THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Chipping Away at Iceberg: Addressing Healthcare Disparities and Equity'

Description:

Join us live from Miami, FL, as we talk about healthcare disparities and equity with Dr. Erin Kobetz of Sylvester Comprehensive Cancer Center and Seth Berkowitz, Director of Patient and Community Outreach at LLS.

In this episode, we discuss how organizations like Sylvester and LLS work together to address healthcare gaps and barriers that patients may face in accessing quality and affordable cancer care.

The diverse population in South Florida has provided opportunities for researchers, cancer advocates and community health workers to implement new, innovative programs with the goal of giving every person the same access to care.

Transcript:

Elissa: Welcome to *The Bloodline with LLS*. I'm Elissa with the LLS patient education team. We are podcasting live from Miami, Florida, with special guests to discuss health disparities in cancer.

Today we will be speaking to Dr. Erin Kobetz and LLS staff member, Seth Berkowitz. Dr. Kobetz is the Vice Provost for Research and Scholarship at the University of Miami. She also serves as the Associate Director for Population Science and Cancer Disparity at the Sylvester Comprehensive Cancer Center and the Chief of Population Health and Care Disparities for the UHealth Oncology service line. In these roles, she overseas center-wide community outreach and engagement efforts and leads programs that deliver health resources to diverse and underserved communities across South Florida. The mission of these programs is to mitigate barriers by bringing cancer screenings, health information, and research opportunities directly to individuals in these underserved areas.

Joining her to increase outreach and bring resources to the community is LLS Director of Patient and Community Outreach for Florida and Puerto Rico, Seth Berkowitz. For over 25 years, Seth has been working in oncology and developing unique programs to educate and support blood cancer patients and their families, including a young adult cancer support group. Together Dr. Kobetz and Seth serve on the Sylvester Community Advisory Committee which pursues initiatives that ensure that research endeavors reflect the needs of all members of the community and promote Sylvester's goals for community outreach and engagement.

Welcome Dr. Kobetz and Seth.

Erin N. Kobetz, PhD, MPH: Hi.

Elissa: So, Dr. Kobetz, our topic today is on health disparities and healthcare equity in cancer. Could you share with our listeners what these terms are and why they are important to address?

Dr. Kobetz: When we talk about health disparities, we're talking about the unequal distribution of disease between different population subgroups. It could be individuals of diverse races, sexual orientation, ethnicity. And what researchers who are trying to advance cancer equity do is try to understand the multilevel etiology of that disparity, so that they can meaningfully make progress on attenuating it through evidence-based intervention, which needs to involve community participation.

Elissa: We hear these terms quite a bit, both healthcare equity and healthcare disparities. They’re often used interchangeably. What is the difference between these two terms?

Dr. Kobetz: I think it's a matter of how you decide to look at the problem. When you're talking about disparity, you're focused on the problem. When you're talking about equity, you're focused on the solution. And so, I like to really talk about cancer equity because it gives us the possibility of dreaming big beyond just defining a problem to really nominating solutions and strategies that can allow for sustainable impact.

Elissa: Now, in your roles at University of Miami and Sylvester, what do you and your team do to address these disparities?

Dr. Kobetz: The National Cancer Institute (NCI) requires all designated cancer centers to consider the local cancer burden and how the cancer center can work collaboratively with diverse community stakeholders, such as LLS, to address that burden through meaningful action and intervention. In my role, I oversee that whole body of work, which is entitled community outreach and engagement. The goal of community outreach and engagement is, one, for our cancer center to appreciate how cancer is distributed through our catchment area, which is South Florida, the four-county region that spans from Monroe in the South to Palm Beach in the North, is home to about 6.3 million individuals or a third of the state's population at large, as well as our crude cancer burden. South Florida is characterized by unparalleled multiculturalism. We think of it as the future demographic of the United States and that allows us to pursue research that our colleagues elsewhere can't begin to conceptualize.

