

Tiara Brown on Helping Inform the Public on Research Studies

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- TIARA BROWN: 00:08 [music] I would encourage them to be open to learn about what studies are out there and how it's helping the general population, not only themselves but other people.
- JOAN BANKS-SMITH: 00:21 Welcome to our podcast series, My Life as a Research Assistant. This series is brought to you by Kessler Foundation, where we are changing the lives of people with disabilities. I'm your host, editor, and producer, Joan Banks Smith, creative producer for Kessler Foundation. Throughout this series we'll meet up with research assistants from our mobility, spinal cord injury, stroke, traumatic brain injury, and neuroscience and neuropsychology centers who have been with the Foundation for over a year and some that are now senior research assistants, nurses, M.D./M.S. candidates, postdocs, and those that have entered into many more professions. In this episode I met up with Tiara Brown, a former research assistant in our Center for Spinal Cord Injury Research, and is now a doctoral student at Fairleigh Dickinson University. Let's listen in.
- BANKS-SMITH: 01:20 Could you tell us on an average day, what you do here at the Kessler Foundation?
- BROWN: 01:25 As a research assistant for the spinal cord injury model systems, I help with the overall project, so that includes not only enrollment but also-- so from the medical records we do data abstractions as well as following up with participants who have been enrolled in this longitudinal study. And so right now we're following up with participants ranging from their first-year follow-up to 20 years and plus, so being in the role of having the opportunity to complete questionnaires and also going on inpatient and recruiting patients while they're getting rehabilitation to enroll in this particular study. So it ranges in the roles. So on a typical day, depending on what takes precedent and what needs to be accomplished, I may be on an inpatient floor, speaking with families, the doctors, as well as patients and their families to explain what the research study is, how it not only helps the hospital but patients, while they're getting rehab and in the future while they're in the communities. Another day may look like looking at medical records and reviewing what variables the scientists will need to review and to work to disseminate information. Also doing follow-up calls with participants to see how their life is going after having treatment at the hospital. So we'll ask some questions about their satisfaction with life, different psychological factors, as well as their health, health questions, and their integration back into society and their family. So not only for enrolling participants but also following up with them and also if they need any outside services, matching them with the right resources as well.
- BANKS-SMITH: 03:36 Participants that are in most of your studies, do you find that they are generally a certain age? And/or the different types of traumatic brain injury they may have acquired?
- BROWN: 03:48 Particularly with the spinal cord injury populations about 80 percent are males. And so average age increased in over-- from 29 years during the 1970s to 42 years old

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currently. So generally the the age range is about 49, around that age frame. But there's patients that range in age. But that's just the average. So I see primarily males, middle-aged, but there're also females. There'll be female patients who've sustained a traumatic spinal cord injury. And not so many children, at least that come here for care, that enroll or qualify for this study.

BANKS-SMITH: 04:39

So the folks that have come in for a spinal cord injury, for instance-- could you just tell us some of the types of injuries?

BROWN: 04:47

Oh, yes. That's a great question. So primarily the number-one cause for spinal cord injury-- it can range from-- it starts with a car accident, so vehicle injuries; and then falls, violence-related injuries, so whether someone was shot in a violent act; and then sports-related injuries. So that's generally the numeric order. And then they range from other incidents as well, but those are the top four.

BANKS-SMITH: 05:27

Right. What made you decide to to come to Kessler and to do this type of research?

BROWN: 05:34

Thank you for that question. I've had to think and reflect about that question often as I was applying to doctorate programs. They want to know why are you interested in research or the type of education you're studying and do you really passion about it-- how do you feel, do you really have a passion for it. So when I was studying at LaSalle University for my bachelor of arts degree, I minored in women's studies, and I had to conduct a-- I conducted an independent research study, and I worked closely with the professor. And I was able to look at different variables affecting family relationships. And I went out and I recruited over about 200 students to help participate in the study, and we went through the data analysis and literature reviews. And then I presented it and did poster presentations, and that was my first time really having a taste. I had classes, statistics classes and research methods, but actually having a chance to be in the trenches and know what that's like and then do a presentation and see how it can actually help inform the public and hopefully have an influence on relationships, I was intrigued and I wanted to know more about it, not only education but experience-wise. So I was applying to different jobs, and this was an opportunity that presented itself that I had decided to not only pursue but to accept, because I felt as though it was more in line with what I wanted to do long term, which was get my doctorate in psychology. I wanted to not only have that clinical practitioner piece but also understand the research piece as well.

BROWN: 07:30

So I learned more about Kessler Foundation and the wonderful work that they do. And being exposed and having a minor in women's studies, I learned about a lot of the-- a lot of the issues that women have faced over the years, but it also expose you to other populations, whether it's racial discrimination or people with disabilities, different aspects that they face. So to have the opportunity to work with populations that I may be less educated on and to grow and to have more knowledge about, really intrigued me. And that's how I learned about Kessler-- through close friends. I live in New Jersey. I'm aware of the name. And just doing my own research on it, it was a place I definitely said to myself, "I would love to work there." And I'm glad I made that decision.

BANKS-SMITH: 08:23

Very good. We're glad to have you.

