# Seanastef Kwah

## Sickle Cell Stories: Patient Perspectives and Healthcare Reflections

## Summary Of Speaker Contributions

**SPEAKER 0:** Acts as the interviewer for the "Sickle Cell Stories Then and Now" project. Their contribution focuses on systematically gathering data regarding the patient's history, hospital experiences, transition to adult care, mental health, and community support systems to identify systemic gaps.

**SPEAKER 1 Seanastef Kwah:** Provides a detailed account of living with sickle cell disease, transitioning from pediatric to adult care, and navigating the UK healthcare system. They highlight the challenges of medical dismissiveness, the lack of integrated mental health support, and the vital role of peer-led community organizations in managing the condition.

## Key Points And Decisions

**Medical Care and Protocols:** There is a clear disagreement between the patient's lived experience and current hospital protocols. SPEAKER 1 notes that while awareness has increased, medical staff often rely on "textbook" assumptions rather than assessing the individual patient, leading to dismissive treatment.

**Mental Health Integration:** Both speakers agree that mental health is a critical, yet neglected, component of sickle cell care. SPEAKER 1 identifies a lack of standard psychiatric support, which has contributed to cycles of depression and self-harm.

**Community Support:** The discussion highlights a significant lack of institutional community support, such as home-based nursing. SPEAKER 1 confirms that peer-led groups like "Plasma of Hope" are currently the primary source of emotional and practical support.

**Decisions:** The participants acknowledge that systemic change is required, specifically regarding the implementation of mandatory mental health screenings and more empathetic, individualized pain management protocols.

## Next Steps

**SPEAKER 0:** Committed to synthesizing these findings into the project report to advocate for improved clinical guidelines and better integration of mental health services within hematology departments.

**SPEAKER 1:** Committed to continuing their advocacy work and encouraging the sickle cell community to prioritize genotype testing and proactive mental health support.

SPEAKER 0
[ 00:00:00,877 ]Hi Shana Saf, how are you today?

**SPEAKER 1**
[ 00:00:02,717 ]Very good, thank you. Yourself?

**SPEAKER 0**
[ 00:00:04,687 ]Uh, not too bad, thank you. Thank you for agreeing to be part of this project, Sickle Cell Stories Then and Now. Uh we're going to be asking you questions about your experiences living with sickle cell both within the hospital setting and the community as in, you know, home or, you know, wherever within the community. And if there's any questions that you don't feel comfortable with, please do let us know. You don't have to answer it. And uh please answer to the best of your knowledge, okay? Uh I'm going to start by asking you when you were diagnosed with sickle cell, if you can remember?

**SPEAKER 1**
[ 00:00:44,447 ]Yes, I can. I was diagnosed in nineteen ninety-six. So I was nine months old when I was diagnosed.

**SPEAKER 0**
[ 00:00:52,107 ]Okay, was that in the UK?

**SPEAKER 1**
[ 00:00:55,097 ]No, that was in Cameroon, in Buea, Cameroon.

**SPEAKER 0**
[ 00:00:57,637 ]Okay, and how did your family receive that? How did they deal with it?

**SPEAKER 1**
[ 00:01:03,447 ]I don't think they fully understood what sickle cell is or what it means. They just had an idea like sickle cell, the way they would put it, is an illness that when a child has, they expect it to be short-lived. They're going to die before they get to twelve or if they make it past twelve, they'll die by twenty-one. That's just all they knew.

**SPEAKER 1**
[ 00:01:25,827 ]They didn't know anything else. Right. And no, no knowledge was being given to them from the hospital. They just gave them that information so they could do with what they could.

**SPEAKER 0**
[ 00:01:36,387 ]Okay. Can you tell us if you can remember what your experience was, um, with sickle cell when you were young?

**SPEAKER 1**
[ 00:01:49,487 ]It was hard 'cause living in a society where they don't fully understand the condition, there's so many misconceptions, misunderstandings, and the myths, there's so many myths when it comes to sickle cell. So, growing up, I didn't have friends. Other parents wouldn't let their kids play with me because some of them got sickle cells, contagious. And some were worried that if I played with their child and I got sick or something happened, they were going to blame me for it. So, I grew up in isolation.

**SPEAKER 1**
[ 00:02:24,107 ]Yeah, it's cool.

**SPEAKER 0**

[ 00:02:26,237 ]And um it is how old are you if I didn't ask that.

**SPEAKER 1**
[ 00:02:31,837 ]until next time

**SPEAKER 0**
[ 00:02:33,047 ]So you're 29, pushing 30. So you're a big girl and a baby at the same time. And you are now in the UK?

**SPEAKER 0**
[ 00:02:43,397 ]How was it when you were in the UK and then and how many years ago was this?

**SPEAKER 1**
[ 00:02:51,597 ]It was twelve years ago that I moved to the UK. When I first got to the UK, it wasn't easy because I had educated myself about sickle cell and knowing how to take care of myself, what needs to be done and what doesn't need to be done. But when I came to the UK, I realized that it was almost like Cameroon. The only difference is they do have the facilities, but the knowledge still isn't there.

