

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Hodgkin Lymphoma Part 1: Struggles of a Young Adult with Cancer'

Description:

Join us for a special two-part episode as we speak to Dr. Christabel Cheung, a two-time Hodgkin Lymphoma Survivor. In Part One, Christabel tells us about her longtime journey with lymphoma, including a relapse and going through the second diagnosis during a global pandemic. She shares her struggles of not only a diagnosis, where she is in the small percentage that didn't respond to first-line treatment, but also going through cancer as a racial minority and young adult. Be sure to tune into Part Two as she delves more into health disparities for young adults and BIPOC (Black, Indigenous, People of Color) communities.

Transcript:

Edith: Welcome to *The Bloodline with LLS*. I'm Edith.

Elissa: And I'm Elissa. Thank you for joining us on this episode. Today we will be speaking with Dr. Christabel Cheung who is a two-time Hodgkin's lymphoma survivor. Dr. Cheung is an Assistant Professor at the University of Maryland School of Social Work and a member of the University of Maryland's Greenebaum Comprehensive Cancer Center. Dr. Cheung's research interests in psychosocial oncology are primarily focused on the relationship between financial hardship, occupation, socioeconomic status, and adolescent and young adult (also known as AYA) cancer patients. She is also interested in the social determinants of health, health disparities, and health equity. This is a special two-part episode covering a variety of topics from Hodgkin's Lymphoma to health disparities amongst the young adult and BIPOC Communities. Welcome Dr. Cheung.

Dr. Christabel Cheung: Thank you so much for having me, Elissa and Edith.

Edith: Now before we get into today's topic, we want to get to know our speaker a little bit more; and we definitely like for our listeners to get to know them as well. So, Dr. Cheung, how would you describe yourself?

Dr. Cheung: Because the nature of our topic today is on a rather sensitive area of talking about health disparities, racism, and particularly in our current context of the twin pandemics of COVID-19 and the uprisings against racism and police brutality. One thing that I often like to do, especially because we're in a podcast situation where people can't see our faces and even with that, that's a lot of assumptions, right?

I'm a BIPOC embodied researcher or, more specifically, I'm a 0.5 generation Chinese American cisgender woman, and I use she/her pronouns.

Edith: Dr. Cheung, what does BIPOC mean?

Dr. Cheung: BIPOC is an expansion of POC. It's still okay to say POC. It's not offensive or anything, but BIPOC means black, indigenous, and people of color. So, it's really amplifying black and indigenous populations and still saying POC as well, but, oftentimes in plain-speak, we might just say POC or because we've been saying POC for so long, right.

Elissa: Also, for our listeners who may not know, cisgender is defined as one's gender identity corresponding with their sex assigned at birth.

Edith: So, Dr. Cheung, how did you become interested in psychosocial oncology?

Dr. Cheung: Well, it was really prompted by my own experience. I'm a two-time survivor of Hodgkin's lymphoma as you mentioned in the introduction. Prior to that I was always interested in social services and social welfare. And so, before my first diagnosis, I had already earned my master's in social welfare in gerontology from UC Berkeley and was working as a gerontologist and a community activist. Community organizing are the roots of my approach to social welfare. And I was an activist in San

Francisco Chinatown with my Chinese American community and the larger AAPI (Asian Americans and Pacific Islanders) platform nationally as well.

And so, I really was focused on older adults and aging. So, when I was first diagnosed, I was a 32-year-old Director of Diversity at a national nonprofit focused on the field of aging. And I was diagnosed with Stage IIB Hodgkin's lymphoma. And then three years later I was diagnosed again with Stage III Hodgkin's lymphoma.

But, really, I think it's, being a psychosocial researcher, we can talk about all the symptoms as well. I had all the typical B symptoms – the fever; the sudden weight loss, which as, you know, a young woman, I didn't blink an eye at, and I thought this is kind of great. I was losing weight suddenly without trying. And until it got kind of gross, right? It was too much weight loss.

And then extreme fatigue, drenching all over body night sweats every night. I had all-over-body rash. I actually went to see a dermatologist because I didn't know what was wrong with my skin. I had difficulty swallowing. I had a chronic cough where it got to the point where I stopped eating around other people because I was coughing up blood while I was eating. And I was young enough to not, think that like that's not a big deal. Maybe not young enough but maybe like just ignorant enough to think that that wasn't a big deal.

