Improving Outcomes For People With Previous Disability Before Stroke – Dr. Eva Mistry

Dr. Eva Mistry is leading a project that aims to improve patient outcomes for people who had a previous disability before they had a stroke.

Dr. Eva Mistry MD

Highlights:

Transcription:

Dr. Eva Mistry 0:00
Our plan with this study and I hope that more and more studies will kind of adopt, is to work with this wonderful group of our patient partners to come up with materials, and shared decision-making tools that could be used by clinicians and patients in a language that they can understand what the study means and what the implications are for that particular patient that is being seen at the bedside, right? Because these results are generated based on 1000s of patients' data, but then how do you translate it to that particular person that you're seeing at the bedside? All of the very important things.

Intro 0:47
This is the Recovery after Stroke podcast. With Bill Gasiamis, helping you navigate recovery after stroke.

Bill Gasiamis 0:59

Hello, and welcome to episode 244 of the Recovery after Stroke podcast. My guest today is Dr. Eva Mistry, who is an Assistant Professor of Clinical neurology and rehabilitation medicine in the College of Medicine at the University of Cincinnati.

Introduction – Dr. Eva Mistry

Bill Gasiamis 1:16
With a team of over 12 sites across the United States, Dr. Mistry is working on a research project that for the first time is specifically looking at how to better support stroke survivors who have had previous disability before they had a stroke. Dr. Eva Mistry. Welcome to the podcast.

Dr. Eva Mistry 1:36
Thank you. Thanks for having me.

Bill Gasiamis 1:38
My pleasure, thank you for being here, can you give us a little bit of background in the kind of work that you do in the research that you do?

What does Dr. Eva Mistry do?

Dr. Eva Mistry 1:46
Sure, as you know, I'm a stroke neurologist at the University of Cincinnati, and I do clinical research and stroke, mostly in clinical trials in the acute stroke space, so kind of optimizing medical management after acute stroke, I'm also kind of involved in novel treatments, both medication wise and devices wise of acute stroke.

Dr. Eva Mistry 2:17
And the types of studies that I do range from kind of development, early phase development of these new treatments to all the way to kind of more late phase comparative effectiveness studies around increasing equity of, you know, providing these treatments to stroke patients with various co-existing kind of conditions and things like that. So, but mostly around acute stroke, therapeutic from early phase to like phase clinical study.

Bill Gasiamis 2:55
How did you become a neurologist in this field? What is the interest? How do you get excited to learn about this type of thing, and then help people who you don't know who have had a stroke?

Dr. Eva Mistry 3:08
My journey to neurology kind of began very early in medical school I liked all my basic science subjects, everything related to the brain very, very much and that kind of I knew that I would do something that was related to the brain. When I was in training and residency in neurology, kind of stroke neurology, or vascular neurology was particularly interesting to me, because you could help people in real-time by a kind of being present and thinking fast, and acting fast could mean surviving with disabling deficits versus recovering from a stroke.

Dr. Eva Mistry 3:52
And it kind of called to me, and that's why I kind of chose vascular neurology, it's really good I was going to do big clinical vascular neurologist after that, and I planned to just practice in a hospital setting as a stroke neurologist, but I started dipping my feet into research right after some of the very large, you know, device based therapy trials came out in 2015.

Dr. Eva Mistry 4:24
My first kind of question was about management after that procedure, clinical management after that procedure, particularly related to blood pressure management. And so that kind of just dabbled through and I kind of did one study after the other in that space and then gained some methodologic expertise and then it kind of just branched out into various questions.

Dr. Eva Mistry 4:51
I will say that the one thing that has helped the most is kind of, in clinical

research, you see patients with an open mind. And that just helps you consider your next research question because you identify the gaps in the way you practice and the data that you have and don't have.

Dr. Eva Mistry 5:12
And so that has been eye-opening. In terms of what keeps me going in clinical research is just a sense of purpose thereafter to kind of know that the work that I do helps many people and not just somebody that I am seeing in real-time at the bedside at the moment. And so it just kind of knowing that I'm able to affect, you know, human health at large, that kind of gives me a sense of purpose to keep going and clinical research.

Bill Gasiamis 5:46
Yeah, it's pretty cool. Do you have to be a very curious person to work in your field?

Dr. Eva Mistry 5:55
I think so I think as I had mentioned before, I think you have to have an open mind about where the gaps are and identify those gaps. And then definitely curiosity plays a lot of part. But then there's more to it. You know, you can have questions.

