Babade.wav

Sickle Cell Stories: A Patient Perspective Interview

Summary Of Speaker Contributions

Geraldine Asino (Interviewer): Representing the "Sickle Cell Stories Then and Now" project, supported by the National Lottery Heritage Fund, Geraldine facilitated the interview to document the lived experiences of sickle cell patients. Her goal was to capture the evolution of care and the personal impact of the condition across different healthcare systems.

Speaker 1 (Babade Olusola): A patient living with sickle cell disease for nearly five decades. They provided a detailed account of growing up with the condition in Nigeria, the transition to the UK healthcare system in 2013, and the ongoing management of severe health complications. They emphasized the role of mental resilience, family support, and faith in navigating the challenges of the disease.

Key Points And Decisions

Healthcare System Comparison: The interviewee noted a significant improvement in care upon moving to the UK, specifically highlighting the benefit of specialized teams (e.g., the SCAT center) compared to the lack of specialized infrastructure in Nigeria.

Systemic Needs: While acknowledging that the NHS is better funded and structured than the system in Nigeria, the interviewee identified a critical need for increased clinical research, trials, and policy focus on mitigating long-term complications.

Impact of Complications: The interviewee reported that sickle cell complications have led to multiple surgeries and an inability to work for the past three years, significantly affecting their financial and social life.

Awareness and Therapy: There was a consensus on the need for better publicity regarding new treatments like gene therapy. The interviewee expressed that while they were previously unaware of the specifics, they view such advancements as positive developments that require broader public dissemination.

Next Steps And Commitments

Project Documentation: Geraldine Asino committed to incorporating this testimony into the "Sickle Cell Stories Then and Now" archive to ensure the patient's experience is preserved and used to advocate for improved care standards.

Advocacy and Awareness: The interviewee committed to continuing their journey of resilience and sharing their story to provide guidance and hope to young people newly diagnosed with sickle

cell disease, emphasizing that the condition is not a death sentence.

SPEAKER 0
[00:00:02,531]Okay Thank you so much for coming in today.

SPEAKER 0
[00:00:08,651]Thank you for being here and agreeing to share your story with us. My name is Geraldine Asino, and I'm interviewing on behalf of Plus Mark Hope and our project Sickle Cell Stories Then and Now. And this is supported by the National Lottery Heritage Fund.

SPEAKER 0
[00:00:29,821]Let's see.

SPEAKER 0
[00:00:30,941]So this project is about capturing real experiences of people who have lived with sickle cell disease. So we can document how care has changed over the decades and make sure those experiences are heard and never forgotten. Your story is very important to us. You have lived with sickle cell disease across two countries and two very different healthcare systems. Yeah. And you've also experienced the condition in a way that very few people in this project can speak about. So we genuinely are grateful that you are here to do this.

SPEAKER 0
[00:01:09,811]Yeah. There are no wrong or right answers. Feel free, speak naturally in your own words. You can pause at any time if you feel a little bit overwhelmed.

SPEAKER 0
[00:01:22,971]Take it at your own pace. You can skip any questions that you don't want to answer. Yeah, and if you're not comfortable with anything at all, you let me know.

SPEAKER 0
[00:01:34,151]So yeah, in total control. That's okay. Do you have any questions before we start?

SPEAKER 1
[00:01:40,521]No, no, because trust me.

SPEAKER 0
[00:01:42,241]Okay. So this section is about growing up with sickle cell in Africa. We're just going to go a little bit into that.

SPEAKER 0
[00:01:53,631]So firstly, can you tell us about your childhood growing up with sickle cell disease? How much did you and your family understand about the condition at the time?

SPEAKER 1
[00:02:06,331]Uh, well that's a good question though. Uh, I've been... I've been... I would say I... I grew up to understand that I have sickle cell disease and it's actually from birth.

