

The Cancer Professionals Podcast

"With equity, everyone wins"

(Intro music)

00:00:10 Lydia

All people affected by cancer deserve equitable care and support. How can we, as health and social care professionals, advocate and support people to close the gap?

00:00:20 Bami

Also look at the little, little things that professionals can do to make a difference, because for as long as everybody thinks that- this inequity issue, it's so big- for as long as people look at it like that, it will never get solved.

00:00:37 Lydia

Hello, I'm Lydia and my pronouns are she/her

00:00:40 Carly

And I'm Carly and I go by she/her. Welcome to the Cancer Professionals Podcast, a podcast from Macmillan.

00:00:46 Carly

In this series, we chat to a wide range of guests, including health and social care professionals, to lift the lid on current issues faced by the cancer workforce.

00:00:56 Lydia

If you enjoy this episode, please subscribe, rate and share with your colleagues and friends. We'd also love to hear from you. Please get in touch to ask questions, give feedback, or even to suggest topics you'd like us to talk about on the podcast by emailing professionalspodcast@macmillan.org.uk.

00:01:16 Carly

In this episode, we explore the topic of equity, inclusion, and representation in cancer care. We're joined by Bami Adinepekun, an equity consultant who brings both professional insight and personal experience having been diagnosed with breast cancer. She shares her story, including the moments she had to advocate for equitable care and explains the vital difference between equity and equality.

00:01:43 Carly

Together, we discuss why focusing on small, meaningful changes can make a big difference.

00:01:48 Lydia

We will be hearing real stories from Bami that speak openly and honestly about the lived experience of marginalised groups, specifically people from ethnic minority backgrounds. Experiences that, for many, are woven into everyday life, including when navigating health and social care settings.

00:02:07 Lydia

These stories are powerful, personal and sometimes difficult to hear, but they're also essential because as health and social care professionals, we know that understanding people's lived experience is key to providing compassionate, person-centred care.

00:02:23 Lydia

They offer us an important opportunity to learn, reflect, and think differently about how we show up for the people we support.

00:02:31 Lydia

We're really grateful to Bami for sharing her experiences with us, and we invite you to listen openly, reflect deeply, and consider what actions or changes you might take away from what you hear.

00:02:43 Carly

So today in this episode, we're here to talk with Bami, and we'll be talking about equity, inclusion and representation in cancer care. And we know that the experience of cancer care and cancer treatment varies hugely, with people from ethnic minority backgrounds experiencing significant inequities.

00:03:05 Carly

And we know that one of your key motivators through what you do is to help us to understand that health and social care professionals can all play a part in driving that positive change in this area. So on that note, welcome to the Cancer Professionals Podcast.

00:03:22 Bami

Thank you for having me.

00:03:24 Carly

So, shall we start with you telling us a bit about you and what brings you here today?

00:03:31 Bami

My name is Bami, I'm a single mother of an amazing adult daughter. I'm an author, so I published my book 'Navigating your new normal' in 2017. I'm a speaker, I'm an equity consultant, I'm a non-executive director, board member of an organisation called Llais, which is the organisation in Wales that is a voice, we're there as a voice for ordinary citizens of Wales, when it comes to health and social care, and my company is called 'Inspired to Soar'.

00:04:06 Bami

And my mission is to help everybody achieve equity, to equip organisations, different kinds of organisations whether it's public, whether it's private, whether it's non statutory, and equipping their leaders with tools so that all of their stakeholders can- so that they can win through equity.

00:04:27 Bami

And the thing, it's like, if ever there was a time that we need to talk about equity, it is now.

00:04:35 Bami

This is the time to put equity at the centre of the agenda and then, I'm gonna talk about it because in achieving equity, everybody wins.

00:04:44 Carly

Absolutely. And I'm interested to know if you're happy to share about your own cancer experience, which of course also plays a part in why you're here today.

00:04:54 Bami

Cancer has been part of my life for nearly 35 years.

00:05:00 Bami

So in over 30 years ago, my late mother was diagnosed with breast cancer in Nigeria, and then she died at the age of 46. I was a carer at the time. Fast forward many years later, my big sister was diagnosed with breast cancer and she died at the age of 46. So about 8 years ago. And then, I was diagnosed in 2014 at the age of 37, going on 38. So basically, so out of all of the three women in my family who've had breast cancer, I'm the only one who's still here.

00:05:34 Bami

So, and the thing it's like- when it comes to the way cancer impacts you and everything like that, it's a wake up call in any way shape or form. But for me, I decided that- OK, you

know what- I wanted to see, why are there differences? Why are there differences in outcomes, differences in experiences, and all of that stuff?

00:05:58 Bami

And my own experience was then the catalyst for me to go- OK, I want to know more. I want to know the reason why. There were experiences that my late sister had when it comes to her cancer journey. So, for example, when she needed wigs and she was referred to someone who made wigs for white women. Now, our hair, of course as a black woman, our hair- we love our hair. Every woman, every woman has an attachment to their hair, but more so as black women, because we're able to do so many things with our hair. Now, so to lose all of that- to lose your breast, to lose your hair, you're being- you feel like you, you're stripped of your femininity, which is what my sister had. And then to now go to the place where you're supposed to get something to help you, which was a wig. And she got there, and I will never forget. When she went there, she left the place and she called me and she was crying. She was like "these wigs- they don't even think about us. It's as if we don't exist".

00:07:08 Bami

Now that was 2011. I would have loved to tell you that things have changed since since then, but as I will come to my own example, as recently as 2024, you will realise that- in some instances, it seems as if we go two steps forwards and three steps backwards, and that's the reason why we now need to not just talk about this, but highlight the reasons why things are not changing fast enough.