**SPEAKER 1**
[ 00:03:24,497 ]so there's still very much ignorance and there is so much negligence still going on even though they have the facilities to help. So when I moved to the UK, I I struggled for the first few years by myself and I was lucky enough to meet a few doctors that were willing to work with me who put in the effort to learn and to understand my condition because even though I have sickle cell anemia like others, this disease affects every individual differently.

**SPEAKER 1**
[ 00:03:57,607 ]So, they need to understand each patient as an individual to be able to help them and suit their needs.

**SPEAKER 0**
[ 00:04:06,827 ]Thank you. Um, can you describe what your experience was like in the hospital back then?

**SPEAKER 1**
[ 00:04:19,587 ]Back then it was more of, you're in the hospital, you need pain meds. They give you pain meds when they think it's right and that was it. There wasn't very much investigation. So even if you're complaining about something, you're complaining about pain or persistent symptoms, they just attribute everything is, oh, it's got to do with your sickle cell, that's how sickle cell works. They don't do any further investigation to see if something else is actually going on with you, because they don't understand that sickle cell comes with a lot of complications.

**SPEAKER 1**
[ 00:04:59,297 ]so they assume that it just has to be pain and once you have pain medication, you're sorted.

**SPEAKER 0**
[ 00:05:05,517 ]and it's sort of like that was twelve years ago. Is that still the case now?

**SPEAKER 1**
[ 00:05:10,567 ]Unfortunately so.

**SPEAKER 1**

[ 00:05:12,887 ]Unfortunately so. The difference now I would say is that we are creating awareness, we are advocating for ourselves and I think they are listening. They're not listening enough, but they are listening. Okay.

**SPEAKER 0**

[ 00:05:31,077 ]What would you say your experience is like in A&E now compared to, say, twelve years ago?

**SPEAKER 1**

[ 00:05:41,577 ]It's a lot better now. It's a whole lot better now 'cause we now have the sickle cell cards which were sent out to us. So when you go into A&E, you present that card, your wait time is a lot, a whole lot shorter than it used to be before. And now they tend to respect care plans well, to an extent. But at least there's that now. But before, you can wait for up to eight, nine hours in in A&E, well it's the ET now. But yeah, the...

**SPEAKER 0**

[ 00:06:15,037 ]I was just going to ask you what it was like before, but thank you for mentioning that. And how would you compare the way doctors and nurses used to treat you back then to how they're treating you now, in terms of their understanding and awareness of sickle cell?

**SPEAKER 1**

[ 00:06:36,167 ]If I have to be honest, I think doctors and nurses treated me better back then when they didn't understand the condition, 'cause they did put in the effort to learn and to make me feel better. But now that they have some sort of knowledge, they do everything based on assumption, based on textbook settings. So it's a lot harder for me now than it was back then.

**SPEAKER 0**

[ 00:07:06,917 ]Why do you think that is?

**SPEAKER 1**

[ 00:07:09,287 ]I think because they've been pushed so much to learn more about sickle cell that whatever they've learned from textbooks and training, they're bringing them out to the field and they're assuming that that's the case for every single patient.

**SPEAKER 1**

[ 00:07:25,477 ]So they don't, before they would try to, you know, make sure you're not in pain because they don't know why you're in pain. They try to make sure you're comfortable and they give you hydration, you know, the fluids are going through, you're hydrated. They check your Hb level, if you need a transfusion, you're getting that. But now, once they look at the blood test and they don't see anything disturbing as I would say, they say, "Oh well, looks like you're okay, so just go home and keep taking your home medication." Meanwhile, you're really struggling. So I think it's a lot worse for me now than...

**SPEAKER 0**

[ 00:08:04,437 ]C

**SPEAKER 1**

[ 00:08:04,987 ]was back then

**SPEAKER 0**

[ 00:08:06,227 ]Right. Um, the next thing I'm going to ask you is transition.

**SPEAKER 1**

[ 00:08:10,597 ]Okay

**SPEAKER 0**
[ 00:08:12,107 ]Have you ever been under pediatric care?

**SPEAKER 1**
[ 00:08:15,047 ]Yes, I am.

**SPEAKER 0**
[ 00:08:16,267 ]And how was that transition into adult care?

**SPEAKER 1**
[ 00:08:21,027 ]The transition was hard because unlike with education, you're a minor.

**SPEAKER 1**
[ 00:08:26,827 ]they're very careful with what they do, what they say, and how they say it, and making sure that whatever it is they're deciding is what's best for you. But as an adult, I feel whatever decision they make, they do what's best for them and not for you as a patient. And it was hard but I wish I didn't grow up.

**SPEAKER 0**
[ 00:08:50,147 ]Right. Um, I'm sorry to hear that. What types, in terms of treatment and management, yeah? What types of treatments or medications were you offered when you were younger? Is it different to what you're taking now?

**SPEAKER 1**
[ 00:09:04,217 ]No, it's not different. It's just the doses.

**SPEAKER 0**
[ 00:09:08,327 ]different

**SPEAKER 1**
[ 00:09:09,227 ]sweetie

**SPEAKER 0**
[ 00:09:10,177 ]Um,  have there been any changes in the way that your pain or complications are managed? To just look back like the past many years or how many years you've been in adult care. Have there been any any changes to your care plan or how your pain has been managed both in the hospital and

**SPEAKER 1**
[ 00:09:38,797 ]Yes, there's been a lot of changes. I've been moved around with medications quite a lot because living with sickle cell, we tend to take a lot of pain medications. So, not just pain medications, so many different medications to help control the disease, but at some point your system gets immune abuse resistant, so they need to move things here and there to see what works best for you.