Dr. Eva Mistry 6:16
But then there's about finding somebody who finds your question interesting, and the way you communicate to them, especially funders who, give you the funding to do that research. So there's a little bit of an art to it about how you write it how you synthesize your question and things like that. So there, there are a lot of layers to be a researcher. But definitely, curiosity is the first one.

The gap in stroke recovery

Bill Gasiamis 6:42
The thing that you've mentioned a couple of times already is the gap, you talk about the gap, we hear about that from stroke survivors a lot, one of the biggest gaps that I'm trying to feel is the one where you have a stroke, you go to the hospital, you get patched up, and then you go home, that is a massive gap, because every bit of information that's necessary is missing because we've never been here before.

Bill Gasiamis 7:09
We don't know what to ask, we don't know how to solve problems. And there seem to be so many of them, that we don't know where to start. And this is what the podcast does, it kind of fills in a few of those knowledge gaps. And what I try and do is paint a picture for people listening to the stories that stroke survivors share that there's a terrible situation that makes them end up in the hospital, then there's a difficult time at home.

Bill Gasiamis 7:42
And then over time, there's some form of turnaround and some kind of a recovery. And then there's some kind of return to not normal, but return to life. And it follows that path. And it's a very common theme. You see it for most people that the timeline is very different for everybody. There isn't a specific I can't say to everybody you've had a stroke that six weeks, or, you know, that's nine months or it's not like a knee injury or some other type of injury, like a muscle injury.

Bill Gasiamis 8:19
So people struggle to go through the process of dealing with the unknowns all the unknowns about stroke. How do we move on from this they probably have had a muscle injury or knee injury or some kind of injury in their life. And they've always had that beautiful timeline that they can recover and then get back to life.

Bill Gasiamis 8:47
And what's hard is when you get back, you're dealing with fatigue, and you're dealing with all the trauma, perhaps brain surgery, and you're dealing with all those things. And then somebody says to you have to exercise. And I know how important exercise is it is probably because I'm writing a book and one of my chapters is about exercise and the benefits of exercise.

Bill Gasiamis 9:13
But then, for me, exercise was never harder in my life until I had brain surgery. And then I had it was more important than ever but then also was the hardest time to do it. Tell me a little bit about exercise specifically and how it benefits people who are recovering from stroke.

Dr. Eva Mistry 9:36
I think exercise definitely kind of helped in the simplest terms, rewiring the brain to the maximum potential that you could have for stroke recovery. Again, as you

mentioned, that potential looks different from person to person. So many factors affect it.

Dr. Eva Mistry 10:00
I think the biggest factors that affect everything from how it was treated in the acute phase to what happened in the hospital, what kind of prevention treatments are offered, and then what kind of rehabilitation therapies or exercises or speech therapy or occupational therapy has been offered for how long the doses, different kinds of experimental recovery therapies that were offered, things like that.

Dr. Eva Mistry 10:26
There are so many variables, social support, after stroke is an extremely important variable that affects people's recovery quite a bit. What kind of caregiving and what situation do they have? So there are so many variables, and that's why everybody is different in terms of their trajectory of where they go, and how they go there. But in terms of exercise, yes, it's extremely important.

Dr. Eva Mistry 10:55
But we as clinicians also understand that, that's hard, not just because of the maybe physical disability that's been sustained as part of the stroke, but there's a brain injury and brain injury causes chemical imbalances that in itself can cause fatigue and mood change as motivation changes.

Dr. Eva Mistry 11:18
And so it's all kind of a part in parcel. So oftentimes, that our patients also tell us is that, you know, the fatigue is kind of out of proportion to the actual physical limitations, and that has a lot to do with how, you know, the brain is injured. That's the bottom line.

Pushing your limits despite the fatigue

Bill Gasiamis 11:41
The fatigue is out of proportion. I love how you explained that, because it's so out of proportion, it cannot even be better explained. And sometimes there's a really big price to pay. I remember, in my first few days of rehabilitation in rural Park Rehabilitation Hospital in Melbourne, where I'm from the one or two minutes of rehabilitation, ended up becoming half-a-day recovery or longer.