And, I had shortness of breath; and my heart was racing. And I really went to the doctor because I thought, I think I have mono or something. I think I just need some antibiotics. And it turns out that my body was actually hosting and growing cancer for the last two years before.

So, the tumors had gotten so large that they had collapsed my left lung. They were crushing my heart, so I had these gigantic tumors that were, I think, 16 centimeters, 11 centimeters. They filled up my entire chest; and so, my heart was racing at almost 160 beats per minute, I believe. And so, when they told me it was Stage II, I went home, googled it, came back the next day, and I was just like, "I don't think it's that

big a deal." Like I was telling the doctor because, "There's four stages to cancer. I looked it up last night." And I'm all like, I think different people have different responses to trauma, right?

Edith: Right.

Dr. Cheung: I definitely have like a depressive response. Some people are, you know, like fight, flight, or freeze, right? I'm more of a flight person. So, I was just kind of like, trying to run away from the idea of actually having to intervene on it.

But so, he basically said to me, and I think this is very, very common for younger people who often present with large tumors that are a later stage. "You're not going to die from the cancer. It's not even going to get to Stage III before you probably have a heart attack," because the tumors were so large that they were crushing my heart and unable to expand.

Elissa: Oh, wow.

Dr. Cheung: And I hear other stories from my fellow young adult cancer survivors. I hear this very, very commonly that it was the threat of a blood clot or the threat of something else that actually was more life-threatening than the cancer because of the size of the tumors and the position.

So, I think we really have to think about host biology in terms of addressing cancer and cancer survivorship. And so that also relates to, you know, how the cancer is intervened upon and sort of the late effects of all the treatments as well.

But I think that as a psychosocial researcher, it's also important for me to acknowledge the psychosocial context of what was happening in my life besides just the disruption to work. Right, so I had already worked in the field of aging for eight years. So probably the last three years were the two diagnoses of cancer, the disruptions.

And so, I was eight years in a field that's career-directed, you know, you're almost mid-career. I think typically we say ten years in a field you're pretty solidly mid-career.

So, my last job, I was the Executive Director of a nonprofit called San Francisco Village, which was all about helping older adults age in place in their own homes for as long as possible. And I was very passionate about that work but had to step down because I had to go pursue this bone marrow transplant process; and I think that disruption and I was lucky enough that I was able to find a different direction that ended up being an ascendant direction as well – and that's just pure luck, I think.

It's important for us to think about the psychosocial context, the impact on career, the impact on relationships. I had a partner with my first diagnosis; and after I found out that I was diagnosed the second time, I ended the relationship with him because I didn't want to do that to someone else, which is a very common story of younger people. Right?

And then your friend networks are not mature enough to handle something like cancer. I often think that if I had just the one diagnosis maybe because then that would have been maybe like a one-year project that I, you know, dipped out of and then came back in. But, you know, it's kind of like, "Oh, I had a gap year."

But I was very, very seriously ill on and off for the span of about eight years; and, and I think that part of the sadness in friendships is that I kind of became the person that people wanted to protect me from the sad things that were happening in the world or in their lives. And so later on I would hear that things like my friend had multiple miscarriages; and I didn't know until years later. Or, you know, all the struggles that they go through; and it's just, "I didn't want to tell you at the time because you were already going through so much." Right?

And so, I think there's this period in your life long after the actual cancer treatment, too, where you're sort of engaged but not fully engaged because we as a society don't really know how to interact with someone who is seriously ill and managing something

that's life-threatening. And so, I think because of that, one of the hardest questions that I was asked was, and, and it's always a question that I avoid, is when someone asks, "Are you in remission?" Because I had to lie about it for a year and a half, for 19 months between my first and second diagnosis. We knew after my first scan following my first diagnosis that the cancer was growing in the scans. But we couldn't access the tissue, and the protocol for second-line treatment requires a tissue sample. And so, I had multiple extensive biopsy procedures in my thoracic region to try to access the tumor. But chemotherapy from the first diagnosis had sort of petrified my organs, and they were no longer rubbery and healthy; and you couldn't move around them very easily.

And so, we had to just wait for it to grow big enough, and that took 19 months to do until we finally got a piece of it. And so, I was very depressed during that time. I needed to not say anything. I needed to hope for the best, hang onto my job, and the people all around me were saying, "I don't understand why you're depressed. It's over. Hodgkin's lymphoma, 93% success rate." And, you know, I was in that unlucky 7% that fail first-line treatment.