What community outreach and engagement necessitates is not only that we understand how cancer is distributed through South Florida, but we work in a manner with diverse community stakeholders to both appreciate the etiology of that burden, and to make meaningful progress towards addressing it. That involves the Community Advisory Committee that Seth is a part of, that involves various data resources that help us understand from cell to society cancer risk factors and conditions that may be driving variability in cancer risk and outcome throughout South Florida, working collaboratively with community stakeholders to overcome historical skepticism around research participation, and then to close gaps in cancer education and screening.

I think, most importantly, what community outreach and engagement does is ensure that there's alignment between the focus of our research portfolio, including our clinical trials, how cancer is distributed within the area itself, and really forces attention to achieving alignment between the sociodemographic composition of the area and our accruals to clinical research studies, thereby maximizing diversity and equity in research participation.

Elissa: There is something to be said when you're talking about community outreach and being, in the field and talking to people that are going to go through cancer, whether it's for themselves or others, and making sure that they know about these resources and that what you have to provide fits their needs, right?

Dr. Kobetz: 100%, and maybe Seth can speak a little bit about how we've worked together on various initiatives. LLS has been an early stakeholder in the work that we were doing, even before we were NCI (National Cancer Institute) designated. Seth has always been a ready partner to really speak to the needs of cancer survivors who are navigating blood-related malignancies and adolescent and young adult survivors (AYA), in particular. When we do outreach and engagement, we recognize there's a diversity in the cancer experience. And what I've been so grateful for is the voice and perspective that Seth brings to our Community Advisory Committee, so that it can focus our work to best meet the needs of the stakeholders that he and LLS particularly serve.

Seth Berkowitz, LCSW, CCLS: I think it goes both ways because the work that the Community Advisory Committee does has so many community-based groups represented, that it's an opportunity not only to listen to what they have to say about the needs of their community and, therefore, we can design programs around those needs, but it also really helps us to share what we have available and have trusted individuals in those communities sharing that information. When you talk about health disparities and underserved communities, you need trusted people within those communities to be able to speak on behalf of LLS and other organizations about the resources and the information that's out there.

Dr. Kobetz: I love that because I think one of the things that the Community Advisory Committee helps accomplish is co-learning and capacity building. So, there may be a community-based organization, let's say that's focused on the Haitian diaspora community in South Florida. They may not know of LLS, but because of LLS's representation on the Community Advisory Committee, relationships are forged, bridges are built, and there's the opportunity to then leverage the relationship with Seth to accomplish meaningful things for individuals within the diaspora community that another community-based organization may have as the focus of their constituency.

Elissa: I love hearing about how you're really trying to address those needs. As a member of the young adult cancer community, I was diagnosed in my 30s with leukemia. It's so important to get our voice heard by the healthcare community and having them understand our needs and what we go through to be able to address that, hopefully, for people that have come after us and that they will have an easier experience. They will have access to the resources that they need to make cancer easier to go through, that whole experience. I think that's really important.

Seth, now your role at LLS is to do outreach to the local communities in both Florida and Puerto Rico. These are pretty diverse populations, as Dr. Kobetz mentioned, and one mission of LLS is to make sure every patient has access to quality and affordable care. What have you done in your role to address healthcare disparities?

Seth: We've done a lot of patient education targeting these underserved communities. Offering programs in Spanish with trusted physician speakers who speak their own language. We've also done that in the Black and Brown communities in

South Florida, bringing physicians and nurses who look like those communities to talk about, not just myeloma, but all the blood cancers. I think in many communities across the country, particularly in the ones here in South Florida, a taboo thing you don't talk about cancer, right? You know, grandma died of something, but you don't talk about what that something is.

But maybe you need to talk about it to get screened properly to be aware of it because even if there isn't a lot of early detection strategies for blood cancers, there's still things to be looking for if you know you have a family history of these diseases. But if you don't know that that's what great grandma died from, you don't know to look for those things. And being part of these groups really helps us outreach and do that and get that education out in the community.

We just had our Florida Blood Cancer Conference. And one of the things I really liked when I looked out in the audience, I saw a diversity of both speakers who represented the South Florida community really well and then also the audience looked like our community. We saw people of all different ethnicities. We saw people who are from different cultural groups here in South Florida, the variety of Hispanic and Latino, and Latinx groups that we have here in South Florida, that variety of Black and Brown communities, because in South Florida they're diverse as well and it's very different here for both of those communities than it probably is anywhere else in the country. Like Dr. Kobetz said, that's one of the things that makes it a unique spot. These groups are spreading out of just being in South Florida to other places.

