Armany Omale

Sickle Cell Caregiving: Perspectives and Challenges

Summary Of Speaker Contributions

Speaker 0 (Armany): Acted as the facilitator for the "Sickle Cell Stories Then and Now" project. Her contributions focused on eliciting detailed perspectives regarding the daily responsibilities of a carer, the quality of NHS healthcare services, the impact on mental health, and potential areas for systemic improvement.

Speaker 1 (Carer): Provided a candid and detailed account of the intense physical and emotional labor involved in caring for a patient with sickle cell. She highlighted her role as an advocate, medication manager, and constant presence in hospital settings, emphasizing the necessity of being "combative" to ensure the patient receives appropriate care.

Key Points And Decisions

Systemic Challenges: The carer identified a significant lack of specialized training among hospital staff regarding sickle cell, noting that patients are often treated based on generic textbooks rather than individual needs.

Communication Gaps: There is a perceived failure in communication between different hospital departments, specifically between hematology and pain management teams, which often leaves the patient without adequate care during off-hours or weekends.

Advocacy as a Necessity: The carer expressed that she is forced to "cause chaos" and file formal complaints to ensure the patient is heard and treated, as standard procedures often fail to prioritize the patient's specific crisis needs.

Mental Health Impact: Both parties agreed that the emotional toll on carers is significant and currently unacknowledged by the healthcare system, with no formal respite or support services offered.

Decisions: The discussion concluded that the current reliance on the carer’s persistence to secure basic care is unsustainable and that systemic changes in staff training and inter-departmental coordination are required.

Next Steps And Commitments

Speaker 1 (Carer): Committed to maintaining her role as a fierce advocate for the patient, refusing to stand down despite the personal exhaustion and the "troublesome" label often applied by staff.

Improve the prioritization of sickle cell patients in emergency and ambulance services to prevent

unnecessary delays in treatment.

SPEAKER_0
[00:00:01,586]Hi, I'm Annie. How are you today?

SPEAKER_1
[00:00:03,416]I'm okay.

SPEAKER_0
[00:00:04,426]Thank you for agreeing to be part of this um project Sickle Cell Stories Then and Now. Um we're going to be asking you questions uh as a carer for Shona Steph. Uh I just want you to give us a perspective of your experience or experiences of caring for her as someone living with sickle cell. And if there's any questions that you don't feel comfortable answering, please let us know. But uh we'd like you to answer to the best of your knowledge.

SPEAKER_1
[00:00:38,126]Okay.

SPEAKER_0
[00:00:39,146]So, can you just tell us a bit about your role in caring for her?

SPEAKER_1
[00:00:46,646]Um, roles in caring for synesthete is advocacy, meal prep, medication prompting, um, just a human nudge to whatever is happening and how to deal with it, and a human reminder, human alarm clock to say, you know, you can take a break, you know, you don't have to do this. Um, and yeah.

SPEAKER_0
[00:01:17,546]Okay That's interesting. Thank you. And how did you come to be involved in her care?

SPEAKER_1
[00:01:27,656]Her very first admission that I witnessed was very scary. Um it was the first time that I as an individual ever went to a hospital, whether to see somebody or just be in a hospital setting. It was the first time and seeing everything that was connected to her, the PCA, the oxygen, the ethanox.

SPEAKER_0
[00:01:54,706]Okay So how did you come to be involved in her care?

SPEAKER_1
[00:01:59,986]So, going back to the very first time Sinister got admitted, um seeing everything connected to her. There was oxygen, there was PCA, there was before the oxygen there was ethanol knocks. Um watching how many people had to try to cannulate her, watching them change to different teams and departments, and seeing her do all of that or go through all of that, and nobody by her side. And I had to ask her, "Is this your worst admission?" And surprisingly, it wasn't.

