“Alternative Ways” to Access AAC Technologies

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Hello, my name is Pancho Ramirez. I’d like to express my gratitude for the opportunity to present before you all today. I would’ve loved to be there in person, but I wasn’t able to travel due to health issues.

I am enrolled in a clinical trial conducted by the University of California, San Francisco (UCSF), which is developing groundbreaking communication technology to produce words from thought. First, I’d like to discuss how I started communicating with my family and the people around me. Then, I will get to the clinical trial, what the research is about, and the goals, hopes, and expectations. If I mention the researchers before, know they are from the clinical study. And with that out of the way, let’s get into it.

I wasn’t a disabled person my whole life. At the age of 20, I could walk, I could talk, I could do anything on my own. I used to work and provide for myself. I was a healthy, happy young man, full of dreams and much to look forward to. Unfortunately, fate had other plans awaiting me, and my life was about to go in an unexpected direction.

In June 2003, almost 21 years ago, I suffered a car accident that led to a brain stem stroke, leaving me paralyzed and unable to speak. I’ve lived in northern California nursing homes and hospitals ever since. While living in a nursing home, I taught myself English and earned my GED and a web developer certificate.

The first time I was able to communicate with my family was when I was in a hospital in Berkeley, California. I was burning up with a high fever, and they were visiting me from Sonoma, about an hour away. I was desperate, trying to communicate something to them, but I was not able to. I also had a UTI infection spreading through my body very quickly, and it was eating me alive.

Because I couldn’t stay still, my sister told me, “We are going to understand whatever you are trying to tell us, somehow or another, my brother.” She grabbed a piece of paper, wrote down the alphabet and a pen, and pointed to each letter accordingly. I nodded, yes or no, whenever she pointed to the correct letter and wrote it down. That way, they figured out what I wanted and what to do about it.

Around November 2003, I moved to a different hospital in Healdsburg. A brilliant young man was working as a nurse assistant. He was very nice and compassionate toward people like me, someone unable to help himself and communicate. He brought a laser light, attached it to a baseball cap, and posted a letter board with the alphabet on the wall before me. That way, when I needed to say something or the nurse had a question, they picked up the laser, pointed to the alphabet, and wrote everything down. I did not know English yet, so it was only in Spanish.

As time went by, people from the hospital bought a laptop and a baseball cap with a stick pointer attached to it for me to use. I believe the purpose was to keep me entertained and to communicate better. I was delighted! Even though I did not know how to use a computer before, it was a new phenomenon for me. It took me a long time to get the hang of it and learn all the basics, but I did, more or less!

The most challenging was to press down the keys on the computer. I had to accommodate myself as close to the desk as possible. The computer must touch my stomach; otherwise, I couldn’t reach it. Next, I had to lean over the keyboard and poke the keys, one by one, with my stick. I end up very tired of doing it all day, but I love it!

In January 2007, I was transferred to the nursing home I live in Sonoma. The hospital nurses and staff from Healdsburg gave me a brand-new laptop and a baseball cap to bring with me so that I could communicate at the nursing home. It was rough for the first few days. I was full of depression and missing my people back there. However, they thought it was better for me because my family lived in Sonoma. Indeed, I adjusted to the facility as time passed and made a decent living. I will always be grateful to those nurses, nursing assistants, and everyone who worked there. I had a way to communicate effectively for many years, thanks to them and their good heart!

The researchers gave me a laser pointer and a letter board to communicate with them, and when I go out on my own. Whenever I needed to say something to anyone, I just had them pull out my communication tools, and I was all set.

Since I have the laser pointer and the letter board I dared to go to stores: CVS, Whole Foods, and Safeway, to do my grocery shopping. I go to Dutch Bros as well, a drive-through coffee shop. I love to go there for my coffee or cool drinks, because all the staff members are very good to me.