Elissa: Now, one way you both work together to address disparities in South Florida is the Sylvester Community Advisory Committee. Could you each tell us more about the committee and things that you have been working towards?

Seth: As Seth mentioned, the committee is comprised of different community-based organizations throughout South Florida who are focused on cancer prevention and control, survivorship, health equity. We, obviously, have religious organizations represented. We have survivors, caregivers, civic activists, individuals who have the ability either through their work or their personal experience to organize others around a common purpose. In this case, the common purpose is cancer and cancer health equity.

Something that we have been working on is naming priority cancers to be the focus of the work that Sylvester researchers pursue from bench to population. The reason we want our Community Advisory Committee to help name those priority cancers is we believe that we should not just do research for research sake. We want that research to be meaningful and to overlap with how the community perceives cancer and where there's opportunities for both novel science and intervention.

I think what was really interesting about the conversation around priority cancers is that the Community Advisory Committee didn't want to pick a cancer. What they really challenged Sylvester to focus on was social determinants of health. And their rationale, which I agree with wholeheartedly, is that social determinants of health affect all cancers, regardless of site, and potentially disproportionately affect certain communities or population subgroups worse than others.

And with COVID, I think the impact or at least social consciousness about the role of social determinants in driving cancer risk and outcome is better known. And so that's a thing we're working on. What we do with a charge like social determinants?

Elissa: Right.

Dr. Kobetz: That's a hard thing to operationalize. How do we respond to that in a way that resonates with the community's perspective in nominating that focus and also shows our commitment to working collaboratively with the community to make progress on addressing the influence of social determinants on cancer?

Elissa: For our listeners who may not know, can you explain what social determinants of health means?

Dr. Kobetz: Social determinants of health are all of those structural and access barriers that affect an individual but are not individual in orientation. Think about poverty in the neighborhood where you live. Think about crime. Think about availability of green spaces for exercise, food deserts or pollution, access to care. These are social determinants, and what social determinants do is influence disease risk above and beyond an individual's personal proclivity for developing that disease.

And there's been a significant body of research, that talks about when you have women, even women of higher socioeconomic status living in neighborhoods that are poor, their ability to comply with routine mammography is far more constrained than a wealthy woman living in a wealthy neighborhood or even a low-income woman living in a wealthy neighborhood. That speaks to social determinants. And what the community is saying is that if we can attenuate that influence, we will shift the distribution creating conditions in which most people can be healthy regardless of their individual risk for developing cancer.

Elissa: Yeah, absolutely.

Seth: If you think about a person who lives in one of these poorer communities, they probably have to travel 30 minutes or more to get to a doctor's office, or a major hospital, or cancer center. And if you have someone who lives in certain neighborhoods, they don't have to travel that far. The same things goes for grocery stores. You don't have a grocery store in a lot of these communities. The main source of food is the local mom and pop store that may not be able to stock fresh fruits and vegetables as readily or as easily as those who live near a major grocery chain. That's where the difference is. And also transportation is another big barrier that falls into social determinants of health because a lot of the people who live in those communities take two or three buses to get to cancer treatment that might take you an hour to get there and back, impacts how you're going to feel and be able to do that treatment getting to and from care. That's where LLS's travel assistance program comes in, to understand and recognizing that. Or even getting from the suburbs to a city to get treatment and the cost of parking. All of those things are challenges. And when you're not working because you're sick with cancer or your work is limited, it really then begins to snowball and impact it even more.

Dr. Kobetz: And sometimes people, because of the social determinants impact on their lived reality, may have to make difficult choices about whether they can comply with treatment. And we know in order to achieve the best outcomes, adherence to a prescribed treatment protocol is necessary.