SPEAKER 1
[00:02:27,031]So when I got aware of myself, aware of the situation and all of that, it actually affected me a lot. Most times I'll be in and out of the hospital. My parents spend a lot and it's quite emotional to realize what was going on then. But yet, it's a lifetime long, I mean it's a kind of condition that you have to live with. Yeah. So you have no choice than to just and adjust to the reality of the ailment and start living your life around it.

SPEAKER 1
[00:03:05,271]So it's not really a good thing to be honest, but I find a way to live my life and to adjust to the situation. Like I said earlier, it's like most time in the hospital, most time because I remember back then when I was in school, uh most of the time like uh I'm I'm out of school for several weeks within a within a short period and I fall sick very frequently when I was in Africa.

SPEAKER 1
[00:03:45,291]so it was very challenging. So I have to be honest, a very challenging situation.

SPEAKER 0
[00:03:51,191]Thank you for sharing that. So, what was healthcare for sickle cell like when you grew up? Was it available to you, uh, or was it not?

SPEAKER 1
[00:04:02,381]Uh, I would say it's available but not in close proximity to where I live. So that's a very big challenge because for sickle cell patients,

SPEAKER 1
[00:04:15,121]Whenever you have crises, you need prompt attention, prompt access to healthcare, but back home in Nigeria, it's not... the healthcare system is available. There are some hospitals, but they are not very good that can attend to such situations, but we are not in close proximity to where I live. So sometimes we have to travel to get access to healthcare support.

SPEAKER 0
[00:04:45,871]Right.

SPEAKER 0
[00:04:47,281]Thank you for showing that. Um what methods did you, your family or your community use to manage your condition before you came to the UK? Were there traditional remedies or community knowledge that played a role? What'd you say?

SPEAKER 1
[00:05:04,731]Oh yeah, because there really was and I wouldn't say they are all correct. Uh a lot of misconception about the ailments. Some people believe there are different beliefs surrounding it. So but all I know is I believe in science so much and I believe in the medical aspect of it. So there is some traditional knowledge and all of that but I don't really believe in that.

SPEAKER 0
[00:05:34,911]C Right. So, how did sickle cell shape your life and your sense of yourself as a young person growing up?

SPEAKER 1
[00:05:51,431]I think the condition on its own is just it makes me stronger and makes me believe that uh in any situation you have to remain positive and strong for yourself.

SPEAKER 1
[00:06:09,251]That's all I can say about that.

SPEAKER 0
[00:06:12,321]Okay. Thank you for that. We're going to move on to your life coming into the UK and the NHS. Okay. So what brought you to the UK and how long have you been living here?

SPEAKER 1
[00:06:24,911]I think I've been in the UK since, I think, twenty October twenty thirteen. Uh, I think I spent over ten years in the UK. I came into study

SPEAKER 1
[00:06:38,661]uh Kimas is a student um What's the question again?

SPEAKER 0
[00:06:44,941]What brought you to the UK?

SPEAKER 1
[00:06:47,301]Yes, I came to study. thank but I left but then thereafter I settled down here with family

SPEAKER 0
[00:06:55,381]Yeah. Okay. So that was getting tricky there.

SPEAKER 1
[00:06:59,311]Ugh.

SPEAKER 0
[00:07:00,131]Okay. So when you first came under the care of the NHS, what was the experience like? What surprised you positively or negatively coming in with sickle cell?

SPEAKER 1
[00:07:12,181]Um, yeah. I think I noticed there was a difference in the care system in Nigeria and in the UK.

SPEAKER 1
[00:07:22,961]And the major, the first thing I noticed was that there are specialized teams.

SPEAKER 1
[00:07:35,001]uh, will I say, we have

SPEAKER 1
[00:07:41,661]Under the NHI system, we have this specialized team for sickle cell disease . I'm registered with the SCAT center in Birmingham. My GP encouraged me to refer me to them. And they, they, I never since then they've been trying so much, they did a lot. They've, they give, they officially give me regular appointments to come for treatment, uh to come for checkup and all of that. So that doesn't happen in Nigeria where I come from.

