Y. Stories to Save Lives

Interview Y-0003
Stephanie Atkinson
25 June 2018

ABSTRACT – Stephanie Atkinson

Interviewee: Stephanie Atkinson

Interviewer: Maddy Kameny

Interview date: June 25, 2018

Location: Dunn/Newton Grove, NC

Length: 1 hour, 1 minute

Stephanie Atkinson was born in 1981 in Clinton, NC, in Sampson County. Her mother worked in food service, and then at Lundey's (later Smithfield's) pork factory, and became a supervisor. Stephanie's father held a variety of jobs, and is now a hab tech at CommWell Health to help others struggling with addiction. Stephanie describes her mother's experience having to leave work and change her lifestyle due to two hip replacements, and supporting her through her medical appointments. She describes herself as an empathetic and independent child. Visiting the doctor was not a part of her childhood, and she discusses her experience visiting the dentist for the first time in her 20s. Some of her fear resulted from negative experiences with the dentist from both parents. She discusses her parents' asthma. She recalls home remedies such as honey, and alcohol with banana peel used by her grandmother. Stephanie works with HIV-positive patients, and discusses the challenges faced by young people and women, the difficulty for patients to take pills, patient trust and Tuskegee, and the barrier of transportation. She gives her opinions on telehealth/telemedicine and mobile clinics. She talks about how being a nurse affects her perception of her own health, and about juggling motherhood and work. Stephanie describes positive experiences with pregnancy, and a caring OBGYN. She started working at CommWell Health in 2007, and returned in 2013. She discusses working with illiterate patients, and to be aware of patients' reactions to assess whether they have understood instructions. She recalls working with patients who were migrant farm workers. Stephanie discusses an experience with gallbladder pain and subsequent removal. She had intense stomach pains, and her pain level was not properly acknowledged by the triage nurse. Even once her symptoms were treated, the underlying condition was ignored until she demanded a solution. This interview is part of the Southern Oral History Program's pilot project to document health and healthcare in the rural South.

TRANSCRIPT: **Stephanie Marable Atkinson**

Interviewee:	**Stephanie Marable Atkinson**
Interviewer:	Maddy Kameny
Interview Date:	June 25, 2018
Location:	Dunn, North Carolina
Length:	1:01:07

START OF INTERVIEW

Maddy Kameny: —sound quality, so what I'm going to have you do is just talk a little bit about, like, something that doesn't matter, like what you had for lunch, so I can make sure that, like—sorry. [laughs]

[0:00:09.6]

Stephanie Marable Atkinson: That it sounds okay?

[0:00:10.5]

MK: Personal space, yeah. [laughs]

[0:00:11.2]

SMA: It's fine.

[0:00:12.3]

MK: But, yeah, that everything sounds okay. So.

[0:00:14.4]

SMA: Today I had for lunch a Zaxby's salad. It was pretty tasty, although I would have preferred some French fries or an ice cream sundae or a Kit Kat milkshake or an apple pie. I don't know, I'm a foodie. [laughs]

[0:00:33.2]

MK: In Pittsburg, which is where I lived before Chapel Hill, they put fries in their salad.

[0:00:39.5]

SMA: Really?

[0:00:40.1]

MK: Yeah. [laughs]

[0:00:41.6]

SMA: How does that taste?

[0:00:42.7]

MK: I never tried it because I was like, “I can’t.” [laughs]

[0:00:45.3]

SMA: It just seems kind of weird, like you’re taking something that’s supposed to be healthy and you’re trying to make it bad by putting fries in there.

[0:00:50.6]

MK: Yeah. All right, so everything looks good there. Cool. Thank you so much for meeting with me, Stephanie. You can make yourself comfortable, and if we ever need to pause or anything, that’s fine too. Do you want to turn the volume off on that? Awesome. You’ll probably get a lot of emails. [laughs]

[0:01:13.7]

SMA: Probably.

[0:01:13.7]

MK: All right. So let's start with talking about how you came to CommWell Health, kind of how you got interested in healthcare and interested in what you do now. [0:01:27.8]

SMA: So this is actually my second time working for CommWell Health. I worked here from 2007 to 2009. I became a nurse in 2006, so when I came here in 2007, I had not been nursing very long. So I kind of felt like I didn't know if that was my thing, so I kind of, to try some other stuff, and I came back here in 2013 and now I've been here for five years. I really like what we do, because we're serving populations that are underserved and just don't have the means for a lot of things, and it's very rewarding experience to see people who otherwise, without this clinic and the services that we offer, that they would be struggling to get those services. It's very rewarding to be able to help patients go from a place of feeling like there's no hope and there's no service to coming here and being able to get medical, pharmacy, dental, behavioral health, WIC if needed.

There's so many services available, it's just nice to—and I've always wanted to take care of people. I realized that early on, at a younger age, that I enjoyed that. That was a thing that I enjoy doing, helping fix people. That was my thing. So I often joke when I worked at the hospital, patients would be like, "How long have you been a nurse?" And I'd tell them, and they'd be like, "You're such a good nurse."

And I'm like, "Yeah, because I was born to be a nurse." [laughs] So that's one of my little—I was born to do this.

[0:03:05.2]

MK: So when you were a kid, would you, like—you knew you wanted to do something medically related or—

[0:03:13.0]

SMA: Well, when I was younger, younger, I really didn't know. I just knew I wanted to do something, but it was, like, in high school. I took the CNA class and became a CNA while I was in high school, and that's when I really figured out, "Oh, I really like this." So as a kid, I don't remember—which, I'm also kind of that person who I don't think outside the box much, so if it's not something that's attainable for me at the time, I have a hard time dreaming. I'm a very concrete person. I know that about myself. So I think probably as a little child, the reason why I wasn't thinking those things is because it didn't seem real. So I don't have much of an imagination, as my husband says. [laughs]

[0:03:55.9]

MK: You're practical.

[0:03:55.9]

SMA: Yeah.

[0:03:57.9]

MK: So what about—can you tell me more about your childhood?