00:07:41 Bami

And also look at the little, little things that professionals can do to make a difference, because for us, long as everybody thinks that- this inequity issue, it's so big. For as long as people look at it like that, it will never get solved. We'll just go from one report to another, one inquiry to another, and that's it. But, if we look at it as the fact that- OK, this, yes, this is a big issue, but everybody has a part to play, and you know what? One of my favourite sayings in my work, and one of my favourite sayings I tell people is like- how do you eat an elephant? One bite at a time.

00:08:23 Bami

So this inequity issue, and the issue of inequity and representation in cancer care, it's an elephant, but everybody has a tiny bite that he can take.

00:08:37 Bami

And some of these, a lot of these tiny bites, they don't take money, they don't take huge investment, they don't take huge budgets. They just take- thinking differently, engaging intentionally, listening differently.

00:08:52 Bami

And being committed to expanding the way of doing things, doing things differently, you know.

00:09:01 Carly

Hmm, I think that's really important, particularly for this conversation. And it's something that we try to talk about in all of our episodes, about the fact that everyone has a part to play. And actually there are small things that everyone could do.

00:09:18 Carly

And I wondered what other aspects of equity do you focus on in your work at Inspired to Soar?

00:09:24 Bami

The bulk of my work now is to do with changing institutions, because- now, let's talk about the elephant in the room. One of the biggest issues, one of the biggest impediments to equity in healthcare as a whole, is institutional racism in healthcare. Now, here's the thing.

00:09:47 Bami

That makes people uncomfortable, because nobody wants to admit or acknowledge that we still have- that this is still happening in 2025. When it comes to institutional racism, rather than looking at it as something to be defensive about or whatever like that, I believe that the way we have the conversation matters.

00:10:11 Bami

So whatever kind of cancer professional you are, whether you are a specialist nurse, whether you are an oncologist, whether you are a surgeon, whether you are even a receptionist in the hospital, in the clinic. Everybody has a part to play, because cancer patients and their loved ones, we encounter professionals all along the way and the way you make people feel matters, the way people, the way you treat people matter.

00:10:45 Bami

And all of these little, little things, they contribute to, not just the- not just the experience of the patient on the journey, but also to the outcome. So now, let me explain.

00:11:03 Bami

Say for example, someone who presents. OK, so someone, a patient from an ethnic minority background goes to a doctor to say that "OK, I'm in pain", and the doctor is asking "ohh, what kind of pain is it" or- and the person is saying "I'm in a lot of pain" but as we know from so many studies anyway- patients from ethnic minority backgrounds are filled in, are routinely filled in pain management. Again, I have an experience of that as recently as September 2023, when my pain was dismissed, you know, because, because, I'm not, because thinking about it, a lot of the things that people use professionals can use as a measure of pain or whatever it is, and all of that. So, whether they change in skin colour or whatever it is, you wouldn't see any of that with me. So, imagine someone who's been dismissed, who's been fobbed off by a medical professional because the pain was mismanaged. The pain was minimized, and then, it then, that can easily lead to a later diagnosis. So can you see what I'm talking about in terms of not just the experience but the outcome.

00:12:25 Bami

And the thing it's like, and when you're talking about experience and outcomes, we cannot divorce either from each other, because when you are not listened to, when you are made to feel, or when you are othered, when you are, when you are not made to feel like you belong, it's a hard slog to actually get- push to get your voice heard, especially at a time when you're vulnerable, which you are as a patient, as a cancer patient.

00:12:56 Bami

And this is the reason why these kinds of conversations, they are vital. We cannot stop talking about them.

00:13:03 Lydia

I imagine as well that it's like- you lose, if someone dismisses you so often, you'll lose a lot of trust with them. And then to get that trust back is so much more difficult, isn't it? Yeah.

00:13:14 Bami

Yes. Yeah, yes, yes. And that's the thing, because you know- a lot of times we talk about, oh, trust, trust, trust. Oh, trust me, I'm a doctor. Trust me, I'm this. Trust me, I'm that. But the thing it's like, trust has to be earned.

00:13:33 Bami

And when you've dismissed or belittled people or- because, think about it, when you are dismissed or when you are not made to feel that your pain matters, or that your pain is high enough to be sorted out, and you're left in agony and everything like that. It strips you of dignity, let me just say that now. Because I remember, after one of the surgeries that I had,

they want to remove the lymph nodes or whatever it is. I was discharged from the hospital without my pain medication. And it was pain medication I took with me to the hospital.

00:14:22 Bami

And thinking about it, I was discharged because I had to do it as a day- It had to be a day surgery because I didn't want my daughter to go and stay with somebody else again, because nine weeks before that I'd had a major surgery where she had to stay with people, friends for a couple of weeks and all of that, so. And as a single parent, all of these moving parts matter.

00:14:45 Bami

So, I remember that by the time I came out of anaesthesia and everything like that, I kept asking the nurses- Is there anything that I need to?- Because when I got to hospital, I was told to bring my pain medication.

00:14:59 Bami

So they took my pain medication and locked it up. When I came out of surgery and my friend came to pick me up and everything, I had- I could- I knew I was forgetting something, but I couldn't remember. So I asked the nurses- Are you sure? Is there anything else you need to give me? Blah, blah, blah. They said no. You can just go. If it was as if they just, were just dismissive of me- "Just go" and everything like that. It was as if they had better things to do.

00:15:30 Bami

One of the conditions of me being discharged that day was that- OK, I needed to have an adult with me for the night, because otherwise I- because by right I should have actually stayed in hospital overnight, but I had to beg the surgeon to let me go home so that my daughter can stay home.

