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Today we're addressing a troubling and urgent trend. Cancer rates in people under 50 have surged by an alarming 79%. This according to the Yale School of Medicine. Among the most common cancers affecting women are breast and cervical. Diagnoses of either cancer change lives in an instant. In this episode, we'll hear a compelling and deeply personal story from a breast cancer survivor, and we'll be joined by our expert panel to look at the big picture surrounding early cancer detection.

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This conversation is not just about statistics. It's about awareness, action, and hope. Now, to guide us through this topic, we're joined by Nicole Siggraph. Nicole, thank you so much for being here. Thank you. Happy to be here. You are a nurse practitioner and but you're also here as a patient as a breast cancer survivor. And I would love if you could start by just telling your story about your breast cancer diagnosis.

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Sure. I've really learned to navigate living on both sides of the bedside, and I think both have really impacted my journey. But my breast cancer journey really began before I was born. My grandmother died of breast cancer when my mom was only four years old. My aunt, my mom sister died of breast cancer when she was in her mid 40s, and my mom was diagnosed at 42 and is a 20 plus year survivor.

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But I always knew I had this strong family history and that really shaped my journey to become a nurse practitioner. But I knew this family history and really saw it. Genetic testing, knowing that to try to understand why this was happening in my family. And it was through knowing my genetic risk that I found out that I had a very early stage breast cancer at the age of 26, at the age of 26?

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Yes. Were you a nurse practitioner yet at that point? So I had just graduated. I was doing actually a nurse practitioner residency program at a large community health center in Connecticut. I was talking to a young woman, a patient my age at the time, 26. She was telling me about a family history nearly identical to mine. And I said, have you ever considered genetic counseling and testing?

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And she said, well, what would you do if you were in my shoes? And I thought, oh, I have been putting this off. I know what the right answer is. And so I put in a referral for her to see a genetic counselor. And I called that day for myself to make an appointment. And I really credit that as how I was empowered to make really important decisions, because once I knew that I had this genetic risk that put me at higher risk for breast cancer, among other types of cancers as well, then I was able to plug in with the high risk oncologist who was able to order baseline testing, and it was from

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there that we very unexpectedly found the cancer. So, you know, as health professionals, we so often stay focused on trying to help our patients. But that patient encounter literally could have saved your life. I think about it all the time. It really took for me to have to kind of take my own advice to, to follow through. Right.

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We can get busy and schedules can fill up. And sometimes things like that are intimidating, right? It had big implications, the results of those tests, but I'm incredibly grateful that I did it. So walk forward now to you. You get the diagnosis. Yes. So what was ordered as a baseline MRI came back abnormal. And I was told, because I was young, that probably something would show up on the MRI and not to worry.

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So I went in for an ultrasound. And I remember the radiologist coming in, which I knew was a little strange. And the radiologist said, can you stay? We should just do a biopsy today. And I thought, no, I have patients on my schedule. I can't stay right now. So I actually waited a couple weeks to be able to get an appointment on another day.

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And it was really I was going to be a compliant patient. I really viewed it as I was checking a box. My high risk oncologist said, we really don't think this is cancer. We just need to, you know, make sure you're okay. And it was there that they repeated the mammogram for a second and third time, which I kind of know is code for we don't like the results.

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We want to see if it's something else. And I remember the nurse when I walked down the hallway to the biopsy room, holding my hand extra tight, which I knew as a nurse. You kind of do when you're where they're concerned. And after the biopsy, I remember saying to the radiologist, what do you really think is happening here?

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And I remember her saying and looking at me and saying, well, it's not always cancer when it looks like that. And it was kind of the first time someone had said very clearly that we thought this could be cancer. It was one of those moments my blood run cold. I'll never forget that kind of sinking feeling in my stomach.

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It's one of those moments I knew without knowing because of course we needed to wait for the results. Took a few days. I was actually at work at the health center, seeing patients with my white coat on and my stethoscope around my neck missed a few calls from my oncologist because I was busy with patients, and it was the end of the day that I got the call.