**SPEAKER 1**
[ 00:10:10,237 ]'Cause I, for example, was doing really well with morphine under pediatrics and even as a young adult, but when I got to proper adulthood after 25, morphine stopped responding. If anything, I now react very badly to morphine. So they've had to switch things around to find other medications that would help with the pain better.

**SPEAKER 0**
[ 00:10:34,597 ]Okay Are you currently receiving blood transfusions or blood red cell exchange?

**SPEAKER 1**
[ 00:10:41,547 ]Red cell exchange, yes. Blood transfusions, no. But I used to be on a monthly top-up of blood transfusion for two years.

**SPEAKER 1**
[ 00:10:51,397 ]but as a result of that, I got iron overload. So my ferritin level is quite high and we had to stop the blood transfusions and we've moved to metal exchange.

**SPEAKER 0**
[ 00:11:03,057 ]Just picking up on what you've just said there, iron overload. Did they tell you there was a risk of this when you were having blood transfusions?

**SPEAKER 1**
[ 00:11:12,137 ]They didn't mention that. They didn't, they didn't tell me. I didn't even know that was a thing till I went to school with the fiddle last story, I started learning these things and then I'm like, well, there's so there's so much we don't know about these things.

**SPEAKER 0**
[ 00:11:31,287 ]Okay. Do you think that is something that doctors need to explain better to patients?

**SPEAKER 1**
[ 00:11:39,737 ]Oh definitely, most definitely. As much as they're trying to help us, they need to make us aware of the risk. So when you're making a decision, you're making a conscious decision. You're deciding that, okay, I'm doing this, but I know this is likely to happen. And when that happens, you're not going to be very shocked and at least they would have already had a backup plan towards that just in case that happens. So they really do need to be more explicit with the treatments that they're offering or they're proposing to us.

**SPEAKER 1**
[ 00:12:16,407 ]we should really be aware of the downsides of that. Yeah. Okay.

**SPEAKER 0**
[ 00:12:21,877 ]any challenges or problems with red cell exchange?

**SPEAKER 1**
[ 00:12:27,997 ]Yeah, I do react to my site exchange really badly. So for the first week after my site exchange, I am unable to function. I am tired, feeling weak, hot and cold, night sweats, nausea, all of those things because, I mean, it's blood, it's liquid, but it's also a foreign object in our bodies. And our system was built to attack anything foreign. So sometimes when you get blood transfusions or exchange, your system knows there's something new and it's trying to fight against that.

**SPEAKER 1**
[ 00:13:07,867 ]So in my case, that goes on for a whole weekend. It's not a nice thing to experience.

**SPEAKER 0**
[ 00:13:13,307 ]No, it's not at all. Um, so how has your access to regular treatments like transfusions or exchanges changed over time if at all?

**SPEAKER 0**
[ 00:13:27,157 ]access

**SPEAKER 1**
[ 00:13:30,317 ]I think at some point I stopped getting my blood exchanged due to blood donations.

**SPEAKER 1**
[ 00:13:39,917 ]'cause like they, given that I was reacting a lot to these exchanges, they presumed that maybe it's because I wasn't getting enough blood donated. So they had to stop my exchange for a while or they moved it from four weeks to six weeks to to six weeks and at some point even stretched to eight weeks. And by the time it gets to eight weeks, I'm already admitted in hospital because I just couldn't hold on anymore with the pain and everything.

**SPEAKER 1**
[ 00:14:13,587 ]So, I guess we do really need more people to donate blood, especially people from the Black community to donate more blood, 'cause they have no idea how many lives they're saving just by donating.

**SPEAKER 0**
[ 00:14:28,877 ]Thank you so much for saying that. Couldn't overemphasize. So, I'm going to ask you questions about your relationships with healthcare professionals. Okay.

**SPEAKER 0**
[ 00:14:39,657 ]In terms of your interactions, how were your interactions with healthcare professionals when you were younger?

**SPEAKER 0**
[ 00:14:49,237 ]Was it ? How can I put this? Um, do you feel like they were empathic or...

**SPEAKER 1**
[ 00:14:59,897 ]Yeah, they were very sympathetic and

**SPEAKER 0**
[ 00:15:02,257 ]empathetic

**SPEAKER 1**
[ 00:15:03,517 ]very empathetic and they were nice, they were kind, they were understanding. They communicated really well. So even when I'm struggling and maybe I don't have the strength to talk, they would always find other better ways to communicate with me. But as an adult, they are rude, they are very mean, and they are very dismissive.

**SPEAKER 0**
[ 00:15:31,837 ]Hello

**SPEAKER 1**
[ 00:15:32,767 ]very dismissive

**SPEAKER 0**
[ 00:15:36,167 ]How does that make you feel?

**SPEAKER 1**
[ 00:15:40,027 ]It makes me feel like I don't matter. Because it is my health, but if you're making

decisions without any consideration of how that will affect me or you, you don't even want my contribution towards that decision, it means I don't matter. I'm just

**SPEAKER 1**
[ 00:15:58,597 ]one of your case studies. Yeah. And I don't want to be like that because of what's happening with my life. It's your career, but it's my life and I believe that my life is more important.