Bill Gasiamis 12:12
There seems to be a massive price to pay. And I can see how that can put some people off from getting back up the next day to let's do this again. So it gets better, though it does improve, why is it important to get to the limit and then push beyond the limit? Or the barrier or whatever that is? Why is it important to sort of get there and do it, even though it's hard?

Dr. Eva Mistry 12:43
Um, I would say that definitely kind of pushing the barrier is a first disclaimer that you should always follow your physical therapist and occupational therapists' advice and don't push yourself beyond what they say you should, because, as you said, it's about consistency, it's not about pushing that barrier one day and not being able to get up for next three days, it's about, you know, consistently doing the maximum you can consistently.

Dr. Eva Mistry 13:15
But also to the stroke recovery happens, almost kind of, you know, exponentially in the first three to six months after stroke. And so I would say kind of pushing yourself to the maximum in that early phase and kind of getting the most off that early recovery period, is maximally important. And I know that that's the hardest period as well. And that stroke is quite fresh and everything.

Dr. Eva Mistry 13:44
Everything is not frank, your life has changed, you know, in an instant. And so that's hard. But also, that's the kind of the right window to gain maximum benefits from what your therapists are asking you to do. So I would definitely kind of recommend following their advice, keeping at it consistently, and not overdoing it to the point that you can't get up the next day and can't do it again. But yeah.

Intro 14:12
If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through your mind. How long will it take to recover? Will I recover? What things should I avoid in case I make matters worse, doctors will explain things, but obviously, you've never had a stroke before. You probably don't know what questions to ask.

Intro 14:37
If this is you, you may be missing out on doing things that could help speed up

your recovery. If you're finding yourself in that situation. Stop worrying and head to recoveryafterstroke.com where you can download a guide that will help you it's called Seven Questions to Ask Your Doctor about Your Stroke.

Intro 14:56
These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke, they'll not only help you better understand your condition, they'll help you take a more active role in your recovery, head to the website. Now, recoverafterstroke.com and download the guide, it's free.

Bill Gasiamis 15:15
Tell me a little bit about the project that you've been working on.

The Disability Grant Project by Dr. Eva Mistry

Dr. Eva Mistry 15:19
I'm involved in many projects, but the one that I'm assuming you're talking about is the disability grant. And that's funded by the Patient-Centered Outcomes Research Institute, in the United States, the project is fundamentally just trying to understand the comparative effectiveness of a treatment called endovascular clot retrieval treatment to medical management for patients who have a pre-existing disability before their stroke.

Dr. Eva Mistry 15:51
And so that could be from many conditions, including a previous stroke, or kind of, you know, having a knee replacement or being in a wheelchair for other reasons and things like that. And so we're trying to understand if offering this particular treatment to patients who have a pre-stroke disability, improves their outcomes after stroke.

Dr. Eva Mistry 15:51
This shouldn't be a question, but it is, why it is because in stroke when we research new therapies, we tend to kind of exclude patients who have pre-stroke disabilities. The reason why we do it is because we want to measure the outcomes of these new therapies in terms of how much disability was saved in the long term.

Dr. Eva Mistry 16:39
And if you include patients who are kind of disabled at baseline, and you reduce the chances of understanding that if there was an improvement in function and things like that, that kind of translates into gaps in how we offer clinical care to patients who have pre-stroke disability.

Dr. Eva Mistry 17:01
And so the project is just trying to fill that gap with after generation of data to understand if we should be, you know, offering treatment to pre-stroke disabled patients and, in the long term big picture goal is to generate data so that the future researchers don't end up excluding patients with pre-stroke, disability as a knee jerk reaction. But really kind of think about what outcomes and this population look like and how they can use this data to make sure that the stroke research is equitable for all patients in the future.

Bill Gasiamis 17:41
That's a really interesting thing. All right, this is gonna sound strange, but maybe not to you because you've been doing some work in this field. But I never considered that this was gonna sound so bad when I said I never considered that people with a previous disability could have a stroke.

Bill Gasiamis 18:00
Oh, my God, I can't believe I haven't said that. But it's such a strange thing. Because you see people who are disabled, you assume they've had a stroke or something like that already. And that's why they are physically disabled.

Bill Gasiamis 18:18
But it makes sense that they're just normal human beings who are susceptible to stroke. Is there a possibility that people who are previously physically disabled and therefore in a wheelchair are at higher risk of certain types of stroke?

