

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'Overcoming Barriers: Navigating Cancer Care'***

#### **Description:**

Navigating the maze of cancer care can be overwhelming.

Join us as Sara Grisales Jaramillo, LMSW, of CancerCare® discusses the challenges patients face in accessing affordable treatment and strategies to improve cancer outcomes.

#### **Transcript:**

**Elissa:** Welcome to *The Bloodline with LLS*. I'm Elissa. Thank you so much for joining us on this episode.

Today, we will be speaking with Sara Grisales Jaramillo, Insights & Call Center Program Manager and oncology social worker at CancerCare. She provides supportive counseling and resources to anyone who is affected by cancer, including people with cancer, their loved ones, and people who are bereaved.

Sara is a first-generation immigrant, bilingual social worker. She provides comprehensive presentations and trainings, sharing insights and stories of her clients as well as impacting factors they face on a day-to-day basis. Welcome, Sara.

**Sara Grisales Jaramillo, LMSW:** Hi, thank you for having me.

**Elissa:** So, our topic today is Healthcare Disparities. What are healthcare disparities in cancer care, and why is that an important topic to address?

**Sara:** So, healthcare disparities refer to difference in access to healthcare services. In this case, difference in access to cancer care. And it is important to address, in oncology specifically because disparities essentially determine how an individual will

experience a cancer diagnosis, how they will cope with a cancer diagnosis, and their treatment outcomes as well.

So, for example, disparities impact having access to early detection screening services. If there's someone who does not have access to this service, it is likely that they can be diagnosed at a later stage than having more complications with treatments and that it also impacts the quality of care that people receive. This goes from the treatment they receive from their medical team as well as hospital social workers, anyone who is on the treatment team. And it also impacts the way caregivers care for patients as well, and so disparities are factors. They can be psychosocial factors. They can be racial identity. It can be ethnicity, gender identity, and all of these factors impact the way a person experiences a diagnosis.

**Elissa:** You mentioned psychosocial factors. Could you define that for listeners who may not know?

**Sara:** So, psychosocial factors include finances, socioeconomic status. It also includes race/ethnicity, geographic location, religious beliefs, anything that encompasses a person.

**Elissa:** Okay, so particularly with finances, I'm sure a lot of people listening can resonate with having to deal with finances and that being a potential burden in even accessing cancer care, right?

**Sara:** Absolutely. Within my work with individuals, I've noticed that finances is one of the biggest burdens, whether it is finances to pay for treatment or just general expenses, right? If a person is already struggling to make ends meet, whether that is paying for their rent, paying for their food, paying for their transportation, that is going to add a layer in when they're diagnosed, because then they are going to have additional expenses, right? With what they're already struggling with, which can be housing, food, all of those factors that I mentioned, now they have another expense that is medical expenses, transportation to and from treatment. Some individuals are



not able to receive any benefits like Social Security or Disability Benefits, and so those are all added layers that impact the way an individual experiences a diagnosis but also how they view their cancer journey.

**Elissa:** What are some of the groups of people who may be more likely to face healthcare disparities?

**Sara:** So, BIPOC individuals, or an acronym for Black, Indigenous, and People of Color, which is essentially the groups that face most difficulty in access and most disparities. But it goes beyond just race and ethnicity. There's also sexual orientation, sex assigned at birth. All of those factors also makes an individual vulnerable to disparities.

So, any community that has been marginalized historically. It can be race and ethnicity; but it also can be individuals in the LGBTQ+ community.

**Elissa:** You recently led a community dialogue session for BIPOC patients, survivors, and healthcare professionals at CancerCon®. It's a young adult cancer conference by Stupid Cancer®. You just defined BIPOC for our listeners, but could you share a little bit about what this session was about?

**Sara:** Absolutely. This was a wonderful event that was hosted by Stupid Cancer, and I had the privilege and honor to lead this discussion. So, this community dialogue was really to provide a space for BIPOC individuals to share what their experience is like being a cancer survivor or being a healthcare professional in the oncology space. We also had caregivers, and so we've really discussed discrimination, how they've been treated by medical professionals but also the barriers that they experienced throughout treatment and after treatment. This was really to just provide a space because sometimes people don't have the space to share their experience, their challenges. And then other people don't feel comfortable sharing outside of a community that they have something in common with.

**Elissa:** So, they felt like they could be quite a bit more open about sharing the experiences that they have personally had?

**Sara:** Absolutely. And it also fostered that space where people can be really honest about some of the improvements that the healthcare system can have as it relates to a cancer journey or a cancer diagnosis. But it also allowed people to find community within each other, which is an important factor that I can talk about later on in terms of a cancer journey and things that can be helpful.

**Elissa:** That's wonderful. One thing you just mentioned that was also in the session description was how to navigate the burden of discrimination while seeking healthcare. Could you tell us more about what patients may experience in cancer care?