SPEAKER_1
[00:02:38,916]Seeing all of that going on, it was too much for me. But it was normal to her. And normal not just in the sense of getting admitted, normal in also the sense that she's going to be by herself. And I didn't think it was fair for anybody to be going through any of that all by themselves. Even if it's just to come and just give fresh milk or home water because the water in the hospital is not the greatest.

SPEAKER_1
[00:03:07,036]Um, so I started to get myself involved very deliberately and very consciously because I didn't think it was fair for anybody to go through all of that by themselves. And hearing that it was the, it wasn't the worst admission.

SPEAKER_1
[00:03:24,436]for me that felt like that was a lot, but it wasn't how I was finishing, so

SPEAKER_0
[00:03:30,616]Wow, seeing what you have gone through and what you've experienced, how did that make you feel?

SPEAKER_1
[00:03:38,326]I was scared. I am still scared. Um, because there's some days where you can tell that

SPEAKER_1
[00:03:50,956]it's a law and she's just hanging in there. Even though she's trying to convince herself that it's not a law. There's some days where you really just want to scream and choose yourself. Don't do any other thing apart from doing things for yourself. But she has to leave her regular life.

SPEAKER_1
[00:04:10,416]and doing that scares me sometimes because she has a very complex health situation and you can't, she can't just be going out with friends. She can't just be hopping. And I know she's someone that struggles as a person. Um, she wouldn't want to go in a wheelchair, she wouldn't want to use her crutches because she's out with friends and doesn't want to be judged. But I'm scared that you do all of those things and you end up in the hospital and there's people out there.

SPEAKER_1
[00:04:45,136]Your body's gonna suffer. I'm gonna suffer. Sometimes it's not just about your body suffering, it's about the emotional toll it takes. Seeing the fact that after she comes out of that hospital, she doesn't remember anything we spoke about in the hospital.

SPEAKER_1
[00:05:02,536]And it's a significant time 'cause we're frequent customers of the hospital. So, I still am scared of all of it. But the fact that I'm scared doesn't mean I should walk away.

SPEAKER_0
[00:05:19,216]Thank you. deep What does a typical day or week look like for you?

SPEAKER_1
[00:05:26,286]For Um

SPEAKER_0
[00:05:30,556]being her carer

SPEAKER_1
[00:05:32,566]Yeah.

SPEAKER_1

[00:05:34,496]It's mostly about making sure we're getting to appointments, making sure we're calling the GP, making sure morning meds, afternoon meds, evening meds are taken, 'cause she doesn't like taking meds. Um, and I understand because taking meds all for the rest of your life every day, it's it's it's tough. Um, making sure places are warm, having to check, oh if we're going here, do they have enough heating systems so you don't get into a crisis. Um because the cold is a huge trigger for her.

SPEAKER_1
[00:06:13,836]making sure that the people she's going out with are not going to be some sort of trigger because she gets triggered emotionally as well. Um so it's prepping of both medication, um interaction, um the home settings, um because it needs to be warm and yeah, sometimes it can get as bad as prepping for showers. Um and other times I may have to carry her out of bed.

SPEAKER_1
[00:06:51,086]Um, yeah, that's a typical day.

SPEAKER_0
[00:06:54,846]Thank you.

SPEAKER_0
[00:06:56,116]Um, I'm going to move over to healthcare services and just ask to the best of your knowledge and I know that you've quite involved in her care. Um, what has your experience been like dealing with NHS services on her behalf?

SPEAKER_1
[00:07:18,476]I've been turned away from the NHS. I've been threatened to be removed by security because I was advocating for her. Um, they listen but they don't hear.

SPEAKER_1
[00:07:36,056]Um, and they don't consider anything that goes wrong with a patient suffering from sickle cell as anything other than sickle cell. So if she's coughing too much, it's a crisis. If she's breathing loudly, oh, maybe it's a sickle cell. Um, and that is very frustrating because other than sickle cell, this person is a person that could also suffer from other things. But everything is tagged and termed sickle cell.

