school and work affect their life, and I talked briefly about that. But think about not just that it interrupts their life and that's inconvenient and annoying, but think about what it *feels* like for them, beyond just the practical and having to get the treatments in place and not having insurance and so you're trying to scramble to find money and insurance, and do they qualify for SSDI and etcetera, etcetera. Think about how that feels for them. Just sit with it. What does that feel like for a young adult to have to be pulled from their entire support system? What happens to their sense of self? It probably gets pretty rocked. Their sense of who they are, what they had defined, how they fit in their community has drastically changed.

And then the concrete needs that we can help with, which are really easy ones, are things like transportation. We can help them find resources for that. Lost wages, childcare, and accessing disability benefits and support. Those are things, concrete things, we can help do that help us feel like we're helping them.

And then helping them identify some of the restricted abilities. There are laws out there to protect them. There are a lot of laws out there to protect them, and with the new administration there's becoming even more and more. So we are on a roll to really helping our survivors be protected and being able to be and stay insured.

And then help them talk through their future employment concerns. It is true that some employers, especially—mostly small organizations that have—I don't know the number, but there is a number for them—under a certain amount of employees, can discriminate in offering you insurance. Larger companies, there are a lot of things built in where they can't. So they need to know, again, their own state laws and the legislation out there that's out there to protect them, and we need to know that as their healthcare providers as well, so that we can help advocate for them.

Slide 59 **Interpersonal Issues**

Thinking of the interpersonal issues. The relationships with the parents and family support. I

mention this again, role reversal that happens within the home. Their mom suddenly becomes “the mom” again. We call them “helicopter moms.” Everybody knows what those look like, hovering around, intervening in everything. And that can be great at times. At other times you actually watch—I’ve watched a couple of young adults almost sink inside themselves. And I don’t know if you’ve ever seen that, but it’s really sad to watch a very vivacious young adult come, get the information, and then suddenly their parents take over and they just start disappearing into the background and they just kind of go with their program. They’re not asking questions, they’re not doing anything, and they do lose a sense of self. Those are the kids that get sent to me for counseling because they’re depressed. So keep an eye on those kinds of signs.

The interruption to autonomy, and the boundaries between parents and child.

So one of the things we’re going to talk about is information giving with parent and child. If the child is over 18, what is that child’s right? They have the right to be an adult, right, so their parent really doesn’t have the right to that information. How can we as healthcare professionals respect both parties, but honor and treat our patient, who is the adult child?

The interpersonal issues around social involvement, relationships with peers and dating. Again, this is the age group of people dating, getting married and having children. These are huge. Think of all the developmental milestones we go through between the ages of 18 and 39. They are monumental.

Thinking about dating, how do I tell someone that I’m a survivor or how do I tell someone that I’m in treatment? And one of the things we recommend in our group is role-playing that uncomfortable discussion. Some kids are really comfortable just saying, “So I’m a cancer survivor.” Some people wear t-shirts that say it, so it’s, like, out there on their first date. Other people will wait until the third or fourth date, and that’s probably the more typical. You wait until you’re really sure you want to be in this relationship more, and then you disclose. And there’s ways, again, they can role-play with their friends, we can role-play in group. A lot of times I really encourage them to think about what else defines them. Being a cancer survivor is a small percent of who they are. It very well may have changed the route of the life choices they made and are making, but it’s a small percentage of what and who they are. So to write some kind of almost an ad about themselves, to really look at what they have to bring to the table besides being a survivor.

How can we help them with thinking about having and managing a family? Can we get them resources, can we talk to them about that up front? I know there’s a huge discrepancy in care and fertility management between girls and boys right now, or young women and young men. Some of that’s because of the lack of resources we have for young women. But those discussions should be given up front.

And I’m going to get on my soap box for just one second and just say I think it is our responsibility as healthcare professionals, whether it is a female or male, whether we have the options for fertility preservation or not, to give that information up front before we start treatment, that their fertility has a good chance of being affected, and that here are the options or lack of options. Because if we don’t, I really believe we are not giving them true informed

consent. If they are not given that information and don't have a say in what they want to do, and even if that means they want to wait 30 days to try to have a cycle, so that the eggs can be extracted, they have the right. They need to be informed of the risks, but they have the *right*. We don't have the right to take that away from them. Okay, off my soap box, back to this.

Talking about managing career and role reversals, we've mentioned that.

Slide 60

Interpersonal Issues (Continued)

The relationships with the healthcare. So what do we do? Here are some final tips.