Dr. Eva Mistry 18:34
It's a good question to answer. So in terms of data, we know that anywhere from 15 to 30% of the patients that we see in the emergency room with stroke have a pre-existing disability. So this is not a small proportion of patients that we're talking about, it's probably fully 1/3 of our stroke population.

Dr. Eva Mistry 18:56
But in terms of the high risk of having a stroke, it could theoretically be the case.

I mean, a lot of these patients, like you mentioned, pre-exists before stroke, and that is why they're disabled, having a previous stroke increases kind of theoretical your risk of having a future stroke.

Dr. Eva Mistry 19:14
So in that sense, you would, you know, some specific types of functional limitations may kind of increase that risk as well. For example, if someone is wheelchair bound and does not move their legs too much, they can form blood clots in their legs and they could secondarily have a stroke from those and things like that. So it is a bit complicated to answer kind of depending on what the cause of preexisting disability is. But yeah.

Bill Gasiamis 19:41
And what was the complication with people who were previously disabled? In including them in their studies in the past, what did people feel was happening? Did they feel that perhaps it was messing with the data or did it at a level of complexity that was too hard to deal with? Or how was it that they were being excluded?

Dr. Eva Mistry 20:08
I think it's probably the latter. And the reason is that as I mentioned, the outcomes of these therapies were measuring a score called modified rank in the score, which is a score that goes from zero to six, zero is no disability. One is some two with kind of mild disability, three of moderate disability 4 or 5 (inaudible) disability, six is deaf, so it's kind of a varied disability-centered score.

Dr. Eva Mistry 20:36
And so the research studies that we have been designing thus far, just kind of say that because our outcome is measured on the zero to six level score on what the patient's disability level is, we're not going to include anybody say, for example, has an MRS two or greater, or three or greater meaning mild or moderate disability, because at the end of the day, if we include patients who have a pre-existing MRS of three, no way at 90 days, their MRS is going to be less than three, which is what therapy is trying to measure.

Dr. Eva Mistry 21:13
And so it kind of adds a level of complexity. But what we're trying to do with the study is kind of arm the researchers with the data of what the outcomes or

relative outcomes of these patients with them without therapy looks like so that they can account for that in their research studies and say, hey, you know, if we include persons with disability.

Dr. Eva Mistry 21:39
Maybe we should use this alternate outcome measure for them or account for this kind of level of, you know, change or, or reduction in the effect that we're we'll see, but well, we should include these patients, because A, they are quite a bit of a significant proportion of the patients that would be eligible for research. And so you're generating more generalizable results at the end of the day.

Bill Gasiamis 22:07
And you're increasing the pool of people that you can bring into the study as well.

Dr. Eva Mistry 22:13
Exactly, exactly.

Bill Gasiamis 22:15
I imagine that's difficult, trying to find people to bring into studies to give you accurate data, or to give you information that you can use to get some sort of an outcome is it hard finding people?

Dr. Eva Mistry 22:33
You know, acute stroke research is always a little bit hard. Because if you think about it, kind of probably patients are at the worst time of their life, their families, and it's just kind of it hits you like right lightning, right, there's no warning and then you're in a setting in the ER, and you're being seen by doctors that you have no rapport with a relationship with, you're probably seeing these new faces and the first time.

Dr. Eva Mistry 23:03
Hopefully, I can say for the healthcare community in general, that we generally have the best interest of the patients that we're seeing in front of us. And that's why we offer research, but it is hard to build trust, it's hard for patients to see this doctor whom they've never seen in their life, no matter how much they say that they're saying things in their best interest.

Dr. Eva Mistry 23:25
It's just hard to build that trust and consent to research studies and acute stroke

research. So these are complexes, sometimes it's kind of a life or death type of situation. So we understand that and so it is generally harder to enroll in acute stroke research studies compared to say, for example, cancer research where you have a pre-existing relationship with your doctor or clinician.

The Turnaround time for starting a research project

Bill Gasiamis 23:54
So when you go through a process to come up with the idea for the study, then it gets funded. And then you recruit people to do the study, how long does it take to get to the end of a study like that? How much time and effort goes into that?

Dr. Eva Mistry 24:13
Every study is a little bit different. In terms of more stringent funders, for example, PCORE, or your NIH or things like that they require from researchers information that is backed by data on how many patients they expect they will recruit, say in a month or a year, and how many sites and so they require kind of a very well laid plan on how many patients how many sites at what rate and so with that math, it's going to take us four years to finish the study or five years to finish the study or finish the recruitment.