And even with that, second-line treatment had very, very bad pulmonary toxicity and got radiation pneumonitis from radiation. So, I've lost half of my lungs to cancer and am dealing with the impacts of other late effects now too. But because of that, I couldn't finish the final infusion of my bone marrow transplant. And so, as a consequence of that, my prognosis was not that great and somewhat, just unknown once I finished the aggressive cancer treatments.

And when I started the doctor program and pursued AYA cancer research, I went into the program thinking that that would be sort of my final gig because the last prognosis that I had been given before that, I was told that I had an 80% chance of two to three years before the cancer returned.

All my colleagues are talking about their five-year plans, their ten-year plans, and I was just like, "I just want to make it to 40."

Edith Aquino: Right.

Elissa Baldwin: Yeah.

Dr. Cheung: I hope I'm still alive. You know, like that, that kind of stuff.

So just a different perspective, but also, I, you don't stop being human. You still want those things. You want those experiences. So that's what I mean by the psychosocial context and what happens to patients after cancer treatments.

Elissa: So, I am also a blood cancer survivor, and I feel like my diagnosis helped pave my career path. Do you feel like your diagnosis has influenced your career at this point?

Dr. Cheung: Absolutely. You know, after the bone marrow transplant process, I was told that I had to be not working for a year afterwards. That's typical. I think that's standard of care. And what happened was, this was one of the rare moments where LinkedIn was not just annoying me. But someone pinged me on LinkedIn, and I somehow actually even looked at it, right? And so, it was a former professor of mine who hit me up and said, "I'm going on medical leave. Do you want to come in and just substitute for me for a year, back at Berkeley, back in the gerontology program?" You know, and substitute for her as a field consultant and lecturer.

So, I went back there, and I went against medical advice; and I'm not saying go against medical advice, but you've got to do what you've got to do because I needed the bread to come in still. So, I was financially driven. I needed health insurance, all this stuff. And I was paying, before that, I had COBRA as my health insurance; and it was, I believe it was \$1,800 a month. So, it exceeded my rent actually at the time. And so, it was just really, really high.

And so then, I just thought, no, I need employer health insurance; and so that's what really drove me. And, and I went back and did that for a year. And while I was there, the former dean of the school said, "Why aren't you getting your PhD?" And I was just kind of like, "I don't even know why I'm here. I know I was the student that was like, 'I'm never going back to school'".

And so, he really sat me down and talked to me about it and said that this could be an opportunity for me to do adolescent/young adult research; and I'm so compelled to do something with the experiences that I've had and all of that. And so that's what led me to it.

In the process of prepping for my doctoral career, I started googling and just articles on what had been done so far in terms of social welfare, social work research in this area. And Brad Zebrack's name kept popping up, and it was this BJ Zebrack, BJ Zebrack; and I was like, "Who is this BJ Zebrack?" And so, I just started googling him further, and then I found out that he's an embodied researcher himself. He is now a 35-year survivor of Hodgkin's lymphoma, diagnosed at the age of 25.

I reached out to him. I didn't want to be too weird, so I waited until I actually started the PhD program and could say I'm a student contacting you. So, it wasn't just like, "I'm just a random". But then, then I called him up, and I, at the end of our conversation just about his research, I said, "You know, there's actually a fellowship at the University of Michigan, a health disparities fellowship; and I'd be really interested in doing it with you." And so, then he became my mentor, and after that we've continued to collaborate.

As a student, he hired me onto various projects; and we've just continued to work together. And he's been an excellent mentor. So, I think that mentorship in particular for, some people call embodied researchers survivor scientists or patient turned researchers. But there's something about embodied knowledge; and maybe, Elissa, you can relate to this. There's something about embodied knowledge that other

people can get to compassion, which is a professionalization of like sort of your, your emotions, right? But empathy, you can't get to unless you've been there, right?

Elissa: Agreed, yes.

Dr. Cheung: And there's an immediate knowing, not to say that it's better, but it's a different piece of the pie. Right, so we want the whole pie to be captured, and it's just a unique and different piece of the pie that would be missing if you weren't there.

Elissa: Yeah, you can bring in that perspective from a patient.