Our relationship with this population needs to look different than it does with ped[iatric patient]s and older adults. Our communication needs to be more direct with them and them as the patient, not their parents. So when you're having a conversation, and I've been in settings where this has happened, where the physician and/or the nurse are talking to the parents instead of the adult, sitting right there. And that's because that dynamic has shifted, and the young adult has kind of gone into the background and allowed the parents to step it up. I don't believe that's okay. We need to be speaking to the patient directly.

Don't assume that the young adults do or don't want their parents or significant other present when they are getting information at diagnosis and after. So just because their wife or their husband or their partner is there, that doesn't necessarily mean they want that person to be present when they're getting information. So ask that patient, that young adult, who do they want in the room when they're getting information, or would they like their partner or their mother or their father to be present during that? Ask first before you just start talking.

Don't use medical jargon. Don't talk down to them like they're children either. Don't try to connect with them in an artificial way. At this age, people kind of read through the BS. They just kind of read it and they know it, and so they're more up-front with that. And they will turn away if they don't feel like you're being authentic with them.

So talk to them in their language. E-mail. Text message—and again, we'll talk about some of the ethical issues with these in a moment. Text message them, and be aware of their therapy time. Simple things like, why would you give a young adult an 8:00 appointment? Do you really think they're going to show up? I mean, *I* wasn't awake at 8:00 at 21. Now I am, I have an 11-month-old, now I'm up at 5:00. But before, nobody is going to come at 8:00. So think about their therapy time. Even simple things like that, we can keep them engaged if we just stay mindful of their developmental milestones.

Slide 61

Interpersonal Issues (Continued)

And lastly, think about offering them fertility and support, again, resources up front. It will not freak them out. It gives them information. They may not want to talk about it then, but I can bet you money they will come back to you because you're the person that initiated the discussion.

Talk to them about the sexual changes they may experience up front. Don't wait for them to come to you and say, "I'm not able to get an erection any more," or "It feels like my orgasm isn't as intense." Don't wait for them to do that, especially with young women who are having pain now with sex, who may have been celibate, monogamous or virgins before, now they're having sex and they think sex—it's normal to be painful and they don't know any different. Unless you tell them it's not supposed to—I have many young women who've been in a relationship, their first sexual relationship after treatment, and have ongoing painful sex because they didn't know that wasn't normal. And they have vaginal stenosis and other complications from the treatment. They didn't know until I said, "Oh, my gosh, are you using lubrication?" or "Have you been talked to about dilators?" They didn't know. So give the information up front. They'll come back to you if it's too much.

Start a young adult group in your area. We really support the model of nurse and social worker. It's a fantastic model. It brings two different perspectives. It offers them a broad range of information, and it works really well.

Develop a common rule of follow-up treatment for your young adult population. Have it in writing, and e-mail it to them as well. Make sure that they have the follow-up plan, not just their parents.

Slide 62

Pretending Things Aren't So Serious

I want to close with a quote. This is Julie, and Julie just recently relapsed and is just—she is probably the symbol of hope for our group. She is an amazingly optimistic young woman. And what she said, I asked if she had anything she'd want nurses and social workers to walk away with about her care. And she said, "You know, I don't really have any quotes or anything to share with them, I've had such a positive experience with everyone in the medical community. It's funny, because I miss seeing my friends in the infusion clinic and at my doctor's office. Interaction with people was what I wanted the most when I was sick. And with leukemia you just become so limited in terms of where and who you can visit, that I always looked forward to talking to the nurses, doctors' assistants, secretaries, everyone. Maybe if you just want to remind everyone that when appropriate, humor can indeed be the best medicine. I loved that everyone joked with me. It was so nice to pretend that things weren't so serious." So sometimes, although denial can be dangerous, sometimes a little denial is really good.

Slide 63

What Can I Offer Them?

Remember what you can offer them best is face-to-face support. Be there, be present, be open and willing to talk about things that other people aren't willing to. Network and connect with them. Educate them in their own time.

And then here are some great resources that have tons of information for young adults that you can use and connect with them with. And again, there are online support groups you can connect

them to as well.

Thank you.

Slide 64
Panel Discussion

Carson Jacobi:

Thank you, Sage.

We have some time for a panel discussion, and we're going to talk about some ethical issues. I think Sage will probably start.

Sage Bolte:

Actually Nicole.

Carson Jacobi:

Nicole will start the first one.

