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Pediatric Stroke: One Mother's Story

Kenda Shea Grover
Associate Professor College of Education and Health Professions
University of Arkansas

Abstract

In this article, a mother whose young child experienced a stroke will discuss her experience navigating the medical, rehabilitation, educational and social systems following the child's stroke and resulting disabilities. To assist life care planners and health professionals, an interview was conducted with this mother who has interacted with these various systems for 14 years. The interview provides a first-person account of being a parent of a child who sustained an unforeseen insult which resulted in the need for various health interventions and how the child's needs have changed over time.

Someone in the United States experiences a stroke every 40 seconds (National Center for Chronic Disease Prevention and Health Promotion, Division for Heart Disease and Stroke Prevention, 2020). A stroke occurs "the blood supply to part of your brain is interrupted or reduced, preventing brain tissue from getting oxygen and nutrients" (Mayo Cinic, 2019, para. 1). While the majority of individuals who experience a stroke are adults, strokes also occur in children, and are termed pediatric stroke. Pediatric stroke remains one of the top ten causes of death in children between the ages of 1 and 19 in the United States (National Center for Chronic Disease Prevention and Health Promotion, Division for Heart Disease and Stroke Prevention, 2020). Like many conditions, pediatric stroke can occur at different times and may manifest in various ways. In fact, Ferriero et al. (2019), note that there are 28 different ways to characterize a pediatric stroke. A pediatric stroke can be classified as neonatal (occurring from 28 weeks' gestation to 28 days of life post-birth) or childhood (28 days to 18 years of life) and can be categorized as either ischemic or hemorrhagic. Regardless of when the stroke occurs, lifelong impairments resulting from the event can be significant and substantially impact the child's cognitive, behavioral and emotional wellbeing. Family systems, caregivers and society all feel the effects of a pediatric stroke. For a recent comprehensive review of the work of leading researchers in the field who synthesized existing evidence on evaluation, causes, and outcomes of pediatric stroke, the reader is referred to Ferriero et al. (2019). For purposes of this article, one mother will tell the story of how pediatric stroke affected her daughter, her role as a mother and her family.

Interviewer: How did the disability onset occur?

In 2007, I was the mother of a 13-month-old daughter, Madeline. I put Madeline down for a nap and when she woke up, I saw her pull up to her crib, just like normal. I went into her room and took her out of the crib and as we were going downstairs to have some lunch, Madeline suddenly had this very piercing cry that I'll never forget. Of course, I never really suspected something was wrong, so my first thought was that she wanted something back in the room, so I took her back to the room. She just kept crying and I couldn't tell what was wrong, so I took her into my bedroom and laid her down on my bed when I noticed a very subtle turning movement of her left hand, which made me think she was possibly having a seizure. I should say here that I'm a nurse and prior to being a nurse, I worked for 10 years as a physical therapy assistant.

So, I called 911 and waited for the ambulance to get there but when the paramedics arrived, they did not really act like anything was majorly wrong. Maybe it's because I am a nurse or maybe simply because you do not believe anything will ever be wrong with your child, but I was not really alarmed at this point. The first responders even asked me if I wanted to drive Madeline to the hospital myself and I'm thinking to myself, *"How am I going to put her in her car seat and strap her in and drive her?"* So, they agreed to take us and during the ambulance ride, held her and her pulse at that time was 80, which for an adult is completely normal, but for a baby is very concerning but the paramedics still did not seem worried. The ambulance driver did not even turn on the lights most of the way to the hospital, which, again, made me think that nothing was really wrong.

Interviewer: What was your inpatient experience like?

When we arrived at the hospital, there were a bunch of people hooking her up to everything, trying to get the IV started etc. Keep in mind, this was 2007, and we did not all have cell phones and I knew I needed to call my mom but could not find a phone. When they took Madeline for a CT scan, I called my mother, relaying that I thought that she had experienced a seizure and my mom – I'll never forget said, "*Oh my God, we're coming right there*."

