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Opening

Esosa: So, when they were very young, I think they used to think I was the worst mom in the world. Because I was teaching them independence. They see that whenever they got sick, I would say, "Okay, medication time and we are going to go about our business. In my heart of hearts, I was always burning up in there. But I had to encourage them so that they can put one foot in front of the other and move on. Both of them had to learn at a young age that they are the commander of their own ship.

Episode introduction on the trike 01:21

Good morning. It's about 6 a.m. I'm out riding my trike and doing an experiment here just using my earbuds and my iPhone. I'm thinking about the podcast that I'm producing this week which will follow in a moment. It's the interview with Esosa. It's a very interesting interview. It's very sober. What's sobering about the interview to me is several things. One is the challenges of Health Equity. It's amazing how difficult this is. The baseline difficulty of having sickle cell and supporting two daughters with sickle cell. Having the added burden of bias and lack of appreciation of, as Esosa will say, listening, the lack of listening that happens. And I wonder if whether the lack of listening is bias or whether the lack of listening is just a habit? Listening isn't easy. It's not easy for me. I also found really interesting in the interview was how Esosa set Fatima up for advocacy, early on. And how

much advocacy, Fatima just had because that's just the way she is. She's an outspoken, assertive person. But it seems like her mother put her in the situation of understanding herself. What kind of pain do you have? Is it pain that is uncomfortable? Is it pain that will keep you home? Is it pain that needs medicine? Or pain that you need to go to the hospital? Being an advocate requires self-awareness and self-expression - the ability to express yourself.

One of the things that I've learned doing these interviews with young adult and a parent with complex medical conditions is that there's a time where all they can really do is manage the moment. And then there's time, a little bit of time for preparing for the next moment. And even less time for self-advocacy. And a tiny bit of time to think about advocacy for others. And naturally those times, those amounts of times vary depending on the ebb and flow of symptoms and life. But it seems like those things are in everybody's mind. Well, it's a lot harder to ride my trike and talk on an iPhone than then I thought. So here's the episode. Enjoy.

Introducing Esosa Ighile 20190215 06:04

Health Hats: I'm on the phone with Esosa Ighile, who is the mother of a dear friend of mine and we're going to talk a little bit about Fatima and her Sickle Cell and how she managed, how they managed together over the years. So, Esosa. Can I call you Esosa?

Esosa: Yes, that's fine.

Health Hats: Okay, great. So, can you tell me a little bit about yourself, where you live, and what you do?

Esosa: Okay. Hello everyone. My name is Esosa Ighile, and I'm a Tax Analyst for the TJX Companies, Inc. First of all, I'm a mother of five and a wife. I have five children, two girls, and three boys. Fatima is my second daughter. My oldest daughter is Juma, and both of my daughters happen to have Sickle Cell Anemia, which we have dealt with for about 30 years.

Health is fragile 07:17

Health Hats: Wow, let me ask a couple of questions about yourself. Where were you when you first realized that health was fragile?

Esosa: Hmm. I thought the sky was my limit, that I could do anything, but with health then you realize that some things you can't fix. So, I thought I was a fixer-upper, fixing everything for everyone. Yeah,

What does healthy look like? 07:46

Health Hats: Okay. So now that you've had these years of managing not only your daughters' health, but other family members what does being healthy look like to you?

Esosa: I think being healthy is everything we have. I know that there is a parable that says health is wealth. So, when you have your health, you are the wealthiest person in the world, but without your health, everything kind of falls behind.

Commander of their own ship 08:19

Health Hats: So, as you know Fatima and I have talked many times over the past few years about her challenges with Sickle Cell. Over that time I've really grown to know and appreciate her self-confidence and her assertiveness for herself. And I'm sure you've been key to that. So, when she was a child, you were her advocate, you were her organizer, you were her support system. So when did you first start thinking about her being an independent person as she started to you know, she was no longer completely a child and started becoming aware that she had something and it was a drag, and it was interfering with her life? And so it's that point you're taking care of her, and you're managing everything that's associated. But then there comes the point where she starts thinking about her own independence and her own abilities and what she wants in her life. And how did that begin?

Esosa: I think what I did with my girls especially is that they, I think, naturally have self-esteem, and they are self-confident. So when they were very young. I think they used to think I was the worst mom in the world because I was teaching them independence. They see whenever they got sick, I will say, "Okay medication time and we are going to go about our business." In my hearts of heart I was always burning up in there, but I had to encourage them that they can put one foot in front of the other and move on and both of them had to learn young at a young age that they are the commander of their own ship. So basically when they were teens. I used to talk to them about their disease and also with the doctors. I would let them give their own opinion of what is going on. I remember one time Fatima had gallstones that needed to be removed at the age of 12, I think.