SPEAKER_1
[00:08:15,496]and being on the other hand of not being the one laying on that bed is very frustrating to hear and deal with. And because I have a very loud voice when I do tend to speak, um, in terms of us, oh, you want a bully yours? Oh, it's not about bullies, it's about making sure you guys are doing the right thing because at the end of the day, this is not your family member. You just want to get paid. And sometimes it just feels like it's, uh, they're here again.

SPEAKER_1
[00:08:49,686]Um, yeah, I'm not quite sure if I answered the question.

SPEAKER_0
[00:08:54,016]No, that's really good. That's really good. Thank you. Yeah, and I think that's what is echoing across a lot of the carers. And uh, we're just hoping that things get better because you are talking, you are also a warrior and people don't realize that. So, um, my next question is, do you feel the hospital teams listen to you as a carer and take your concerns seriously?

SPEAKER_1
[00:09:20,806]Now, I feel like they've been forced. I feel like I forced their hands to do that. Um,

previously it was like, um, uh, well, she knows best. So, 'cause I've had to write multiple complaints to pals. I've had to walk up to bed managers, ward managers. I've had to scream, I've had to cause chaos. So, I think they now listen just to avoid my drama. Um, and I don't care how they listen or why they listen, I just want them to listen and act on whatever they're listening to. So now, yeah.

SPEAKER_1
[00:09:57,886]because if they weren't listening, I would write something.

SPEAKER_0
[00:10:01,616]That's really good. And do you think this is something that other carers should

SPEAKER_1
[00:10:06,286]Yes, most definitely. Don't keep quiet. Don't keep quiet.

SPEAKER_1
[00:10:11,116]Yes, you might get termed as, oh, yeah, you're troublesome. Yeah, you're troublesome because you're fighting for the right care for the person, for a family member, for a loved one. So whatever term that you would be termed as, so long as it brings the care, yeah, go ahead.

SPEAKER_0
[00:10:32,266]Yeah, thank you. Um, are there any differences between routine care and emergency care? Have you experienced any differences?

SPEAKER_1
[00:10:41,936]Um, I wouldn't say there's a significant difference only because Sinister doesn't get routine care. Most of her care ends up being emergency care. Um, but I wouldn't... the only routine... it's just a rare selection that she has that might be a routine. But even that, she's only managed to have that twice out of hospital admission. Every other time it's been in the hospital. And the prep is okay, but only because they know I'm going to make a fuss.

SPEAKER_1
[00:11:18,636]So they send all the kids to the house a week before 'cause I also have to do a COVID test. Otherwise they can't let me in the room with her. Because the other people with cancer patients are doing some sort of thing. Um but yeah, other than that, she always ends up having emergency care. So not much room for routine care.

SPEAKER_0
[00:11:40,176]I see. Do staff keep you informed and involved?

SPEAKER_1
[00:11:44,356]Again, I forced them to. Um usually they would just do as they please and say nothing because they would claim to tell her, but she can't retain any information. Um while she's alert and conscious, her decision-making is very thin. Um so I have oftentimes had to phone the foundation doctors, um Wonder Ward, and request to be kept in the loop for what's going on. Um or what changes are they planning on making?

SPEAKER_1
[00:12:24,116]Um, alternatively, I would speak to the clinical nurses.

SPEAKER_1
[00:12:30,496]um, and if I don't get a response, I write again. I'm not, I'm not afraid to write. I'm not afraid to scream on top of my voice. So, and I think right now they're just avoiding me. So they

would rather give me what I want than make a fuss. And every other person realized that, oh. Okay.

SPEAKER_0
[00:12:53,426]uh in terms of emergency situations and hospital admissions, how many crises or emergency hospital visits are handled from your perspective like when there's a crisis, how do the hospitals handle this?

SPEAKER_1
[00:13:09,116]First of all, sickle cell patients are not prioritized on that ambulance waiting list. They say we'll put you on the highest priority and someone's going to be with you shortly. It might take four to six hours.