00:15:47 Bami

So I got home, my friend who dropped me off was like, lived like 45 minutes/ an hour away, the hospital where I did the surgery was about half an hour away, and my friend who was staying with me or whatever- that one- she couldn't drive at the time. So you can imagine about an hour or so later, the pain now hit.

00:16:07 Bami

Now, I now call the hospital to say- that was when I remembered that they took my payment- and I said "OK, can I have my medication back please?" "Ohh", they said, "oh, I should send someone to come and get it".

00:16:19 Bami

I said- I don't have anybody to come and get it. My daughter is 9.

00:16:24 Bami

At the time, I wasn't driving, but even if I was driving, I just had surgery. I cannot do it. The friend who was staying with me, I had to stay indoors and everything. The friend who brought me had left. There was nobody I could send because this was like 8:30/9pm at night.

00:16:40 Bami

And now I asked them if they could please send the medication to me, or send a prescription to, maybe like a 24-hour pharmacy or something like that, so that I can at least maybe ask a neighbour to go and get it. They said no, I should come and get it.

00:17:00 Bami

Now, by this time, the pain was so bad I thought I was going to lose my mind.

00:17:08 Bami

And these people kept- they were just dismissing. They were like, "OK, what? Forget it". And I'm like- do you realise how much pain I'm in?

00:17:17 Bami

So in the end, it took nearly 24 hours, and the medication, the medication that I had it was, it was a controlled one because it was one of the morphine related ones. So my GP had only just issued it to me like 2-3 days before, so this nurse told me that I should wait and call my GP. So, let's say from 8:00 PM to 8:00 AM in the morning that my, before my GP surgery opened. I don't even want to tell you what kind of night I had.

00:17:50 Bami

It was one of the most harrowing experiences of my life.

00:17:54 Bami

And that's saying something as somebody who could handle it, a lot of pain. In the morning I asked the nurses, I said, "OK, now it's morning. Can you at least send the medication to me or whatever?" No, there's nothing they can do. I should ask my GP. I called my GP and my GP rightly said that- OK, we've only prescribed this medication, we cannot do that. So I now had to call them back and I said- my GP wants them to contact them. They were like- oh, this is not something they would do. In the end, my friend now had to take over the call because I was crying so much. I was crying. I was hyperventilating. I couldn't think.

00:18:32 Bami

As nurses, when a patient is being discharged, you are meant to have a checklist of what to give them, and part of what you give them is their prescribed medication. You don't lock their medication up and not give it to them.

00:18:46 Bami

So, long story short, I didn't get my new prescription medication until like 3 o'clock/ 4 o'clock in the afternoon.

00:18:54 Carly

Gosh, that sounds like such, like you said, a harrowing experience. Really, really difficult.

00:18:59 Bami

Yeah, it's the kind of experience I would never wish on my worst enemy. And that's the thing. Now, why did I tell that story? I'm telling that story because- when it comes to pain. Now, here's the thing. Somebody can easily say that- oh, those kind of things happen to people, even people who are not from an ethnic minority background.

00:19:20 Bami

But here's the thing, again- let's look at evidence, let's look at data.

00:19:27 Bami

There are more patients from ethnic minority backgrounds are failed in pain management than people who are white. It's- the data is there. The facts are there.

00:19:41 Bami

You know, and that's why we cannot but talk about this. So now, in that kind of scenario and everything like that, what needed to happen was- at the time when I was admitted for that surgery and they took my medication. All they needed to do was pay attention, make a note and say, look, make sure you give her medication before she leaves.

00:20:07 Bami

You know, but let's even say, OK, mistakes happen, you forget. When I told you that I was in agony.

00:20:16 Bami

And had lymph nodes removed, you know, and I was still recovering from my bilateral mastectomy with immediate reconstruction, which is how my cancer was diagnosed in the

first place. And then I'd now had lymph nodes removed as well. So we're talking two major surgeries in a space of just over two months.

00:20:33 Bami

So I was still, I was dealing with a lot of pain.

00:20:38 Bami

So the one thing that I shouldn't have been deprived of was the pain medication I needed.

00:20:45 Bami

So it's that extra care. So any, every single professional that's hearing my voice, please be mindful of how you treat people. Pay attention.

00:20:58 Bami

If someone says they are in pain, don't just think because of the colour of their skin, that the pain... or because you cannot see their face go red, or because they're not screaming, or because they're not shouting that that means their pain needs to be dismissed. That's not right. And it doesn't cost money to listen.

00:21:19 Carly

Absolutely.

00:21:20 Bami

See, I didn't- see, I haven't spoken about that experience for a very long time because it was a very harrowing one. But it's interesting the way this conversation has come, and I've had to, and that's come out as well. But I believe there are professionals there who need to hear it.

00:21:36 Carly

Yeah. Well, thank you so much for sharing. Thank you for being open. And yeah, you're absolutely right- having the voice and hearing the experiences first hand from someone who has experienced that, like yourself is really, really powerful and really, really helpful for people who are listening because it can show what happens when it isn't right and then actually what people can do better. And like you said, it's in, in in that instance that you shared, it's not, it's not huge, it's about listening. It's about not dismissing. It's about, you know, understanding. I really appreciate you sharing that story. Can I just go back a little bit?

00:22:15 Bami

OK.

00:22:15 Carly

I just wanted to pick out- because I think this will be helpful for listeners, just to clarify.

00:22:20 Carly

We've talked a little bit about the term equity.

00:22:25 Carly

And I wanted to just touch on the difference between equity and equality because I think that's quite important because we'll be talking, we'll be using that term quite a lot in this. So I wanted to get your definition on it.

00:22:40 Bami

OK, so here's the thing. You know, we talk about equality a lot.