Dr. Cheung: Yeah, and initially I had various academic mentors that said, "Oh, are you sure you really want to do this cancer thing? You're a little too close to it." And I got a lot of advisement that to not go in this route. So, when I first started my fellowship with Dr. Zebrack, I went to Ann Arbor; and I said, "You know, I'm not sure if I want to stay doing adolescent/young adult cancer. I want to explore it with you in my time with you. But I'm not sure because people are telling me that maybe it's going to be hard for me to be taken seriously as an objective scientist. I'm going to be perceived as having bias."

Which is interesting because in other fields, there's an assumption that embodiment is absolutely a benefit. Right? Like we couldn't imagine having the field of women's health without any women.

Edith: Right

Dr. Cheung: I'm trying to get the word out that you can be a quantitative researcher. You can run statistics, statistical analyses, you can do that. And actually, even those who don't have the patient experience of whatever they study, oftentimes they're compelled because their mom had cancer or their brother had cancer, their cousin. You'd be surprised that most people are compelled by some sort of personal story that we don't, you know, we don't march on Washington because of a pie chart. We march on Washington because the stories pull us and compel us.

Elissa: It's about the personal connections.

Dr. Cheung: Right, right. So definitely, absolutely compelled by experience.

Elissa: So, about that health disparities fellowship, I would love to hear more about it and the projects that you worked on. Was there anything in particular, besides going to Dr. Zebrack that pulled you to work with health disparities?

Dr. Cheung: You know, it was rooted in my own experience. I mentioned my pulmonary function or lack of pulmonary function as a major issue for me. I generally say I've lost half of my lungs, which really means more specifically there's three measures of lung health. One is the, the tissue, the surface area, right? So, I've lost 40% of the tissue. And what I do have left works at 57% for an average woman my age is what I was told. But my oxygen exchange in and out is fine. I can get to, you know, 100 sometimes in all of that. So those are the three measures. And what was interesting is that I got all of those data points based on a long, I would say it was an eight-hour day at the pulmonary clinic where you're on a bicycle, then you're on a treadmill, then you're lying down, then you're in a chamber and you're blowing up, then you're holding your breath, then you're closing your eyes, and you're not. And then you, you know-

Elissa: That's a lot.

Dr. Cheung: It was just eight hours of this. And at the end of those eight hours, I got this now and it had all that data on it and then the head of the lab, the PI there, the principal investigator for all the research said. So, here's the data. It's adjusted for LatinX and Black patients, but we don't have any data for Asians. So, you can just assume it's probably not as bad because Asians usually have smaller lungs.

Elissa: Wow, okay.

Dr. Cheung: Well, first of all, I was like you wasted my time. And it was a hard day of testing, right? But it was so disheartening because here it's a state-of-the-art lab in



the State of California, which is like almost 40% Asian, right, like in any of the major cities. And if they don't have data on Asian Americans, who does? And across my cancer experience, it's like that. It's just assumed. And, you know, I'm not a teeny tiny, you know, petite person. Like I'm, you know, 5'6". I'm like 150 pounds. I would assume that I have like sort of average size lungs.

So, I was just really, really upset about that and wanted to do something about it. I think those stereotypes are really, really damaging. And, I think in terms of psychosocial stereotypes, one that I really had to contend with is the idea that I think oftentimes there's an assumption that in communities of color, we have a lot of social capital amongst us in terms of social support for one another from like gigantic families or just faith-based communities or the activist communities that we come from in my case or what have you.

But for me, part of my story is that I left home for the first time when I was 15 and have been completely disconnected from my family of origin across my life on and off since then. And so, my family, they knew I had cancer but were not at all involved.

So, I have a family of choice, and what I always say to my social work students now is that when people have families of choice, it's a moving target. It's usually temporal. Like it's usually bound by time. In this moment in time and this location, these people are your family.

And sort of to tie-in the late effects and the idea of not having what's conventionally thought of as family members is that because I was young, my social support then was not fully mature enough to then carry me through a lot of what was happening around me. And so, I drew upon a lot of my friends' parents and, you know, whatever I could in the moment. I was very lucky that I came from a strong activist community in the San Francisco Bay area; and so, my AAPI aunties there were very, very supportive. I also was adopted in by a Native American Lakota tribe, one of my friends lives Lakota ways, and that was part of my healing journey as well.

And so, none of that sort of made sense oftentimes when you have to list, you know, the three people that are allowed to visit you, so I think that's commonly a challenge.

And so, flash forward to now and dealing with the late effects. Right before COVID, I had a really nasty fall. I fell flat on my face, like face-planted.