Something you said, Seth, made me think of part of the way that I teach our medical school students, which is, let's say somebody shows up and they have increased risk of Type 2 diabetes. And you say to them, "Well what you need to do is lose some weight, so we suggest that you exercise 30 minutes to an hour every day and make sure to eat healthy food, primarily fruits and vegetables. Nothing packaged." And that person lives in a neighborhood where there is not the availability of green space, or even if it is, it may not be safe, and it’s a food desert, so they don't have ready availability of the very foods that you've recommended as medicine, what do you do for that person?

Now you've just given them recommendations to attenuate disease that they can't possibly fulfill even if they're inclined to do so because the context in which they live constrains their ability to make progress on that recommendation.

And to the transportation point, transportation came up as a really big issue and a social determinant that necessitated attention as part of the Community Advisory Committee. Now my own work is in cervical cancer. Cervical cancer is an objective marker of health disparity, the reason being is when women have ready access to routine screening and timely follow up, they don't develop, let alone die, of cervical cancer. We also have primary prevention available through the HPV vaccine. That's not readily accessible to all adolescent girls and boys everywhere. And so, this has been my focus.

We looked and saw that there's a higher incidence of cervical cancer in communities without ready access to public transportation. Well, that provides a solution, right, because we can work, maybe not in this instance with LLS, we could work with the American Cancer Society. We could work with Lyft. Sylvester has mobile vehicles that brings screening to communities. Through that collaboration and that focus on addressing the barrier that transportation creates in terms of access to primary and secondary prevention, we're being responsive to social determinants.

Elissa: Two things come to mind when we're talking about transportation, one, we saw during COVID with the disability and the communities with cancer and chronic illnesses, it made it extra hard to be able to get to medical facilities to their appointments. What do they do when they are at significant risk of dying from another disease, something completely different. So, that brought up some issues there with getting to medical care. And then, of course, we have our rural community members, for blood cancers, in particular, they need specialists. They need people that specialize in this cancer. How do they get from a rural community to a major cancer center?

Dr. Kobetz: And do they even understand that that's in their best interest, right? Like, so much of this is really structural and that's why I think the collaboration between LLS and an NCI-designated cancer center like Sylvester is so incredibly important. It allows us to combine our voices, to give it volume and to advocate for policy change that, hopefully, gets us closer to this promise of equity.

Seth: I had an opportunity to address a small group of medical students in my travels, and they were talking about how they were doing a health clinic in a diverse housing community and how they were doing BMI (Body Mass Index) screenings and all these different things.

They were talking about people needing to address those, they were singling out those people with high BMIs. And I said, "But if you're going to make change in this community, everybody in this community can benefit by healthy food and exercise. Instead of putting a stigma on those people with high BMIs, why aren't you figuring out, as part of your regular intervention, how do you offer exercise classes, walking groups, bringing healthy foods in or build a community garden that they can grow their own food and come up with things that help overcome those social determinants of health for everybody in the community, because the entire community can benefit from that, not just those people with high BMIs." And then it takes that stigma away from them. Yes, you need to address any health issues that came up, but beyond the health Issues, do you need to think about it in a new way and not single people out because that doesn't really help them. They don't need to be singled out.

Dr. Kobetz: So, when I teach, I also teach on the difference between medicine and public health, and I borrow very much from my favorite book called *The Paradox of Prevention*, which was written by Geoffrey Rose. And what Geoffrey Rose talks about is that for too long public health has adhered very closely to medicine even though the dogma of the discipline of public health is inherently different.

So, what you're describing is medicine, right? You go into a community, and you focus on high-risk individuals. What public health and a focus on cancer equity necessitates is that you focus on the conditions which affect all people in the community, regardless, if they're high risk, average risk, or low risk. In focusing on those conditions, you shift the distribution of risk back in a way that creates the potential for achieving equity in disease outcomes, including cancer.

Elissa: We've talked a lot about getting out into the community. How does community outreach and engagement actually reduce healthcare disparities? Are there any other pieces of the puzzle that are needed as well?

Dr. Kobetz: That's a really good question. The number one thing that community outreach and engagement does is it creates a platform for ongoing dialog. I think that when scientists or clinicians don't hear from the community, we run the risk of not serving the community adequately. So, community outreach and engagement provides that platform.