SPEAKER_1
[00:13:21,246]And when they eventually get there, they're in pain. They ask them ten thousand questions. Where are you breathing? Where is he?

SPEAKER_1
[00:13:33,836]Yep, that's why it's called a sickle cell crisis. I don't feel like the paramedics are trained properly to handle a sickle cell patient. They are so even, you can't be asking a sickle cell patient that's in an active crisis, what is your GP surgery?

SPEAKER_1
[00:13:51,146]That's the kind of question they ask.

SPEAKER_1
[00:13:53,416]And when they eventually, 'cause she has a care plan that is very well known. And if I'm calling the ambulance, I'll call the clinical team and tell them, um, she's on her way or we're calling the ambulance, get ready. Um, because I don't want her to have to stay there and wait ages, otherwise, we've had times in the past where she's just going to be in that corridor for four hours. But she's in an active crisis. Nobody, nobody's seen that. So, when they eventually got her, the last admission, I had to say to the paramedics, the crisis is active.

SPEAKER_1
[00:14:32,126]She's in so much pain and discomfort. Blue light.

SPEAKER_0
[00:14:35,246]C

SPEAKER_1
[00:14:36,366]And they were like, um, I'm not sure I have to call. And I was like, yeah, make all the calls now. I'm not going to let you go if you're not blue-lighted because you've already taken four hours to get here.

SPEAKER_1
[00:14:46,696]Um, and then you get to the hospital and some of the nurses at that time, you should be able to go back and see that this person is a regular customer. We don't like being regulars, but we are regulars. That's when you want to come and say, oh, well, have you ever had morphine before? Um, morphine is going to make you feel drowsy, it's going to make... It's not our first rodeo. It's sad, but it really isn't our first rodeo. Just give the medication and let the person just go because she's struggling. I know they have a duty of care to explain.

SPEAKER_1

[00:15:24,026]When you go back to that book, when you see how many times this person has been in, you should know that explanation is not what they want right now. They want that pain optimized and controlled. Or having to go back and start talking. And sometimes they wouldn't let the carers like myself answer those questions. Oh, we need to hear from her. She's in an active crisis and she's in pain. Yet you want to hear a date of birth from her?

SPEAKER_1
[00:15:50,786]Sorry.

SPEAKER_0
[00:15:52,066]Yeah. That is, yeah. Yeah. Do you think these experiences have improved or worsened over time?

SPEAKER_1
[00:16:01,686]improvements are nice Wassening, I'm not quite sure we're at the level of worsening, but I don't think there's an improvement.

SPEAKER_1
[00:16:09,846]only because they are not teaching or training their staff on how to deal with sickle cell patients. So when a new nurse comes in, she does the same thing that the other ones are doing because she's not informed. There are over seventeen hundred sickle cell patients in the country. I think that's enough to have a section or a group of team or nurses if it's about five nurses, somebody or assist or the sisters make them understand, should you get a sickle cell patient, this is how you operate.

SPEAKER_1
[00:16:40,516]But that's yet to come.

SPEAKER_0
[00:16:43,736]And do you feel her pain and needs are responded to quickly and appropriately?

SPEAKER_0
[00:16:51,556]Okay

SPEAKER_1
[00:16:52,836]Some teams are waiting for painting, they can't do anything except paint tells them to jump. Even the hematologists will tell me, "Oh, I'm waiting for a painting." You're a hematologist.

SPEAKER_1
[00:17:03,306]you studied this. Why are you waiting for a pain team that only deals with pain? What she's going through is not acute pain. It's chronic pain.

SPEAKER_1
[00:17:12,546]It's always going to be there. And it's a chronic pain because of the blood that Q started. But you can't prescribe anything. You have to wait for the hematologist, for the pain team. And then the pain team doesn't work after five o'clock. And they don't work on the weekend. So on weekends and after five, their hands are tied.

SPEAKER_1
[00:17:31,876]So, no.