Elissa: Oh, wow!

Edith: Wow

Dr. Cheung: I was walking on the sidewalk. I split my sunglasses in half.

Elissa Baldwin: Oh, no.

Dr. Cheung: Split my, like yeah, split my nose open, and like my lip, and chipped a tooth, split my thumb open. And I was by myself with my little service dog. It took this relay race of strangers to get me to urgent care, and then I got stitched up.

So, because of the nature of my fall, my care providers are now concerned that I'm experiencing cardiotoxicity from the chemotherapy. Anthracycline chemotherapy is a risk factor for cardiotoxicity, as well as radiation to your thoracic region. Right, so the mediastinal radiation that I received for Hodgkin's lymphoma.

Elissa: And they felt that made you potentially fall?

Dr. Cheung: Yes, that it was my heart. I commonly fall because of my lungs, just because of low blood pressure too, the sort of turning around too fast. But that you can kind of control. But the sudden nature of the fall, right?

So, I was being followed for cardiotoxicity. COVID happened. I was brand new to Baltimore. I had just started the job. I was like about like six months into Baltimore City all by myself; and all you hear was just rising case counts and then suddenly my new physician, who I just met, is telling me don't come back into the clinic. We'll mail

you the heart monitor. You should slap it on yourself. We'll just collect the data. And I was really worried that I would fall in my apartment and nobody would be there-

Elissa: Nobody would be there.

Dr. Cheung: To take care of my dog really.

Elissa: That's scary.

Dr. Cheung: I was more worried about my dog. And so, I gave one of my coworkers who I had just met. She's wonderful, and I gave her a key to my apartment and just said, "I don't know how you would use this or why you would use this, but I know you're a dog person, and I just want, need someone else in this city or on the East Coast to have a key to my apartment."

Elissa: It almost makes you want to get a Life Alert in your, you know, in your 30s or 40s. I mean it seems crazy.

Dr. Cheung: I actually had a Life Alert when I was going through treatment for cancer, yeah, yeah. It was kind of sad, but the way that I got it, but, because it was a friend that gave it to me. And I was just like, "Well that's pure acknowledgement from the outside that I'm alone in the world".

Elissa: Yeah, you don't think about that as a young adult that you could be living by yourself, and you could fall, or something could happen and then what? What would you do? Would your dog alert people?

Dr. Cheung: Yeah.

Elissa: I don't know.

Dr. Cheung: Yeah, exactly. Yeah, no, it was particularly helpful. I had a pelvic surgery where I couldn't walk for a month, and so I was sort of like slithering on my stomach, like commando crawling on the floor to get places, you know, like for a while.

And so, it was very, very helpful then because it actually helped me get out of bed because I felt better about taking the risk to move, as opposed to just staying in bed all day or what have you.

So, what happened is as a consequence of COVID, I really realized that I needed to get back to where my informal support was. So much of our healthcare system relies on informal support so I've been sheltering in California since then.

So, my flight out of Baltimore, there were 14 people on my plane.

Edith: Wow.

Dr. Cheung: It was, yeah. It was nobody, and everybody, I think, that was you know on the plane had such a purpose to go to family members or be elsewhere for whatever purpose. The woman who sat next to me was a student at Hopkins who was doing the same thing, kind of what I was doing, because she had some health concerns too.

We're all tele-working right now, so it makes no difference. And we're all on Zoom from wherever we are. So-

Elissa: Yes.

Dr. Cheung: -it's still the same collaborative.

Elissa: Got to deal with the time zones. That's it.

Dr. Cheung: And if anything, I feel like I'm working three times more just because everything's online and accessible and there's so much more work to do because things are online, right, so.

Elissa: So, you brought up a good point about just young adults and needing that support and what would you say to young adults that need to get that support? I know that you've spoken at CancerCon before. For our listeners who don't know what

CancerCon is, it is a young adult conference put on by Stupid Cancer; and it's a great way to get support once a year through a big conference and meet other cancer survivors.

But I would love to hear, just kind of what your general thoughts are about getting that such important support for young adults that we don't seem to get very easily with the people who understand.

Dr. Cheung: Right, I think, and I'm such a proponent for educating yourself in the process of getting the support. So, one of my actually relatively new lines of research is focused on antiracist patient engagement of adolescents and young adults in the process of conducting our psychosocial oncology research.