Dr. Eva Mistry 24:58
And then there's the follow-up period usually for a stroke study, that's about three months. So, taking this into account, we had to build what we call kind of a recruitment and retention plan. It's a whole kind of five-page document, we had to submit to the funders to justify that it's going to take us five years based on this calculation, and things like that.

Dr. Eva Mistry 25:18
So generally, it's the grants are about five years, typical grants are about five years. But of course, there's no rule that you can't get it done in, you know, a shorter period is great if you can get the study done in a shorter period than that.

Bill Gasiamis 25:35
Once the study has been done, and the research has been created, and you have some data then what happens, then? What's, do you do with that data? How do

you implement that into, say, a hospital setting? Or how do stroke survivors benefit from that?

Dr. Eva Mistry 25:54
Great, great question. So once we have that data, we conduct what we call statistical analysis. And that has also kind of plans for those are usually specified before you start to study to be most kind of robust that you will stick to what you said you were going to do. And so we do the statistical analysis according to that plan and find out if the treatment worked, or it didn't work, or were there safety issues, things like that.

Dr. Eva Mistry 26:26
And if it worked, it didn't work better in a certain population, versus the other things like that. Then we publish those results for the scientific community. And we put it up on the clinical trials.gov website as well for patients to click and see what those study results were.

Dr. Eva Mistry 26:47
All of this is done in a de-identified manner, meaning none of the patient identifiers are included anywhere, this is all kinds of bulk aggregate data published so that nobody can kind of go back and trace to a particular patient. So after all of that, as done, different things happen.

Dr. Eva Mistry 27:09
So the hope is that the clinicians will read it at least if the studies are published in high-impact journals that they will read it and they will mullet. A lot of times these results are kind of presented at large scientific conferences where a lot of stroke doctors and clinicians nurses and things like pharmacists.

Dr. Eva Mistry 27:32
And so hopefully, the results are kind of disseminated broadly to the scientific community that they will start offering to patients. But the funder that I was alluding to earlier, the Patient-Centered Outcomes Research Institute, and our study as well is kind of very keen on making sure that patients are partners in the study.

Dr. Eva Mistry 27:53
And so in our study, we work with three patient partners. One is a stroke survivor, one is a caregiver of two parents who have suffered from stroke. One is a person

who has lived with a cardiac heart condition-related disability for her entire life to give us a perspective of what is it like to live with a disability not related to stroke. And what would you like to happen to you if you had a stroke and things like that? So all in all,

Bill Gasiamis 28:25
just a quick break, and we'll be right back to the interview. As a stroke survivor, I understand the difficulties of finding the right information about post-stroke nutrition. That's why I developed the course Five Foods to Avoid After Stroke. While most people are talking about what to eat after a stroke to support brain health and recovery, very few are talking about what you should avoid eating after a stroke.

Bill Gasiamis 28:49
If you want to support your brain to heal and are curious about the five foods that may make matters worse when you consume them, then you may benefit from this course. In the more than five hours of interviews, we discuss the five common foods that cause inflammation in the body and brain how they could interfere with healing, and how they may make fatigue worse.

Bill Gasiamis 29:10
They're just $49 This five-part series of more than five hours of interviews with full PDF transcripts for download. mp3 is for download, and videos will give you everything that you need to know about the five foods to avoid and why the modules include eight reasons to quit sugar after a stroke. seven reasons to quit caffeine after a stroke. Eight reasons to quit gluten after a stroke.

Bill Gasiamis 29:36
Six Reasons to quit dairy after a stroke and six reasons to quit alcohol after a stroke. And probably that is one of the most important things that you have to and should quit after a stroke. It's interfering with your recovery.

Bill Gasiamis 29:53
Visit recovery after stroke.com/courses For this and other specifically designed short and easy To understandable courses that are made by stroke survivors for stroke survivors, once again, you'll get more than five hours of content, all audio is available to download in mp3 format for listening on the go full transcript of all the content to take notes on, or read instead of listened to.

Bill Gasiamis 30:19
Presented by a stroke survivor for stroke survivors, also presented by a trained nutritionist and performance coach, you will also get 24 hours of access, lifetime access to courses purchased, and you'll be able to interact with yours truly, in the comments section, go to recovery after stroke.com/courses to check them out now.