[0:04:02.3]

SMA: So I grew up in Clinton, North Carolina, and that's a very rural, lot of farmland. Sampson County is very huge, but it's a lot of farming. So I went to the city schools because we didn't live out in the county, and that was like a mix, so I enjoyed it. I went to Clinton City Schools the whole time. I grew up for a period of time with my parents. They were married, and they ended up eventually getting a divorce when I was in middle school, and then we spent the last couple of years living in low-income housing

with my mom. And my dad was struggling with substance abuse, so there was a period of time that although he was available, he wasn't available, but he has been clean for seventeen years now.

[0:04:55.6]

MK: Wow. That's great. Do you have any siblings?

[0:04:57.7]

SMA: Yes, I have two sisters and two brothers. I grew up with the two sisters. The two brothers were older, and my dad from a previous relationship.

[0:05:07.9]

MK: Okay. So, and pardon my ignorance, but Clinton is close to here, right?

[0:05:12.8]

SMA: Yes, it's probably about twenty-five minutes from here.

[0:05:13.8]

MK: Okay. So was it like more rural of an area? Like, how—

[0:05:18.9]

SMA: Oh, it's the same. It looks like this. The only difference, I would say, is that it's grown up a little, so whereas there's no Walmart close to here, there's actually a Walmart in Clinton, and they got that when I was in high school. And they have a few more things. Like, they actually have a Ruby Tuesday's and a few more restaurants, but as far as the way it looks in the city, there are a lot of places that you can go to, but there's still a lot of people who where they live it's very rural, it's a lot of farmland and cows, horses, that type thing.

[0:05:53.5]

MK: So what did your parents do?

[0:05:55.5]

SMA: My mom always worked for a period of time in food service. She did a lot of cafeteria work, and then she transitioned from that. She worked at what used to be Lundy's and then turned into Smithfield's. I don't know if you're familiar, but it's like a pig plant where they produce—you've probably seen it in stores—Smithfield bacon. So she went from working in their cafeteria to working in the actual factory part of it, and she kind of advanced on up to a supervisory level eventually before she had to leave because she had to have both of her hips replaced, and now she's on disability.

My dad, he's done a number of things. He was always very good at whatever he did, but he did things from working at the newspaper place, being part of that, helping to create the newspapers in Clinton, and to working at an antique shop, working at a place that built church pews. He's done a variety of things. Currently he is a hab tech at the Harvest House residential program here on site. So after being clean for such a period of time, he decided that that would be rewarding for him to kind of help people get to where he is, so that's what he does currently.

[0:07:19.4]

MK: So you talked a little bit about your mom's issues with her hips. What was that like going through that when your mom was—

[0:07:25.9]

SMA: Oh, wow. That was kind of challenging. I was an adult at the time, but my mom had worked two, three jobs at some point in our lives, so when she started to experience the pain and she got put out of work for a short period of time, and she was

seeing all these specialists and going and trying to figure out what was wrong, until finally they said, “You have avascular necrosis and your hips are deteriorating. One is better than the other, but you are probably going to have to eventually have both of them replaced.”

And they replaced the first one, and when she went for her follow-up of having the first replaced to see everything was well, he was like, “I have good news and I have bad news. The first hip that we replaced looks great. It’s working just like we wanted it to. The bad news is that what used to be your good hip is now just as bad as the bad hip was before we replaced it, so now you need to replace the second one.”

So she had her hips replaced about six months apart. Very taxing for somebody who had been doing a lot of stuff, so with that, she ended up being out of work longer, and at that time she was still dealing with the fact that she thought she was going back to work. “I’m just going to get better and I’m going to go back to work.” Well, that turned into having to be out for an extended period of time, which for her led to some depression and feeling sad, because if you’re somebody who worked all the time—and working at Smithfield plant, she worked sometimes during the year six, seven days a week, so she would be working every day. That’s part of who she was. She was very work-driven.

So from that to having to be home and going to all these doctor’s appointments and not being able to do the things that she used to do, that was a bit challenging for all of us, I think, so we kind of replaced some of the things we used to do. We spent more time together. My sister had a baby, and she kind of helped. She became that person to go over to keep her company and help her and be available and that type of thing. So she has replaced that work with being able to spend time with her grandchildren, because then I

also had a baby, and so that has helped her feel like she is doing something valuable. But that was a tough transition for all of us, I think.

[0:09:49.0]

MK: So how was that, like interacting with the medical system? Because were you like a spokesperson for her or—

[0:09:55.6]

SMA: At times. I think one of the things that happened for me is just by the luck of the draw, when it was time to have her hips replaced, it was actually going to be replaced—because in Clinton, there's only one orthopedic doctor. There's not options to shop around. And I was actually working at the hospital at the time, so when she was going to have the surgery, that means she would have the surgery at the hospital and she would come to the floor that I worked on once the surgery was complete.

So I feel like that worked as an advantage for me because I was able to—not to say that I feel like that doctors or nurses treat people better or different, necessarily, because they know the person that they're working on, but it's nice to be able to know somebody directly that is going to be working on your mom, because I was able to go to him and say, "Hey, that's my mom that you're going to be performing that hip surgery on."

And he was able to come back and be like, "Hey, your mom's surgery went well," blah, blah, blah, you know, just kind of putting me up to speed and feeling like that I was finding out the details that I needed to find out.

And then even my coworkers, because—with my mom's permission, of course—because my mom is the type of person who, she'll say yes even when she doesn't

understand, which I think is part of a lot of people who navigate the healthcare world, like they feel like they shouldn't question when somebody tells them something. Even if they're using medical terms, they don't even think, "Oh, well, let me ask them what that means."

So for a period of time, I went with her to appointments, and then the doctor would be talking and she'd be nodding her head and the doctor would think that she understood and I would interject and say, "Did you understand that?"

And she'd be like, "No."

And I'd be like, "I didn't think you did."

And then he would re-explain, but I feel like that if I wasn't available to do that, then that wouldn't have happened. And then sometimes after the appointment, things that I didn't catch that she didn't understand, she might would ask me a question and I would break it down for her.