I'm still not thinking anything is wrong but I'm standing there looking at all of these people doing these things to my baby, but they did not tell me anything. They never said anything to me. After they brought Madeline out of the CT scan, I happened to see the doctor on the phone and he said, "*we need someone from NICU to come down and intubate a baby*." And I was like *What?!* And I went over to him and I

grabbed him and he's still on the phone I said, are you talking about my baby? And he's kinda holding me off and saying you know; they need someone to come down right now. And I ask again, ARE *you talking about MY baby?* And so, then he said yes, and that Madeline had a bleed on her brain.

At that point, I don't really remember what happened, other than they had the chaplain come down and someone was there to walk us up to our room. Of course, I didn't realize what was happening, but the hospital staff thought that if there was a baby brought in whose pulse rate was in the toilet and had a brain bleed, the child had been abused. So, they took me to the ICU, where there were four or five police officers. But this was all new to me and I was not even aware that it had anything to do with me. I had to be interviewed by the forensic pathologist who was actually the one who said that it was not shaken baby syndrome and she said we didn't "fit the profile" – whatever that is. One thing I learned after going through this is because everyone thought it was child abuse, when they talked to me, even though I was a nurse, they were very accusatory and mean and condescending to me.

Interviewer: What was the experience of learning about the condition like?

Everyone kept saying, she's bleeding on the brain and it looks like a stroke and it acts like a stroke--but no one would ever say that it was a stroke. The treating neurologist told us that Madeline would likely not walk again and he did not believe she would be able to do anything. Madeline spent days in the ICU in Oklahoma, without anyone saying what it was or what we should do. Then, all of the sudden, they extubated Madeline and the following day, they said it was time for us to go to rehabilitation. They asked us where we wanted to go for rehab, but we had no idea where to go. They told us that the best place was in Texas, so we chose to go there. In the hospital, they did not have the equipment to perform an angiogram to really determine what caused Madeline's stroke, so it was suggested that we have an angiogram when we were in Texas for rehabilitation. So again, one day they pulled my baby off of the vent one day, the next day, we were off to rehab. We put our 13- month-old daughter, who was completely limp, in the car to drive her five hours to the rehabilitation facility.

Prior to this, Madeline was a typical 13-month-old who was walking and talking. And now I had a baby who could not talk, who could no longer sit up and could not move her left side at all. On the trip, I remember carrying her into the bathroom to change her diaper and I was holding her, this big kid, and I wondered if people were thinking what's wrong with my baby.

Interviewer: What was the rehabilitation experience like?

When we arrived at the rehabilitation facility, we were put into a room and we just sat there waiting for someone to come and tell us what to do. I mean … we had never done any of this before and no one really gave us any guidance even once we were there. We were just there at the mercy of everyone and no one really informed us of anything. I had no vehicle there because my husband had driven us to Texas, so I rode their van from place to place. I do remember that they handed me a notebook that had *Traumatic Brain Injury* on it, which was very disturbing to me. Up to that time, at the hospital in Oklahoma, some of the doctors and nurses were referring to Madeline's condition as a traumatic brain injury but the resident pathologist had said that it was not a traumatic brain injury. But, somehow, the TBI diagnosis followed us to rehab and they would say, "her traumatic brain injury" and we would respond that it was not a traumatic brain injury.

Once the angiogram was completed, the pediatric neurologist diagnosed Madeline as having a stroke. However, he did not know why she had the stroke. He thought it was perhaps an aneurysm or arteriovenous malformation (AVM) but because there was so much damage from the bleed, there was no real way to tell. He referred to it as "*freak of nature*" which was very unsettling to me because I wanted to do whatever it took to prevent this from happening again. He told us that he believed Madeline would recover fairly well but she would probably never be able to compete athletically.

Luckily, being a nurse with a physical therapy background, I had a lot of self-knowledge of what would be happening, and I really learned about how much a parent must advocate for their child. I remember this one occupational therapist who would come to the room while Madeline was sleeping, and she would say that she would simply come back later but then would never come back. After her doing this several times, I learned to say, "*we are here for inpatient therapy and she needs to be getting therapy, so wake her up because this is what she needs*." However, the therapist would not do it and I had to go to the department director because what if I was a parent who did not advocate, where would that leave us? After approximately eight weeks of inpatient rehabilitation, it was like okay, you are finished with therapy, see you later!