Health Hats: Gallstones?

Esosa: Oh, yeah, we went to the doctor's three or four times the hematologist on call. Her hematologist was away out of the country. So this particular doctor will tell her, "Sickle Cell crisis, take medication." She would look at him and say, "I don't get sickle crisis on my stomach. This is not a crisis. I know that something is wrong." We went three times. By the fourth time, her regular hematologist was back. All she had to do was touch it and go, "Oh no, gallstones." But Fatima kept telling this other doctor that, "No, I don't get Sickle Cell crisis in my stomach." He wasn't listening. So that's another problem with this disease. Straightforward teaching my children and other kids with Sickle Cell anemia are not in tune with the experiences of the patients, but she knew right where she was a teenager that she needed to be an advocate for herself.

Health Hats: Yeah. Wow, that's a story. So this is your telling about when she was in high school?

Esosa: Yes,

Health Hats: Okay. And she got her care in Framingham and Worcester? Yes.

She won the fight 12:11

Okay, and then she decided to go to the University of Pittsburgh?

Esosa: Yeah, she did

Health Hats: And so that must have been a challenge for you.

Esosa: That's why I fought her all the way to the end. I did, you know because she won the fight.

Health Hats: So yes, I guess. It was concerning to you because?

Esosa: It was too far away from home. And as the Mom, I thought I had all the control. I'm the only person that will help her. You know. Yeah, So the hematologist convincing me to let her go and just let everything go. That she will be fine. So then I did.

Long distance challenges 13:03

Health Hats: Yeah. What happened like the first time when she was away from home and she had a crisis?

Esosa: I had four other kids to take care of. I couldn't run to her. So that was terrible. Yeah, but I kept monitoring her over the phone and I had the hematologist in Pittsburgh. I actually met him a couple of years ago, but for years, I will speak to him or the nurse practitioner. Yes, so I will be getting updates on what was going on.

Health Hats: So, you established a relationship before she went?

Esosa: Yes. I did.

Health Hats: I see. Wow, I can imagine. Oh goodness. What did you think what were the challenges that you saw her having long distance?

Esosa: Yeah, with long distance and being a typical college student. It was difficult because physical stress is another thing that can bring on Sickle Cell crises. So she used to run to catch the bus. Anyone who knows my Fatima she doesn't keep the time. Knows that she's not very good with keeping to time. So she will be running, and the bus will be moving. So she's running to catch the bus. A couple of days later, too much stress will land her in the hospital. Yeah. She was good at managing it at home first before going in. But when she was there, I felt like she was alone. That was very hard.

Health Hats: Yes, and I mean it seems like she established a good support system in Pittsburgh. Yeah, both medical and friends.

Esosa: And yes she did, and she actually has a mom in Pittsburgh that I call her mom.

Health Hats: Oh, really? Oh, yeah. I didn't know that.

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Emergency treatment gone wrong 15:24

Like one of the things that Fatima and I have talked about since she moved is challenges with you know, going to the emergency department into a strange community and having difficulty getting the treatment that she needed because they saw a young woman of color who they thought was drug-seeking.

Esosa: Yeah that's all their lives.

Health Hats: And so is that something you had to deal with all along?

Esosa: Yes. I have had to deal with that all along. It was so bad. A few years ago, she went to Nigeria to do research on Sickle Cell Anemia and my daughter being who she is picked up this stomach ulcer from Nigeria.

Health Hats: Oh, no.

Esosa: So every time she went to UMass Medical. I'm going to name them because they have done so much harm to my family. So every time she went to UMass Medical, they'll say it's a Sickle Cell crisis and they'll keep giving her medication. She'll be there a week then she'll come home and start throwing up. Two days later she's back. So after the third time, it took resident who was from a foreign country dragging me not dragging me, but taking me out of Fatima's room, into the lounge and he says, "talk to me." I said all her life they've told me she cannot get addicted to pain medication. But this is the stuff I'm seeing every time she's releasing is like a drug addiction like so what is this? I talked to him and he goes, "oh my goodness, we might be treating her for the wrong symptoms." So then looks deeper and found out that she had picked up his stomach ulcer not a Sickle Cell crisis. So because they were using pain management to treat something that was not Sickle Cell crisis she was getting into a problem with the medications.

Health Hats: I see. Yeah, so okay. So this is a different angle than I was familiar with like she's talked to me about not being able to have get pain relief for a Sickle Cell crisis. You're talking about.