So I feel like it's been helpful being in my role and being able to be in that environment and see some things, because I actually learned—when you become a nurse, it's like you learn bits and pieces as you're exposed. School just does not teach you all the stuff that you need to know, and working at the hospital kind of helped me see people recover from knee surgery, hip surgery, so I had a different insight when it was time for my mom to have the surgery by watching people actually transition through that process. So that was helpful.

[0:12:23.4]

MK: Do you think that's impacted the way that you interact with patients?

[0:12:27.1]

SMA: Just the hospital work or seeing my mom?

[0:12:31.9]

MK: Just anything, like personal experience with, you know—like with your mom's situation, for example, I mean, the doctor not knowing that she didn't understand or—

[0:12:42.0]

SMA: Yeah, well, I think the more time I spend with a variety of patients, not just my mom, but just the exposure that I've had with a variety of patients, it kind of heightened my awareness of things to pick up on. I think when I first started off, I was kind of oblivious to patients who couldn't read. If somebody told me they forgot their glasses at home and could I read something to them, I would never have thought that they were lying to me and they didn't forget their glasses at home, that they actually couldn't read, but now when somebody tells me that they forgot their glasses at home, I'm thinking like, "Oh, maybe they can't read and I'm having a moment here." But I don't take that as an opportunity to make them feel bad. I just read it to them, but it helps me to be more aware.

So I think that the other thing that I have learned is to watch patients' reactions. So like when I'm explaining something, even when they say yes, I'm looking at their facial expressions to be more aware, because people can say yes to you and they really have no clue what you just said, so sometimes I'm looking at their—if the face looks puzzled, even though they say yes, then I explain it in a different way.

I sometimes don't even say, "Did you understand that?" I just reword it and go with it so they don't feel like they're having a moment where—I don't want them to ever

feel like I'm trying to treat them like they're not smart or like they don't know anything, but—or sometimes I give them the opportunity to kind of tell me what the plan is. "Oh, so what are we going to do from what we've just discussed?" That way, whenever they say something back to me, I can kind of assess whether or not did they really comprehend what I'm trying to ask them to do.

[0:14:26.3]

MK: Right. That makes sense. I'm sure that they appreciate that. Yeah. It seems like the providers here have a really good understanding of the community.

[0:14:37.0]

SMA: Yes.

[0:14:39.5]

MK: Do you have memories of what your parents would do when you and your siblings would get sick when you were younger?

[0:14:47.7]

SMA: Yes. Like I said, my mom always worked and my dad always worked, too—because even in his addiction, he was a functioning substance abuser, so he needed to work because he needed money to support his addiction—so because of that, one of the things I realized is that we didn't go to the doctor. When we were required to—we had our immunizations and things like that, but as far as if you had a stomachache or you were nauseous or you woke up and you had a cold or whatever, you just needed to make an executive decision to stay home, because there was no calling my mom for her to come from work to pick you up from school. So if you went to school sick, you stayed at school all day and you just knew better the next day.

So, when we woke up in the morning, we were responsible for, one, getting ourselves up. There was no, "Mom's going to come and wake me up and make sure I get to school on time." If you were catching the bus, then you were responsible for making sure you didn't miss the bus, and if you had homework or assignments or whatever, you were responsible for completing those tasks. So I think that we were very independent and that we had no other choice as far as like our parents had to work, we didn't have the luxury of them being able to take us to school or be available.

So I think what that taught me is that, even now I don't necessarily go to the doctor, unless I feel like I need to, you know? It's that I'm not going to just go because, oh, my big toe hurts. I'm going to kind of wait it out to see what's next. Like, "Uh, is it turning a color? Like, do I think it's going to fall off? Now maybe I should go to the doctor." You know what I mean? But I think that's part of because my parents, that wasn't something they did.

My first dental experience was the first time that I worked here. I had never been to the dentist. There was a time when I was younger that my parents had planned to take us to the dentist, but something happened with the insurance and the cost and they were like, "Oh, no, we can't afford it," so I never actually went. So I was probably twenty-five or -six or -seven the first time I ever went to the dentist.

[0:17:02.4]

MK: What was that first experience like?

[0:17:05.3]

SMA: [laughs] It was a little bit—well, let me just say my first experience, my wisdom teeth on the bottom had come in and they came in facing the tooth in front of it,

so it had grinded the tooth in front of it and created—I had an infection and my mouth was swollen and it was like a lot of things going on, so my first experience was very scary. I thought I was dying, because a toothache, if you've never had one, it's like one of the most painful things that you can experience. I remember—I hadn't had my son at the time, but I remember people ranking that on up with childbirth. That's how horrible it is.

So I was very nervous, but I went to the dentist that day, and it was crazy because there was a training going on, so the dental clinic was actually closed, but somebody, upper management, actually went in and got the head of the man that was over the dental clinic at the time and he came out and he saw me and he said, "Oh, yeah, you need to take this antibiotic, and the pain is going to go away because I'm going to get rid of the infection. But I encourage you to come back and get that tooth removed, because if you don't, then you're just going to—this is going to happen to you again."

And so I remember thinking, like, "I don't ever want to experience that pain again," so I kept my appointment. And thankfully, thank God, the first—when I came back, I had saw the oral surgeon and he removed three teeth, and it was in a very short timeframe. It was good and numb.

It was one of the best experiences, and so because of that, I have no issues with going to dental now. I'm just grateful that my experience was pleasant, because I knew growing up, my dad had to go to the dentist for something and he complained that the dentist pulled the wrong tooth and just that whole—and still today he has dental work that needs to be done that he hasn't followed up about because of that bad experience he had when he was younger, of the dentist—what he says is, "He pulled the wrong tooth."

And if [he] says that, I believe him. Like, “That’s not even the one that was giving me trouble.”

[0:19:06.6]

MK: Wow.

[0:19:08.1]

SMA: So do you have a sense of how your parents were raised in terms of, like, health and healthcare?