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And I remember saying in the in college, thank you for being so persistent and reaching out. I really appreciate that. And she said, no, no, I really need to talk to you. Your results show that you have cancer. And I remember crying. I don't even remember starting crying. I just was crying. And my medical assistant came in to the room I was in.

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And I just remember her rubbing my back and saying, it's going to be okay. But it really was in an instant that I went from being this health care provider who had recently graduated, and who was so excited to learn about preventative medicine, to being a patient in the blink of an eye. And you were 26? Yes. Yeah.

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So talk a little bit about how you went from being, you know, obviously comfortable in the health care arena as a nurse practitioner to transitioning in literally an instantaneous blink of an eye to being a scared patient, just like anyone, regardless of whether they have initials after their name or what was that range of emotion like? Were there times that you felt well-supported?

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Were there times that you felt alone and and did you and maybe both? I appreciate that question, because I think there were times that people defaulted, that I knew all of this. I knew everything about breast cancer and how to be a breast cancer patient, but I didn't. My specialty wasn't oncology. It was primary care, which I think sometimes I had to say.

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Could you explain that again to me? I'm not familiar with these terms or with what that means. In other times, I think it was empowering. I was able to say, could I talk to a social worker who maybe can help me navigate some of these pieces and give me some advice and sort of advocate for myself in that way?

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But I think the most valuable experience I kind of had in this was having my mom's journey. So my mom had been diagnosed when I was in high school, and so I ended up having the exact same surgeon as my mom. Our mastectomy so complete removal of the breast tissue were ten years and a few days apart. And I remember going into that operating room being terrified, having made a big decision about a big surgery and the surgeon popping up from the back area where she was prepping, and she said, Nicole, I took good care of your mom.

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I'm going to take good care of you. And that was the best way to go into surgery. So I think, you know, it's unfortunate to have this really strong family history, but I think it's been really strengthening and helpful in some ways to have that. So you mentioned the things that kind of worked in your favor or were helpful to you.

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Was anything not helpful? I would say some of the issues might have been around, kind of expecting me to know some of the things that weren't there. I think in my first breast cancer journey, it was pretty straightforward. It was a very early stage breast cancer. So I chose to have a mastectomy to decrease my chance of reoccurrence.

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So when they broke down the statistics of my chance of the breast cancer coming back, it was upwards of 89% in my lifetime. And I thought, I don't want to do this again. And unfortunately, I did end up having to do it again. But I think when I look back on a potential blip, I think some of it just has to do with a lack of information around how to navigate young women in breast cancer.

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So, for example, we were trying to decide how if I needed to be on a medicine called tamoxifen to decrease my risk of reoccurrence. And I remember the oncologist kind of hemming and hawing and saying, well, you can decide if you want to be on it or not. And I remember thinking, this is a big medication that has implications of risk of blood clot, risk of uterine cancer, you know, other side effects that are unpleasant, like hot flashes and changes to your hair, changes to your weight.

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But I think part of why she maybe struggled with that decision was I think there was a lack of data to really support with my cancer, and the risk benefit ratio. So I think just knowing that we just need more information around statistics and data to help people shape their decisions. What about in general emotionally psycho, socially or logistically?

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Medically? Were there times that you felt more isolated, more alone, more invisible than others? I think it came more with my second breast cancer diagnosis, which happened when I was 34. It was June of 2020. I was living in New York City, where I still live. For those of us, all of us remember that was a really peak time for the Covid pandemic, but in particular for New York City.

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And I was working from home. I had moved my arm and had my implant up and felt a lump, and I hadn't felt that before. And I remember flashing back to kind of asking my health care providers, since you aren't going to be able to screen me for breast cancer moving forward, how would I ever know if it came back?

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I remember them saying, well, you'd feel it and you would see it. So I definitely felt something that hadn't been there. I had just hiked Mount Kilimanjaro a couple months prior and thought, oh, I'm not a nature girl. Maybe I had done something implant, but I ran into the bathroom and I could see a lump that I hadn't seen before.