**SPEAKER 0**
[ 00:16:08,897 ]Thank you. Um, can I just pause? Donc, comme ça peut être because she's looking at me in the camera, I see. I'm gonna put that camera here.

**SPEAKER 1**
[ 00:16:18,607 ]No, no, no. I think it's it's it's

**SPEAKER 0**
[ 00:16:21,877 ]So, the next thing I want to ask you is

**SPEAKER 0**
[ 00:16:26,797 ]Looking at your experiences of crisis management within the hospital setting, do you feel that there is enough understanding of managing sickle cell?

**SPEAKER 1**
[ 00:16:42,837 ]Não A very big no.

**SPEAKER 0**
[ 00:16:46,217 ]Okay. What do you think can be done about this?

**SPEAKER 1**
[ 00:16:51,377 ]I think medical professionals do need a lot more training. They need to take a few courses, a few courses on empathy.

**SPEAKER 1**
[ 00:17:03,357 ]They do really need that. 'Cause in as much as they study various illnesses, diseases, disorders in school, they need to understand that that's a textbook setting. It's not real life. So when they're on the field, they need to learn and understand patients as individuals. Even not as individuals, maybe as a group. You see that you have this group that came in and the pain score was on a hundred. No matter how much you give them pain meds.

**SPEAKER 1**
[ 00:17:40,927 ]Maybe we should try hot water therapy or heat therapy for these patients and see if it would work.

**SPEAKER 1**
[ 00:17:48,837 ]The second set might always come with a pain level of like six or something. What can we do to make them go down to three or two?

**SPEAKER 1**
[ 00:17:59,447 ]Is it just pain meds they need or do we need to check if other complications are happening with their systems or if it's mental health issues or are they stressed? What can we do as a system to reduce their stress levels?

**SPEAKER 1**
[ 00:18:15,907 ]it's not all about payment. And they think we just want payment. No, we don't. We

don't like it, we don't like how it makes us feel. We just want to be understood. We came in because we needed help. We just want to be helped.

**SPEAKER 1**
[ 00:18:30,467 ]Ich schaue das jetzt noch mal an.

**SPEAKER 0**
[ 00:18:32,827 ]Thank you. That's deep.

**SPEAKER 0**
[ 00:18:37,507 ]We're going to move into mental health and emotional support, which is a very big part in psychosocial.

**SPEAKER 0**
[ 00:18:47,007 ]has mental health ever been discussed as part of your care?

**SPEAKER 1**
[ 00:18:54,827 ]No.

**SPEAKER 1**
[ 00:18:56,397 ]not as part of my care. I mean, for ten years, I never got any assistance with mental health, be it a psychologist, be it a liaison from the psychiatric team, nothing.

**SPEAKER 1**
[ 00:19:16,247 ]I had to ask when I couldn't take it anymore. That's after I had done self-referral and I wasn't making it for sessions because I was in hospital. And I got sent back to the community because I wasn't, I couldn't make it the normal referral table. I now went into the hospital and I said, please, I need help. I need to be referred. That was when I found out that hematology and oncology, they do have a clinical psychologist.

**SPEAKER 1**
[ 00:19:51,877 ]No one ever mentioned that to me for ten good years.

**SPEAKER 1**
[ 00:19:56,697 ]It took me screaming and begging for help and nurses calling constantly, bleeping and saying we are worried about this girl. We know her, she's always bubbly, but the staff we are seeing now is not the staff we know. Can somebody come and see her?

**SPEAKER 1**
[ 00:20:14,907 ]That's when it finally came along.

**SPEAKER 0**
[ 00:20:18,067 ]Okay. I'm going to take you a step back a bit. How has sickle cell affected you mentally?

**SPEAKER 0**
[ 00:20:29,167 ]Again, if it's difficult to answer that, please let me know.

**SPEAKER 1**
[ 00:20:36,367 ]It is difficult but I would answer because I want people to understand that

**SPEAKER 1**
[ 00:20:44,167 ]Sickle cells are not just what they see. It's not just about being in excruciating pain,

but it's about self-doubt, self-sabotage, isolation, and sometimes self-harm.

**SPEAKER 1**
[ 00:21:04,327 ]because we go through so much pain that we think it's just better not to be here. I for one, I've gotten to a point where I felt like maybe if I'm not here, it'll be better. I wouldn't have to be in pain. The doctors wouldn't have to feel like I'm bothering them. The nurses wouldn't have to feel like I'm asking for too much because I keep bursting the buzzer.

**SPEAKER 1**
[ 00:21:30,527 ]Sickle cells damage your mental health. 'Cause you don't have a life.

**SPEAKER 1**
[ 00:21:39,347 ]All you know is being in pain, being in hospital, being out of hospital. When you want to say you want to live life a bit, oh no, you're back in hospital because it's like, why do you think you need to have fun? Why do you think you need to do things for yourself?