SPEAKER 1
[00:08:19,041]That's a huge difference between the healthcare system in Nigeria and here. And because in Nigeria, uh we only have access to the general physician, don't have a specialized team or, and here in the UK, you have different teams that attend to you when you are having an issue. They know they will refer you to different consultants to attend to your health challenges but in Nigeria it's not like that.

SPEAKER 0
[00:08:49,151]Okay. Was there any negative side to it at all?

SPEAKER 1
[00:08:53,741]Um, yeah, I would say because most of us like exclusive pressure, most of our

condition, some of the healthcare providers in the UK, they don't really understand it. But I can, with the exception of the specialized team, but others struggle to understand what we're going through.

SPEAKER 0
[00:09:21,151]All right. Thank you so much for that. Can you tell me how the NHS cares compared to what you had experienced before? What was better and what was the difference?

SPEAKER 1
[00:09:34,151]Uh generally speaking I would say NHSC is at least a bit better from the healthcare system in Nigeria. Um in terms of funding and in terms of policy making, though they still need to do better. But I think it's better in those two areas: policy making, funding. Um

SPEAKER 0
[00:10:01,971]When you say funding, what do you mean?

SPEAKER 1
[00:10:06,411]Yeah, when I say funding, I mean the way the NHS is put together as a whole is well funded by the government, but in Nigeria, you guys have poor funding, bad governance, bad government decisions and poor bad policy decisions.

SPEAKER 1
[00:10:29,741]when you form- you know, when you formulate a policy

SPEAKER 0
[00:10:34,171]Yeah.

SPEAKER 1
[00:10:34,771]and you in England, I think the way they formulate their policy, they ensure that they execute it, but in Nigeria it's not like that.

SPEAKER 0
[00:10:47,091]Hello

SPEAKER 1
[00:10:47,751]Okay. different

SPEAKER 0
[00:10:49,181]Yeah, that's a good thing to note. Well, so have you ever felt that being from Africa affected how you were treated by the healthcare professional here in the UK?

SPEAKER 1
[00:11:00,481]Huh. That question is a bit tricky but because I always overlook a lot of things I don't take note of things like that. I always focus on what I want to do. I can't really say either yes or no to that question.

SPEAKER 0
[00:11:19,391]That's okay.

SPEAKER 1
[00:11:20,791]be neutral

SPEAKER 0

[00:11:22,561]Yeah. Okay Have there been times when you felt dismissed, not believed, or not treated with the urgency that your condition required?

SPEAKER 1
[00:11:32,601]No

SPEAKER 0
[00:11:33,671]Not at all.

SPEAKER 1
[00:11:35,311]what

SPEAKER 0
[00:11:36,101]Okay. That's good to know.

SPEAKER 0
[00:11:40,891]Alright.

SPEAKER 0
[00:11:42,111]So we're moving on to living with the multiple complications of the condition. Over the years, sickle cell has caused a number of health complications for you. Can you please tell us what those are and how they have developed over time?

SPEAKER 1
[00:11:59,061]Oh, it's difficult because I've experienced a lot of complications due to sickle cell and it makes life harder by the day. So, it's really, really bad. I don't know how to be honest with you.

SPEAKER 1
[00:12:17,171]not that's

SPEAKER 1
[00:12:19,761]I've had to adjust a lot of things. And presently, I'm having difficulties with my heart. Like four, about four surgeries.

SPEAKER 1
[00:12:34,591]and it is all due to sickle cell complications but I thank God I'm still alive today. Um, it's not... it's not something that is pleasant.

SPEAKER 1
[00:12:49,981]complications are just coming and you just have to accept your fate or deal with it and live with the condition

SPEAKER 0
[00:12:58,881]Yeah. Okay. So looking back, do you feel that earlier better or better management of sickle cell could have been prevented could have prevented or reduced some of those complications?

SPEAKER 1
[00:13:14,741]Yes, I strongly believe that it could have reduced it.

SPEAKER 1
[00:13:21,521]I believe so much that better management, better... I wouldn't say better

management because the condition is being managed, but I believe they still need to do more research because these complications are anticipated, but yet, I believe there might be some way of reducing the effect or tackling the effect before it comes on.