When you want to advocate for health equity, it means that you have to be on the front lines, and that you have to have a tangible presence in communities that you may never actually treat a patient from. You need to be there helping overcome the distrust that lives in many underrepresented communities around research and the benefits for community well-being. So, I think community outreach and engagement accomplishes that.

To a point Seth raised, community outreach and engagement also maybe destigmatizes cancer. In many communities that are medically underserved and or underrepresented, there is tremendous silence and fatalism surrounding a cancer diagnosis. That comes from the fact that many individuals in those communities, by virtue of limited access to the formal healthcare system, are diagnosed late when prognosis is poor and treatment efficacy is low. So, people believe cancer is a death sentence because that's the only thing they know, and you need to start having the conversations about cancer prevention and early detection and why those things matter.

So, community outreach engagement for Sylvester, how we are on those front lines, is we work collaboratively with community-based organizations. We now have three game-changer vehicles (The Sylvester Game Changer Vehicle is an air-conditioned motorhome vehicle that is equipped with two private rooms for consultation and cancer screening, and a multimedia area for education about cancer-related topics) that go into communities and provide targeted education and screening for different cancers for which screening exists, so skin cancer, cervical cancer, colorectal cancer. We do screening for *H. pylori*, which is one of the primary risk factors for gastric cancer. We do screening for hepatitis B and C, which is associated with hepatocellular carcinoma. We do screening for head and neck cancers using a point-of-care technology that was developed by Sylvester faculty. This is really important because many head and neck cancers are diagnosed extraordinarily late; and beyond the increased risk of mortality are associated with significant morbidity.

We navigate individuals to mammography. We do testing for HIV because South Florida is the epicenter for new infection. We do testing for other sexually transmitted infections. We navigate people who want to quit smoking. We navigate individuals to spiral CT if they have a history of smoking. These game-changer vehicles not only close gaps in access to cancer education and screening, they also provide an opportunity for individuals who otherwise might not participate in research the ability to do so.

Why? Well, one, we run a number of protocols off the game-changer that are structured as researcher service. We provide you screening. And as part of that screening, you offer us data that can inform how we do screening better. Also, our game-changer vehicles are the first instance in the United States where Epic [EMR], which is our health systems electronic health record, have been deployed outside of a traditional clinical setting.

Elissa: Oh.

Dr. Kobetz: And the reason why this is so important is that we have two critical initiatives that are part of the registration process in our electronic health record. One is consent to contact, where if you meet study eligibility and criteria, you can be contacted for participation. The other is universal consent where you say, "You can use all of the data in my electronic health record, including leftover specimens collected as part of routine physician visits, for research purposes."

And the reason why that matters, is because it increases the potential for equity and research participation. And if you want to make progress to achieving health equity, not having equity in research participation is a critical impediment.

Elissa: I just wanted to come back to those terms again for a moment, the healthcare disparities and the healthcare equity. Like you talked about, one is the problem that we were looking at and one is the solution. So, just made me think of when we're referring to equity, we're really thinking about, are we making sure that people in the rural communities, people in the poor communities, people that are farther away from a doctor, don't have healthy food nearby can have that same access to the care and screening as somebody nearby a cancer center or that has healthy food available or may live in a better community? Is that right, that we're really looking to make sure that all people in all different areas of life with different social determinants of health can all have the same access to that care?

Dr. Kobetz: Yeah. There's this really beautiful image, and I don't know if it was put out by the Centers for Disease Control or the National Institutes of Health, and I'm sure LLS has a version of it, where it shows visually what equity tries to accomplish. There's a fence and on the other side of the fence is a baseball game and you have three people of different heights trying to be able to see over that fence. Equity is providing them the relative opportunity for them all to be able to do so given their personal advantage or disadvantage. And when I mean personal advantage, somebody who's really tall maybe needs less of a lift than somebody who's really short. And that's what equity is.

Seth: And even more so with that, it's not just that you raise up the person who maybe has the least, but you try to raise everybody up. You try to make it equal to begin with so, that they're all sort of starting on a more level playing field.