Empowering Patients and Clinicians through Shared Decision-Making Tools – Dr. Eva Mistry

Dr. Eva Mistry 30:42
Our plan with this study and I hope that more and more studies will kind of adopt this is to work with this wonderful group of our patient partners to come up with materials then, and shared decision-making tools that could be used by clinicians and patients in a language that they can understand what the study means and what the implications are for that particular patient that has been seen at the bedside.

Dr. Eva Mistry 31:13
Right? Because these results are generated based on 1000s of patients' data, but then how do you translate it to that particular person that you were seeing at the bedside? All of the very important things.

Bill Gasiamis 31:28
I'm curious about these types of studies. Often, I talk to people about studies, and they're done by English people, English-speaking people. Do these studies ever get translated into other languages for application in other countries or for uptake by researchers doctors or patients in other countries? That

Dr. Eva Mistry 31:52
That's just a great question. So in terms of the kind of the primary publication itself, it is usually in English, but this shared decision-making tool or kind of a, a kind of summary of results in lay language. In this particular study called Tester that I talked to you about, we have budgeted for translation costs to have those translated into common languages.

Dr. Eva Mistry 32:26
To help facilitate those bedside discussions, not just in other countries and the United States, there are regions where we have many non-English speaking patients.

Dr. Eva Mistry 32:36
We have chosen our sites to have representation of non-English speaking patients, and we have kind of budgeted for translation our costs and non-English language consent from translations we want those patients in our study to make sure that that it applies to all of those patients, not just English-speaking patients. So yeah, excellent question.

Bill Gasiamis 33:05
I know that in Australia, there's not so dramatic amount of population where English is not spoken at all. I know, my parents, when they immigrated from Greece, in the 60s, they've kind of learned to speak enough English to get over the line. And there was always a now there are translators available, not that they're involved in any studies or anything, but every time there's been a hospital visit or a doctor's visit, there's always a bit of a language barrier.

Bill Gasiamis 33:33
And I feel like perhaps they miss out on some things that they would benefit from simply because they don't understand the application to them. After all, it's being explained by somebody who perhaps is not fluent in Greek. And that's okay. Like, I kind of get it. Then I interviewed some researchers from the United States who are based in the border towns between Texas, and Mexico.

Bill Gasiamis 34:03
And that's a completely different world there compared to what it would be like, for example, in New York City, or one of the other major capitals, and she deals specifically with Spanish-speaking people.

Bill Gasiamis 34:16
And it was interesting for me to remember that now that we're talking about this and, and the problem, you're doing this great work, and then and then there's a whole bunch of people in a community who potentially miss out because of this lack of translation. Now, is it a new thing to have research data translated into different languages?

Dr. Eva Mistry 34:38
I would say, unfortunately, yes, we should have probably been doing this all along. I think that it's happening more and more as we kind of start becoming aware of the patients and people that we're leaving behind by not thinking about these things proactively and an ongoing Half of the scientific community sadly, yes, but I hope that we will do better by making sure that we translate our results in inappropriate languages.

Dr. Eva Mistry 35:11
So for testing, we have New York City, for example, Mount Sinai has a ton of this kind of diversity of the patient population, including various languages. We have Miami, a lot of Spanish-speaking patients, and LA, a lot of Spanish-speaking and other languages. So we're hoping to kind of tap into that geographic and ethnic diversity to generate more equitable and generalizable results across communities to

Bill Gasiamis 35:44
Is it a blind spot, perhaps from the funder's perspective, because you guys go to the funders, and you say to them, Hey, we need some money in this, okay, here's some money for the research. And then they don't say, here's some money for everything else. after that.

Bill Gasiamis 35:57
So you're limited, as well as it's just perhaps something that hasn't been considered because the data seems to be the most important thing. I feel like the scientific community hasn't placed enough importance on just what we're talking about in the decades beyond right now.

Bill Gasiamis 36:16
In, getting that information out, there seem to be a lot of people who love research, love learning, love discovering, but disseminating information is not necessarily their key attribute. It's not something that they love doing. And it kind of is a, it seems to get lost. And there seems to be a bit of a blind spot in that space. Does that resonate with you? Or is that maybe me just going to a different tangent?

Dr. Eva Mistry 36:42
I think I wouldn't have it, it's difficult. So what you're alluding to, it's a science on

its own. It's a walk of science of stone, it's called implementation science, of understanding how research results are, are taken by both the scientific community and patient community, and understanding the barriers for why not?