Nicole Rosipal:

So I wanted to add just one thing to Sage's, which was an excellent presentation. Everybody, thank you very much. She was speaking about scheduling appointments not at 8 AM. Also, work with your physician assistant, nurse practitioner, physician, on scheduling medications. My patients are on post-stem cell transplant tacrolimus, get discharged from the hospital at 9 AM, 9 AM tacro. The first follow-up appointment post-discharge is okay, so what time do you really wake up, and what time are you really going to take this medication? Because I know that you're not going to wake up at 9. And so we work with them and collaborate with them on that time because I know most likely they are going to be up at midnight. So taking their med at noon and midnight is a reasonable thing. Just food for thought.

So some of the ethical issues that we want to discuss with you, one of them being information-sharing. I just wanted to give a couple of stories about some patients that I had interactions with and my team had interactions with, and how we worked with them with their information-sharing.

First one is an 18-year-old female. She was one year post-stem cell transplant with graft-versus-host disease. She was initially diagnosed with severe aplastic anemia at the age of 12. Mother and patient initially had a very, very close relationship. However, the patient then turned 18, and she became very nonadherent with her medications. She was lying to the healthcare professional, to our team, and also to her family and her mother. She did not want her mother involved at all anymore. Her mother was not allowed to come to the appointments, was not allowed to know about her medication regimen, was not allowed to know how she was doing medically or

anything. On the flip side, however, she wanted her mother to continue to pay her medical bills, continue to pay for her apartment, her cell phone and her gas because she would like to pay for her cigarettes and wanted help from her mom to pay for her gas to get to her medical appointments.

So needless to say, mother would call us, completely in tears, upset, how do I talk to my child, how do I talk to my daughter about this? At first approach, the young lady said, “absolutely no way am I involving my mom.” So a couple of visits, I sat down with her and we talked about the pros and the cons of having her mom involved and that it didn’t have to be an all-or-nothing ordeal. Mom didn’t have to know absolutely everything. We weren’t going to talk about if she was smoking, if she was out there doing whatever. Promised if the young lady became promiscuous, I was not going to share that information with Mom, but that there were some medical decisions that—Mom knew this child since she was 12 and could help her make her medical decisions to benefit her the best.

So fortunately, she came around and we were able to get social work involved, myself, the physician and Mom and patient in the room together and work out a contract, all of us together. So that way the entire team knew what we were allowed to share with the patient and what we were allowed to share with Mom. And this actually has worked out very nicely. So that way when Mom calls and says, “Nicole, I’d like to know such and such,” I can say to her, “I can’t share that with you.” “Oh, yeah, that’s right, but what about this?” So it’s worked out very well, and it’s helped the mother and also the patient—they have actually been able to come back together and form a relationship again, which has worked out.

So the important thing here, though, is to understand your state laws and HIPAA, et cetera. State laws, usually at the age of 18 years of age, patients can start to make their own decisions. However, in some states, such as Nebraska and Alabama, this doesn’t start until 19. And interestingly enough, in Mississippi, it’s 21 years of age. However, we were talking earlier that if you have a child in the state of Texas, I don’t know other laws, but at 15 or 16 years old, then you’re emancipated from your own parents and at 15 or 16 you can make your own medical decision, if you have a child yourself. So just know your state laws and know what you can speak about.

The next example I wanted to give was about a 21-year-old female patient. She also was admitted for stem cell transplant for severe aplastic anemia. Prior to her diagnosis, she was living away from home, going to college, very active, doing great socially, et cetera. Since she was diagnosed, she had to move back home, and she became very dependent on her parents. Furthermore, her father was a physician—and a physician at our institution. So he would show up in the middle of clinic visits and completely take over. And as Sage was discussing, you would just see her slowly slip into the background and not talk at all, not give her opinion at all. And he was making decisions post-transplant. For example, we wanted to be able to exchange her central line so that we could draw tacrolimus levels out of it, and he didn’t want her to be able to do that. He wanted to continue to have her peripherally stuck.

So I very politely, as politely as I could, asked the physician to leave and the mother to leave, and discussed with this young lady, “You are 21 years old, these decisions are your decisions,

you can continue to have your parents involved in this decision-making, and we need to work out with your parents what decisions you're going to make and what decisions they're going to make." Because she *wanted* her parents involved. She respected her parents' decisions, and she respected the fact that her father was a physician and that he did have some knowledge that she did not. So we really had to work through that. And after that 30- to 45-minute discussion, she came back to—it was wonderful to see her liven up again. And then when Dad came back in the room, she looked at him and said, "I'm having it exchanged." And so we were able to exchange her line, and from then on, things have been much better. We've had a few hiccups, but having that initial conversation and explaining to both the patient—because she didn't know her rights, she'd never been exposed to the healthcare—in the past, she was aplastic anemic, she was completely healthy until this experience.