SPEAKER_0

[00:17:33,816]Ah, thank you. Uh, I'm going to move to mental health and emotional support. And I know sometimes it's deep, deep, but please do not hesitate to answer if you don't feel comfortable.

SPEAKER_0
[00:17:46,696]How has caring for someone with sickle cell affected your own mental health or your emotional well-being?

SPEAKER_1
[00:18:00,056]hard. It's very hard.

SPEAKER_1
[00:18:05,296]knowing I'm constantly at the verge of when is the next visit? It's been two weeks, it's been two calm. I'm constantly waiting for that shoe to drop. And then when the shoe drops, I'm waiting for harassment from the healthcare professionals. Um, or I'm waiting for that cycle in her head where she's like, why is it that it's only you that has to be here? I don't have the answers to that question, but it breaks my heart every time we have to go through that ordeal.

SPEAKER_1
[00:18:41,756]and I can't have conversations with her in the hospital because it's New Orleans. She's not going to remember.

SPEAKER_1
[00:18:48,956]I can't make decisions when she's in the hospital because there's no point. So, it's really hard watching that happen. It's really hard seeing her cry multiple nights before an admission only because she's avoiding going into the hospital. I should be able to put my trust in the healthcare system when she gets into this mild crisis. Let's call her very quickly, but we can't because we don't know how that would affect her. Then ending up not reacting at all until it gets severe.

SPEAKER_1
[00:19:29,286]A

SPEAKER_1
[00:19:30,356]that whole transition from mild to severe. It's very daunting because she can't sleep, I can't sleep. Sometimes she can't walk, I can't walk. I have to carry or do things. She doesn't want it to happen, but it has to happen because that's the only way out. And just watching her just stay in pain and I can't do anything about it. I have screamed enough. I have carried, I have tossed things around, I have written. My hands are really tired. I can't do anything.

SPEAKER_1
[00:20:10,886]It's really hard. And there's no support.

SPEAKER_0
[00:20:16,686]That was going to be my next question. Have you ever been offered any support services or any respite?

SPEAKER_1
[00:20:22,856]Nein

SPEAKER_0
[00:20:24,366]Okay.

SPEAKER_1
[00:20:25,206]nein

SPEAKER_0
[00:20:25,776]Do you feel that the emotional side of caring is acknowledged?

SPEAKER_1
[00:20:31,386]No, I... I... I don't even think that they think that that's a thing to be acknowledged.

SPEAKER_1
[00:20:40,186]I, yeah, I don't... I don't really see the writing end time soon.

SPEAKER_0
[00:20:46,926]And we think that's something that definitely needs improving.

SPEAKER_1
[00:20:50,956]Yes.

SPEAKER_1
[00:20:52,156]because inasmuch as we want to be there for our loved ones, we have individual challenges that's already draining to our mental health. Um, and then compiling that to watching your loved ones struggle, um without you being able to do anything. Not many carers are willing to put up a fight. It's not because they don't want to, but because they can't. And I can't imagine how much more struggle they have to deal with mentally just because they're watching their child struggle and they can't do anything. And they can't scream, and they can't fight, they can't run.

SPEAKER_1
[00:21:31,096]Um, yeah.

SPEAKER_0
[00:21:33,576]Yeah. In your opinion, how well do you think different parts of the healthcare system communicate with each other?

SPEAKER_1
[00:21:44,926]I never knew, do you know?

SPEAKER_1
[00:21:48,686]Apart from an MDT meeting that they claim to have on Thursdays, um, where clinical nurses come together with a group of hematologists for one big branch to have a chat, I don't actually think they do communicate with each other as much as they should.

SPEAKER_1
[00:22:09,736]Um, they just go and read the last line of the notes and feel like, yeah, let me act on it.

SPEAKER_1
[00:22:18,116]they don't even if they're not communicating with each other, you'd expect them to extensively read on a patient before they come and try to do anything. But I think they would go under the umbrella if we're understaffed.