So, it was a reaction to the situation of our BIPOC patients, right, feeling even more isolated because oftentimes even if you do get to these large conferences like you're saying, they're super white.

Elissa: They really are.

Dr. Cheung: Right? Super-duper muper.

Elissa: Yeah, yeah. But then how do underserved populations even get there?

Dr. Cheung: Right, there's a reason why they're underserved to begin with.

Elissa: Yeah, exactly.

Dr. Cheung: And so, telemedicine has responded so well and so rapidly to our new COVID context of doing things online. I hope that conferences and content and knowledge becomes more accessible as a result of that as well and we learn to use online conferences more efficiently.

But I really encourage young people to get involved in research, to learn about, you know, clinical trials. If they were involved in clinical trials, they can really contribute to building that knowledge base.

But to make sure that they're doing it in ways that are meaningful and that they are not serving as the token young person or the token black patient who's going to end up bald and on this website for eight years, and the young person in, who was 22 at the time that they agreed to it had no idea that their face/head situation was going to be thrown up on the website for that long.

I'm very connected with our BIPOC AYA patient community; and I commonly hear, "You know, I went to this meeting because there were so many on the flyers and on the website. There were so many pictures of BIPOC patients. But I got there, and I didn't see one."

Elissa: That kind of makes me cringe a little bit.

Dr. Cheung: Right, and so I think that we need to make sure that we're coming through on the promise of what we're doing; and the token engagement of patients is very, very damaging and particularly for young people who are still developing. Young people of all races, right, because we are then supporting existing structures, longstanding structures of racism if we continue in this direction, right?

But we really have this opportunity, and I think that I love AYA oncology. So, I think AYA oncology can lead the way in terms of showing the larger field of medicine that we can do this, we can take an antiracist lens on all that we're doing. And, and it's okay to admit that a previous policy or practice was racist and is racist.

Elissa: Yes.

Dr. Cheung: It's okay to do that. I think we need to stop denying. You know, my antiracist work is really rooted in the theorizations from Dr. Ibram X. Kendi; and he really talks about how the problem of racism in the United States really is the denial.

Right, that the heartbeat of racism in America is denying racism. And the sound of that heartbeat is, "I'm not a racist."

But what if we depersonalize that? What if we stop labeling people and we just start naming the behavior so that I can say, and I'm in the middle somewhere of the racial spectrum, right? I'm a brown-skinned Chinese woman. What if I'm able to say, "I'm sorry. What I did yesterday, that was racist. What I did was racist. But this is what I'm going to do to do better." What if we lived in a community that was accepting of that? We need to create places where we can all learn from each other and do that in a way that's professional and lasting and corrects the past structures that have not been working.

Actually, recently on, and I can give you an example of that. Recently a colleague, we were simply editing a paper; and I suggested we should say, "For racial minority patients, blah, blah, blah" or "For ethnic minority patients, blah, blah, blah." Right? So, his comment and it's just a written comment bubble thing was, "Why not just say white and nonwhite?"

My comment to that was why is white always the point of reference? By saying that you're saying that white is a point of reference. And sometimes it is. There's never a one size fits all for everything, right? Sometimes you do want to just say white or nonwhite. But so, it's not to say that that's across the board true. But what if we decided in terms of gender to say you're either male or nonmale?

Edith: That's a big deal, yeah.

Elissa: People just really don't think about those kinds of things and think about what, you know, what they're saying, what kind of a deal that it is because that would be a big deal. It would be a big deal for women, for nonbinary. Transgender, that would be a huge deal to just say male or not male. And there's so many people that you're leaving out when you talk about it like that.

And I think a lot of people don't think about it, where maybe we should. Maybe we should start to think about it more and actually think about what we're saying, and words matter and terms matter.

Dr. Cheung: Right. Yeah, and I think we're just all afraid of fumbling in front of each other and especially in the health space where physicians are not allowed to make mistakes. We don't talk about the mistakes that physicians make.

Dr. Brian Goldman's TED talk on mistakes that are made in medicine was really, really great where he drew this baseball analogy where he said that, essentially, physicians are asked to bat a thousand. And we just don't talk about the mistakes.

Elissa: It's not realistic.

Dr. Cheung: Really that person is sort of exiled from the community if they made a mistake. So, I think all of that is really, really important; and I'm really hopeful that we can do something to improve the situation for racial minority patients.

You know, the, particularly the prevalence of social media and the fact that the adolescent/young adult population spans the age range of ages 15 to 39 means that we capture almost every type of social media.