**SPEAKER 1**
[ 00:21:58,837 ]So with that, you just find yourself drowning in depression.

**SPEAKER 1**
[ 00:22:06,277 ]you find yourself doubting if you're worth it, anybody putting any effort in you. If anyone is acting up around you, you think maybe it's your fault. Are they tired of hearing me say I'm in pain? Are they tired of seeing me in pain?

**SPEAKER 1**
[ 00:22:25,297 ]It's a lot. It is a lot. and the medications we take Oh my god. the medications we take

**SPEAKER 1**
[ 00:22:36,557 ]the longevity is insane. I mean, I know we don't see it because we're in so much pain that we need this mess to keep us going.

**SPEAKER 1**
[ 00:22:48,007 ]But sometimes you take pain meds, you feel better pain-wise, but you can't remember anything for periods of time. You don't remember what's been happening.

**SPEAKER 1**
[ 00:22:59,867 ]you you are drowsy and

**SPEAKER 1**
[ 00:23:06,207 ]You can't even think straight, you can't make decisions for yourself, and that's when the doctors think it's the best time for them to come and have a chat with you.

**SPEAKER 0**
[ 00:23:14,717 ]right

**SPEAKER 1**
[ 00:23:15,697 ]So, it's just, it's just a lot and there's so much time to talk about that now.

**SPEAKER 0**
[ 00:23:21,757 ]Thank you. I'm just going to pick something that you mentioned. Um, please feel free if you don't feel comfortable answering that. You mentioned self harm. Have you ever tried to harm yourself?

**SPEAKER 1**
[ 00:23:35,917 ]I have tried a couple of times. And I have tried different methods because if method A didn't work, I would want to try method B because I am tired.

**SPEAKER 0**
[ 00:23:48,177 ]Do you feel you've had support with that?

**SPEAKER 1**
[ 00:23:53,737 ]No. No.

**SPEAKER 1**
[ 00:23:58,597 ]'Cause before I was so ashamed to talk about it. To be honest, to say, you know what, this is what is happening with me. I need help. But I got to a point where I felt like with all the things I'm doing, people do need me out there. So if I am not here, some people would not get the support they need because I am the midpoint between these people and their destiny helpers. So I had to encourage myself to do better and I asked for help.

**SPEAKER 0**
[ 00:24:38,037 ]uhh

**SPEAKER 1**
[ 00:24:38,747 ]But I still didn't get help.

**SPEAKER 0**
[ 00:24:41,627 ]Have you ever had help in the past? Have you suffered mentally in the past? abhi

**SPEAKER 1**
[ 00:24:46,967 ]I have suffered mentally. I was diagnosed with depression in 2015.

**SPEAKER 1**
[ 00:24:55,387 ]I was offered antidepressants, but at that time I didn't think that I needed it. So I declined and I thought I could sort it out by myself. That didn't work out. And I went back and I was like, okay, I will take it because I feel like I need that help. That was with the GP. The GP prescribed antidepressants.

**SPEAKER 1**
[ 00:25:20,537 ]But it wasn't a very big prescription. I don't understand how that works. It wasn't a very big prescription.

**SPEAKER 1**
[ 00:25:27,997 ]So I took it and when it was time to get the next dose they were like, "Oh, but you seem to be doing better." Well, yes, I'm doing better 'cause you gave me meds to take. And they're like, "Okay, so I guess that worked."

**SPEAKER 1**
[ 00:25:46,597 ]And stopping that abruptly took me back to square zero. 'cause there was no winning off, there was nothing.

**SPEAKER 1**
[ 00:25:56,207 ]It just took me back to square zero and that's where the self-harm came in.

**SPEAKER 0**

[ 00:26:02,207 ]Okay. What do you think can be done to have better access to mental health support?

**SPEAKER 1**
[ 00:26:12,327 ]I think just like they would refer us to the pain team, they would refer us to an eye clinic, it should be standard for them to refer us to mental health teams as well.

**SPEAKER 1**
[ 00:26:25,007 ]that should be a part of it because that's completely left out. But they don't understand that mental health even plays a greater role in triggering our crises than physical pain most times.

**SPEAKER 0**
[ 00:26:42,617 ]Thank you. Thank you for saying that. Um, before I move into community support, something I wanted to ask. How is your experience with the ambulance service?

**SPEAKER 1**
[ 00:26:56,257 ]Hmm. It's fifty-fifty.

**SPEAKER 0**
[ 00:27:00,687 ]Okay.

**SPEAKER 1**
[ 00:27:02,057 ]And that's mainly because you don't get the same paramedics every time.

**SPEAKER 1**
[ 00:27:07,457 ]So there's some days that you're going to be placed and you would meet ones that are sweet, nice, they're willing to listen, they read your care plan, they take good care of you. Then you meet the ones that you meet the know-it-alls.

**SPEAKER 1**
[ 00:27:20,817 ]So I will tell you, they have the protocol they follow, so they're not going to follow your care plan. Okay. So for that it's fifty-fifty.

**SPEAKER 0**
[ 00:27:28,697 ]Okay Thank you.

**SPEAKER 1**
[ 00:27:30,147 ]Oh no, by the way, time. In winter the return is the same.

**SPEAKER 0**
[ 00:27:34,957 ]Okay.

**SPEAKER 1**
[ 00:27:35,607 ]is how it works.

**SPEAKER 0**
[ 00:27:36,467 ]Thank you for mentioning that. Um, so when you have to call the ambulance or 111 or whichever emergency services you have to contact to get into hospital, I have heard um people complain about the questions that they ask them while they are in severe pain. Can you explain that? Have you experienced that?