Dr. Eva Mistry 37:14
If not, and so there's a whole branch of implementation science and, and their particular funders that are interested in implementation studies, the particular ones being per quarry, a lot of focus on how this will kind of get to the end users and, and not just patients and users can be, can be insurers, for example, right?

Dr. Eva Mistry 37:38
They need to know and understand what we did, why we did and what this means to make sure that appropriate treatments and interventions are reimbursed and paid for end users could be clinicians, there are many, many different types of end users, and there could be caregivers, a stroke, pop, you know, depending on what the study is.

Dr. Eva Mistry 37:59
So that's one of the focuses of pakery. There's HR HR Q, which focuses a lot on implementation science as well. So there's a whole branch of science that focuses on exactly this four-stroke, I agree with you that we probably haven't tapped into the potential of implementation science to the fullest, and we should.

Dr. Eva Mistry 38:24
But it's, the research resources are limited. And so I don't want to say that it's a weakness of the funders or anything like that, but I think that that's something that we should kind of try to think more about and hopefully fold into our study designs more and more.

Bill Gasiamis 38:44
I didn't mean to say anything nasty about the funders, who of course, we're grateful for them. It's just in my mind. That's kind of what it seems like but I'm, I'm speaking as an observer, somebody's completely out of the scientific process. I don't understand it at all.

Bill Gasiamis 39:03
Other than I benefit from it, There's no doubt that I've benefited from the work that other people have done. In rehabilitation or brain surgery, I've benefited from all the things that have ever been done with regards to stroke and, and

recovery from a hemorrhagic stroke.

Bill Gasiamis 39:21
So I'm eternally grateful. I love it when I get to it to interview researchers, such as yourself. And I know that I know that there are challenges. That's why I love to give a voice to people who have a study that they want to tell people about or give us a bit of an insight.

Bill Gasiamis 39:40
And also, why the other reason I love to interview them is because I think it's important for me to make stroke survivors aware that they should become available for these types of studies so that they can allow this type of work to be done so that others who come after us benefit from that work, because we've benefited from the work that other people have done before us.

Bill Gasiamis 40:06
So I think it's really important that the community is one. And we all benefit from that. And we all need to work together. So you've been doing this study now for a little while. How long has the study been running this study about, including people with previous physical disabilities, in understanding how they need to benefit from rehabilitation services after a stroke,

Dr. Eva Mistry 40:36
which were just getting started. And so just next month, and in a couple of weeks, we expect our kind of funding to arrive. And so we've been kind of working on what we call the study protocol, which is kind of the document that outlines exactly how research is going to be done, and what are the kind of stuff between the can and watch, they need to assess, and at what point, things like that. So that's called the protocol.

Dr. Eva Mistry 41:07
That's what we're working on right now. Submitting to we call the Institutional Review Board, so IRB approval after, you know, submitting the protocol. And that's what we're working on right now. But April 1 is our start date officially. So we hope to start patient enrollment after all of those steps are kind of completed in the next four to five months.

Bill Gasiamis 41:34
If a patient can enroll early, are they able to put down their interest in this

particular study to be involved in the study early on, or is that something that has to happen later,

Dr. Eva Mistry 41:48
this study kind of enrollment happens within just the first, you know, three to five days of the hospital stay. And so it is a pretty, you know, kind of a sub-acute study if you will, so patients presented the ER kind of get the treatment, standard care. And then after that, they're enrolled in the study to assess what their pre-stroke level of functioning and quality of life was, and things like that.

Dr. Eva Mistry 42:13
Then we follow them after the discharge can collect some of the data on what kind of rehabilitation therapies they received, where they got discharged, and what the social support was after discharge. So generating some kind of robust data on on that and then evaluating what their functioning is, what their quality of life is, and 90 days after stroke, to then kind of compare those who got treated versus those who didn't.

Bill Gasiamis 42:47
And how do you plan to enroll these people? Where do you find them? How do you bring them into the project?

Dr. Eva Mistry 42:54
So we usually enrolled them in the hospital setting. And so every hospital has a different workflow on how to identify these patients. But most commonly, there's what we call a stroke code system where a stroke alert gets activated anytime a patient with acute or sudden stroke comes to the hospital.