Edith: Right.

Dr. Cheung: Right? And so that platform is so strong, and I think we really need to engage with that so that no young person who's going through cancer, should feel isolated because of that, right? So, it's a lack of improvement in survival rates for ages 15 to 39, not because they have any developmental similarities. You can't compare a 15-year-old with a 39-year-old. Yeah, I often get that question.

Elissa: There're so many different issues that affect young adults that are not affecting pediatric patients, and they're not affecting elderly patients. I mean when you're getting into fertility, dating, sex, career, all of these different things that are, are

not necessarily affecting the older population and certainly not affecting children. And all those issues need to be addressed as well, and they need to be addressed, I think, separately. And it's not happening quite as much as I think young adults need it to.

Dr. Cheung: Yeah, and Elissa, maybe you had this experience as well; but I just assumed that most cancer patients have this experience, but there are many nights alone where it's just you and your laptop, and.

Elissa: Go down the rabbit hole.

Dr. Cheung: You're basically doom scrolling about your diagnosis, and-

Elissa: Yes, definitely.

Dr. Cheung: -you go down, and you're like, "Oh, my gosh. Was my tumor 7-1/2 centimeters like this guy's?"

Elissa: The first thing the oncologist said was, "Please do not Google your diagnosis. Just don't, please."

Dr. Cheung: And, of course, you do it.

Elissa: I somehow managed to get through the end of my treatment without seeing the overall survival rate, which I was glad because it was 26% at the time.

Dr. Cheung: Wow!

Elissa: So, I'm glad I didn't do that. But, yeah, you can go down the rabbit hole, completely.

Dr. Cheung: Yeah, and it's-

Elissa: Ooh, it's a little dangerous sometimes.

Dr. Cheung: -as a response to that, that's why I started blogging about my cancer experience.

Elissa: Tell us about your *Jade Gangster* blog.

Dr. Cheung: Okay, so the blog is called Jade Gangster. I don't actively blog anymore, but I did for a while, until probably the last couple years. But, essentially, Jade Gangster was a pseudonym that I created because as a young person, I didn't want my digital footprint to be affected by cancer. I didn't want to later on need to get a job and then my CaringBridge pops up and everyone's like wow, she's going to die.

Elissa: Definitely don't want that.

Dr. Cheung: So, so basically, but the name Jade Gangster was, Jade is a metamorphic gem that has very deep meaning for Chinese people. I'm Chinese. And gangster really is a metaphor for the young adults' cancer experience because cancer picked me, like it or not, and the only way out is when I die.

And it's important to note that it's not if I die; it's when I die. I still have the cancer tag, and you can call me a survivor or whatever on the street. When I go see the doctor, I'm a patient. So, my goal with that was to reach out to other racial minority patients. And so, it was really effective in doing that, and I don't know if it's true, but the AYA oncology community likes to say that it was the first to really address the situation of racial minority patients in terms of the blogosphere. But how can anyone say that? I don't know.

But there's so many. So, I've now expanded it into a book, so I put it together into a book. I'm looking for a publisher, editor, or someone. So, if you know someone.

So, it's really important for me to get the story out there of what it's like as a younger person to go through the cancer experience twice for an extended period without the



assumption of support from family members, which is such an important assumption that our healthcare system relies on.

Elissa: That is all we have for today in this special two-part episode on Hodgkin's Lymphoma and Health Disparities with Dr. Christabel Cheung. Be sure to tune into Part 2 of this discussion, as we delve more into health disparities for young adults and BIPOC patients with cancer. Subscribe to the Bloodline today, so you don't miss out on this great conclusion to our chat with Dr. Cheung.

And thank you to everyone for listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families.

To help us continue to provide the engaging content for all people affected by cancer, we would like to ask you to complete a brief survey that can be found in the show notes. This is your opportunity to provide feedback and suggested topics that will help so many people.

We would also like to know about you and how we can serve you better. The survey is completely anonymous and no identifying information will be taken.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

Have you or your loved one been affected by a blood cancer? LLS has many resources available to you – financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to LLS.org/PatientSupport. You can also find information specific to young adults at LLS.org/YoungAdults. All of these links will be found in the show notes. Thank you again for listening.

Be sure to subscribe to *The Bloodline* so you don't miss an episode. We look forward to having you join us next time.

BEATING CANCER IS IN OUR BLOOD.