SPEAKER 0
[00:13:52,161]Okay. So how do you manage your health day to day alongside everything you're living with? What does that look like in real life, in practice?

SPEAKER 1
[00:14:03,821]As I've already admitted that living with sickle cell is very challenging, it's a very difficult situation. But I thank God for friends and family and the support from organizations like Plasma of Hope and so with that, unfortunately, I entered living my life.

SPEAKER 0
[00:14:25,061]Yeah. So would you say your complications have affected your ability to work, your relationships, and the life that you wanted to live?

SPEAKER 1
[00:14:35,481]It does.

SPEAKER 0
[00:14:36,591]How

SPEAKER 1
[00:14:38,461]At the moment, for the past three years, I've not been able to work due to complications from sickle cell.

SPEAKER 0
[00:14:46,561]Okay.

SPEAKER 1
[00:14:47,221]and that's telling on my finances. It's telling on my ability to move around in society. It's affecting my family. It's a lot on my partner, but I thank God for the people surrounding me that have always been there for me.

SPEAKER 0
[00:15:08,261]Thank you.

SPEAKER 0
[00:15:10,191]Okay, so we move on to the human and emotional journey. You've already mentioned the effects on your relationship, but how has living with sickle cell disease for nearly five decades and all that has come with it affected you emotionally and mentally?

SPEAKER 1
[00:15:29,471]Yeah, I try as much as possible to guide my emotions and to ensure that

SPEAKER 1
[00:15:37,251]I live my life in a way that I understand, okay, I have a condition, but uh I try as much as possible not to allow it to affect me mentally because if that happens, that's another scenario on its own. So I am conscious of that and I try as much as possible not to allow this to affect my mental health.

SPEAKER 0

[00:16:03,491]Yeah.

SPEAKER 1
[00:16:05,151]It's not easy, but I try as much as possible to guide myself from being depressed. I don't allow it to depress me. I just try to be positive in every situation. Otherwise, you'll be facing too many situations at the same time.

SPEAKER 0
[00:16:29,941]sure

SPEAKER 1
[00:16:31,311]So you just be, you have to just be conscious of that and be intentional in the way you live your life and protect yourself from certain situations like depression and all of that.

SPEAKER 0
[00:16:48,841]Okay. So what has kept you going through the hardest period? Have faith, family, community, or something else been your source of strength?

SPEAKER 1
[00:17:01,061]Yeah, I just live my life by the day and with the support of my immediate family and I just choose to be happy and keep going. So, I have a lot of support from my family which I rely on and a couple of friends and some, yeah, friends and family have been keeping me going.

SPEAKER 0
[00:17:27,471]That's great. So what have you had to give up because of sickle cell and what have you absolutely refused to give up?

SPEAKER 1
[00:17:40,271]Give me more peace, like if you have to give up just like probably you want to end living.

SPEAKER 1
[00:17:50,831]So, I refuse to do that by myself. I refuse to be... I choose to be alive and I choose to be happy.

SPEAKER 1
[00:18:00,931]So I don't want to lose my happiness, I don't want to lose my life and I'm fighting for that.

SPEAKER 0
[00:18:11,331]It's amazing.

SPEAKER 0
[00:18:13,151]Okay, we move on to what needs to change and what gives you hope. So based on your experience of both African and UK healthcare, what do you think the NHS still needs to do to better for people living with sickle cell disease?

SPEAKER 1
[00:18:30,531]Uh, as we all know, sickle cell is a genetic condition.

SPEAKER 0
[00:18:35,131]Mm-hmm.

SPEAKER 1

[00:18:35,811]Um, I think the NHS and the UK government needs to improve. They need to do better in clinical research and trials. This will help tremendously in improving the life of people living with sickle cell disease. They need to do more research, more clinical trials, allocate more funding and all of that because this is a condition that affects, uh, the Black ethnic group more than any other ethnic group.