One of the things that's great about game-changer vehicles and the program here at the University of Miami and Sylvester is that they said, "Before we can start to screen, if we find something, we have to be able to find care for those people." We're not just screening to screen. We want to be able to address those things early so that patients get access to care early and have good outcomes, then they can share that story with the next person and that grows of that exchange of information and support.

Elissa: That's really great. Now, our final question today. On our patient podcast homepage, we have a quote that says, "After diagnosis comes hope." In each of your roles, what would you say to provide hope to our underserved communities as you work to close the disparity gap and provide equitable care to all people affected by cancer?

Dr. Kobetz: I'll get personal for a second. When I was diagnosed with cancer about 18 years ago, there was a moment where I thought I was going to walk away from cancer research, that once it became personal that I would have lost the necessary objectivity to do rigorous science.

Then I made a conscious decision, to turn my pain into purpose, and my research is very, very personal. The work that I do with community outreach and engagement is very personal, and it harkens back to my own diagnosis where given my medical capital, I had the ability to move from, "We think something's abnormal," to a biopsy, to surgery in a really accelerated timeline.

And despite the speed at which I was able to navigate that timeline, I was still overwhelmed by unbelievable anxiety. I remember thinking, if I get through this, I have to commit my life to this idea that everybody should have the same kind of experience that I did. That it's not okay for a woman to feel a lump in her breast and to not be able to have a diagnostic mammogram for six months. Beyond the anxiety, the outcome of the illness could be invariably different by the delay. If somebody is experiencing symptoms of a blood malignancy, why should they have to ignore because they don't have access and ability?

So, I drew a lot of hope from my research. That in doing work with and in communities that we have the power to transform the possible. And that by doing the work that we do collaboratively with Sylvester and LLS and other community organizations with whom we work individually and collaboratively, that we are part of the solution.

Now, I used to have people ask me, "Isn't it ever depressing? You're just chipping off the tip of the iceberg, the part that you can see." I don't fail to acknowledge that there's more work to do than me, Seth, Sylvester or LLS could ever potentially imagine, but I know that we're on the right path by doing the work now. And through our intentional efforts and commitment to equity, we unveil more of the iceberg than would have been seen otherwise.

Elissa: What about you, Seth?

Seth: I really think that what I do on a daily basis is educating the community, right. I say the community, because it's not just about going and educating patients in these underserved communities, but it's also taking the opportunity to educate and work with providers and say, "Hey, you did this program, and I looked out in the audience, and it was a program for myeloma patients; and there were not a large number of Black and Brown people in the room, and that's a problem. So, let's figure out the next time we do this program how do we do it in a community that looks that way so that we make sure that the room looks like it should. And how do we talk to providers and say, "How do we build the next generation of oncologists, social workers, nurses who look like the communities they're serving as well and come from those communities and encourage people to go into this field where they need people to look like them in these fields?"

And when you see people who are doing that work, it's amazing how much they can accomplish when they move the needle forward so well because they come from those communities and understand the needs and bring the next group of people with them. And only takes 1 or 2 at the beginning, but 1 or 2 turns into 4 and 5 and then 10, and continuing on so that it continues to grow. Those are the things that I see, the big changes in all the years I've been involved. Recognizing it and making the changes that are needed to give hope to patients.

Elissa: Well, thank you so very much, Dr. Kobetz and Seth, for joining us today on *The Bloodline.* I loved this discussion of healthcare disparities and really just what we can do about it. Dr. Kobetz, when you were talking about chipping off that iceberg, I think that's so important that even though, we can't see the bottom of the iceberg, we don't know how far down it goes, but we can do something today. We can make it better for the people tomorrow and just keep chipping away and getting deeper and deeper into it and spread this around the country what you're doing, because, obviously, the United States is a very diverse country. What you are doing here can set a wonderful example for the rest of the country and, hopefully, close that gap of healthcare disparities. So, thank you both so very much for being here and really appreciate you.

Dr. Kobetz: Thank you.

Seth: Thank you.

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. 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.

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. You can find this link and more in the Show Notes or at TheBloodline.org.

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.