00:22:45 Bami

And you know, there isn't any cancer trust, cancer organisation or whatever that does not have an equality policy. Every organisation has an equality policy. And then, we need to ask ourselves the question that- OK, if we've been talking about equality, the Equality Act is, I believe, 2010 and if we have such a piece of legislation and all organisations are doing things about equality, then surely things should change, but here's the thing. These days, people now use equality and equity interchangeably, but they're not the same. So here's my take on it. Equality says- let's give everybody the same thing, then surely everybody should be OK. But what equity acknowledges, though, is that people's starting points are different.

00:23:36 Bami

And that you have to mitigate any proud disadvantage or obstacles, and then give people what actually what is actually fair, what is suited to what they actually need. Let me give you an example, equality versus equity.

00:23:56 Bami

So, as one of the side effects of the lymph node removal that I had on my left arm, I've got lymphedema.

00:24:03 Bami

And it flares up from time to time and everything. I was referred to the lymphedema clinic and of course I needed to wear the sleeve.

00:24:12 Bami

So when they measured me for the sleeve and everything and I asked them- OK, what colours are the sleeve? And they're like- ohh they're the skin tone sleeves. I'm like- what do you mean, skin toned. They're like- ohh, brown beige, and all of that. So I said- look at me very well.

00:24:30 Bami

I am a black woman. How do you expect me to wear a beige sleeve? And here's the thing. And I was also a working woman. It will be a different thing if you are expecting me to wear something that will wear to bed, and you will never see the light of day.

00:24:50 Bami

But I have to go to work, I have to speak in work, and I said- no, I cannot do it. They said ohh sorry we don't have it. I said- I do know that black sleeves exist. Now here's the problem. Because of the because of the way the lymphedema presented or whatever like that, they've done measurements.

00:25:10 Bami

I cannot go on to Amazon and order it because I wouldn't know the correct one to buy.

00:25:16 Bami

And in any case, under the NHS, this is something that I needed for help. We're not talking something cosmetic. So eventually they said- ohh sorry. And I said, I put my feet down, I said I'm not wearing the beige.

00:25:30 Bami

I said you have to find me the black. So then I said Ohh, there's a supplier in Europe. This was in Swansea, right? So there's a supplier in Europe and everything like that. So I waited three weeks, and then they ordered it.

00:25:42 Bami

So that was then. So, and of course that particular set of sleeves I wear, I wore them on and off for like a few years and everything.

00:25:50 Bami

And things calmed down quite a bit, and then the lymphedema flared up again last year.

00:25:56 Bami

So I needed to have the sleeve again. So remember, think about this now, ten years after.

00:26:04 Bami

And here was I thinking everything should be- this should be a walk in the park. We've dealt with this before and everything. And then I went to go and get- I went to the appointment and everything.

00:26:18 Bami

Again- what umm, what colour of sleeves do you want? I said I wanted black. Ohh, no we don't do black. I said you will have to do black. I said because I need to go to work. Because, can you imagine? So, imagine I'm only- I'm giving a keynote and I've got a beige whatever. It doesn't matter how nicely I'm dressed. That makes- that sticks out like a sore thumb and everything like that. And for me it's... it robs me of dignity. It robs me of it, strips me of a little bit of my confidence too, because I don't want to have to be to, to stick out like that.

00:26:59 Bami

So they said- OK, they will order me the black one, blah blah blah, and everything. Fine.

00:27:04 Bami

About a week later, they called me and said that the sleeves were ready.

00:27:09 Bami

So I picked up the sleeves. Excited. OK, look, this should be fine. Thank God I actually opened the box as I stepped out, I opened the box. Guess what- beige. So I now had to go back in and I said- I specifically asked for black because of my skin tone, because it's better for me work-wise, living-wise. "Ohh well, that supplier did not have black therefore..." And I said- but here's the thing, if the supplier did not have black, what you needed to do was call me and tell me that- OK, this particular supplier did not have black. You will have to wait a bit longer while we order you the black. I said, but not only did you not do that, you gave me the beige, expecting me to just keep quiet.

00:28:02 Bami

You didn't tell me.

00:28:05 Bami

I said- so, you fix it. That was 2024.

00:28:10 Carly

And I think you saying, like you said, they were maybe expecting you to be quiet and you weren't. I think that's really great and really important that you were able to call it out. And the sad thing is there will probably be lots of people who for various reasons, they feel that they're not able to or they're worried to call it out.

00:28:29 Bami

And that's what I'm going to come to. And this is the saddest part of it.

00:28:36 Bami

And that's one of the reasons why I go on about the things I do. Most of the time, cancer patients from ethnic minority backgrounds, because of the treatment at the hands of professionals, when it comes to things that boost dignity- they don't complain, they don't say anything, they just push it down and just be miserable and feel whatever. Because they've been silenced for too long, because they've been belittled and they've been dismissed, and they've been made to feel that they're nuisance. So for example, when somebody is telling you- because the receptionist was almost trying to imply that- well, it's beige, why can't you wear it? I'm like, do you realise what this does to us? Do you realise what this does to me, to my dignity as a person?

00:29:32 Bami

And the thing. And here's the thing.

00:29:34 Bami

Because, these are the things that professionals need to realise that, they matter.

00:29:41 Bami

These are not small things, so I'm gonna give another example because again, we're talking about equality and equity, and this matters because when it comes to policies, when it comes to ways of doing things, I want professionals to start challenging some of these things quietly because- so for example, if somebody, if your procurement says that you only supply beige sleeves- why?

00:30:11 Bami

Unless you are living in a part of the country that doesn't have any single person from an ethnic minority background, then you have the case. But even in small, even in parts of Wales where there are not that many people from ethnic minority backgrounds, we've still got about 2%.