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And so another moment where my blood kind of ran cold and was able to get in with my oncologist and get the diagnosis eventually. But I think it was that second diagnosis where I was undergoing chemo and radiation and more surgery during a pandemic that it felt really challenging to navigate. And I felt alone because physically I had to be alone with a lack of immune system.

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But I think where I felt invisible in my journey might just be as a young woman. And I think when I've talked to other young women who have gone through breast cancer, I think there's a lot of considerations for our age group that are tough. And as someone who hasn't had children yet and who really wants to have children, that's been really, really challenging to navigate.

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And I often feel a little unique in those struggles. What's interesting about what you just said, Nicole, is that the times that you felt alone or unseen or just isolated in this process had something to do with the fact that you fell out of the the range of the common or typical woman with breast cancer just because of your age, which I think is so important because it really speaks to how much normative kind of bell shaped curves exist in health care.

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Unknown

Now we know it as health care professionals, but when you're on the other end of it, if you don't look like the typical patient, that oftentimes is enough to make someone feel invisible. Absolutely. And I think I appreciate that comment, because breast cancer in particular is an umbrella term for a lot of different types of, of a breast cancer.

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But there's hormones that are implicated, different proteins, different staging. There's so many nuance to it that really it is personal and individualized to each person. And when I talk to other breast cancer survivors, we always kind of do that quick exchange of, oh, which which side for you, which, which stage in which proteins and things. And so I think even within the breast cancer community, people can feel a bit more isolated if they have, for example, triple negative, which is really aggressive or different type.

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So I think male breast cancer, yes, 1% of the cases that occur in men and yeah. So how did your personal experience with your medical team, doctors and nurses really impact then your role as a nurse practitioner after? If you take, you know, breast cancer out of the picture, out of the equation, how did it change you? I think for the better, ultimately, absolutely.

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For the better. I think I had a deeper insight into fear, a deeper into insight, into the unknown. And I think when we are in the office talking to patients, that it's very easy to say, well, you'll just do X, y, z, you'll take this mat and you'll go for this test and it will be okay. You know, this is the plan.

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But when you're on the other side and you don't know all of those pieces and what all of those things really can mean when you're living that day to day, I think it can be really, really overwhelming. So I think knowledge is power, right? And sometimes it can be overwhelming. But to know information can be really helpful. I think I always, and I hope I always had a level of empathy and compassion with people, but I think that deepened to just really hold people's hands and say, let's talk this through.

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There's a very common saying, live like you're dying. I don't know if it originated in the world of oncology or cancer, but it certainly fits there as it does in other places. After you were diagnosed, do you feel like that infiltrated your life at all? Absolutely. And I don't want to sound cliche, because I feel like it maybe has felt and become a little cliche, but it absolutely stopped me in my tracks.

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I think it made me really evaluate what's important, which is living life to the fullest. I think after that experience, I developed a love of travel that was always there, but I actually agreed to go on the trip. So friends call me up. They say, do you want to go? And I just say, I don't even care. That's nice.

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I just say yes. And I think I appreciate that part. I think I realized life is, is is truly short. At 26, you don't think about that. You're thinking career. You're thinking marriage and children and family building. And it did give me that insight of what do I enjoy, what do really brings joy into my life, and how do I how do I maximize that while still balancing health and work and family and all of those things?

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I want to ask you to connect the dots on something very important. The title of this podcast is The Visibility Gap. Certain cancers are more visible than others. What's your opinion on breast cancer? And, you know, obviously you can speak both as a nurse practitioner, but also as a breast cancer survivor when something is more physically visible than not.

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And by the way, not necessarily just visible to the public, visible to you. Right. Every morning, every night when you get dressed and undressed, you're visually reminded of your cancer journey. Do you think that helps or hurts? I think it has become a chapter in my book, not the whole book. And I think that's been really helpful. And so I do have moments where especially right when I'm getting dressed that I'll say, oh, wow, my body has really been through a lot.

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But how I reframe that is my body's been through a lot, and it's made it through and it's recovered and it's come along in all of that. And so there are moments I definitely get sad, and I definitely see these big scars and think, oh, why did this have to happen? But then I also think I have options of how I can look at this.

