Jasmine Conteh

Oral History Project: Lived Experiences of Sickle Cell Disease

Summary Of Speaker Contributions

Mary Claire (Interviewer): Facilitated the oral history session, focusing on gathering personal insights, emotional reflections, and the lived experiences of parents raising children with sickle cell disease.

Jasmine Conteh (Parent): Provided a detailed account of her daughter Esther's diagnosis and the daily challenges of managing sickle cell disease. She highlighted the physical and mental toll of caregiving, the lack of local emergency support, and the importance of community organizations like Plasma Hope.

Key Points And Decisions

Diagnosis and Emotional Impact: Jasmine shared that the diagnosis was initially devastating and induced feelings of guilt, as she was unaware of her own sickle cell trait until pregnancy.

Systemic Barriers: A major point of contention is the lack of awareness in local emergency services (Walsall). Jasmine reported that local nurses often lack the training to treat sickle cell crises, and ambulance services frequently deprioritize her daughter because there is no visible bleeding.

Logistical Challenges: Due to inadequate local care, Jasmine is forced to travel to Birmingham Children's Hospital, which is both expensive and physically exhausting during a crisis.

Support Systems: Both speakers agreed that cultural stigma remains a significant barrier, causing many families to suffer in silence. Jasmine emphasized that organizations like Plasma Hope are vital for providing emotional guidance and financial assistance.

Next Steps And Commitments

Jasmine Conte: Committed to continuing her advocacy by participating in this project to provide a voice for other families and encourage them to seek support despite cultural taboos.

Mary Claire: Committed to documenting these experiences to raise public awareness and advocate for better training for healthcare professionals and emergency responders regarding sickle cell disease.

SPEAKER 0
[00:00:00,725]Okay.

SPEAKER 0

[00:00:02,325]Uh good morning Jasmine uh my name is Mary Claire and this is uh sickle cell stories then and now thank you for giving us the consent to record your experience of um living with sickle cell uh this your child living with sickle cell this segment focuses on the lived experience of parents raising a child with sickle cell disease

SPEAKER 0
[00:00:30,205]and the questions we're going to ask you are designed to guide the conversation and capture personal insights, emotions and reflections for this oral history project.

SPEAKER 0
[00:00:43,035]Um how are you today?

SPEAKER 1
[00:00:45,385]Yeah I'm good thank you madam.

SPEAKER 0
[00:00:47,845]Right lovely great so we're going to start by asking you can you introduce yourself and tell us a little bit about your child?

SPEAKER 1
[00:00:58,975]My name is Jasmine Conte. I'm a mother. I'm a parent of a sickle cell child called Nym Esther. Esther.

SPEAKER 0
[00:01:12,465]What's her personality like?

SPEAKER 1
[00:01:15,375]Esther, well she is a shy child I would say because it's difficult for her to make friends.

SPEAKER 0
[00:01:25,275]Right.

SPEAKER 1
[00:01:26,065]at first but after getting to know you she will be friendly and yeah open up with you.

SPEAKER 0
[00:01:34,995]Okay that's good to know um does she have any interest in anything that she likes?

SPEAKER 1
[00:01:41,795]Esther likes swimming. She likes roller skating.

SPEAKER 0
[00:01:46,575]Oh wow.

SPEAKER 1
[00:01:47,575]She likes to challenge herself to do certain activities but then there are some after doing them she'll be she will be unwell for instance like roller skating she likes roll doing a lot of roller skating that then after a while she will say oh mommy my feet are aching me because she has pushed herself to the extreme.

SPEAKER 0

[00:02:15,485]Okay. Do you have any other children?

SPEAKER 1
[00:02:17,965]Oh yes I've got us I've got a son but

SPEAKER 0
[00:02:21,755]How old?

SPEAKER 1
[00:02:22,495]He is twelve but he hasn't got sickle cell.

SPEAKER 0
[00:02:26,855]Okay and what makes um Esther special?

SPEAKER 1
[00:02:31,885]Well a condition of course makes us special because I give her well I'm not being if I'm not being I'm not giving her as a favorite child but she needs my care and supports more than the one who is well

SPEAKER 1
[00:02:50,725]so she's special to me.

SPEAKER 0
[00:02:53,865]And when and how did you find out that Esther has sickle cell?