[0:19:13.9]

SMA: I think that my parents didn’t go to the doctor a lot, but I will say that when of the things that my mom told me that was very interesting is that my mom is missing several teeth in the back, and whenever we had a conversation about it one day, what she told me is that when she was in school, that they sent a paper home to her parents and that what they said was, is that they wanted to pull these teeth as a preventative—because they could potentially get cavities at one point. And there was actually nothing even wrong with the teeth, and because her parents didn’t know any better, they signed the form and they removed a lot of teeth that really didn’t need to be removed.

[0:19:54.4]

MK: So they had a similar experience, actually. That’s crazy. Do you know about any—like, if they didn’t go to the doctor much, do you know, like, what they—when they got sick from the home?

[0:20:08.5]

SMA: So my mom, I think my mom and my dad, just based off what I can recall, they did a lot of home remedies. So there were a lot of things when we were growing up, "Oh, just drink some honey," and, "Just mix this."

And even still, probably five years ago, my grandma had this concoction that was some type of alcohol with a banana peel, and that was supposed to be for arthritis and leg pain and she was swearing by it, like, "This works." She was dropping off bottles to everybody, like, "Try this if you're having pain." So I think they used a lot of home remedies. They just didn't go to the doctor a lot.

My mom, after the hip surgery and replacement and all that, she goes to the doctor all the time now, but I think that's something that she realizes that she has to do just based off her experience. My mom also suffers from asthma, like *horrible*, so much so, a couple of times she has been hospitalized and intubated because, like, the asthma attacks get that bad. If she gets a cold or a cough or something, that that can send her spiraling.

[0:21:19.9]

MK: Wow.

[0:21:21.3]

SMA: Yeah. My dad has asthma, too, but his seems to be much better controlled. But my dad doesn't go to the doctor either. My mom goes now because of her experience, but my dad is still not following up. I remember probably about four years ago, my dad was coughing and he was sick and his asthma was acting up, and he said, "If I don't do something, I'm going to end up at the emergency room."

So I remember calling down here to get him in to see somebody, and he saw somebody and got a breathing treatment and a steroid injection and got some stuff done, and what they told him was, "You have got to start following up at the doctor." Like, "You are just coming in when you need something. You can't do that. You really need regular maintenance."

So I think he's been better about trying to follow up. He did, I know, within the last year, schedule a regular appointment instead of just, "I'm sick. I need to see somebody."

[0:22:18.6]

MK: That's a good step.

[0:22:21.9]

SMA: Mm-hmm.

[0:22:21.9]

MK: Do you think—what is it? Do you think he doesn't trust the healthcare system or, you know, he had a bad experience? Like, what do you think?

[0:22:33.6]

SMA: I think it's just a combination of things. I think he grew up in a time where people just didn't go to the doctor because they couldn't afford to. And then I think that there is some mistrust there, especially for the dentist, with him pulling the wrong tooth. But then I also think my dad just—he's not somebody who wants to go to the doctor. He's like, "I'm fine," you know?

[0:23:03.4]

MK: Do you see that sometimes with patients also?

[0:23:05.9]

SMA: Oh, yes. Absolutely. For patients I feel like that two things happen. First, sometimes they come in and when they first get here, they're really sick—so not only have they been diagnosed with HIV, but sometimes they've also been diagnosed with AIDS, and in that, their immune system has been knocked down. They're sick, they lost weight, they might have thrush, they can't eat, they can't drink, all those things going on. And when they come, they're kind of feeling desperate, almost like, "Help me. Fix me."

And then, once they get the medications and things they need and they kind of recover and bounce back and they reach that point where they gain weight and their CD4 gets up and they're eating and they're looking normal again, it's like that part of them that feels like, "Oh, I'm fine now," makes them fall off and stop coming to their appointments or stop taking their medications, because it's almost like they forget that the only reason why they're at this point is because of what they've done to get to that point. It's like, "Oh, I'm better now, so I don't want to go to the doctor. It's an inconvenience."

I think it's especially bad for two populations: one, young; two, women. I think young people just sometimes don't have the presence of mind to care about their healthcare, because we've all been young and we kind of think we're invincible and that we don't need anything, we don't need to do anything. And then women, I feel like everybody is more important than they are, so it's more important to take care of their mates or their children or their parents or their aunts, uncles. Whoever it is, they'll find somebody that's more important than they are, and then they won't follow up.

[0:24:56.1]

MK: Is that something that you talk to patients about? Or do you have, like—I guess, do you have personal relationships with patients and you try to follow up with them and—

[0:25:07.8]

SMA: Yeah. So what I find is that because the population that we serve are patients who are [HIV] positive, we oftentimes replace their family. So many patients have experienced stigma from their family or just feeling like they can't really be who they are, they can't really share their diagnosis because they'll be judged or their family members will look at them differently, so we become their safe place. So we also become everything they need, which includes encouraging them to do the things that they don't really want to do. So I often take that as an opportunity, because I think once patients realize that you are invested in them being healthy, they're more willing to listen to you when you tell them, "You should really come to your appointment," or, "You should really consider taking your medications."

[0:26:02.0]

MK: Right. Not just a random person telling them.

[0:26:04.3]

SMA: Right.

[0:26:05.2]

MK: What are some challenges that you think this community faces?

[0:26:09.7]

SMA: Well, the fact that we're rural and that there—if you don't have a car, there's no Uber or Lyft or cabs, really. I'm not 100 percent certain, but I don't think there

are *any* cab services left in Clinton, and when I was growing up, there was only one or two when I was younger, and now I don't think anybody does that anymore. And then in Dunn, I don't know if they have that, but, I mean—and then we're in such a rural setting. We had a patient one day who took an Uber from Fayetteville to here.

[0:26:48.2]

MK: Ooh, that's far.

[0:26:49.1]

SMA: Yeah. And we didn't even realize that he was going to do that, but when realized, we were like, "You do realize there's no Uber back, right? Because there's no Uber here." Like, nobody is sitting around waiting for somebody to need a ride because it's such a rural setting. So I feel like that's one of the biggest challenges we face, is transportation.