SPEAKER_1
[00:22:39,046]The thing was lying. stop We have ten, we have twelve other patients. Um, that's not my concern.

SPEAKER_0
[00:22:49,706]Okay, pause.

SPEAKER_1
[00:22:53,626]Salut.

SPEAKER_0
[00:22:56,046]So, I wanted to ask what types of support, if any, practical, emotional, informational, will be helpful but are missing.

SPEAKER_1
[00:23:12,226]practical for carers like me to stay in the hospital.

SPEAKER_1
[00:23:19,786]And it doesn't give us food by the way.

SPEAKER_1
[00:23:24,086]because, well, I'm not supposed to be there. Um, so something to eat, something to drink, because sometimes I feel like it's a setup the minute I leave, they might not let me back in. So I'm going to have to stay until my body can no longer take it, then I leave.

SPEAKER_1
[00:23:47,226]Um.

SPEAKER_1
[00:23:49,436]emotional, I think just coming through for the sickle cell patient. It would be relieving for me because I know that there'll be one, two, three people here. Um, so I could take a minute to pause from being a carer. I could take a minute to just breathe my own air.

SPEAKER_1
[00:24:16,316]I think that also works on the emotional and the mental side of it. Um, because if I know that there are other people around her during the daytime, I could take steps back and just go home, freshen up, eat, maybe work from home instead of working from the hospital. Um, or maybe sleep. Um, because I can't sleep during the day. And at night sleeping is luxury because ten other people are going off.

SPEAKER_1
[00:24:56,136]or because she's crying in pain. So, if there are other people that community, uh, come through in terms of physicalities being present, um, it would take the edge off me because I know that she's not by herself. She wouldn't have to start thinking why am I in this ward, she would be distracted from the thoughts of why she's unwell. And then I would take steps back for myself because sometimes being with her doesn't change what would be done in the hospital.

SPEAKER_1
[00:25:33,836]but it changes how she would think. She's not alone.

SPEAKER_1
[00:25:38,486]it serves as a distraction. So if another person or another person can serve as that physical distraction, it would give me time to take steps for myself.

SPEAKER_1
[00:25:51,506]or to add to bedtime or to read through the medical notes 'cause I take the medical

note after every hospital admission. I request for the admission note. So then I'd figure out what team needs to do better and then find it again. But there's no time for that. I can only act on what's happening at that moment. Because when we get back home, we have to deal with recuperating at home, then re-getting back into life, and then maybe not immediately, but sometimes always immediately heading back into the hospital. So yeah, that that support would be nice.

SPEAKER_1
[00:26:31,116]and it wouldn't just serve for the carer, it would also serve for the patient as well.

SPEAKER_1
[00:26:37,146]without... without two... two hours is a significant time for us to just go to the car or go somewhere and just... just breathe.

SPEAKER_0
[00:26:47,946]fantastic Thank you. Looking back over the time you've spent caring for her, what changes, if any, have you noticed in how sickle cell is treated?

SPEAKER_1
[00:27:02,786]They are still very inclined to treat sickle cell as a textbook.

SPEAKER_1
[00:27:11,836]Sickle cells react differently to different individuals.

SPEAKER_1
[00:27:17,096]and whilst they think that they're doing great, some of them still don't understand that it's not what you read in the textbook. It affects them differently. Um, so some of them have been forced to think that way because they have seen her over and over. She has almost eight admissions in a year. So, seeing her eighth admissions and then the shortest time we spend in the hospital is two weeks.

SPEAKER_1
[00:27:51,826]So, they've then been forced to say, "Oh, the last time you came, you weren't acting this way," or "this wasn't the concern." They've now been forced to think about it. Maybe we should try this. And they've now been forced to take in opinions from myself and herself because of course what they're reading in the textbook doesn't seem to be working for them. Um, some of them, there's changes, just very little of them. But most of them are still very adamant to the fact that sickle cell is what they read in the textbook.