**Sara:** There's so many different factors that layer in and so many different experiences. But I think some of the main themes that I've noticed within my work at the community discussion but also in general, having access to proper care. Many BIPOC individuals or any marginalized community struggle with having a good quality of care. So, what does this look like? They may have a provider that does not offer a standard of care or does not offer different treatment options; or they may have a provider that does not understand them culturally. They may have a different idea of what a treatment goal or a treatment plan would be as opposed to someone who really values, let's say, their quality of life. But, some of the struggles here is that some providers may not understand culturally what the wants and needs are of a patient.

That's one of the main ones, but cultural humility plays into that. So, the ability to stay curious about why some patients or caregivers may make some decisions about their care. Or why they may not be able to afford certain treatments or why they may not be able to adhere to some of the treatments that are recommended. So, the cultural humility piece, that understanding or the curiosity, rather, it's missing in the

BIPOC community and from what BIPOC individuals have shared in so many different forums.

Bias and stereotyping is also a topic that comes up a lot in terms of burden, right, in individuals that have to face this while seeking healthcare. So, implicit bias and stereotyping is something that often happens because, one, it's human. Right, we all have biases, but when it's not addressed in the healthcare setting, it may impact the delivery of care that the provider gives to the patient.

Language barriers is also one of the biggest factors when it comes to navigating a cancer diagnosis as a BIPOC individual. In my experience, of course, with the Hispanic and Latino community, the language barrier is very present but in other communities as well. And this impacts the delivery of care because they may have translating services, but sometimes it may not be accurate or sometimes it may not be in tune with the person's dialect or the person's hometown, which that in itself provides a lot of differences in how people interact with each other. And so, that's also a really big barrier because then patients are not understanding exactly what treatments mean or even just exactly what they're going to undergo.

If there are patients who do not understand what their treatment means, it is unlikely that they're going to adhere because they may be also struggling with fear. They also may be struggling with thinking about their own mortality; and that all influences how they experience their diagnoses and what treatments they choose to take if they choose to take any treatments.

**Elissa:** You talked a lot about the different healthcare disparities that patients can face. What can patients or their loved ones do to advocate for themselves and obtain the best quality of care?

**Sara:** There's a lot of different things, and this just depends on the individual. So, for people who are listening, you may try this and, and it may not be helpful because it may not be the point where you're at in the journey. But that doesn't mean that there



aren't other things. So, I will mention a couple of things that have been helpful overall; and then, I have people that, whether they're my clients or in my support groups, that they'll say, "This doesn't resonate with me" or "This is not something that I feel like could be helpful"; and that is totally okay.

But the main portion is education. So, educating yourself about what your treatments are, what your diagnosis is, educating yourself about healthcare facilities, the role of your medical professionals.

Some people may not know what all of this entails. That can be really overwhelming, and it can be scary. So, learning more about the diagnosis, learning more about the treatments that are offered, seeking a second opinion. Talking to people within the oncology space to learn more. Then, most people feel empowered to make their own decisions within their care. And they'll be able to identify when the disparities are happening because, for the most part, within the BIPOC community, we may know that they're happening; and sometimes it may seem normal. Or it may seem something that they're used to.

**Elissa:** Yeah.

**Sara:** And so, educating yourself about the standard of care, about treatment. Then that helps identify when there's a discrepancy or a disparity's happening or discrimination.

Another helpful tool is getting support from organizations. So, joining support groups, joining counseling, peer-to-peer mentoring groups. This all helps with the feelings of isolation that most people experience when they are diagnosed with cancer. So, talking to people who, one, either have the expertise and can provide guidance, or talking to people who understand exactly what you're going through and that could offer support either in the way it's saying, this is happening to me too; and this is how I navigated this. Or I'm feeling this too; and I don't know how to navigate it. But you're not alone and so that's also another area of support that can help with advocacy

because it's not always just about reporting something or speaking up. Sometimes, it's just learning about what this means and how this is impacting you individually.

**Elissa:** Yeah, and I'm sure a lot of people that are listening today might not even realize that they face healthcare disparities. Like you said, it may seem perfectly normal. Nobody feels like cancer is going to be this really easy experience, right? Whether you have racial or ethnic disparities, or if it is from being a young adult, or living in a rural area or poverty. There's so many different things that people face and so, maybe identifying it first that there is a disparity there would be helpful?

**Sara:** Absolutely. And also, too, because with a cancer diagnosis, there's a lot of uncertainty that comes with that. That creates anxiety, worry, and fear. And so, having something tangible like having information about all of your diagnoses and treatments, but having information about services that you can have, because also people don't know that there's services that can help with psychosocial concerns. People don't know that there are hospital social workers, patient navigators. That's where the education piece comes in that can help with not just reducing some type of disparity, but also it can help emotionally because it can provide some type of comfort for the patient or the caregiver or the survivor.