And then considering that the population that we're serving, most of them don't have insurance. Yeah, there's Medicaid transportation, but you've got to have Medicaid to get Medicaid transportation, you know. So I think transportation is one of the biggest barriers we face.

And then lack of knowledge, because I feel like although we serve patients on a sliding scale that don't have insurance, patients are not always aware that we're here, and it's crazy, because we've been here for a long time. We've been doing this for a long time. We've taken several approaches to getting the word out, but it's just like—I don't know if it's because maybe they're not running in the circles of where we have provided the advertisement or what has happened, but some patients just don't even know that we exist.

[0:28:08.3]

MK: What about assets? What do you think, like, this community has to sort of solve some of the problems that you were talking about either with the HIV patients or just patients in general?

[0:28:22.1]

SMA: I don't know. I feel like that we as the clinic, we try hard to try to remove those barriers, but I guess I'm trying to think of some new way, because clearly what we have been doing, although it has worked some, hasn't worked on the level that I wish it would have. And I'm kind of puzzled as to what we could do.

I know me personally, I try to educate the people I encounter, and I know that's a small step, but I feel like that if I'm educating my friends and family members and people I go to church with and people who I run into in the grocery, that kind of will have the trickle effect. It's slower, but I think if we could get more on social media, I think that we would get more people. I will say that I feel like that the longer social media is around, the more older people get onboard for whatever reason, for their own reasons. I feel like that sometimes they're just trying to connect with family members and things like that, but if we could be advertising in those circles, maybe that would help. I don't know.

[0:29:57.6]

MK: Yeah. What do you think about, like, telemedicine? This is something that a lot of people are kind of starting to talk about for rural areas, like doing Skype appointments or, like, telehealth type—

[00:30:12]

SMA: I worry, because I think the physical assessment is very important. But I think that it's great in that something is better than nothing, so I think that it would be beneficial in some way, but I guess I feel like there should be some stipulations to that. Like if you're going to do that, then how does that work—especially for our population, because they see the doctor at a minimum of twice a year, but that's your very, very healthy patient that has done everything they're supposed to, always take their medicines, viral load undetectable, no other real health concerns, may have a primary care doctor in their local place where they live. And then you have patients who see the doctor quarterly, and then patients who are seeing the doctor quite frequently because their viral load is not suppressed.

So my concern would be, what does that look like. So if we start doing telemedicine, where do they go to get their labs? How do we know that they're doing—because although we're having a conversation with them, I as the patient can tell you I take my medicines every day, and if there's nobody to draw my blood to really give you the results, then how am I helping?

I think telemedicine is good in some ways, like if patients need counseling, because then, you don't necessarily need, in my mind—and I may be wrong—you don't necessarily need a physical assessment to have a counseling session, which I think a lot more people could benefit from behavioral health services. But that's a whole 'nother—but I guess it would just depend on what you were treating the patient for, because, I mean, if you think about it, patient has high blood pressure, do you want to really have a face-to-face visit, because what does high blood pressure look like? I can have high blood pressure right now and you can't tell from having a conversation with me. Or if I'm

diabetic, I can have high blood sugars and you wouldn't know, or high cholesterol. So, to me, I guess my concern would be, even though something is better than nothing, how effective would we be doing? Because then at that telemedicine, are then you going to prescribe patients medicines based off seeing them on a screen? Like, how does that work?

[0:32:47.8]

MK: Yeah. I mean, those are all good points, and these are—people are kind of at, like, the very beginnings of talking about how it would look, but I don't think people want to replace it completely because of all the things you just said, but—

[0:33:04.1]

SMA: Well, I think one of the things that we talked about that I think would be very beneficial—and unfortunately and fortunately, the doctor that serves as medical director of the HIV program, her dedication to the patients in the program far exceeds anything that I've ever experienced in my whole nursing career. One of the things that we have discussed is a mobile bus, like to go around to treat patients, maybe going to certain counties that we could target and be there at certain times to provide treatment out in the field to patients with—everybody kind of there, like be able to get labs, see the doctor. Kind of like the dental mobile bus that we have now, something similar to that, but to provide HIV or hep C or PrEP services.

That, I think, would be very beneficial, because then we would just need to kind of tell people, "Hey—," or put the word out, "Hey, if you have hep C, that bus is going to be at this location on every other Thursday at this time," and people could kind of just randomly show up. I think that would be a very beneficial thing for patients that have the

option to do, because if we're going to where they are, then one of the things that we find is that patients find rides to local places, to the grocery store, to the pharmacy, to pick up the things that they need to pick up. It's just hard when they have to travel, like—Fayetteville is forty minutes, at least, and sometimes over an hour, depending on where patients live, so when you think about that, that's a big favor that you're asking of somebody to transport you to a clinic—that's going to help you, but, I mean, it's far.

[0:34:55.9]

MK: Yeah. So, I mean, Fayetteville's a bigger city, so it seems like you guys have HIV services that they can't get there.

[0:35:03.7]

SMA: So what happens for Fayetteville is there is a clinic that does accept patients that are uninsured, but they have, like, a cap, so once they reach a certain point of uninsured patients, then they are only accepting insured patients, and once they reach that point, then all of that overflow of patients who don't have insurance and need transportation, they kind of end up here.

[0:35:28.8]

MK: Are there certain things that you think patients are not comfortable talking about with providers, from your experience?

[0:35:37.4]

SMA: I would say that our patients are an exception. There are some patients who are not comfortable talking about certain things, but I feel like some of the relationships that we've built with the patients allow them to be more vocal with us, so I feel like that they are more willing to share some intimate personal details, and I think that's a

combination of them feeling like that we're their family and having several experiences with us. That gives them the opportunity to develop the relationship, you know?

[0:36:18.2]

MK: Yeah.

[0:36:18.2]

SMA: So I feel like that—although I do see that still happening, because we as a team work so well together, you might tell the service coordinator that you're having a problem and it's still going to get back to the provider because we communicate. And I think sometimes patients forget that, but I think sometimes it's strategic. I'm telling somebody who I know because I'm not necessarily comfortable having this conversation, but I know they're going to tell somebody else.