When I started to go into stores and shop for anything. I had trouble letting anyone know my communication tools were in my backpack. Luckily, my head didn't fall off my neck for nodding too much, because I can't point it out with my fingers! I tried to signal with my head, turning back and forth, looking towards my backpack. However, I can't possibly turn my head around all the way back, and I confused people instead. After many times coming back home with my bag empty from the store due to lack of understanding, I had a phenomenal idea! I wrote a note, printed it out, laminated it, and hung it in the front of my wheelchair, so anyone who read it would know what to do and get them immediately. It works – I didn't have any more problems! Well, once in a while, whenever somebody chose to ignore me.

In May 2020, when COVID-19 was still new, the researchers gave me a gyroscopic air mouse to operate the computer called Quha Zono. It comes in two pieces. One is the receiver. It's like a USB, it connects to the computer and automatically pairs both devices. The second one, the mouse, could be on your glasses or in a holder that goes over the head, like a headband. Then, one may use a virtual keyboard that computers have built in, and then you can type or navigate through the internet as you wish.

I fell in love with this device. Suddenly, I didn't have to wear the baseball cap to communicate or use my computer anymore. During my outings, I use the laser with the glasses and the letter board. They are easy to carry around and straightforward to use. Plus, I can communicate in my native language because the alphabet is similar between the letters. I think this is very important because my family doesn't speak English, and I am more comfortable with it.

I also have my own AAC device, but I can't always have it with me. Well, I can, it can be mounted on my wheelchair, and it has a battery that can go five or more hours, but it is too bulky and blocks my view. Thus, I would rather not have it with me.

The device is called the "I-series" with the Communicator 5 from the Tobii Dynavox company. A speech therapist from San Francisco (UCSF) helped me get it. I got it through my insurance. Getting approved took a long time. When I was searching for AAC options, I went for this one. I thought it would be a good one, but it was disappointing. It comes with many features, some of which are good to access, but others are not easy to navigate. It has the eye-tracker option, meaning it can be operated by eye movement, but I preferred it with a head mouse, like the one the researchers gave me. I thought the system would be faster, but now I don't know.

It has Zoom, the app, so it was nice because I hold many meetings. Unfortunately, I couldn't use it very well. It was overcomplicated. It has a phone app, too, to connect your phone and control it remotely. I was excited, thinking I could make phone calls from there, but I could send text messages only. The machine can speak Spanish, but it was challenging to make it work the right way. The voices sound horrible, and you must search and download them online. So I ended up not using it as much as I wanted. I would instead use my computer.

A device like this for the sole purpose of communication might be okay. However, most users don't want a device for communication only. I don't. My intention to get an AAC device was so I could use it for everything I do on the computer, not just talking.

After many years at the nursing home. I had an appointment with a neurologist from San Francisco (UCSF) on July 14, 2016. His name was Gary Abrams. I was very excited about that because I was told that UCSF was one of the best hospitals in the nation, and has the best doctors who specialize in neurology, so I was looking forward to it. My first thought was, "Oh, the doctor is going to want to keep me there at the hospital and do many studies until they figure out how to fix me. Oh yes, finally." Oh my goodness! I don't know what I was thinking. It was a great dream, though.

When my sister, a friend, and I entered the office to see Dr. Gary Abrams, he started speaking and doing some assessments. I had to send him a brain MRI before my appointment, and after a while, he said, "I saw your MRI, and I have to give you another disappointment. I know many people think we do miracles here at UCSF. I wish that were true, but unfortunately, we are just doctors doing the best they can, like most doctors do. I'm afraid my answer is not what you wanted to hear, but I have to tell you anyway. My friend, there is nothing we can do for you."

He went on and said, "The stroke you had was very severe. It damaged a great part of the brain, and consequently, many brain cells collapsed." He was about to end the appointment when he talked to me about this clinical trial, which was supposed to start in August. However, it didn't take off until the beginning of 2019.

He explained to me a little bit about the study. He said that they may place an implant in the surface of the brain of the participant and such implant would be used to connect the participant to a computer system. Then, the computer system should collect brain signals transmitted by the device. So people operating the system would be able to manipulate the brain signals, so the participant could, hopefully, control a robot arm.