So I guess the moral of the story is, know your state laws, and talk with your patients and families and try and pull them together.

Sage Bolte:

Eric and I want to briefly talk about something that we have become—it's become one of our soap boxes—another thing we've become very passionate about, as we've watched and worked with many of the nurses on our floor, as well as again with the young adults, so please stay put for this part of the talk. Don't get up and leave. We think this is really important.

So we've talked about that this is the online generation, and we want to talk to you a little bit about the challenges with that. Because one of the challenges we're seeing is nurses and patients Facebooking and "friending" each other. Now if you are "friends" with your patients, I don't want you to freak out and think I'm going to throw a mallet at you, but I'm going to challenge you on why it's ethically wrong. And I'm sure that's going to be uncomfortable, and that's okay.

One of the things that, as Eric and I have talked about, there are very clear guidelines for us as social workers about patient boundaries and what that looks like. And although oncology—it's much grayer I think for all of us in oncology—we fall in love with our patients, we're working with mentally healthy patients, we run into our patients at the grocery store and if they approach us, we engage in a normal conversation. It's very different than working in a psychiatric unit or other more private, privacy-respecting areas of medicine.

But as social workers, we have very clear guidelines about what is boundary crossing and what is not. It would be a boundary crossing for me to go out and have a cup of coffee with a young adult's partner or spouse, even if we were talking about the care and how that person was doing. It would be inappropriate and a boundary cross if I was "friends" with one of my patients on Facebook. Unfortunately, for nurses, there really isn't that clear of a guideline on some of those ethical issues with relationships.

So Eric and I have talked about what we might think and why we feel that "friending" and some of the social networking institutions out there are actually pushing the line with ethical boundaries and why it crosses, beyond just it being inappropriate at times, why it puts other people at risk.

So we want to give an example of this. This is Jeremy, who's a 22-year-old leukemia survivor, in for six weeks post—or for allo BMT [bone marrow transplant]. He has a long history, *long* history, as an inpatient in the institution, having spent his first induction chemo the year before, and several subsequent stays with us. So the nurses know him very, very well. His family is in the local area and visits in the evening. We don't see many of his friends coming in and out. He seems pretty isolated, and he has a history of depression. His mother, father and sister do come in the evening.

He was diagnosed in college and has been back and forth throughout for his treatments. He has a history of substance abuse, pretty significant substance abuse, which has unfortunately labeled him as a med-seeker, and so therefore actually some of his care has been I think interrupted, and probably he's been treated differently.

There's a questionable comorbid mental illness. He clearly was depressed, but we wondered about some other things. Isolated from friends due to his cancer experience. And then he's not in a long-term relationship, but has a history of several heterosexual relationships. In fact, he was like hopping from one relationship to the next, in some ways trying to fill this void.

So you want to talk about some of the issues? Why don't we talk about the issues that came up with Jeremy?

Eric Cohen:

Go ahead.

Sage Bolte:

Okay. So the issues that came up with Jeremy—I was actually his primary therapist, and he would come in and we'd be talking and he'd say, "Well, I was texting with"—I'll give her a name—"Julia the other day." And Julia is one of our floor nurses. And for me, it was the first time I'd been faced with this issue, but it raised a giant red flag for me. Why is a nurse and a patient who are of the same age texting back and forth, and what are they texting about? So I pushed a little bit, without showing that I was concerned, and what they were texting about was many things. What he was doing that night, where they were going to go to dinner, "Yes, we're going to go to dinner." What they were going to do as far as treatments. He'd ask her questions. And then I found out more and more that on Facebook, they were actually having dialogues about—he would post like, "I feel like you-know-what." And then she would respond and reply because they are friends, they had access to information on each other. She would respond and say, "Have you tried this?" or "Did you do this?"

If you just think about that just for a second, one, everything on Facebook is public knowledge, so she's now given a prescriptive treatment to a patient online that everyone can view. Now he was very open about his disease, it was on his Facebook page, so it wasn't like that was a big secret. But not only that, she's now connected with him, so she's identified herself as a healthcare professional on his Facebook page. Other people know that she's his nurse. She's

giving prescriptive pieces onto the Facebook page. And the biggest problem is that she's friends [on Facebook] with many of us, other healthcare professionals, that do not want our patients to access us. So suddenly, we as other healthcare professionals, are getting [Facebook] "friend requests" from this guy. And it puts us in a very awkward situation, to say, "No, I don't want to be your friend." Because no, I don't want to be your friend. I'm not your friend. I love you and I care for you, but I'm your healthcare provider, I'm not your friend.