Esosa: Overmedicating. That was in Worcester. But in other states, yeah,

Yellow card for treatment plan 18:06

After that she got a yellow card, they call it, from her regular hematologist. Yes. So whenever she goes to the emergency room in Worcester, she could flash that card and they'll know the treatment plan. Yeah with other states, especially in the South, they have no idea how to treat her pain symptoms. So why she says she's in pain all they see like you said, it's a black woman. I know this is seeking pain medicine and she stood her ground a few times, but I have gotten so angry at sometimes that they were going to kill my daughter for me just because some of them stand on the moral high ground. Yeah, especially when she's pregnant. "Oh, you're pregnant. You're not supposed to take this." But she always has a smart comment for them, "Would you rather I die?!" You know, so but it's been difficult going around the country. I wish she stayed here in Massachusetts, but...

Health Hats: Yeah, but so so when you talked about the gallbladder and you talked about the ulcer. I have multiple sclerosis and my family doctor says to me, "Well, you know you may be you may have multiple sclerosis and all the issues associated but with that but you're still a 65-year-old white man with white man problems." It seems that somebody with complex issues like Sickle Cell they still have normal person issues.

Esosa: They could get the flu they could get a stomach ulcer. Or side because in us for the first assumption from most doctors is to think this is Sickle Cell crisis.

Health Hats: Yes, and then miss what's underlying?

Person standing in front of a doctor knows their body better than the doctor 19:07

Yes. So if you were, you know, Queen for a Day and you could make a couple of changes to the medical system so that your journey with Fatima and with your daughters could have been easier. What would you like to see different?

Esosa: What I would like to see are doctors who have compassion and doctors who are good listeners. I wish doctors will listen more to patients rather than coming to conclusions without the patient's input because whoever is standing in front of a doctor knows their body better than the doctor. So if they would just listen. Good listeners always come to good conclusions. Yeah.

The whole family feels it. Where should I be today? 21:05

Health Hats: So being a parent of children with Sickle Cell is very draining and so how have you managed to maintain your own health while you're dealing with all this?

Esosa: I'm a God-fearing person. I believe that God always takes care of his own. Well, I've tried to do that. There are challenges. Of course, there are. Because it can be fatiguing. Yeah, it doesn't only impact the patient. It impacts the brothers, impacts my husband, impacts me. But I know they are the ones who feel the pain, but we feel the pain for them, and it disrupts life. Yeah. Yeah, when you are stuck in the hospital, you then start to decide where should I

be today? Be with the one in the hospital. Be at home, cooking dinner for the others. Uh-huh. It's a very hard thing, but you have to keep looking forward and hopefully, good things come. Yeah, like my grandchildren.

Health Hats: How many grandchildren do you have?

Esosa: I have two of them from Fatima.

Health Hats: Yeah, it's great. I have two also. It's Heaven.

Esosa: Yeah. Yes, it is. Yeah, I don't get to see them enough, but I love those video chatting with them. Yes and just saying that Fatima was able to go through all the challenges of life. And have those two kids. They are the joy of my life.

Health Hats: Yes, absolutely.

Medical coverage, a right for us all American citizens 22:48

So what should I have asked you that I haven't asked you?

Esosa: Medical coverage.

Health Hats: Oh, Yeah, Medical coverage. Yes.

Esosa: That is something that has. You know prior to Obamacare every time Fatima is enrolled in school or Juma, my daughter is now enrolled in school. Then I have to go into a panic mode. How are they going to have medical coverage? Yeah, because now thanks to Obamacare. They had coverage through me until 26 years old. Only if they're not in school right. With them, they can't be school every semester. If you miss half of the semester, then you have to withdraw. So I hope this is a conversation we have in this country about medical coverage and know that it is a necessity and it's also a right for us all American citizens.

Health Hats: Well, thank you so much for talking to me. What I'm going to do is next week. I'm going to talk to Fatima, and then I understand you're headed to Nigeria. Yes, I am. Yeah, and maybe when you get back we could arrange a call for the three of us together. Okay, I would appreciate that.

Esosa: No problem. We'll do that.

Health Hats: Well, I'll never forget your hospitality to us Fatima's wedding. That was a lifetime experience.

Esosa: Thank you for so much for coming and thank you for being a mentor to Fatima.

Health Hats: Yeah, my pleasure.

Esosa: I really appreciate you and your wife.

Health Hats: Thank you. Thank you so much. Have a good evening.

Esosa: Thank you. You have a nice weekend. Thank you, bye-bye.

Episode close 25:03

So much said in a short time. Learning to be commander of their own ship at a young age, challenges as a young woman of color, don't come to conclusions without listening, the whole family feels it, medical coverage as a right. I'm blessed to know this family! Next week we'll hear from Fatima and Esosa together.

Extra 25:50

It's really fun being able to experiment with this art form of podcasting. It seems like, unlike this writing something. There are many different ways you could do it. You can speak off the cuff or off the trike as I'm doing now. You can write a script and read it. You can interview people. You can record sounds. You can use music. Pretty cool.