00:30:32 Bami

So, just because the 98% is OK, does that mean the 2% of the population, does that mean they don't matter?

00:30:42 Bami

And here's the thing, when I'm talking about the equality- because, through the lenses of equality, the equality lens only says- Ohh, we've given everybody a sleeve, so that's fine.

00:30:55 Bami

But equity is saying- is the the beige sleeve, is it OK for everybody?

00:31:04 Bami

If it's not OK for everybody, how about we have a conversation with you?

00:31:10 Bami

This is not OK for you. This is what suits you. We will give you what you deserve. Restoring dignity.

00:31:18 Carly

Before we hear more from Bami, here's a quick message from Suzz about additional learning in this area.

00:31:24 Suzz

We know that the experience of cancer treatment and care can vary. Those living within marginalised communities are more impacted by variance and inequities. The Macmillan Learning Hub hosts a range of learning resources to help ensure an effective person centred approach to support everyone living with cancer. These resources include developing cultural competence and improving care for LGBTQ+ people living with cancer.

00:31:53 Carly

Thank you, Suzz. That's great to hear. And if you'd like to know more, see the episode description for more details. Now let's get back to the conversation.

00:32:02 Lydia

And yeah, I mean, there's there's so many things that I wanna say, but it's not about me. It's about you and what you've got to say, so.

00:32:08 Lydia

Yeah, I think what you're highlighting there is they're literally just thinking about the white population and that is just completely wrong. And as you say, they're saying it's equality because everybody's got a sleeve, but they're completely missing the point of equity.

00:32:23 Lydia

And I think the thing that comes across when you're talking Bami is that you're so, I mean, you shouldn't have to, but you are so easily able to advocate for yourself and your needs and to point out what's wrong and what's right.

00:32:36 Lydia

I wonder if you have any advice for our listeners for those health and social care professionals about how they can advocate for people who are going through cancer treatment or who are going through cancer care, who perhaps, they don't want to speak up or they aren't able to advocate for themselves. Do you have any advice to those professionals?

00:32:56 Bami

OK, to address that, I'm going to say something that is uncomfortable for me to say. There are different reasons why people don't speak up sometimes. Sometimes that is tied to their life circumstances, as in the cultural setting. So for example, some women who are not empowered. Now, remember what I'm saying, I'm being very careful by what I'm saying. I'm not generalising, I'm just saying. Sometimes it can be because people do not have a voice in their own lives before. Sometimes it can be because they've spoken up before and they've been pushed back and as a result, whatever. But let's not even forget, let's even put all of that aside. Cancer itself is something that pushes you down because, as vocal as I am, there have been instances when I've been in too much pain, when I've been in too much distress that I haven't spoken. So, case in point, 2022.

00:34:07 Bami

I had to have a liver biopsy again, because one of my liver things was not great and they wanted to check if everything was OK.

00:34:17 Bami

But needless to say, I found that biopsy thing very painful because it felt like someone were going into me and shaking me up on the inside.

00:34:29 Bami

And I remember the doctor. OK, so the specialist doctor who did it told me that as soon as I got to the ward I should ask the nurses to give me painkillers straight away because I will be in a lot of pain.

00:34:47 Bami

So I went, I got downstairs to, well, I was wheeled downstairs and everything like that. And I asked for pain relief. The first person I spoke to, the first nurse I spoke to, I said- please,

I'm in a lot of pain. Can I have painkillers? And she went- ohh, you mean you have slight pain, do you?

00:35:07 Bami

And then she left.

00:35:09 Bami

Now here's the mistake and this is why I'm saying that, you don't always have the energy or the headspace to advocate in that instance as well. That day I was in so much pain, the pain was what I was just trying to ride through. Do you- can you believe that from the time I got to the ward, I had to wait three hours before they gave me pain medication.

00:35:38 Lydia

Yeah. it's just.

00:35:40 Bami

This is 2022, so we're not talking that long ago. Now, I did complain afterwards I wrote a complaint, one of the senior nurses sent me an e-mail and said- ohh, they will look into it or whatever. Do you know till tomorrow they never go back to me.

00:35:57 Bami

And it just became too much of a hassle.

00:36:00 Bami

And I just left it. So if that can happen to me as someone who is vocal, someone who knows our rights and everything like that, and this is what I'm talking about, about the power dynamics. So now let's talk about power, because there's no way we can talk about equity and representation without talking about power.

00:36:20 Bami

Because it a lot of this is about, it's about power to, power over, power towards.

00:36:26 Bami

Because, when it comes to institutional racism, it's all about power structures as well. Now, I always say, I tell medical professionals, healthcare professionals in general, I tell them that they are powerful people.

00:36:42 Bami

Now the truth of the matter is like, a lot of times they they find it hard to believe me because they're understaffed, they're overstretched, they're stressed, they don't have the resources, they need, their their leaders are demanding all sorts and everything.

00:37:00 Bami

As a healthcare professional, as someone who works with people with cancer, you are a powerful person. Let me explain, because you have the power to do something that will affect the experience of that patient, or maybe even their outcome over time. And I always say to healthcare professionals, please, please, please be mindful of the power that you have, and be prepared to share it.

00:37:34 Bami

This is a long-winded way of answering the question you asked about how healthcare professionals can help, can advocate, it's as fundamental as- see that person, ask them- what will make life easier for you?

00:37:53 Bami

What can I do to help you? What can I do to support you? And so say for example you have someone who is on the quiet side and everything like that, and you know that they're gonna need a wig. You can ask them- would you want me to help you speak to XYZ to make your experience better. That might mean you spend an extra 5 minutes or extra 10 minutes on that patient, but I promise you that extra 5 or 10 minutes will make such a world of difference to that person.

00:38:27 Carly

Yeah.