[0:36:50.3]

MK: Right, right. Um, sorry, I lost my train of thought.

Do you have any, like, specific stories of patients that come to mind? Like, obviously you don't have to say who it is or anything, but anything that comes to the forefront of your mind that made a day worthwhile? [pauses] We can come back to it. You probably see a lot of different people.

[0:37:29.5]

SMA: Yeah. I think the thing is, is that I have so many patients that—and so many things have happened that it's like—it becomes normal, so they no longer stick out. You know what I mean? We do so many things going above and beyond all the time that it's hard for me to even isolate an event, because that's normal. So it's like that's regular,

like going to—trying to help a patient find housing or spending hours with a patient because they're having a moment.

Or I remember there was a time when a patient called and he was experiencing a breakup, and although it was almost like, "Why is this important to you?" but I got it. Even though somebody else might be like, "Well, they weren't even married," and this, that, and they say all the reasons why it shouldn't have been a big deal, but in that moment, it was a big deal to him, so it was a big deal to me. So I wanted to make sure that I provided what he needed, and listened and helped him to kind of navigate that experience, because it's all about perception, you know? Like, what is important to you and what affects you is about you, so even though I might experience a breakup and brush myself off and move on and not be an event, somebody else could be in the bed for weeks because that's significant to them. So, just appreciating the things that people go through.

Also understanding—I know for me, understanding that patients experience challenges. You know how you think, like, "What's the big deal? Take a pill." But for a patient, that might be huge. Because one of my patients told me that part of the reason why he missed his doses is because every day when he took that pill, it reminded himself that he was HIV-positive. Part of the reason why he missed his appointments is because every time he came to see us, then it had to remind him that he was HIV-positive, and that was something he didn't want to deal with. So sometimes you're thinking, "What's so big—why are you so upset about that?" But sometimes it's deeper than what you can see, because you're not actually experiencing it.

And then I also think from a perspective like, I'm not somebody who likes to take pills every day, so I can appreciate that. I don't have any medical conditions that require me to take pills every day. At most, I take a prenatal vitamin. At one time, I took birth control pills, but as far as something like a high blood pressure medicine or diabetes or cholesterol or anything, I don't have to do that. But I realize in just trying to commit myself to take a prenatal vitamin because that was the recommendation from my gynecologist when I decided I wanted to have children—start prenatal vitamins before you're ever even pregnant and keep taking them—I realized in that, that that's a big deal, because I'm having a challenge just remembering to take that prenatal vitamin every day.

So that helped me to look at things from a different perspective and appreciate what the patients were saying more, which they say nurses are the worst patients, and I actually agree, because we know just enough. You know what I mean? We know just enough that we're busy at home trying to diagnose ourselves. "Oh, I have a cold, but I don't have a fever." "Oh, I have a cough, but my phlegm's not green." You know what I mean? So here we are assessing ourselves. "Oh, I listened to my lungs and I don't hear anything. My breath sounds are clear." We know just enough that we triage ourselves out and become the worst patients. We know too much. So I can appreciate it.

I try to look at things from a different perspective often, but that has only come with age. I became a nurse when I was twenty-six, so early on I didn't have that presence of mind, you know? I also do a cultural competency training, which opened my eyes to some things. They talked about how, you know, people had a mistrust, and they went back to the Tuskegee and what it's—

[0:42:12.0]

MK: Tuskegee?

[0:42:12.3]

SMA: Tuskegee where they had the syphilis.

[0:42:13.9]

MK: Oh, Tuskegee. Okay, yeah, yeah, yeah, yeah.

[0:42:16.3]

SMA: And it, like, completely changed my perspective, because they said, "Guess who did this? The CDC. Guess who this targeted? Black males of a certain age. Guess who some of your hardest patients to get to trust physicians are? Black males of a certain age." Well, they remember when. They were present when this thing happened, so as somebody who was living in that age where you saw the CDC take people and use them as a test experiment and not give them the treatment that they needed in order to be treated and cured from something, and then you ask them to trust the same people that—so that's why I see a mistrust in flu vaccinations, because guess who does it? The CDC. And they're like, "Well, the CDC wouldn't give them the penicillin that they needed so they'd be better."

My perspective continues to change as I am exposed, and I think I am a better nurse because of that. I have more compassion. I was always compassionate and empathetic, but I think the more that I can have insight about what patients have experienced or what they've been exposed to, it just helps be better.

[0:43:27.1]

MK: Yeah. What do you do to take care of yourself after a long day of hearing people's stories and—how do you decompress?

[0:43:36.3]

SMA: Well, it's funny, because Lisa was talking about this one day, and she was like, "Oh, well, you know, it's got to be hard, you know, how we sometimes take things home." And I what I told her was that my son doesn't allow that, because when I got home, he doesn't care that I'm a nurse. He don't care that the patients and what their needs are, because it's just about him. He's two and a half.

[0:44:03.0]

MK: Oh, okay.

[0:44:04.0]

SMA: He has no concept of I had a rough day, if I look like I've been ran over. All he knows is, "Mommy's home," and, "Let's play. Sit down and let's do this." Or before he was verbal, it was just like, "Feed me. Burp me. Cuddle me," you know. So I think since I've had him, that's been my—everything gets left at work because of him.

Before that, when I worked at the hospital, I did a bit of—when I was doing the twelve-hour shifts, one of the things that me and some of the nurses that worked there used to do is after a three-day weekend, we would go to Sweet Frog's. That was our thing. It didn't matter if it was 2 degrees or 100 degrees, we would go to Sweet Frog's afterwards. After that Sunday shift, we'd have ice cream—well, the frozen yogurt—and we'd talk.