SPEAKER 1
[00:03:01,115]When Esther was born she had a test in the hospital two days or three days after I can remember then a couple of weeks later the results came back and a nurse came to my house and told me Esther's got sickle cell but then they will need another testing to confirm the diagnosis which was conducted at Birmingham Children's Hospital and then two weeks later the confirmation came that she's got she's been diagnosed with sickle cell disease.

SPEAKER 1
[00:03:41,525]which was devastating for me.

SPEAKER 0
[00:03:44,185]Okay. I know you've mentioned that it was dev stating what were your initial thoughts and emotions after receiving the diagnosis? How did you feel?

SPEAKER 0
[00:03:57,355]Did you know anything about sickle cell?

SPEAKER 1
[00:04:00,635]I have absolutely no idea about sickle cell. What is it about?

SPEAKER 1
[00:04:06,595]I have no idea because where I came from I didn't even know that I had the trait until when I was pregnant with Esther. That's when I knew that I had I with my son. That's when I knew that I had the trait. So I have no idea what sickle cell is.

SPEAKER 0
[00:04:22,215]So when they told you she had sickle cell how did you feel?

SPEAKER 1
[00:04:25,795]So when the nurse told me and explained to me what it is about I felt a bit guilty because I've got the traits. She got the traits from me and the dad as well because the dad has got the trait so that's why she's got the disease. So I felt a bit guilty that I've put my daughter in this position.

SPEAKER 0
[00:04:53,455]Okay.

SPEAKER 1
[00:04:54,615]But then I can remember the nurse advised me that there is help and support in place so I will not be alone.

SPEAKER 0
[00:05:05,325]Okay.

SPEAKER 0
[00:05:08,965]So, um, how old is Esther now?

SPEAKER 1
[00:05:12,355]Esther is eight years old now.

SPEAKER 0
[00:05:14,445]Okay and did you get any support after finding out about the diagnosis?

SPEAKER 1
[00:05:22,805]Initially um I had an health a nurse came to my house and explained to me what are the

SPEAKER 1
[00:05:35,945]What is the care plan for Esther? Things that I should put in place and they are putting in place to support Esther.

SPEAKER 0
[00:05:44,705]Okay.

SPEAKER 1
[00:05:45,445]to have a happy and fulfilled life.

SPEAKER 0
[00:05:51,565]Um I know you said Esther is eight um how often has she been sick with a crisis how often does the condition affect her life and

SPEAKER 1
[00:06:05,825]is when she does have a crisis. I try to support her at home but when it's by giving her painkillers massage painkillers massaged and then keeping her warm but then when it gets out of hand I have to take her to the emergency room.

SPEAKER 0
[00:06:28,285]Okay.

SPEAKER 1
[00:06:29,435]And for us here in Warso, there's none available. I have to go all the way to

Birmingham Children's Hospital, which is very challenging for me.

SPEAKER 0
[00:06:39,135]Okay.

SPEAKER 0
[00:06:41,555]And how has sickle cell impacted Esther's life at home, in school, or with friends, the social life?

SPEAKER 1
[00:06:50,445]Wow with sickle cell yes there is a plan but sometimes it doesn't go the way you plan things because it can happen at any time unexpectedly.

SPEAKER 1
[00:07:03,385]She will go to bed fine and then wake up in the morning. It's a different story, oh mommy I'm in pain.

SPEAKER 1
[00:07:13,205]Then okay she can't go to school because if she can't walk there's no way she can go to school if she's in pain there's no way she can go out to play. If she's having a crisis, she's stressed, she's worried, there's nothing much you can do. You just stay to support her.

SPEAKER 0
[00:07:36,965]And what does that mean for you? I mean, what is the typical day as a caregiver especially during the times that she's not well?

SPEAKER 1
[00:07:45,855]It's very challenging for me. It is really because mentally, physically

SPEAKER 1
[00:07:56,035]it's challenging.

SPEAKER 0
[00:07:57,995]Okay, do you think?

SPEAKER 1
[00:07:59,555]But I have to be strong for her.

SPEAKER 0
[00:08:01,325]Right.

SPEAKER 1
[00:08:02,045]Because it's not only the sickle cell that is not only affecting her physically but it does affect her mentally as well so I have to be a stronger person but it's very challenging.