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And it can be that happened, I survived it. I'm grateful for it, that I had the best outcomes that I could and and how do we keep kind of moving forward with that? Also to the point of what's visible and what's invisible. Your particular personal cancer story is so significant because your first diagnosis was truly invisible. Yes. Caught by early screening, aggressive screening.

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And that was based on your family history. Your recurrence was visible. Absolutely. I think there was a piece of my, you know, my reoccurrence that I had to pivot. My journey was sort of tied up in a pink bow of I was the poster child for early detection. And this is why you do these tests, and then it's all fine.

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Unknown

And I don't want to scare anyone from that. That's the majority of cases. But I think what I learned, and that is that a mastectomy is risk reduction. It's not risk elimination. And so I think that was something I didn't fully understand myself. And so I'm really grateful that I, you know, had been asking questions about how would I know if this came back.

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But I also think, you know, my breast cancer came back eight years after the first diagnosis. So I was beyond that five year mark. I was kind of flying free of my health care providers and my oncologist and the oncology team. And so I think, like we were talking about, there's so many nuances and so many uniqueness is to breast cancer.

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But it is a little overwhelming to think, you know, there can be recurrences later on. And how do you know? Thankfully I could feel and see it, but there's a lot that can. And what do we do with and how do we screen and how do we know who and when and where to screen? I think is a really a really big question.

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And specifically for the rising cancer rates across the board in people under the age of 50s who may not already fall into a screening category, depending on what type of cancer we're talking about. What's your message to those people in terms of, you know, a lot of cancers are not visibly apparent until they're more at an advanced stage.

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What do you tell them? Yeah, and I think that's a conversation. We have a lot with our patients, especially around, for example, colon cancer screening and how the ages have gone down from that. And I think it really is explaining that the power of early detection and really just that when we catch things early, we can fix it and we can treat it every time people come in.

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I run through my list of cancer screening checks, and so it just becomes part of our visit every time that if people are of certain ages or have certain family histories that put them at certain risks that maybe don't fit the age based guidelines, they know we're going to talk about it each and every visit, and we're going to have that conversation.

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What do you think the potential benefits are for our overall health care system in improving early detection? I think there's so many levels, right. Of course, there's the financial level of if we can catch things earlier, it's less expensive, but just the impact on people's life, right? We know when it's caught early or if you can avoid the more systemic toxic treatment, the more disfiguring surgeries.

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Unknown

It just leads to less of a negative impact on life, but not just for that person, but for their families, too. A growing up with my mom, never having her mom, you know, or not having her mom after the age of four. That really is impactful and it changes how people live. My mom's incredibly resilient, but she she missed out on that experience.

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And so I think there's such power for the individual patient. But then also for for families as large I think it would just make society so much better to be able to get in there, diagnose, hopefully treat and hopefully cure. But yet you can't go to the other extreme of screening everyone for every type of disease or cancer or ailment.

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So where is that sweet spot? The way I think about it is I think we can live lives that are as healthy as possible. And I think for right now where we are, we don't have tests for everyone that can give us predictive analysis of what our genes are going to do for us. And so I think one of the beautiful parts of being a primary care providers, we get to have a lot of really great conversations around lifestyle choices so we can control what we can control.

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And and, you know, if we can work on nutrition, if we can work on exercise, not smoking, limiting alcohol, China, sleep well, you know, live a life that's happy and full of meaning. You know, those are the things we can control. And the outcome of that should be healthier lives. But we know that there are some things that where our DNA is program for that we can't fully control, but hopefully we can mitigate a little bit.

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My mom, who is a retired RDN, used to say that all the time control the control of all, which I think applies to medicine as well as life specifically for women. How do you see us kind of narrowing that divide, that gap in health care that unfortunately women are still experiencing? I think it's conversations. I think it's talking and sharing and encouraging and guiding, and I, I love when I see friends that message me and say, I went and got my mammogram because I had a conversation with my health care provider after we spoke and we said, I am at high risk and I should do this, or I should get an MRI.