00:38:27 Bami

So even if it's something like, OK, so one of the things about cancer care is that you are inundated with literature. Oh my goodness, the amount of paperwork you get, and a lot of times it can be overwhelming, not even whether it's overwhelming or exhausting. So when you are handing over all that literature to the person, how about you tell the person that- OK, even though I've given you all of this information and you've got a lot to think about, what is one thing that will make your life easier, right now? Because one of the classes I used to teach with Cardiff University nursing students was- 'what matters to me'.

00:39:13 Bami

And I've always said it that, as a patient, what matters to me is very different to what matters to you as a healthcare professional.

00:39:24 Bami

And that's why, as a professional, you cannot make assumptions, so assume nothing, check all things. It's one of these mantras I learned from a counselling course I did years ago, but it's very true, it's so very true. Don't make assumptions. Ask questions. Check.

00:39:46 Bami

And please, please, please, don't ever confuse your expertise in your discipline for an expertise in the patients lived experience.

00:40:02 Bami

It doesn't matter how much of an expert you are, you are not an authority in the patient's lived experience. Even if you are of the same ethnicity, even if you are of the same background, you are not walking in that patient's shoes.

00:40:20 Bami

So it is important to not make assumptions. It is important for you to ask questions and find out ways that you can support the people to get what they need.

00:40:34 Carly

And the questions that you were suggesting that a health professional could ask are also really simple. So one of the examples you gave is- what is one thing that will make your life easier right now, that's a really straightforward question, isn't it? But like you said, it makes all the difference because it's uncovering. It's not making those assumptions.

00:40:54 Carly

It's not, treating everyone or assuming that what people need are the same.

00:41:01 Carly

It's about understanding that individual as an individual and what they need in that moment and what's important to them, which will vary for everyone.

00:41:11 Bami

Yeah.

00:41:12 Carly

So I thought those were great. I thought they were really good suggestions, thank you.

00:41:16 Bami

Yeah, and they're is easy. And that's the thing, because for me, like I said, I understand the pressure that professionals are under, especially at this time. So any solution that will proffer to begin with, will be things that are easy to do. The people I pushed more challenges on are the leaders, because they're the ones who have the power. So when I'm talking to leaders, it's a different thing because they're the ones who are the big levers to pull. But in the day-to-day experience, because most patients, 99.999% of patients they will never see the CEO, will they?

00:41:58 Bami

And here's this other thing with cancer professionals. Can you please normalize people being able to ask you challenging questions?

00:42:11 Bami

Sometimes as a healthcare professional, you should be open to being challenged because you're a human being and you have blind spots too.

00:42:23 Bami

If a patient is asking you a challenging question, as long as they're not being disrespectful, as long as they're not being violent or whatever like that, I think you should be- you should not see it as a personal affront.

00:42:41 Bami

Because a lot of times when a patient is asking you a challenging question, it's because they're feeling- either they're really, really afraid or they're feeling insecure or unsure, uncertain.

00:42:58 Bami

So for example, I'll give you an example. When I started the journey from 2013, the whole journey was supposed to be risk reducing thing and cutting my risk. That kind of thing. I remember the first time I met my plastic surgeon and now, when I talk about healthcare professionals who I encountered, my plastic surgeon- he's the gold standard.

00:43:26 Bami

Because of the way he treated me. So I remember when I first saw him. I'm like, OK, because I'd read a lot of the literature and all of that stuff. I thought the surgery was going to be about 5 to 6 hours. He then told me it would be anything from 9 to- over 9 hours. I'm like, what do you mean? So he explains the reasons for it, because I had a bilateral mastectomy with immediate reconstruction using DIEP flap- that's using tissue from my belly.

00:44:04 Bami

So you can imagine, all sorts of bionics going on- that's what I call it, and rewiring and all of that, even my belly button was moved, you know? So when I went to see him, I was asking him questions and everything. And the thing was, when my plastic surgeon saw me, he treated me as an individual, so was like- it's OK to ask questions. So I remember asking him, I said- how long have you been doing this? Because as far as I was concerned, if you're going to be putting me under for 10 hours or more, my life is in your hands, literally, you know. So I now said, how long have you been doing this? Because I looked at the complications. So I asked him, I said- how many kind of those complications has he had in his career?

00:44:58 Bami

That question, there are very few patients who will ask that kind of question, but I am not your typical patient. But I was thinking I'm going to be under this man's knife for God knows how many hours.

00:45:13 Bami

Does he understand the things that can go wrong? That's number one. Number two, because in the literature I read all of the signs of the complications that is in the literature. It was based on white skin. There was nothing about what the complications looked like on darker skin.

00:45:34 Bami

So when I now asked my surgeon, he was like- and thankfully he understood darker skin, because with that particular surgery, one of the signs of complications was a change in skin colour.

00:45:48 Bami

Now, think about it. By the time you see a discernible change in skin colour on my skin, I'll be nearly dead.

00:45:59 Bami

So he then devised a different way of checking the blood flow, whatever technical term is used, you know.

00:46:09 Bami

But at the time when I asked him, he was like, he said- I promise you I'm not using you for target practice, he said. I've been doing this a long time. So when I asked him the question, he didn't take it as a personal affront or anything like that. He didn't.

00:46:25 Bami

When somebody is asking you a challenging question, there's an emotion behind it- whether fear, whether anxiety, whether worry.

00:46:35 Bami

And here's the thing- if you don't know the answer, it is OK to say- I don't know, but I can ask someone who does because that was what my plastic surgeon also said. He said- whatever question you have, bring them. He said, if I cannot answer them, I will find others who would.

00:46:55 Bami

That was what gave me the most reassurance. Gave me the most reassurance that- OK, you know what, this man, I am safe in his hands and he will look after me and he values me.

