**qual test**

*Sep 9, 2025 | 11:00 AM | R01 Transcript*

Date: September 9, 2025

Time: 11:00am

**Moderator:** Samantha, my name is Nancy. It's so nice to meet you.

**Respondent:** Nice to meet you.

**Moderator:** How are you doing today?

**Respondent:** Good.

**Moderator:** Good. Before we begin, I just want to give you a quick introduction. I really appreciate you joining today, and we're going to be talking all about SMA and SMA treatment in particular. Everything you say today is completely confidential. I don't even know your last name, so let's just keep it that way. Please try not to mention the name of any doctors involved in the SMA treatment. I do have a few colleagues listening in. They don't know who you are either, and we're recording just for research purposes. If by any chance you mention that you've had a less than ideal experience on a medication my client makes, I have to write up a little report called an adverse event report, and I might have a few questions to ask you about that. Also, I think you agreed to give seventy-five minutes of your time. Is that correct?

**Respondent:** Yes, ma'am.

**Moderator:** So even though that seems like a really long time, every once in a while, I might need to interrupt just to hustle things along because I have a ton of questions. Are you okay with all that?

**Respondent:** Yes, ma'am.

**Moderator:** Will you tell me, are you the person who has SMA, or are you a caregiver of someone who has SMA?

**Respondent:** I have SMA.

**Moderator:** You have SMA? Okay. Can you tell me a little bit about yourself, if you live with anybody else, how you spend your days, just so I have a sense of who you are?

**Respondent:** Sure. I live with my children and my husband, and we have two dogs. I work part-time for a local school, and I am enrolled in school to earn my bachelor's. I do all the other daily things in between.

**Moderator:** That's a lot going on. How old are your kids?

**Respondent:** I've got 19, 17, and 15.

**Moderator:** Wow. You're full on. I have one 16-year-old and two 14-year-olds, so just behind you. And what do you do when you work part-time for the local school district?

**Respondent:** I work at the front desk. When the kids come in late or need to check out, I ensure that they're safely checked in or out and then input some data into the system, whether it be attendance or other various things that are assigned.

**Moderator:** That's great. And amazing you're getting your bachelor's. What are you majoring in? Sorry, these are just nosy questions. They're not crucial, but it helps me get to know you a little bit.

**Respondent:** You're good. I've got my associates in medical coding and billing and medical office admin, so I thought it'd be fun to get my bachelor's in human resource management.

**Moderator:** I mean, there's a lot of detail in both. Right? A lot of systems stuff. Even though I think about HR as people-focused, it's a lot of systems too. Right?

**Respondent:** Yeah.

**Moderator:** Good for you. So you're type three SMA. Is that right?

**Respondent:** Yes, ma'am.

**Moderator:** Okay. And when were you diagnosed with SMA?

**Respondent:** October 2012.

**Moderator:** Wow. I never asked you how old you are. How old are you?

**Respondent:** I'm 43.

**Moderator:** Interesting. You were diagnosed at, like, 30 years old?

**Respondent:** Yeah. Right around there.

**Moderator:** Wow. How did the diagnosis come about?

**Respondent:** Our pastor's wife is a physical therapist. She noticed my gait and told me I needed to see a neurologist. They tested me for a couple of things, and one of our friend's daughters actually has SMA type zero or one. Something told me to get tested for it. I had never really heard about it, didn't know anything about it. But when the testing came back negative for MS and a couple of other things, I just said, hey, test me for this.

**Moderator:** The upsetting part of that story is that it wasn't part of the panel of original things they tested you for. If you hadn't asked...

**Respondent:** Yes.

**Moderator:** Sorry. That's just a little heartbreaking.

**Respondent:** Yeah.

**Moderator:** What a remarkable physical therapist to know that you should see a neurologist.

**Respondent:** Mhmm. Just watching me walk on Sundays and the little bit of interaction we had, she said there's something going on with your gait. You need to get in, and so I did.

**Moderator:** Wow. So all the testing came back negative, and then you said to the neurologist, what was the reaction when you said you wanted to get tested for SMA?

**Respondent:** He was pretty open to it, but he wasn't very well-versed on it. He had to do some research. I was sent to a muscular dystrophy clinic in another town once I got diagnosed to help me learn more about it. He was very limited in his research. Basically, what he found on the Internet is what he knew.

**Moderator:** Sorry. I don't know why I just giggled, but it's intense.

**Respondent:** Yep.

**Moderator:** Had you been seeing a physical therapist before the interaction with the pastor's wife?

**Respondent:** I had seen a doctor for some lower back pain, and they attributed my limp to maybe childbirth. I had my third child by then, and they wanted to do an epidural to block some of the nerves and the pain. I didn't have it done. My husband was in the military, so we moved. When we got to our new duty station, I was going to try to continue care there, but she intervened before then. I just chalked it up to maybe gaining weight because I was always really thin before kids. I lost my ability to run and noticed a few other symptoms, but not being knowledgeable, I just chalked them up to being fifty pounds heavier than I had ever been.

**Moderator:** Wow. 50 pounds is a big change.

**Respondent:** Mhmm. I thought my weight was causing some of my issues, maybe I was too heavy for my body frame.

**Moderator:** It's interesting. Somebody attributed it to childbirth.

**Respondent:** Yep.

**Moderator:** It's just a female problem.

**Respondent:** Right.

**Moderator:** How did you feel when you were diagnosed?

**Respondent:** It was a little bit scary. I didn't know much about SMA as a whole. I only knew what I had seen in our friend's daughter. I had to dive in and try to research. I was scared. I have three young kids. I'm married. What is my life going to look like? My biggest fear was, are my kids affected?

**Moderator:** What do you mean? Can you say more about that?

**Respondent:** I was worried if my kids would have SMA.

**Moderator:** Oh, was there a genetic thing that...

**Respondent:** Mhmm.