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And I think it is encouraging one another and checking in. How did it go? How did you feel? You know, I think we can be a resource for one another to lift each other up, to educate one another, to encourage and to to really cheer on one another when they make a good decision for their health or their screening, and to acknowledge that it's oftentimes not a linear path.

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Right? It's not a straight line always from point A to point C. Sometimes you go around Z. Yes. And I think when it comes to screening and going for your checkups and things, I think each step is a victory. Right? And I think people should celebrate and appreciate when they do go for that mammogram. Treat yourself afterwards with a, you know, a fancy coffee or my weaknesses, cookies.

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Unknown

I love the idea. Any excuse that anyone can take to reward themselves for something proactive, positive, and sometimes difficult that they have done for their health is a great idea. Yes, it's intimidating to go for these tests and to wait for the results. Yeah. For sure. Nicole, thank you so much. I know that your words today made a real impact on so many people, and it really matters.

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So thank you for covering an important topic, especially for younger women. Thanks for sharing your story. Absolutely. And to put all of what we have just heard into context, we have an amazing and esteemed panel of experts joining us. Doctor Margaret Rutherford is a clinical psychologist with over 30 years of experience specializing in treating individuals and couples for depression, anxiety, and relationship issues.

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She is the author of Perfect Hidden Depression How to Break Free from the Perfectionism That Masks Your Depression, and doctor Alana Biggers is an internal medicine physician and public health researcher dedicated to advancing health equity and improving chronic disease outcomes. Doctor Biggers is an associate professor at the University of Illinois College of Medicine in Chicago, and specializes in general internal medicine for adults, preventative health, chronic disease management, and women's health.

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Thank you both so much for joining us. You're so welcome. You. What was your reaction to hearing Nicole's story just right off the bat? I mean, what and I mean, what a great storyteller. It's her life. It's not her story, it's her life. But I was just struck with the clarity and and the depth that she in the in depth that she talked about it both as a a patient and as a, well, not a physician, but a nurse practitioner, a nurse practitioner.

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Thank you. That was striking. And the things that she had learned from that. Yeah. And I will add that she's so young. You know, you think of breast cancer as a as a disease that affects only older people. But it's increasingly affecting younger people. The medical community themselves is not always conditioned to thinking of cancer on the differential diagnosis, which is our word for that list of things we think of when we encounter someone who maybe falls outside of the norm, whether that's by gender or by age.

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Yeah, I had the perfect example of a patient. She was in her 30s and came in. She found her a lump. And we know that most people who in this age group, they usually find, a lump themselves and that ends up being cancer. At the time, you know, I gave her the spiel of, oh, it's likely a, you know, benign fibro adenoma, you know, benign condition.

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And, but I knew better to of not just sitting her off. I was like, okay, now we're going to get a mammogram and we're going to see. And it actually ended up being cancer or so. But had I not, you know, listened to her, we could have delayed again the diagnosis. And we know that's critical to to treating breast cancer.

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Unknown

But on a you say you listen to her. Yeah. But you also heard her. Yeah. And being heard and being listened to might not always be the same thing. Being seen might not be the same thing as having something that's visible right in front of you. How often, Margaret, do those things line up and how often is there a mismatch?

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How often do you think talk from the patient's starting point, right, where they say, no, no, I just said something. Why aren't you responding to what I'm saying? Well, you're you're reconnecting with a passion of mine. I love it. We love fashion because I do think there's a huge overreliance on symptom criteria and checklists in mental health. And and we're missing some unique, more unique presentations of certain disorders.

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Unknown

And it's a huge problem because, again, when you're having mental health symptoms, you often are not thinking real clearly or maybe you're not going to come up with the thing that that doctor or clinician therapist would, would think of to ask or would consider. It's kind of like counting on the patient's to be able to think outside the box and know they can't know what you're not going to see.

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Unknown

You know, they said, but wait a minute. You're you're I've mentioned this to you there, though. It's a if the provider doesn't say, well, that's interesting and let me write this down. They may not know enough to know that that is something that they should bring up. That fear of that everyone can have when going for a screening test in particular, sometimes can keep people from having a test.