00:47:13 Lydia

Yeah, I think, you know, what you're saying there is it's important to feel like there's someone in your corner, isn't it, you know, and coming back to that trust element of being able to trust that someone will, again, advocate for you with your, with your best interests, and I think it was really interesting how you mentioned power earlier and sort of like different power dynamics. And if we're thinking about perhaps change in cancer care, like things like change of processes or change of treatments like clinical trials and things like that, are you able to tell us a bit more about the importance of diversity and representation, specifically when it comes to change?

00:47:53 Bami

OK, this is a big question that I can spend like- see, I can spend the next five years on this one. So you know, it's such a big thing. Clinical trials is one of those very.. for me it's a sore subject in a way because it's a bigger conversation than just cancer professionals. On the one hand, you have pharmaceutical companies who are reluctant to even take on patients from ethnic minority backgrounds into their groups or whatever, like that for whatever reason. But then there's also the other side of this, or whatever, because of the historical issues when it comes to medical experimentation, where there is the lack of trust, and the fear from people from ethnic minority backgrounds when it comes to that kind of setting. So we cannot but look at those two. It's almost like you're talking about two competing themes for want of a better word. So on the one hand, you're talking about pharmaceutical companies who are making who are either consciously or unconsciously narrowing the criteria for acceptance into their trials in a way that excludes people from ethnic minority backgrounds. And that this is important, and this is why equity, diversity

and representation has to be a continuous conversation, has to be a continuous consideration across all levels.

00:49:45 Bami

Does that make sense? So in pharmaceutical companies, they have to be committed to diversity and inclusion, to including people from ethnic minority backgrounds. Because one of the- I believe it was Black Women Rising, which is an organisation that's supporting black women with cancer. And they did a piece of research which was quite significant, where it's saying that more and more younger black women are being diagnosed with aggressive breast cancer and with poorer outcomes.

00:50:34 Bami

Now the thing is like, say you have an issue like that. If you are not inviting people like that into clinical trials and everything like that, you will have no way of knowing why they are- why they're being diagnosed more with this aggressive breast cancers- number one. Number two- why these aggressive breast cancers progress quickly and why the mortality rates are higher.

00:51:05 Bami

And that is the thing with clinical trials. If clinical trials are not representative of the diversity of the population, how are the treatments gonna address such kind of... those kind of groups that are diagnosed, because younger women.

00:51:27 Bami

So younger women, younger black women, being diagnosed with aggressive breast cancer and then presenting late, not even because they're not checking themselves, not even just because that, but because some of the symptoms are not symptoms that they can see. Because for example, if you're talking about a change in, again, if you're talking about a change in skin colour on a black woman.

00:51:56 Bami

If that becomes one of the signs of noticing a change, so maybe like a change in colour on the areola or something like that, with a black woman that's going to be difficult to see.

00:52:12 Bami

Because here's the thing, and this is the way I put this very simply. There's a difference between someone like me who was diagnosed in stage 1 versus somebody who's diagnosed stage 4. The cost- let's even look at the cost to the NHS.

00:52:34 Bami

My treatment is much cheaper than somebody who's stage 4.

00:52:41 Bami

My outcome, my prognosis is great. That other person's prognosis is not.

00:52:50 Bami

So it goes across all through the entire length and breadth of the health system, that- OK, pharmaceutical companies need to realise that to make drugs that will continue to be effective and that would that would make people live longer, it is important for every sector of the population to be represented. OK now on the other hand as well, the clinical trials have to be done in a way that is dignifying, that is open and transparent. Because remember when we talked about trust, when it comes to clinical trials, when it comes to pharmaceutical companies and people from ethnic minority backgrounds, the lack of trust is justified.

00:53:40 Bami

And the thing is, when there is lack of trust, I believe it is the responsibility of pharmaceutical companies and leaders to work to build the trust. It shouldn't be, it shouldn't be people from ethnic minority backgrounds who should try and jump over the hurdle, no. Because there are grounds for it. It would be a different thing if people were just saying- ohh we don't trust, we don't trust umm... clinical trials. We don't trust medical experiments, just because we don't like them, no. Of course, you know the medical experimentation that's been done over years on black people, on people from minority backgrounds, those are very real concerns and they shouldn't be dismissed.

00:54:32 Lydia

I think that's so important, even when you're experimenting with a drug and it is in a clinical trial phase and setting.

00:54:40 Lydia

You need to have that representation to make sure it works for everybody, because as soon as it's licenced, it's going to be used on anybody and everybody. And I wondered if we could sort of go to some practical tips I guess, for professionals on what they can do today, I guess, or tomorrow, or whenever they're listening to this. And I suppose I want to recognise as well that, you know, there are certain things that are systemic issues that perhaps an individual can't necessarily play a part in, but what do you think are the practical tips that people can change that are in their control on an individual level?

00:55:14 Bami

Well, if they've been listening to this conversation, I've been weaving that through actually. When I say listen, listen, listen differently, pay attention. So even that question that I asked about- what can I do to make your life easier right now.

00:55:40 Bami

Things like- not making assumptions. Things like- asking the patient what matters to them, so of course it goes back to that question about- what can I do to make your life easier right now. So one of the things I think professionals should think about, I think they should ask people what kind of support network do they have.

00:56:08 Lydia

Yeah. It really comes down to person centred care, doesn't it? And that really brings back to what you said at the beginning of the episode- with equity, everyone wins and you know we want to get to that point, don't we? Where, you know, everybody is a winner and we're making sure that we're giving equitable care to everyone, which I suppose is, you know, why your work is so important. What are you hopeful for about inclusivity in cancer care and equity in cancer care? Are there certain things that are happening at the moment that you're particularly excited about, that we can talk about?