In previous times, some of the things I've done is slept for a day or spent a day just doing absolutely nothing, whatever I wanted to do, or going to church or hanging out with friends. So I've done a variety of things to kind of detach, but I will not lie to you, these last couple of years with my son has made it where I don't get the option to think

about work. In previous times, even when I was doing some of those other things, I sometimes found myself thinking about work, but being a mom is very demanding and rewarding, but I don't get to think about my patients when I'm home because—and I also have gotten married in that timeframe. So that's the other thing. Like, I have responsibilities. I've got to make sure they get dinner and we have clean clothes and a clean house. So it's just like multitask. I have things to do, and it's just—

[0:45:56.8]

MK: How was that process like for you when you were pregnant and having—that's your first baby, right?

[0:46:02.4]

SMA: Mm-hmm.

[0:46:03.7]

MK: Yeah, how was that like?

[0:46:04.7]

SMA: It was great. I couldn't have had a better pregnancy. I remember I had him the weekend after Thanksgiving, and I left from here—he wasn't due till December the 9th, I think it was, and I left from here that Wednesday with every intention of coming back that Monday and I had him on Saturday. And I actually—this is going to sound bad, but I was not ready for him to come out. I really enjoyed that time that he was in my belly. I really enjoyed the experience. It's one of the most—that connection to somebody is awesome. I loved him the moment I knew he was there, and it was just like from there, it was just like—

[0:46:48.1]

MK: Do you have, um—how were you experiences with, like, providers during that time?

[0:46:56.3]

SMA: I had an awesome OB/GYN doctor. He was great. Every visit—which I met him prior to that because we were pregnant three times before I had my son. First two times were blighted ovums. That's where the egg develops, but there's no baby in the sac, but you get every symptom as if there is a baby there, so the nausea and feeling like, gaining weight and all that. Everything's happening, except there's no baby inside. So I had two experience[s] of that, so I had already been to him before that, before I even got pregnant, and he's always very genuinely concerned and nice.

And one of the things I really enjoyed about him when I first started going to him for my GYN things is that he would do your Pap smear and all, and then instead of—you know how some doctors will just talk to you while you're undressed in that awkward—talk about birth control methods and all that other stuff? When he was done with Pap smear, he'd say, "Get dressed and come to my office." So you'd go to his office fully dressed and you'd sit down and have a conversation to discuss your birth control. And so I really liked his concern. I really liked that whenever I had those blighted ovums, not only was he concerned about me physically, like the medical side, but he said to me, "Are you okay?" Like, "Are you okay?" as far as like, "Are you feeling sad?" You know? Like, he was not just trying to address, like, the physical. It was, "Oh, let me make sure that mentally, that she's okay, because this could be a traumatic experience." So I really liked that.

And then whenever I went into labor, I remember my mucus plug had come out, and they were like, “Oh, you’re not really dilated. Sometimes that happens and people don’t have the baby for a whole week,” or whatever, “so go back home.”

And then the nurse, I remember her telling me, “Well, Dr. Augustine [phonetic],” which was my OB/GYN, “is on call, so if you have any questions, just call up here and have him paged and he’ll call you back.”

And that’s what I did. I went home and I started having contractions, and I was able to call and talk to him and he said to me—he even remembered where I lived, because I lived in Newton Grove and it was in Clinton—and he said to me, “Stephanie, I’m sorry, because I know this is about a fifteen-, twenty-minute drive for you, but really I need for you to come back to the hospital so I can lay my eyes on you and do a physical assessment.” And he was like, “And I don’t mean to make you have to drive back and forth,” he was like, “but just come back.”

And then he was considerate enough that after being in labor—because it seemed like I was in labor for forever—that he said to me, “Why don’t you take a nap first, and then we’ll push.” I really had a great experience. I would recommend him to anybody and I would absolutely let him deliver my baby again.

[0:49:42.9]

MK: That’s great. In terms of parenting, have there been anything that you’ve taken from your own parents, from your childhood, and then, like, affected the way that you’ve parented your son?

[0:50:02.9]

SMA: I think that one of the things that I realized about my parents is that they loved us a lot, you know? They didn't make all the best decisions as far as what we needed—and what I mean by that is my mom is somebody who's always been focused on providing for us financially, but I think what happens as an adult, you want to provide the thing for your kid that you feel like that you didn't get or the thing that you feel like that you needed. So I feel like that that has been kind of what we've experienced. It's interesting, because my mom wants to make sure that she provides financially and my dad wants to make sure that he provides emotionally, and that has always been their characteristics. So I take from both of them, so when I'm providing for my son, what I want to do is I want to be there for him and provide the financial portion and the emotional portion. I want to be that all-in-one, where I feel like I got one from each parent. I want to be—

[0:51:28.6]

MK: How was, um—I kind of want to go back to your childhood a little bit, if you have time. Can you talk about your experiences, like going to school here and just being a young kid around here?

[0:51:42.6]

SMA: My experience was always good. My husband and I talk about school and high school. One of the things that I realized just from having some exposure to some other people who didn't have good experience in school, we—the school that I went to, if you lived in Clinton, you went to the same school. There was no different school, so the people that you met from kindergarten to graduation were the same pool of people. Some people got added, some people got taken away, but you had the same core of people, so

literally the people I knew in kindergarten were the same people that I graduated high school with, so that was always like a good thing. It was no anxiety or anything going back to school, because you were just going back to the same people that you had known your whole life, so I did enjoy that.

And then I feel like that the school was diverse in that it wasn't, like, a predominantly white school or predominantly black school. I feel like it was a good mix, so you got to see people who you could identify with. Of course, you had relationships with people that were not the same race as you, but sometimes that makes a difference. I know just from talking to other people, some of their experience where they went to a school that was predominantly the opposite race of them. They felt kind of isolated or like an outcast, and I did not get that experience. I felt like that it was always—so I enjoyed my childhood and school experiences and interactions and things like that. [0:53:19.4]

MK: Great. Um, I'm wondering, um, what—so if you could change something about the healthcare system, what would it be, if you had a magic wand? [0:53:30.7]

SMA: I would make the services more available to more people. I would give people insurance without these high copays and deductibles and these costs that they can't even afford. I would meet people where they were at, if that meant a mobile bus or home visits or whatever, you know? I would want to make healthcare be something that was normal, like you follow up because that's what you do instead of, that's an event. So if I had a magic wand, that's what I'd do. I'd make more people, like— [0:54:18.6]

MK: Yeah. Um, do you think that healthcare has changed in this community since you were younger?