SPEAKER_0
[00:28:28,406]Thank you. Do you feel that carers like yourself are more recognized and supported now than in the past?

SPEAKER_1
[00:28:36,626]No. No.

SPEAKER_1
[00:28:39,986]If the majority of the carers are like me, I'm very combative. I'm willing to throw punches if needed. Um, but there are not many people like me, whether or not they're carers. Um, so it's kind of hard because when they just tell you, oh, it's eight o'clock, you need to go. They don't want to cause trouble because at the end of the day, once upon a time Steph would tell me, if you leave, if you cause trouble when you leave, they'll take you out of me. So don't cause trouble. So I decided to cause trouble and not leave at all.

SPEAKER_1
[00:29:17,796]Um, I don't think that we are seen or respected. I think that they think of us as just another visitor. Which is not always the case because most single-cell patients that go into the hospital tend to have that one person that's always there every day. So we're not just another visitor.

SPEAKER_0
[00:29:43,936]Just some final reflections. What keeps you going during the tough times?

SPEAKER_1
[00:29:50,436]the fact that there's light, eventually this will work out. Eventually, she's gonna come out. Even if it's just extensive smile for two weeks, extensive craziness for two weeks, we're gonna come out and

SPEAKER_1
[00:30:05,766]have two weeks in our own house and then go back. And in some cases where the previous admission or the current admission is better off than the previous admission, there is light. It's like, oh, okay. At least they're listening. And other cases where complaints are filed and actions are taken, um, it gives me a bit of hope, knowing fully well that, well, now they know I've filed a complaint, they're going to do better when we go back in.

SPEAKER_1
[00:30:41,256]Um, but other than that, the fact that she's not giving up is a great plus, it's a huge plus. Um, because when she gets to that point of giving up, it's not just about the sequel anymore.

SPEAKER_0
[00:31:03,576]What advice would you give to other carers of people living with sickle cell?

SPEAKER_1
[00:31:09,296]Don't stand down. Don't stop talking.

SPEAKER_1
[00:31:13,436]Yeah. Don't stop fighting. You're the only one that knows how much that person exists means to you. Fight for it. Yes, you would be terminally ill. Yes, you would be threatened.

SPEAKER_1
[00:31:26,906]Butter and salt.

SPEAKER_1
[00:31:29,036]because you're the only strength that a sickle cell patient at that time is getting. So seeing them seeing us fight for them gives them energy to carry on. Okay, I'm no one like

SPEAKER_1
[00:31:46,556]Okay. Someone's going to fight if they keep me up pushing me. Okay. Someone's going to talk if the pain team decides to reduce my meds. Um, so never back down, never stop talking.

SPEAKER_1
[00:32:00,956]And when you need that moment to breathe, step out, because you're of no use when you have pent-up emotions. When it's overwhelming, step out.

SPEAKER_0
[00:32:16,356]Thank you. And the final question is what would you like healthcare professionals,

decision-makers, or the public to understand about what it means to care for someone with sickle cell?

SPEAKER_1
[00:32:30,416]We don't like coming to the hospital. We don't like being in that space.

SPEAKER_1
[00:32:36,596]If you guys do your job well, we would not be in the hospital as often as we are. And we would not need to be there.

SPEAKER_1
[00:32:45,996]because healthcare professionals are supposed to care for the patients. The patient would only need external support, not extensive care. But failure to provide your patient extensive care requires external extensive care, which is draining for both the carer and you guys because you guys don't like us.

SPEAKER_1
[00:33:10,386]So, if they do their job better, we would have more assurance that we're leaving our loved ones in safe hands, and we wouldn't need to be a pain in the backside.

SPEAKER_1
[00:33:24,206]But lack of doing their job well makes us have to fight them to do their job right. And we feel like when we stop fighting, then we stop doing.

SPEAKER_0
[00:33:37,196]Thank you so much.