**SPEAKER 1**

[ 00:28:03,147 ]Hello.

**SPEAKER 1**
[ 00:28:04,107 ]I mean, I do understand that they have a protocol to follow. But all those questions that they ask are questions that they consider after they've dispatched an ambulance. Because the state they're asking questions, you're in so much pain, you're so slow to respond.

**SPEAKER 1**
[ 00:28:24,697 ]and time is wasting. Because you asked me if I've lost any blood, the paramedics don't ask me that when they're there.

**SPEAKER 1**
[ 00:28:34,197 ]So, I feel like the questions I understand are a protocol, but they need to cut those questions short. Yeah. 'Cause if it's an emergency, it's an emergency. There isn't any time to be answering questions 'cause sometimes, we're not being difficult. I genuinely cannot talk. I am in so much pain, I'm struggling with my breathing, I cannot talk. Then they get upset at that point that you're not you're... Oh, I can't hear you. Can you speak louder?

**SPEAKER 1**
[ 00:29:04,227 ]Well, this is the loudest I can go. So

**SPEAKER 0**
[ 00:29:07,987 ]Thank you. Uh, I'm going to move over to community support and family life.

**SPEAKER 0**
[ 00:29:14,757 ]Do you think that your friends and family understand sickle cell?

**SPEAKER 1**
[ 00:29:23,657 ]No.

**SPEAKER 0**
[ 00:29:25,127 ]Mmm-mmm.

**SPEAKER 1**
[ 00:29:27,157 ]They would say they do, but they don't.

**SPEAKER 0**
[ 00:29:31,817 ]Okay

**SPEAKER 1**
[ 00:29:33,557 ]Because... well... I just think that if you understand what sickle cell is, you understand how damaging it is to the system, and how draining it is mentally.

**SPEAKER 1**
[ 00:29:58,137 ]You wouldn't get upset that I don't show up for your stuff.

**SPEAKER 1**
[ 00:30:04,457 ]You wouldn't get upset that I'm in hospital and I didn't pick up your calls. And you wouldn't stay for months without checking in on me if you actually understood.

**SPEAKER 1**
[ 00:30:17,637 ]Some people are lucky, but everyone I'm not, I'm not lucky with having that support system from family and friends.

**SPEAKER 1**
[ 00:30:26,887 ]I'm always in the hospital. Sometimes the nurses will ask me, "Oh, are you an international student?" 'Cause I never see anyone come to university.

**SPEAKER 1**
[ 00:30:37,447 ]But I have a long list of people. They just don't show up. But I have now learned not to feel entitled to anybody's time, anybody's love or anybody's care. So, I'm good.

**SPEAKER 0**
[ 00:30:53,217 ]I know that, uh, you went to university, you studied dentistry, so you're a doctor. Can you explain to me what it was like being a student with sickle cell?

**SPEAKER 1**
[ 00:31:08,217 ]It was hard.

**SPEAKER 1**
[ 00:31:10,977 ]I'm just not going to call it anymore than uniform 50, but I don't only have sickle cell, I have a disability which wasn't considered a disability, so I didn't get extra support.

**SPEAKER 1**
[ 00:31:28,447 ]I didn't get extra time, be it assignments, be it for exams, be it missing clinicals. I got in trouble for being absent because they didn't fully understand.

**SPEAKER 1**
[ 00:31:50,327 ]We

**SPEAKER 1**
[ 00:31:51,887 ]we have tutors, but we have tutors as a group. I feel like it would have helped a lot if I had a personal tutor that would help me catch up on lost clinical times or help me catch up with practicals that I missed and stuff, but I didn't quite get that. So I had to work extra extra hard to be able to meet up.

**SPEAKER 1**
[ 00:32:15,757 ]So, I don't think I got enough support in school.

**SPEAKER 1**
[ 00:32:22,467 ]TSA did try to get me a personal tutor, a private tutor. So the TSA is... This is for students, yeah. So, but that tutor was also a uni student studying a different course. So it was just like you were getting me baby steps to just watch me work . There was no one to help me explain something if I didn't understand because I didn't get that time on my lectures to do that.

**SPEAKER 0**
[ 00:32:54,557 ]Okay.

**SPEAKER 1**
[ 00:32:55,477 ]Living in Sudanese homes as well, it wasn't fully accessible for me. So, it was just a struggle all round.

**SPEAKER 1**
[ 00:33:05,497 ]but I couldn't say much 'cause they would tell you, oh well, sickle cell doesn't seem that bad, you can cope, you can manage.

**SPEAKER 0**
[ 00:33:17,517 ]Thank you for sharing that. Um, so, in terms of community being at home, how is it like when you get discharged from the hospital for instance?

**SPEAKER 0**
[ 00:33:35,037 ]How is... how is the support within the community? Is there... I'll make... I'll make it easy.

**SPEAKER 0**
[ 00:33:44,237 ]Do you have any support system or within the community like when you get home from hospital because I know when you come home from hospital it does take some time for you to fully recover.