Interviewer: Did you receive adequate information about the diagnosis?

I would say no... because they would not give us a diagnosis until the angiogram was complete and even then, they could not tell us why it occurred. I was beside myself trying to figure out what could have happened? Should I have seen something? Should I have known something? Should I have done something differently?

Interviewer: What other specialists did you see?

We saw a pediatric neurologist who set up the angiogram in Texas. One of the things that I think was kind of frustrating but certainly also a blessing was that Madeline began to recover so quickly that maybe people did not realize what she needed, and she was pushed through pretty quickly. The pediatric neurologist in Texas followed Madeline until she was approximately 5-years old and then she released

Madeline. Madeline has also had repeat MRIs every 6-12 months, including a T3 MRI that was more in-depth until Madeline was 5.

Incidentally, while Madeline was at the hospital in Oklahoma, they discovered that she had a small hole in her heart. These usually close at birth and we saw a specialist who recommended surgical closure. However, I educated myself about this and through researching and talking with cardiologists I worked with, I decided to wait on the surgery because these holes typically close by age two and Madeline was only 15 months at the time. I sought a second opinion for this, and the second cardiologist recommended waiting on the surgical repair. Also, it is worth noting that the Texas neurologist who was following Madeline had opined that the hole did not contribute to the stroke, because Madeline had a different kind of stroke than is caused by the cardiac condition. With time, the hold closed on its own. Had I followed the first doctor's advice, Madeline would have undergone open heart surgery after her stroke.

Interviewer: What was the transition back home like?

Because outpatient therapy had been recommended for Madeline, the social worker at the rehabilitation center located a program back home to provide in-home care and told us that everyone would qualify because it was not income based. However, after the first visit, we learned that Madeline did not qualify because she was 15 months old, three months shy of the qualifying age of 18 months. During rehabilitation, Madeline had learned to sit up by herself, crawl, communicate but she was still not walking and was still having trouble with her left side. She definitely needed therapy services, but according to their standards, she did not qualify for any services. So again, with my background, I knew she still needed therapy, but someone without my healthcare background might have just accepted it.

We were able to get Madeline into therapy and she had outpatient therapy every day. She had PT twice a week, OT twice a week and speech once a week. So basically, every single day, we went to therapy, which was a lot. I was working, so I would choose to work Saturdays and Sundays so I could take her therapy appointments. But it was a lot to do all those things, work, therapy and you have a little baby who needs to nap. It was a rough transition and it would have been so nice to have some of that therapy at home.

Interviewer: Who were some critical team members who helped?

In Texas, they also recommended having a clotting study, which was done, as was genetic testing. They just gave us a lab script for these things and told us to follow-up with Madeline's primary provider and to fax results to them. Luckily, I had a good relationship with her primary care physician and so I asked her questions about why such tests would be ordered. Incidentally, those tests all came back negative. Sometimes I almost wished that there was something, so that we could have an answer.

I also discussed with Madeline's primary care doctor Madeline's ongoing need for therapy-- I mean she still had a facial droop. She put me in touch with a therapy center that provided speech, occupational and physical therapy that is probably where I received the most guidance. She received speech therapy and occupational therapy for a little while prior to being discharged. But the physical therapist was really the person who guided us in lots of things, for example, recommending having Madeline's hearing and vision checked. She also suggested different types of therapy, Botox or various things that the physician did not really know about. Madeline has participated in lots of different therapeutic interventions including Botox and horse riding, all based on the therapist's recommendations. Also, our pediatrician was very supportive, and she wrote prescriptions for what the therapist recommended. It was the physical therapist who I feel like completely guided Madeline's recovery!

Interviewer: Who did you find yourself able to talk about her condition with?