Dr. Eva Mistry 43:16
And that might be the best way to kind of identify these patients. And then of course, the study team will how to then determine if they are eligible for the study based on what their baseline functioning was, and things like that, a couple of days into their hospital stay.

Required number of people to begin the

study?

Bill Gasiamis 43:33
And how many people needed to have the correct amount of people to start this study or to get the right amount of data.

Dr. Eva Mistry 43:44
Oh, I'm so we are a 12-site study. Every site has what we call a site pi, which is kind of a clinician who kind of leads the study. Every site has what we call a site coordinator, or the coordinator, who is the study staff who helps with the consent data collection, and things like that.

Dr. Eva Mistry 44:04
And so I would say at a given site, there's maybe a staff off group on the ground strap of maybe three or four people who work on this study. And then there's also the national team, in which I have three other PIs with me who work with me and a project manager.

Dr. Eva Mistry 44:26
But then the team is very big like we have a center where they take care of like all the imaging studies that happen. There's the IRB, the central IRB, there's what we call the Data and Safety Monitoring Board, which is made up of people who kind of monitor steady progress and safety issues that are going on that are independent of the study team, Principal Investigator, so it's simple. It's a big team.

Dr. Eva Mistry 44:56
It's huge and then they're patient representatives, as we talked about there. Part of our team as well. And then they're clinician stakeholders that are part of our team to help us make sure that the end clinician end users will use the results that we generate and to make sure that we're doing what's meaningful to them and things like that. So it's big,

Bill Gasiamis 45:17
it's big, it is big. And it's something that you people like me will never understand how big and complex it is. And it's over 12 sides. So that's excellent that it's over such a broad space so that it can get people from a whole bunch of different backgrounds and different places. I liked that.

Bill Gasiamis 45:36
And then it's gonna be a while before we have some feedback from this study, before we have some data, how long do we expect before the data becomes available?

Dr. Eva Mistry 45:47
This study is a five-year study. So it's going to be a minute, before before. But hopefully, we'll enroll faster.

Bill Gasiamis 45:57
Yeah, that's a big commitment, hey, I appreciate you reaching out as well, and coming on to the podcast to share the information about this type of work, stroke survivors need to know that in the background, there's a whole bunch of people working for our benefit, I find that amazing.

Bill Gasiamis 46:16
It's something that I always say to everybody I interviewed who is doing research in this space. I feel like, it's such a lovely thing that people do. I know it's your passion, it's your work, and you have curiosity. But as the end, as the person who's the end user, and the benefits from your studies, I appreciate it.

Bill Gasiamis 46:35
And I want to thank you on behalf of all stroke survivors for doing that. And I know that you're a busy person, you have a family life, and you have children and all that type of stuff. So I appreciate your time. And I hope to be involved perhaps, in the future, when you guys do have data or things that you'd like to report, you get in touch and let us know so we can share that information and tell people about it.

Dr. Eva Mistry 47:00
Well, thank you, I think you're doing the real work. I think, you know, just making sure that the stroke survivors are informed about what's going on in the field. Being that bridge between clinicians researchers and patients is important. And so so thank you for being that voice. We appreciate it. I'm sure the stroke survivors appreciate it too. So thanks.

Bill Gasiamis 47:23
Thanks for joining us on today's episode. Now to learn more about my guests, including links to their social media and other pages, and to download a full

transcript of the entire interview, please go to recovery after stroke.com and forward slash episodes. If you'd like to try the course Five Foods to Avoid after Stroke, go to recovery after stroke.com courses and get on board now.

Bill Gasiamis 47:45
If you'd like to support this podcast, the best way to do it is to leave the show a five-star review and a few words about what the show means to you on iTunes and Spotify. If you're watching on YouTube, comment below the video, like the episode, and get notifications of future episodes. Subscribe to the show. If you are a stroke survivor with a story to share about your experience, come and join me on the show.

Bill Gasiamis 48:09
The interviews are not scripted, you do not have to plan for them. All you need to do to qualify is to be a stroke survivor or care for someone who is a stroke survivor. Or you are one of the fabulous people who help stroke survivors go to recovery after stroke.com/contact fill out the contact form and as soon as I receive it, I will respond with more details of how you can choose a time that works for you and me to meet over zoom.

Bill Gasiamis 48:36
Thanks again for being here and listening. I appreciate you see you on the next episode.

Intro 48:41
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Intro 49:15
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Intro 49:36
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Intro 50:02
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Intro 50:18
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