SPEAKER 1

[00:19:12,541]I think it's more of a blackish problem than any other ethnic group. And so the UK government should see a reason why they should put more, they should allocate more funding, make more policies for research and clinical trials to especially in the area of identifying the impending problems like the complications, do more research and understand how to limit the effects of those complications on sickle cell patients.

SPEAKER 0

[00:19:50,871]Okay. C So, there is a gene therapy for sickle cell disease that has now been approved. What does that mean to you having lived with the condition?

SPEAKER 1

[00:20:02,171]What's

SPEAKER 0

[00:20:03,041]Gene therapy

SPEAKER 1

[00:20:04,771]А, это гентапы.

SPEAKER 0

[00:20:06,941]Yeah, so I think it's a treatment that sort of tries to alter your genes because it carries the sickle cell disease. And um that is supposed to help with the management.

SPEAKER 1

[00:20:22,851]Okay. Uh this one of the things we're discussing, like, um, like situations like this, we need more publicity.

SPEAKER 1

[00:20:33,611]Like this therapy, I'm not very aware. I don't have an understanding of what it means, but with what you've just explained to me, I think it's a positive one. Yeah. It's going to be a positive one. But things like this should get the kind of publicity that it really requires.

SPEAKER 0

[00:20:55,061]So lastly, what message would you give to a young person who has just been diagnosed with sickle cell disease?

SPEAKER 1

[00:21:02,981]um, I would say they they need to be calm and understand the, uh, try to understand the condition very well and be positive, live a positive life, and be ready to fight for their, for what is coming in the future because it changes every day.

SPEAKER 1

[00:21:27,001]It changes every day you live. Today you are okay, tomorrow you are not, but you just have to understand that this is expected and you have to fight for, you have to fight for. The basic thing is fighting for your life.

SPEAKER 1
[00:21:41,651]try to be okay, try to be alive and all of that. So, just live a normal life and it's not a death sentence. Just have to live by the day and live a normal life and be happy as much as you can.

SPEAKER 0
[00:21:56,001]Okay. Alright. Well, that's it for today. Thank you so much for sharing your story with us. Your experience and your honesty will make a real difference.

SPEAKER 1
[00:22:06,451]snoozed

SPEAKER 0
[00:22:07,261]to this project. We're really, really grateful that you took the time to come and do the interview.

SPEAKER 1
[00:22:13,461]Thank you for the opportunity to thank you for inviting me, Henry. All right. I appreciate it.

SPEAKER 0
[00:22:20,301]Thank you.

SPEAKER 1
[00:22:21,501]Thanks.

SPEAKER 0
[00:22:32,801]Okay. That's it.

SPEAKER 1
[00:22:38,321]Сорок минут.

SPEAKER 0
[00:22:39,921]Yeah

SPEAKER 1
[00:22:40,701]Aber es ist nicht nötig.

SPEAKER 0
[00:22:42,261]Um, no, once again.

SPEAKER 0
[00:22:51,001]Okay.

SPEAKER 1
[00:22:52,231]Okay.

SPEAKER 0
[00:22:53,081]Thank you.

SPEAKER 0
[00:23:16,361]share your story with us. My name is Geraldine Asino and I'm interviewing on

behalf of Plasma of Hope and our project Sickle Cell Stories then and now.

SPEAKER 0

[00:23:29,041]And this is supported by the National Lottery Heritage Fund. Let's see.

SPEAKER 0

[00:23:35,281]So this project is about capturing real experiences of people who have lived with sickle cell disease, so we can document how care has changed over the decades and make sure those experiences are heard and never forgotten. Your story is very important to us. You have lived with sickle cell disease across two countries and two very different healthcare systems, yeah.

SPEAKER 0

[00:24:02,561]Yeah. and you've also experienced the condition in a way that very few people in this project can speak about. So we genuinely are grateful that you chose to do this.

SPEAKER 0

[00:24:14,221]Yeah. There are no wrong or right answers. Feel free speak naturally in your own words