And especially again, for young adults, I think the challenges, the emotional connection we make with them, especially myself being young and I am their age, it is hard, it is really hard to be with them and not want to engage with them. Because there is a part of us, we're all in this profession because we want to save people, whether we have a God complex or not, we're in this because we want to love, serve and really save them, from their own selves. And we can't do that. And when they are young people, we really want to connect with them.

And so again, this particular nurse, didn't have many friends, she's a little more socially isolated, and she would come in on her days off and hang out with some of the young adults on the floor. Again, I would challenge that because that is a professional and personal boundary that has been crossed. You're not doing self-care any more. What's the nursing perspective?

Eric Cohen:

Oh, you're doing very well.

One of the things that this progressed into is that the patient texted—sent a text message to the nurse talking about pain medicine and that the physician wasn't giving him pain medicine, and the nurse actually got very upset and called the physician and said, "What are you doing? How can you?" It was just extremely inappropriate.

And then the other part of this, too, is that on Facebook the nurse also was "friends" with a physician. And when the patient saw that, of course, now the patient has access to the physician. So that was a very uncomfortable situation for everybody involved as well.

Sage Bolte:

It also leads to one of the subjects that we may have time to talk about later, but we can touch on, is "splitting." And splitting, meaning they're telling you one thing, they're telling the physician the other. Well, this particular patient did a whole lot of that. He'd come to me in therapy and say this person's not doing this, doctor so-and-so is not doing this for me, I'm not getting my pain medication, the psychiatrist came in and was acting all this. When we got right down to it, he told us each a different story to get his needs met. And that was able to continue through some of the social networking sites that were happening because he was keeping this off-the-books conversation going with his nurse at 11:00 at night, when she wasn't working.

So again, it does put us in a high-risk category for a boundary crossing and ethical violation.

Eric Cohen:

Another thing is that for those of you that are on Facebook and are familiar with Facebook, you know, when we're taking care of these patients, we have limited information about them. And so as Sage mentioned, we do fall in love with our patients, they fall in love with us, we bond with them. But again, it's on a professional level, and we don't really have a lot of personal information about them.

And then we get a friend request and let's say we say yes. And what you find out is perhaps that this patient is a white supremacist. Do we really want to know that information? We don't need that information to take good care of them.

Sage Bolte:

And I *guarantee* it will change the way you treat them, whether you want it to or not.

Eric Cohen:

Right. So we really don't want to have this information about them as well.

Sage Bolte:

Yeah, I don't want them to know my religious affiliation unless I feel comfortable sharing with that. And if I put that on my own private area of Facebook, I don't want them to have that.

The next person, Justine—sorry, this is who we had talked about, the nurse, sorry, I thought that was the next person. So one of the challenges again was once I friend someone, how do I “unfriend” them without them feeling like I'm ditching them or breaking up with them?

Well, one, if we feel like we're breaking up with our patients, I think we're a little too engaged. I do think reevaluating your role and your relationship with them is a really important thing to do every once in a while. And how you can “unfriend” them—and we have—is you just put out an e-mail. And we did it to our young adult group because we have had several requests from our patients in our group, asking us to be their friend on Facebook. And finally after, like, the fifth one of us saying no, we were starting to feel bad, so we just put out an e-mail and said, you know, we love you guys, but we have some ethical and professional boundaries that really guide us in our decision-making about what we expose you to and what you expose us to, and we really feel that Facebook is crossing that line. We will love and support you, we will be at support group, you can friend each other, but friending us inappropriate.

Eric Cohen:

We started a *Life with Cancer*® Facebook group page so our patients can join that group, and on that group we say we can't be your friends and this is why we can't be your friend, but feel free to post—ask us questions on the wall, post things to the wall and that's fine, we'll respond to you there, but we won't allow you to see our personal pages.

Sage Bolte:

That's right. So we are on the Facebook group page, but we've limited our profile, so all they see is our name and our picture. They don't see our family pictures or any of my personal information. That's a way that you can still be engaged in Facebook and engaged with your patients in the patient groups without them having access to your information.

So we talked about that, okay, sorry.