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Unknown

And particularly there is data. Alana Wright, that I would love to hear your your views on of for different racial and ethnic groups, for disparities between different groups when it comes to screening tests for cancer. Yeah. And speaking of that patient again, she happened to be, you know, a woman of color. So, the person who was.

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Unknown

It was a resident clinic. So, didn't think to put her in the box of. Oh, you know, maybe this is could be cancer, because, the incidence of breast cancer among black women actually is lower. However, the, death rates from breast cancer are much higher, like 43% higher. Yes, yes. Well, yeah. So so you have to always take into account the neck up as well as in the neck down.

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Unknown

Yes. There's really a mind attached to the body. And treating the whole person involves and, but also people's support systems and individual networks can also be powerful, right?

Their friends, their families, their coworkers, their work environment in supporting them through routines, screening, or even a cancer diagnosis and treatment. I have a little rubric that I use with my own patients about.

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Unknown

There's a trio. There's there's people think self-care or something is self-compassion is self-pity. It's not. But they get it confused with selfishness and self-centredness. And so women are far less likely to say, well, okay, I should go to my screening, but my son has a game, or my daughter has a game or whatever it happens to be, and and we go, oh, I'm being self-centered.

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Unknown

I need to put them first. And I think that's an issue for so many women that we got all that confused somehow, right? Yeah. The screening rates for women who are 50 and over are about 75%, a little over 75%. But then if you include the women who are 40 and over, it actually drops down to like 65%.

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So you're right, there's a definitely a gap. And people are not taking care of themselves, likely because they have families, they have jobs, etc. I think also it's so important for women and men to understand that as inconvenient as screening or routine health care might be. Think about how much more inconvenient a delayed diagnosis, or a more serious condition that could have been detected at a more treatable earlier stage.

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Unknown

Could be. So I think it's really is about that self dialog and what we can say to ourselves to just kind of get us on the right path and say, okay, I might be scared, this might be inconvenient, I might be busy, but I need to prioritize my own health so that I can be better at my job, better at home, better in my relationships, better for all these people who need me.

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Unknown

Yeah, I always say knowledge is power. They don't run away from the the screening and the diagnosis because earlier you catch it, the more likely you'll survive from it. With breast cancer in particular, the survival rate of for stage one, stage two is over 90%. Really? Yes. But if it ends up being a later stage, stage three four, it drops down to like 30 something percent.

00:29:27:11 - 00:29:55:20

Unknown

Okay, so yeah, in terms of the consequences to the health care system, I know you're plugged in with doing your own research. You're up to date with the research on public health and health care inequities in internal medicine and in our general, state of the health of the country. What are the consequences for treating things at more advanced diseases on a global macro level?

00:29:55:22 - 00:30:21:09

Unknown

Oh, wow. Yes. It's tough, you know, as I say, billions of dollars, billions. Would it be? Yes, billions with the be. Absolutely. And they're projecting even I want to say, in 2040, maybe up to $1 trillion if we do not face these, these health inequities. Yeah. And so on. A micro individual personal level, it cannot be emphasized enough.

00:30:21:09 - 00:30:53:13

Unknown

Right, that treating something at a later stage is generally more painful, more and morbid, more time consuming, more expensive, more stressful. Just the list keeps going on and on. Yeah, absolutely. I lost productivity last time with your family and friends as well. More stress on your your your own personal self. And it's easier quote unquote, even though it's not easy at all to treat at an earlier stage than it is a later stage, for sure.

00:30:53:15 - 00:31:15:07

Unknown

Nicole did an unbelievably brave and heroic job by sharing her story, bringing awareness to cancer in young people on so many different levels. I know that you both agree that she she definitely helped a lot of people, but you also I am positive helped a lot of people today. So thank you so much for sharing your expertise. Awesome.

00:31:15:08 - 00:31:34:11

Unknown

Thank you, thank you, thank you. And we hope today's episode made you feel a little bit more seen of course. Like and subscribe so you never miss an episode of The Visibility Gap. You.