**Elissa:** Yeah. I love that both of our organizations, LLS and CancerCare, provide all this information for patients so that they can navigate these burdens as they go through the cancer experience. And so, that is really helpful. And of course, in-person events where you're getting to connect with other people, even just our LLS Community or social media or other support groups where you're listening to other people and saying, "Hey, I had that experience too." And maybe, having not thought about it before that this is a burden that you have that you could actually navigate through.

**Sara:** And it also reduces the stigma and the shame that people may feel with asking for help. Within BIPOC communities, there is a theme that I've navigated with a lot of

my patients that shame is there. And sometimes shame can paralyze in decision-making, right, or it can prevent you from looking at different perspectives that can be helpful. Talking to other people also reduces that shame because they're also experiencing something similar, or they also have witnessed something similar. And so, that's where all of these great supportive services come in that most people don't know about.

I can't tell you how many people I've talked to in our helpline at CancerCare that they didn't know that there were organizations that can help with counseling, that can help with peer support, that can help with education, that can help with financial assistance. Even if it's a small amount. Most people that I speak to on the helpline, they don't know. Most people don't know that there's hospital social workers and patient navigators that can help address those immediate concerns that create barriers to treatment.

And that portion comes from the literacy part but also access. Some people don't have access to this information. When we talk about people who are geographically in a very isolated place, they may not have access to the Internet; or they may not have access to organizations that are nearby. If it's a rural area, they may have their treatment that is three hours away from them. They may not have any support from organizations locally, which is also something that I see a lot on our helplines. People who have to travel hours to go to treatment. And so, if they have to travel hours to go to treatment, that means that they won't have that much immediate support.

**Elissa:** Yeah, and you brought up just access to even knowing that these exist, whether you have Internet access or not. We did a podcast a few years ago with oncologists that worked on a Native American reservation; and they said that, "Hey, our patients don't have Internet. We have to make sure that we have all the paper documents ready for them with all the resources that they have; and that we're being a go-between to be able to make the phone calls and get them these resources that they so badly need."



**Sara:** And to also just go back to the question that you had asked about what can patients do to advocate for themselves. If you have a family member or if you have a loved one that can go to your appointments, that is one of the main things that we recommend and we suggest because, for the most part, when people are initially diagnosed, they're in a state of shock. So, whatever the medical team is going to be telling them, it probably won't register until later on.

When we look at that in the disparities lens, if they're someone who has a language barrier, that will also add on to that. And it will also impact, again, the understanding of what type of cancer they're diagnosed, what is going to happen next. So, bringing a loved one to your appointments can help with that because it can be a second pair of ears and they can provide that support. They could also even try to advocate on their behalf.

And it doesn't have to be family members. There's some hospitals that have patient navigators. Some have survivors. But again, it all goes to access. If there's someone who only has access to go into the emergency room because they only have emergency Medicaid, and so, their treatment has to be in the hospital, they won't have the same access to those services in a cancer center.

**Elissa:** Yeah, absolutely. You mentioned the language barrier. We did an episode of our *Cafecito con LLS* video series, and it is all in Spanish; and we do have English subtitled versions available. But we were talking to this mother, and her daughter was diagnosed with leukemia at, I believe, 15 years old. And when the doctor was talking to her in English, she thought that he had said anemia. And so, she was not understanding that her daughter had just been diagnosed with cancer. And you could see it in her face. She just completely breaks down when she's recalling all this and how she just didn't understand what was happening because there was not an interpreter there; and she was having to figure this out on her own. It was really difficult to watch; and it really showed that language barrier there.

**Sara:** And even if there's an interpreter, I've had people within my support group and even helplines share that with an interpreter, sometimes one, they may not say everything that the patient is trying to say or trying to convey for whatever reason. And whatever is being translated back, is not matching up to the level of understanding that a person may have.

I'm even thinking about the Asian community because the Asian community has so many different languages. And within their languages, they also have so many different dialects. And so, I'm thinking about how even that portion can really impact how a person understands or their level of understanding of what's going on with them. And if they don't understand, that's going to create more emotional distress; and it's going to then impact how they make decisions within their treatment.

**Elissa:** Yeah. And being educated and understanding your diagnosis is crucial to cancer care and to be able to advocate for yourself.

**Sara:** Yeah.

**Elissa:** So, we've now gone over how to advocate for ourselves. Let's talk about the community. So, what can our communities do as a whole to reduce healthcare disparities?