00:56:43 Bami

Well, in terms of cancer care, one of the things that gives me hope. OK, I will have to talk about organisations. You have organisations like Black Women Rising. You have, you know like organisations that are that are doing research and advocating for people from ethnic minority backgrounds and everything. Now let's talk about the work that Macmillan does itself, and I remember when I spoke at the conference last year. That was one of the things charge I actually put to Macmillan. There is a lot of work that Macmillan has done and is doing, when it comes to making information available, when it comes to research about people from ethnic minority backgrounds and everything, but the only problem is that Macmillan does not talk about it often enough so people don't even know it's there. So there is that. And of course, there's a lot of research that's happening, some of it OK, one of, for example, the research and part of at the moment inclusive cancer prehabilitation you know, so it's funded by the National Institute of Health Research and it's based in Cardiff University. So I'm one of the core applicants looking at the experiences of people from ethnic minority backgrounds, so there's now research like that that's coming up and everything like that. And then listening to patients' voices. So those are the kind of things that that's giving me hope, that's encouraging me at the moment and everything, and of course the work I'm doing with the future healthcare professionals, that kind of thing.

00:58:34 Carly

That sounds like there's lots of things to look forward to. And really exciting.

00:58:40 Bami

When we look at the issues when it comes to inequities in cancer care, it can easily seem like such a daunting thing, and it can seem like- what can I even do? The system is this, and all of that stuff and everything like that. And I am not denying that inequity in cancer care is a big issue, but what I want to reiterate to every listener, is that- how do you eat an elephant? You do it one bite at a time, and in your particular instance, whoever you are, there is a bite you can take.

00:59:23 Bami

That bite you can take can be anything from listening differently to your patients and asking them how you can make their life easier right now- number one. It can be something like- picking up the phone on their behalf to smooth the next step of the process for them. So you pick up the phone and say- ohh this patient needs to come to you, XYZ, you smooth the journey for them. An extra 5 minutes of your time, that will make a world of difference to the person.

00:59:58 Bami

Then there's the whole issue about how you share power. Remembering that you have power but you have to share it because anybody who, anybody who comes to you as a cancer patient, they are vulnerable because it doesn't matter how important or accomplished they are in their ordinary lives, when they come to you as patients, they are vulnerable and there are things that will be done to them. So being mindful of how you share the power so that you accord dignity, so that you make them feel safe because- everybody wants to be seen, they want to be heard and they want to feel that they belong. So as much as possible, do not other patients. And when you are asking questions as well, especially when you are asking certain questions.

01:00:50 Bami

Be mindful that you're not othering the patient, so for example, asking a patient where they are from. Why?

01:01:00 Bami

Unless it's pertinent to the care, why should you be asking a patient where they are from within the context of gathering information for their health, for their treatment? So it's, because sometimes it's the careless things, the careless biased comments that can cause the most pain. So be mindful of that.

01:01:29 Carly

That was great. I think they're brilliant takeaways and you've really very well encapsulated our conversation and distilled them into those. And that was brilliant, thank you. So to bring the episode to a close, we have our regular feature, which is where we ask three questions which we ask of all of our guests.

01:01:50 Carly

So the first question is- if you could go back in time to when you receive your cancer diagnosis, what advice would you give yourself?

01:02:00 Bami

Hmm, that's a, that's a very interesting one. I think one of them would be to be kinder to myself- number one. Number two- so be kinder to myself, not put on due pressure on myself, because this is a marathon, not a sprint.

01:02:19 Carly

Thank you. That was great.

01:02:21 Carly

So question two is- what change would you like to see to improve the lives of people living with cancer?

01:02:28 Bami

I would like for co-production to not just be a buzzword, but to be a reality.

01:02:37 Bami

And because I see this in every level of my work, whether as a board member, whether as a consultant, everything, co-production to move from a buzzword to action.

01:02:52 Carly

Definitely. And something meaningful as well.

01:02:55 Bami

Yes.

01:02:56 Carly

And then lastly, what would you like listeners to take away from this episode?

01:03:02 Bami

That they are more powerful than they realise and no matter your role, you have the capacity and the power to make such a huge difference. The question, though is- how are you going to use your power differently?

01:03:19 Lydia

I love that. I think you've just finished the podcast on like an inspirational answer and hopefully, you know, all of the health and social care professionals listening will be able to start thinking about how they can drive that positive change in their area and just start making a difference for individuals out there. And as we say, to get to that point where equity means that everyone's winning. That's something that we can really hope for.

01:03:44 Lydia

So thank you so much for your time today Bami, and thank you for coming on the cancer professionals podcast.

01:03:50 Bami

You're most welcome.

(Outro music)

01:03:53 Carly

You've been listening to the Cancer Professionals Podcast, which is brought to you by Macmillan Cancer Support. If you work in health or social care, visit macmillan.org.uk/learning to find out more about our Learning Hub, where you can access free education and training. For links to the resources mentioned, see the episode description.

01:04:14 Lydia

If you enjoyed this episode, follow us so you don't miss our next conversation, where we'll be chatting with Sophie Maycock, who is a supportive care clinical nurse specialist and UKONS young and early career cancer nurses Member Interest Group Co-chair.

01:04:30 Lydia

We're also joined by Marian Woodhouse, a lead systemic anti-cancer therapy nurse specialist. Sophie and Marion, at different career stages discuss their roles, the evolving challenges and opportunities in cancer care and how the field is transforming for future professionals.

01:04:47 Carly

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01:04:59

I'm Lydia

01:05:00

And I'm Carly and you have been listening to the Cancer Professionals Podcast by Macmillan Cancer Support.