SPEAKER 0
[00:08:13,755]I know you have to be a stronger person, especially being a caregiver. Do you have any support?

SPEAKER 1
[00:08:21,535]Yes we have um

SPEAKER 1

[00:08:26,395]Plasma Hope is there to give us support and we reach out to Marie who is the organizer.

SPEAKER 1

[00:08:38,515]She's there to support me financially because she gave us vouchers, food and emotionally as well guiding me ways to give Esther support making me stronger to keep on pushing.

SPEAKER 0

[00:09:01,695]Okay um thank you for saying that um you know it's really important to know that you're getting the support that you need um so what we want to find out is I know Esther is eight.

SPEAKER 0

[00:09:19,015]How do you feel about the support especially when she's in crisis like emergency care from when she was born till now do you think anything has changed or is it the same like when she's in crisis and has to go into hospital or GP access?

SPEAKER 1

[00:09:37,585]Well nothing much has changed. Yes they're trying the organization of the hospital they're trying but we still haven't got there yet. So we need more training for our nurses and um carers and support aid that are working with sickle cell children to have more training and awareness how to support children with sickle cell and their families.

SPEAKER 0

[00:10:10,335]Have you had any instances where you felt um she wasn't giving the proper care that she needed?

SPEAKER 1

[00:10:19,795]yes I had but that was in Warso so I had when Esther had a crisis I took her to warso emergency it was a challenging and very terrible experience for me because the nurses there have no idea what sickle cell is all about.

SPEAKER 0

[00:10:39,515]Okay.

SPEAKER 1

[00:10:41,335]So my daughter wasn't able to get the proper care that she needs.

SPEAKER 1

[00:10:46,785]but then the con- when I contacted the consultant at Birmingham Children's Hospital she advised me not to take her to Manor Hospital anymore. I should always take her to Birmingham Children's Hospital.

SPEAKER 0

[00:10:59,025]Okay and what is it like accessing emergency services when she's in crisis so what do you do you call?

SPEAKER 1

[00:11:09,695]um well

SPEAKER 1

[00:11:13,035]I'll call an ambulance but then they will say it's not bleeding because that's when it comes to ambulance it has to be life threatening event and uh life threatening issue because

they'll ask you question is it is it is it bleeding so then it's difficult for me to access ambulance I have to use my own money take a cab and go all the way to barman which is very challenging and expensive for me.

SPEAKER 0
[00:11:41,865]Okay. Um what would you advise other parents who are facing similar situations, you know, living with a child with sickle cell?

SPEAKER 1
[00:11:53,105]Well I would advise other parents that are in the same situation with me to seek out support there organizations there as I'm saying Plasma Hope is a very supporting organization they're there to guide you to to give you information so you make the right choices and to listen to you they're just there to listen.

SPEAKER 1
[00:12:23,755]because sometimes that's all you need. You need someone to just listen and they're good at it.

SPEAKER 0
[00:12:30,775]Thank you.

SPEAKER 1
[00:12:31,605]I'm advising every parent to reach out to them for support.

SPEAKER 0
[00:12:36,095]Thank you how do you feel being part of this project

SPEAKER 0
[00:12:41,795]being a voice for people with sickle cell because we're gathering all this and putting it public and I know that there're so many parents who are still shying away from talking about sickle cell because of the stigma.

SPEAKER 1
[00:12:58,415]For me I'm very happy that I'm taking part in this program because I'm making a voice for other family out there because sickle cell in our culture is like a taboo people don't talk about it and then when they don't talk about it people suffer in silence our children suffer in silence because as a parent if you don't know what to do how how will you support your child to have a fulfilling life so I'm saying to all parents

SPEAKER 1
[00:13:37,385]there's support out there to go for it and make use of it.

SPEAKER 0
[00:13:43,565]Thank you so much Jasmine. We're so pleased you've been part of this project and we wish you all the very best as you continue to look after your family. Thank you.

SPEAKER 1
[00:13:53,925]Thank you thank you my man.

SPEAKER 0
[00:14:01,895]Fantastic. That is yes. Very good. Oh my God. I have to employ you to be my assistant. Wow.

SPEAKER 0
[00:14:13,995]That's very good. Okay let's stop this one.

SPEAKER 1
[00:14:18,295]Ah!