Well, probably the biggest person that I talked to was the mother of Madeline's roommate in rehabilitation. Madeline had a semi-private room, which in the beginning was very irritating because I thought why must I share a room with a complete stranger during this? But, this mother, whose son had a somewhat similar story was the person I felt like I could talk with most because she was the only person that I feel like truly understands what you go through. Today, the kids are 13 and even now it is nice to have someone to talk with who is going through the same sort of things. So, she is probably my biggest resource. Of course, I have wonderful support from my friends and my mom, who are all supportive. I consider Madeline's physical therapist to be family, even though Madeline has not gone to therapy there [because we moved] in probably six or seven years. I remain in close contact with her and if something happens or if I get concerned about something, I text her. And she has seen Madeline grow up on Facebook.

Interviewer: How is Madeline in 2020?

She still has issues with her left side, but all-in-all she pretty much does what she wants. She can run, she can jump, but it's awkward and she has impaired coordination. She has issues with fine motor skills on her left hand. Mentally, she has not had issues. Emotionally, she seems quick to become angered, so that is always in the back of my mind, does that have something to do with the stroke?

She gets Botox every three or four months which means we see the physician the day before, who performs range of motion tests to decide where he wants to inject and then the next day she has the injections performed at the hospital, which involves checking in and sitting there. Because Madeline is now in puberty, she is not comfortable wearing only a hospital gown. I keep her in dance and try to keep her as active as possible. Stretching has been a big thing to combat tone issues.

I think that the biggest struggles that we have now is that Madeline is old enough to realize the difference between her left and right side and she knows that she had a stroke. When she was little, she did not really know this; it was just who she was. But now, she does not trust her left side to support her in certain situations. She did have an accident where she slipped on a trail hiking and broke her ankle, so that caused her to have a little setback. The last two times she went for Botox, she had gained some weight and the doctor pointed that out, which of course made her feel bad. The doctor is worried about additional weight making her impairment worse but as a parent how do I handle this with restricting foods and encouraging exercise without making her self-conscious? I tried to explain that sometimes the doctors do not think about how what they say will affect a 14-year-old girl but what she hears is "the doctor thinks I'm fat."

Interviewer: Can you speak to any funding issues?

As far as funding goes, there really has not been anything other than insurance. Because Madeline did not qualify for the free therapy services, we had to pay for therapy visits. Even though we had insurance, our co-pays were $50 a visit for each therapy. So, five therapies a week times at $50 is $250 a week, which is $1000 a month out of pocket. This made me again think about children who did not have insurance, or parents who could afford to pay co-payments or take off of work to take them to the therapy they need.

Interviewer: How did you learn about resources you needed?

So, at that time, we did not have cell phones or laptops always with us. I had to do so much self-learning because I was the only person that has a vested interest in Madeline. I felt like everyone saw us and sent us on our way. So, the process has been one of constantly googling and researching and figuring out what Madeline needs. I remember looking up articles online so much that I began to circle back to where I started, noting that I had already read many of the articles that I was finding. Because I did not have any guidance, I was trying to make sure that I was doing everything that I was supposed to do. I remember talking to parents in various waiting rooms and sometimes they did not know why they were there. They just knew their physician or a friend recommended it. I am really grateful for my healthcare background because there has been so much self-teaching involved.

There were some online resources that I looked into and tried to be more active with at first. There was a CHASA Stroke Foundation and there was a chat room for parents of children who had a stroke, which was very helpful to hear their suggestions. I eventually quit doing that because it was hard when their children were a lot worse off than mine; and I felt uncomfortable talking when my child was doing so well. So, I would usually read about ideas and things that people tried. It would be nice if there was some sort of website or resource to guide you down the path, but there is not really anything to make sure your child gets therapy, gets their hearing checked, that you see an eye doctor, you know all the different things you need to make sure of.

Interviewer: What advice would you give others who are going through this process now?

Just educate yourself the best you can and be an advocate for your child. Don't take no for an answer. Stay with your child as much as you can because you need to make sure they are getting what they need. Ask questions--What do I need to do? Where do I need to go from here? Where do I go? Who do I call? Educate yourself and make yourself aware of everything that your child needs. If I had taken the advice that was given and had just taken the word of some of the people who saw Madeline, I do not think she would be as good as she is.

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