I got so excited as soon as he mentioned that. I don't even remember if he told me about the second part of the study yet, which was about speech. Two and a half years passed after the appointment with the neurologist when the clinical trial began. The clinical trial's primary goals are to help paralyzed individuals control a robot arm and to allow people who don't speak to communicate through a computer interface.

On February 25, 2019, I underwent surgery for the implantation. The surgeon was Dr. Edward Chang, the leader of the clinical trial. I learned that the implanted device is a tiny sheet of wires called an electrocorticography (ECoG) brain-computer interface that translates neural activity from my sensorimotor cortex into intended speech and motor actions. So whenever I try to speak, the computer spits out the words and prints them on the screen.

When we started recording, it was at the nursing home. They rented a room for a few months, so I could stay by myself and do it there. There were two teams: one focused on the robot arm and the other on speech, [or] "speech decoding," as they called it. For the first couple of years, I worked with the researchers every day, two days with one team and three days with the other, and vice versa.

In the beginning we were doing data collection only. I felt like going back to school again because, for data collection, I had to attempt to say the same word over and over again for so many days. I remember, when we started, it was about data collection every day. I thought, *OMG! Are they going to try to make me speak again, or what!?* Days kept going on and on: *Why did I sign up for this?* I was starting to regret that, just like in school. I wasn't much of a good student who loved going to school – no, not at all! I was going to school because I got in trouble if I didn't. Anyway, that was going to change soon!

Then, we transferred to an office near my home and did the recordings there. It blows me away whenever they connect me to their computer system, like a robot, and start the recording sessions. Especially if we're doing real-time testing, meaning when I'm trying their product, and the words appear on the screen, exactly as they should. Sometimes, I laughed uncontrollably, and it was difficult to stop, as hard as I tried. I have spontaneous laughter that makes me look like [I am] mentally ill, but that's okay, there's a good reason for it.

Five years went by, a long time, but it doesn't feel that way. I feel like it was just yesterday. Maybe I don't want to admit that I'm five years older already! The researchers have released a few articles detailing their findings and hopes for the study going forward.

We have been working on new tasks, more exciting things! For example, bilingual, English, and Spanish speech decoding, avatar synthesizing voice and facial expressions, [and] a digital character that simulates me. The researchers are working on wireless connections, so we won't have to be physically connected to computers or other devices.

It feels like a dream, a fairy tale, but it is not. It's the very reality coming into our lives that is going to be enhanced tremendously! I think this is the type of research AAC users need. When this study gets good enough, and the final product goes to market, we can talk to anyone at any given time, whether taking a walk or at home with family, because we have hand-held devices, which are all the requirements for this technology to work!

In addition, my happiness is not just about the speech studied but because of the second part of this trial, targeting paralyzed individuals. I mentioned it briefly, the robot arm. This was the main reason I signed up for. I always wanted to be able to, at least, feed myself, drink a glass of water, something! I don't want to be dependent on everything my whole life. I believe that [the] robot [arm] can help me with that. Due to time limits, I didn't talk about it too much, but know that paralyzed people are included too!

I'd like to say that many people think this approach invades our privacy because they can read minds. As the implanted device is inside a person's head and can get data from the brain. I don't think that could be possible, not with this clinical trial. For the device to pass data to the computer, I must attempt to say the word [or] sentence indicated by the team. Otherwise, nothing happens.

The researchers tested me under several tasks to prove to publishers that they are not mind readers. I was distracted by listening to the news and podcasts, reading articles, and asking questions. All [this] happened while I was connected to the system, and the task was running on the computer. I was supposed to watch and listen without attempting to say anything for a few minutes, and after a while, I attempted the task again. The same thing happens with the reading distraction. I read a few lines and then tried to speak. What happens? Nothing happened; the computer didn't detect anything or end without detection. My people, we are 100% safe from privacy invasion, at least for now!

Thank you so much!