**SPEAKER 1**
[ 00:33:56,247 ]I don't. I even asked if they could send community nurses 'cause at some point I did have a leg ulcer that needed dressing.

**SPEAKER 1**
[ 00:34:10,487 ]I had to go into the hospital just to be changed. Das war's.

**SPEAKER 1**
[ 00:34:15,867 ]it costs money, taxes and everything. And I did ask if they could even refer a community nurse to come to the house and change it from time to time. That never happened.

**SPEAKER 0**
[ 00:34:26,237 ]So, have you ever seen a community nurse?

**SPEAKER 1**
[ 00:34:29,327 ]I don't know what the community has looked like.

**SPEAKER 0**
[ 00:34:32,327 ]Okay.

**SPEAKER 1**
[ 00:34:33,407 ]Yeah, I don't.

**SPEAKER 0**
[ 00:34:34,527 ]Okay. Is there any community organization that supports you within the community?

**SPEAKER 1**
[ 00:34:41,077 ]No.

**SPEAKER 1**
[ 00:34:45,117 ]I've only um a community who um who does occupational therapist came came into the house once just because the hospital needed them to provide a few equipments for me at home and they needed to come to the house to see what it was like and what would help. That was the only time I got someone outside.

**SPEAKER 0**
[ 00:35:12,117 ]Okay. Can you pause that?

**SPEAKER 0**

[ 00:35:19,617 ]So, I hear a lot of people say how lonely and isolated they feel, and I know everyone is different.

**SPEAKER 0**
[ 00:35:33,197 ]Do you feel the same way living with sickle cell?

**SPEAKER 1**
[ 00:35:36,647 ]I do. I do because the people around me don't understand what sickle cell is or what sickle cell is like. So they do tend to leave you out on a lot of stuff, especially when they've included you several times and you couldn't make it because you're unwell. At some point, they just don't bother anymore. And I understand that because they're like, she's not going to show up anyways.

**SPEAKER 1**
[ 00:36:05,477 ]but it can be a lot for us or for me to deal with when I'm unwell. I don't even have someone to call or to call and check up on me, to text me.

**SPEAKER 1**
[ 00:36:19,407 ]And because I'm so afraid, I'm so scared of rejection, sometimes I tend to isolate myself as well. I say, you know what? It's better I'm alone so I don't get disappointed. So I cut everyone off.

**SPEAKER 1**
[ 00:36:34,597 ]I just stay alone. 'Cause if you're alone, there's no expectations. Without any expectations, there's going to be no disappointments. But it's hard.

**SPEAKER 0**
[ 00:36:46,547 ]Have you had any support with loneliness and isolation?

**SPEAKER 1**
[ 00:36:51,557 ]Oh yes, I have. I have. and it's really changed a lot for me.

**SPEAKER 1**
[ 00:36:57,317 ]'Cause with plasma of hope, you get checkup calls. The time when I don't want to talk, but at least they will understand that you don't want to talk. They won't get upset or feel like you're just being rude. Just having to talk to other fellow warriors as well is very encouraging. We tend to befriend each other, give support here and there where we can. And just knowing that you have something to fall back to when the system is failing you.

**SPEAKER 1**
[ 00:37:37,857 ]You have a support system, you have something you can call a family that is there to listen if you just want to rant, that is there to give you advice if you're stuck. It's been really life changing. So I would say for the past five years, it's gotten a lot better for me. I have learned to deal with things better, to cope with things better. 'Cause when I feel stuck, when I feel frustrated, I know I would have at least one person that would be willing to listen to me.

**SPEAKER 1**
[ 00:38:17,067 ]at least one person that I would call to check if I've gone too quiet.

**SPEAKER 1**
[ 00:38:24,337 ]So, we do need support in the community and I don't know about others, but I know I am blessed. I've been blessed to have lots more hope that's looked out for me for five years and I cannot explain how that experience has been for me, but I can say it's been really life-

changing.

**SPEAKER 0**
[ 00:38:46,077 ]Thank you for saying that.

**SPEAKER 0**
[ 00:38:49,117 ]And um, we're coming towards the end of the interview, but just some overall reflections. Looking back, what would you say has improved the most in terms of care or support?

**SPEAKER 1**
[ 00:39:08,617 ]in general or in specific

**SPEAKER 0**
[ 00:39:11,927 ]general

**SPEAKER 1**
[ 00:39:14,697 ]I would say even though I haven't been that lucky, but just the fact that there's been a lot of experiments that have gone on, they've tried, they've tried to bring forth new treatments.

**SPEAKER 1**
[ 00:39:32,807 ]for sickle cell, it's really good. It's worked for others. It hasn't worked for me, but I know it's helped so many people. That is a good thing.

**SPEAKER 1**
[ 00:39:42,947 ]And another thing that has been great, which my day is very tiny, is the National Secondary School Certificates. They are life changing.

**SPEAKER 1**
[ 00:39:53,917 ]'cause it doesn't matter where you are, if you're not in your area where the ambulance takes you to your local hospital, if you're in a whole different city, having your card is going to make things easier for you at the ET. So I think that's a very good improvement as well.