**Sara:** I love this question because I believe that it's all within the community. The main thing that I will say is staying curious about the needs of marginalized communities. And I say staying curious because sometimes we may have an idea of what communities may need, even if we're a part of that community. So, I may have an idea about what the Hispanic and Latino community needs; but if I'm not curious about it, then I won't give a space to learn new things that I didn't know of. And then if I am curious, then there isn't any space for judgment, because we all have judgment. But we also have stereotypes, right. And so, when you're curious, there's really not much room for stereotypes or bias to a certain extent because we're just trying to listen and learn and understand what's going on.



And I feel like this is really connected to, for example, the way certain communities, and I will say maybe the Latino community and the Black community, how it manifests in terms of how they're seen or how they're seen in terms of pain level. Their perception of pain level, their perception of education. If we aren't curious about that and if we just assume that everyone in that community, let's say, has a high pain tolerance, then we won't give a space for those who don't have a high pain tolerance. That is not anything related to do with race, right? It's just a learned idea.

And so, curiosity is really important, but also talking to people within those communities; and it doesn't have to be in a very professional setting. For healthcare professionals or any professional in this field, even just talking to people outside of work that don't look like you, that don't have the same experiences as you because that's what's needed. We just need to understand a little bit better.

**Elissa:** Yeah. And that's why I love going to conferences like CancerCon because I think that you get put into this space with so many different people, so many different experiences, so many different cancers, so many different identities, and it gives the opportunity to hear stories of people that had a different experience than you. And it really does open you up to, "Hey, these people had a much different experience. They weren't able to make it to their appointments." It's difficult to imagine those kinds of things; but it's so important to listen and, like you said, be curious. I love that phrase, just be curious about what other people are experiencing. And I think that that can open us up as a community to more empathy and compassion for other people.

**Sara:** And also, when we stay curious and when we learn more, it empowers us to advocate on behalf of these communities, because we understand their story and we understand some of the layers and some of the factors that impact these communities in receiving proper cancer care. One thing that I say to everyone, you deserve high quality cancer care no matter where you're from or what you bring or what you've done in life. You deserve great quality care, and some people, historically, that have



been marginalized don't believe that they deserve, or don't believe that there is a system that will provide great quality cancer care.

**Elissa:** Yeah, this discussion is so, so important to have and to be able to learn and, again, hopefully listen to your community and find out what's happening around you.

So, our final question today, Sara, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope. What advice would you give to patients who may face healthcare disparities to give them hope after a diagnosis of cancer?"

**Sara:** I want to acknowledge that there will be spaces where it will feel hopeless; and I want to acknowledge that because that's very real. And I also want to say, just as much as there's spaces that maybe don't make you feel hopeful, there's spaces where people are inspired to provide the support that people need, no matter where you're from, no matter what you bring. There are spaces. There are organizations. There are programs out there. And so, seeking support and seeing how that feels. So, if you seek support and you find someone that is very attentive, very compassionate, that provides great information, there are multiple spaces that way. And seeking support can help you find those.

Also, exploring those resources that maybe you find online or you find through a friend. Those resources can open the door to be connected to organizations that have a mission that aligns with how you want to be treated or you deserve to be treated. There's also programs out there. There's LLS, there's CancerCare. There's so many different organizations that provide support; and you may have to just see which one's the right fit, which can be daunting, but there is that hope there. Like maybe not this one, or maybe this medical team isn't that great. But, there are organizations out there that can help with finding a better medical team or just giving you the tools to say, "Okay, I can't do this medical team. I'm going to go onto a different medical team." If people have access to that.



And also, there are people that provide information on what you're going through. There's podcasts. This podcast features patients? CancerCare also has a podcast with different types of patients. There's support groups. There's online support groups. There are communities out there that can provide that support. And there are communities out there that may see you isolated, and they may go the extra mile, right? And it all starts with just seeking the support.

I've noticed that when people call the helpline, once they know the support is there, they're so relieved because they don't feel alone.

**Elissa:** Right.

**Sara:** And so, there's a lot of isolation and loneliness that may come with a diagnosis, and there's also organizations that can help provide that support, that provide you to find the support if maybe they don't have it available.

**Elissa:** Thank you so much, Sara, for joining us today. This is such an important discussion; and we touched on some really good take-home messages. Seeking support, being curious about others, and, of course, educating yourself more about your disease and being able to advocate for yourself. And so, again, thank you so very much for joining us today, Sara. We really appreciate it.

**Sara:** Thank you so much.

**Elissa:** And thank you to everyone 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.

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In addition to the Lounge, we could use your feedback 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 or at [TheBloodline.org](https://TheBloodline.org). 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. However, if you would like to contact LLS staff, please email [TheBloodline@LLS.org](mailto:TheBloodline@LLS.org).

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 a 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](https://LLS.org/PatientSupport). This link and more will be found in the show notes or at [TheBloodline.org](https://TheBloodline.org).

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