During and after treatment in the online generation, again, some of the threats or the ethical dilemmas is the possible undermining and interference of the healthcare team and the patient's daily care, and we absolutely saw this with this young man. There was so much interference going on because of the splitting and because of the offline conversations that were being had, that I would kind of find out about in therapy, and then the doctor would find out about in conversation or Eric would find out about on the floor and it was really, really unfortunately—it only harmed this patient's care. Didn't affect necessarily his treatment, but it definitely impacted the care he received.

Privacy and confidentiality rules. So if they acknowledge on the Web that they are a cancer survivor, we're not necessarily violating that by disclosing that, but we are violating that they have a relationship with us. And whether they are okay with that or not, we *can't* be okay with that.

And then the relationship boundaries that happen. Again, with this age group it is tough, really tough, speaking again as a young adult, it is tough to have boundaries. There are so many people in my group, oh, my gosh, they are so cool, I want to hang out with them so bad! I want to go and have a beer with them, I want to go and hang out with them, especially being new to the area, I just moved. There are a lot of young adults in my group who probably would be my friend, my best friend, if I wasn't the professional. And it's hard. But it is not my right nor my role to be their buddy. I want to be supportive and be a person in their life who supports and loves them, but I can't go hang out with them after work. One, it would probably take a toll on me, too, emotionally.

So I think we want to open it up to questions. We would love to open this up for questions, comments, ways that we may be able to answer some of the ethical boundaries that you've faced, or even questions about the talk earlier.

Someone's got to be bold and have a question, come on now!

Audience:

[Inaudible] I go into the room for the purpose of giving love and doing my nursing thing, but not for the high that comes back to me. And as long as I go into that room not for the high, but for what I give, then I feel like I'm keeping my boundaries and clear line. Do you agree?

Sage Bolte:

What's the motivation behind it? Absolutely. Always ask. Am I doing this for them or am I doing this for myself? That's a good, usually boundary kind of ...

Eric Cohen:

Tester.

Sage Bolte:

Thank you. Tester. Question in the back.

Audience:

Hi. I just want to ask, the situation with the nurse and crossing the ethical, professional boundaries. What was the follow-up on that? Because I have a situation with one of my staff members like that now.

Sage Bolte:

So we went to the head nurse, right? And we had a conversation with her. And then we did have a conversation—she actually was uncomfortable having the talk with her nurse, so it was then put back on Eric and I. And the issue was addressed, by basically sitting down and saying, it's not appropriate to have these kinds of relationships, what's the motive behind them. And we did it in a very loving, caring way, the issue was addressed. But it needs to continue to be addressed. One of our goals is to do an educational session on the floor, so that all the nurses get it, so nobody is singled out. And that may be a great way for you to address it, is have an in-service for 30 minutes for lunch or even just a break. Do an in-service on boundary setting, and then see if it changes. And if it doesn't, address her the next week or whatever.

Audience:

Thank you.

Audience:

[Inaudible] ... or can anybody join? Like I'm from Washington, DC.

Sage Bolte:

Oh, no, you can come. We are not hospital-based. We service anyone in the Northern Virginia, Washington, DC, Maryland area. So they just call us. We're at lifewithcancer.org. They can go online and they can register for the group, or just call us and get on our e-mail list so that they get the updates. And we're free. Everything we do at *Life with Cancer* is free.

Eric Cohen:

But if in your area there isn't anything available like this, I'm guessing there's a wellness community or ...

Sage Bolte:

She's in DC.

Eric Cohen:

Oh, I thought she said Washington state. Oh, okay.

Sage Bolte:

Yeah, call us!

Eric Cohen:

But there are things available online like Planet Cancer and those kinds of things.

Audience:

Because this is such a very culturally diverse country, how do you deal with, when you're talking about separating the patient from the parents, how do you deal—or even husbands and wives—how do you deal with those cultures, where this is not acceptable? Where now you've got culture coming into it that says no, my child will not make this decision, no, my wife will not make this decision. How do you deal with that?

Nicole Rosipal:

Fortunately, I haven't dealt with a husband–wife situation, but definitely with families and their younger children, or they're becoming young adults. We have a great international service that we'll get them involved to help us understand the cultural boundaries, so that we try and approach them and being culturally sensitive to that. Especially if they're coming from a different country, which we have a lot of at MD Anderson, we have to respect their cultural boundaries, for sure.

Eric Cohen:

Anybody else?

Sage Bolte:

I know all of us are available to you. At any point, feel free to e-mail us or call us or whatever.

Carson Jacobi:

If you can please help me again thank our four speakers. They did a fabulous job.

Again, thank you for joining us.

- END -