**SPEAKER 0**
[ 00:40:11,457 ]Okay.

**SPEAKER 1**
[ 00:40:12,237 ]So.

**SPEAKER 0**
[ 00:40:13,007 ]I just want to pick up on something you just mentioned, I think we should have asked earlier. Have you ever experienced a situation where you've moved out of your normal, uh, treatment area to go to a different place and fallen sick?

**SPEAKER 1**
[ 00:40:29,127 ]Hehehe, hello.

**SPEAKER 0**
[ 00:40:31,467 ]How was the experience? Do they understand your situation or did you

**SPEAKER 1**
[ 00:40:37,897 ]I guess because I was in a bigger city, it was a lot better because they had so much knowledge that I didn't have to struggle to explain. The moment I got there and my friend was like,

"Oh, she's having a sickle cell crisis," they were like, "Okay, we got you." They just went in with the full protocol.

**SPEAKER 1**
[ 00:40:58,757 ]something completely different that I'd never experienced in my hospital. And I was like, oh, this is nice.

**SPEAKER 0**
[ 00:41:03,957 ]Okay

**SPEAKER 1**
[ 00:41:04,447 ]It feels good to see that.

**SPEAKER 0**
[ 00:41:06,117 ]Note

**SPEAKER 1**
[ 00:41:06,617 ]They were very hands-on.

**SPEAKER 1**
[ 00:41:08,267 ]there was no waste of time. They were very hands-on. Next thing, they're sending you to X-ray, they're doing this, they're doing that, and before you know it, my pain had moved from like from a ten to like an eight. Doesn't seem like much, but that's a lot for me. My pain doesn't go off that quick, so

**SPEAKER 0**
[ 00:41:24,607 ]Okay. Thank you. And what would you say hasn't changed or still needs to change in how sickle cell is treated or understood?

**SPEAKER 1**
[ 00:41:39,777 ]the assumptions

**SPEAKER 1**
[ 00:41:43,617 ]Judging a patient by how they look. Just because I'm not screaming, I'm not cursing, I'm not shouting, I'm not being rude, does not mean I'm not in pain.

**SPEAKER 1**
[ 00:41:59,127 ]And just because my blood looks okay, doesn't mean I'm not in pain. Just because my observations look fine does not mean I'm not in pain.

**SPEAKER 1**
[ 00:42:10,427 ]That's one thing I know that hasn't changed.

**SPEAKER 1**
[ 00:42:14,107 ]be from 12 years ago, from last year or last week is the same thing. That hasn't changed and I think they really need to look into that to understand that.

**SPEAKER 0**
[ 00:42:25,927 ]Yeah.

**SPEAKER 1**
[ 00:42:27,307 ]Everything is not always what it seems. It's not always what it looks like. You need to look deeper.

**SPEAKER 0**
[ 00:42:34,067 ]Thank you. And if you can go back and change something about the care you received back then, what would it be?

**SPEAKER 1**
[ 00:42:48,607 ]It would be

**SPEAKER 1**
[ 00:42:52,827 ]tolerating and being too scared to speak

**SPEAKER 1**
[ 00:42:56,727 ]because that led to me becoming septic, 'cause I did see it happening, but I was too scared to speak, and I almost lost my arm.

**SPEAKER 1**
[ 00:43:09,407 ]So I feel like we need to speak up. and nurses need to pay more attention. I know they have a lot on their plate.

**SPEAKER 1**
[ 00:43:24,127 ]But when someone lays a complaint, please look into it. 'Cause we're not just saying this, we don't want to bother you, we know you're having a tough day already. Just look into it.

**SPEAKER 1**
[ 00:43:36,827 ]'cause you might end up saving a very horrible situation. A very big disaster is about to happen.

**SPEAKER 0**
[ 00:43:44,947 ]Thank you. and finally What would you like future generations with sickle cell to experience differently from what you have gone through?

**SPEAKER 1**
[ 00:43:56,697 ]I would really wish for them not to be scared to go to hospital because they feel judged.

**SPEAKER 1**
[ 00:44:06,017 ]I hope that they're going to have a better system that will understand them as individuals.

**SPEAKER 1**
[ 00:44:16,627 ]that will be investigated properly and not just based on assumptions. And I hope that they will get mental health checks.

**SPEAKER 1**
[ 00:44:29,607 ]because that just makes everything worse when your mental health is not in check. It just becomes a cycle. You get unwell, you go into hospital, you're there for quite a while. You come out, you're feeling sad and depressed because you've missed out on a lot of things. Being depressed makes you stressed. Now stress triggers a crisis.

**SPEAKER 1**
[ 00:44:55,477 ]your banking details It's just a second.

**SPEAKER 1**

[ 00:44:57,367 ]but if at least we get mental health checked or the younger generation get way better than we have gotten, it would be better. And oh, also, please

**SPEAKER 1**

[ 00:45:14,447 ]Check your channel types. Check your genotypes. We don't need any more of those. I mean, we love us. We do love us, but we don't need any more of us.

**SPEAKER 1**

[ 00:45:25,807 ]Go to your GP. Tell them you need to get your genotype checked. You get that done. Then you find a white partner for yourself.

**SPEAKER 0**

[ 00:45:36,987 ]Amazing