[0:54:24.7]

SMA: I don't know if it's changed. I just know that I'm more aware of it, because it could very well be the same that it was thirty years ago, but I really don't know because I was—it's not like I watched my parents access healthcare, you know. I hear stories. Obviously I've heard that this clinic has been here for forty years, so clearly we've been providing a service at some degree or another for a period of time, but I just don't think that I was paying attention.

[0:55:00.5]

MK: You're not that—you're not old, either. [laughs]

[0:55:02.9]

SMA: Right. Yeah.

[0:55:04.4]

MK: Yeah. Um, so when—you worked here for a bit and then you stopped and you came back. When was the first time that you came to work here?

[0:55:12.0]

SMA: 2007.

[0:55:13.6]

MK: Oh, okay. So that was, um—you guys were, like—was it this big at that point?

[0:55:18.1]

SMA: Yes.

[0:55:19.2]

MK: Yeah, it's nice.

[0:55:22.2]

SMA: Yeah. The only thing that was different is that when I first started working here, over where you saw WIC used to be dental, and then they built that dental building. And Harvest House, where it's a brick house now, it used to be, like, a trailer. So there's been some improvements and some additions, but as far as the services provided, they were all here.

[0:55:47.2]

MK: Do you think the population has changed in this community since you've been here?

[0:55:50.7]

SMA: Yes.

[0:55:51.3]

MK: In what way?

[0:55:52.9]

SMA: When I was here in 2007, we serviced a lot of migrant farmworkers. We did a lot of migrant farm outreach testing events and things like that. When it rained, when I worked here the first time, the building would be full because the farmers would literally bring busloads of people. "You can't work today, so any problem that you have, you're going to go and see the doctor today." That has changed. I don't see that happening anymore.

[0:56:25.6]

MK: Let's see if I have anything else. Is there anything else that you want to talk about that I didn't touch on?

[0:56:35.7]

SMA: I don't think so.

[0:56:39.9]

MK: Um, I guess, you know, we kind of talked about experiences with healthcare, like with your mom and stuff, but if there's any other family members that you want to talk about, um—

[0:56:53.1]

SMA: I guess there's only one other thing. So probably last year, I had an experience that was a bit challenging for me. I had a couple of bouts of feeling nauseous and throwing up and some stomach pain, and initially I kind of just ruled that out as acid reflux. And I've already told you that nurses are the worst patients, so I kind of self-medicated, gave myself something for indigestion, so on and so forth. And then I had a night, my mom got hospitalized with a bout of asthma, which quickly turned to the left and she ended up in ICU and I went to the hospital to visit her in the ICU, and while I was there, I began to have a stomachache. By the time I got back to my house, the stomachache just kept intensifying, and then I started vomiting and I was vomiting and vomiting and vomiting. And I took medicine to try to make it go away, but the stomach pains just kept intensifying, and I ended up going to the emergency room because I couldn't figure out what was wrong. And it was interesting, because I felt like the person who triaged me was just treating me like I was crazy, and when I told her what my level

of pain was, she was questioning it like I didn't know, and that was an interesting thing for me.

I stayed and I saw them, and they were giving me heavy IV pain medications, morphine. They even offered me Dilaudid. And I said to them, because I'm like, "The pain's not going away."

And they were like, "Well, do you want us to give you a stronger narcotic? Like, we can give you Dilaudid."

And I'm like, "I think you're missing the point. I don't want a pain medicine that's going to make me fall asleep and then I'm just—it's not that I'm not in pain, it's just I'm not aware that I'm in pain because I'm asleep. And, like, I want you to figure out what's wrong."

And so it was almost like after me insisting on my behalf, like, "Figure out what's wrong," that then they did additional tests and I found that my gallbladder was bad and a gall stone had traveled up into the neck of my gallbladder, which was causing all my pain.

And, actually, I end up three weeks later having my gallbladder removed and finding out that my gallbladder had been bad for a long time and it was deteriorated. And what the doctor said to me was that, "You must can tolerate a lot of pain, because there's no way you had that bad gallbladder and you were not having pain at some point."

And I said to him, "Well, I must have mistaken it for indigestion." Bad patient, nurse, treating myself. So that's the only interesting thing that I think that I've experienced that—

[0:59:46.9]

MK: That frustration of not having your pain believed.

[0:59:51.1]

SMA: Right. Well, and also, thinking like if you just offer me more pain medications, I'm going to be happy. I'm like, "I'm not happy, first of all, because I'm still a breastfeeding mommy and I don't even really want these pain medicines. I want a solution."

[1:00:04.5]

MK: Right. It's scary to think of how many people might not have said that the second time and it—they didn't realize what was going on with them. Yeah. Well, I'm sorry that happened, but I'm glad you knew something was up.

[1:00:24.5]

SMA: Yeah.

[1:00:25.9]

MK: Yeah. Um, thank you so much, Stephanie—

[1:00:29.9]

SMA: You're welcome.

[1:00:32.4]

MK: —unless there's anything else you want to talk about.

[1:00:34.5]

SMA: No.

[1:00:35.8]

MK: If you think of something, you can always let me know. We'll be here all week—

[1:00:38.9]

SMA: Okay.

[1:00:40.8]

MK: —bothering more people.

[1:00:43.4]

SMA: Well, it was good to talk to you because it kind of helped me think about different things that I don't really on a daily basis think about—

[1:00:48.7]

MK: Yeah, absolutely.

[1:00:50.0]

SMA: —like that typical healthcare and how that is affecting people.

[1:00:55.3]

MK: Yeah, definitely, so—and it's really cool to get the perspective of the providers who, like, they've been a provider and a patient, so it's like you get that dual kind of thing.

[End of interview]

Edited by Emily Chilton, October 31, 2018