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- BROWN: 08:26 Thank you.
- BANKS-SMITH: 08:29 Now, we know spinal cord injury is serious. But I'm sure you've met with various participants, and there's always one or two people that stand out. Have you encountered that, a participant that was really eager to be a part of a study? What's your take?
- BROWN: 08:46 I would say it ranges. It's a very sensitive time, as you can imagine. Some patients are really excited to be a part of research and want to help in any way they can, and then there's some people who need some time, and they're just trying to get their heads around what happened, to themselves, to their families, how it's going to affect themselves long term. However, it's amazing to see how everyone's different. Not only are injuries different - everyone has a different injury - one diagnosis may affect someone else completely different; they could have the same level of injury. However, even just personality-wise and how people can cope and deal with a traumatic event, that ranges as well. Some people have more of a positive and optimistic outlook. And then there's some who need some time and some real therapeutic services, physically and mentally. But a participant I would say that stands out, that really gets excited, it's a woman, and she's so excited about research, and while she was impatient, she had such a great support system, which I feel like is very important, which it definitely is. And not only were there there for her, but I feel like they were by her side during different education classes and during the whole process of the transition of her learning how to use her wheelchair and any support she needed with the case manager.
- BROWN: 10:28 And through her being such, I think, a caring and optimistic person in general, she looked at the change in her life as seeing it as a change but not necessarily the end of the happiness she originally had. And her family helped to encourage her in that and encourage her to find other support networks that maybe could relate to her as well. So she built on that support that she already had, and she wanted to learn all about the research, to the point she was like, "I want to do anything and everything," and she's researched things across the country. And I had to slow her down and tell her, "I don't know what study that is, but I have some opportunities that maybe you can be eligible for." And thankfully I work alongside Dr. Kirshblum, the medical director of Kessler Institute for Rehabilitation, as well as Dr. Trevor Dyson-Hudson, who is the medical director of the spinal cord injury lab. And she is enrolled in our studies as well as some of the other studies that they're working on, and I see her in the hallway. So this was about two years ago, and she still comes and uplifts and encourages other patients and shows them how she may have-- she'll show them how she-- even it could be small, how she learned a new trick to help her get into a car, but it might be - it might have been difficult for her for initially, but over time it got better. So she's very encouraging to other people and even to myself. I'll walk down and I'll see her in the cafeteria, and she has a huge smile on her face, and she's just really warm and optimistic. And I think it showed, and I can imagine it's not easy every day, but her attitude transcends, and you can tell when you see her. She's a very inspiring woman.
- BANKS-SMITH: 12:38 What would you recommend to people, whether they have an injury or not, or, say, healthy control, about being a participant in our research? It's so important that we have all types of people.

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- BROWN: 12:52 [crosstalk].
- BANKS-SMITH: 12:53 And what would you share with somebody who might be interested in being a participant but they're quite haven't made up their mind whether it's for them or not?
- BROWN: 13:03 I would encourage anyone maybe who was on the fence or was unaware of what research was - that's a term that can mean many different things - to-- I would encourage them to be open to learn about what studies are out there and how it's helping the general population, not only themselves but other people. So I would encourage them to learn more about a research study. And I think something that's new or different-- people can tend to not want to hear about it and stay in a comfort zone, but because of research there's been so many wonderful findings in the world, in science and in other fields, that I think the more people who can volunteer, the better, so that we can not only help-- we not only can help patients who are having services in the hospital and to evaluate the quality of care they're giving based on their feedback from-- whether it's questionnaires or assessments or neuroimaging scans or-- it can range, but also long-term effects and and quality of wheelchairs they're getting or devices or anything that not only can help-- and may not help them in that very moment, but long term it can help other people as well as for them to gain information.
- BROWN: 14:34 And also caregivers, it can be a chance for them to, again, gain more knowledge about how they can help their loved ones and also get the quality in care that they may need too during that transition as well. So I would encourage them to learn more about it and see what they're comfortable with doing. There's some studies that are more involved, whether physically-- and then there's some that have to do with assessments; they can be questionnaires. So it ranges. And then some have-- you may be compensated for your time. So I think it's very important to-- I think knowledge is power. And the more people know what their options are and how it can help not only themselves but others, it can be a powerful thing. It can really change and progress the field that we're in.
- BANKS-SMITH: 15:27 Definitely it can, definitely. Before we go, do you have any parting thoughts that you'd like to share with us? I mean, will you be going off to get your PhD--
- BROWN: 15:38 Yes.
- BANKS-SMITH: 15:39 --in the fall?
- BROWN: 15:40 My parting thoughts would be gratitude and the importance of compassion. Those are two things that have really ignited within me and have transformed and will continue to grow. But I see the importance of being so grateful for everything you have. It can be something that you may take for granted. It could be just being able to open the blind to see the sky or to hug a loved one or to take a breath. It could be that something-- you may take it-- you may take it for granted, but I've just learned and really look for and appreciate the small things and how grateful you should be for every single thing that is given to you, as well as being compassionate. I think sometimes people can be so self-centered and not think about what else is going on

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around them. And it's important to not only check in with yourself but also being there for other people as well.

BROWN: 16:50

And that might be-- it might be hard because you're stepping out of your comfort zone, but you can always learn from other people. So my parting thoughts would be I'm grateful for the opportunity to be a research assistant at Kessler Foundation, because of not only the education I've gained and the relationships I've built but also the lives I believe I was able to help as well through being a research assistant. And I'm very grateful, and I think I've also helped to be more compassionate by not only experiencing and working with patients who have a beautiful story, but also I work with wonderful scientists who are brilliant. And the the employees at Kessler Foundation and in the hospital that we collaborate with and those in the community and caregivers, it really helps to enlighten your perspective on what's important.

BANKS-SMITH: 17:52

Well, we certainly wish you the very best. [crosstalk]--

BROWN: 17:54

Thank you, Jody. Thank you for this opportunity.

BANKS-SMITH: 17:58

Oh, you're more than welcome. And I'm sure you'll be back--

BROWN: 18:01

Oh, yes.

BANKS-SMITH: 18:02

--because you're so close, so that will be nice to be able to see you as you go through your PhD program.

BROWN: 18:06

It was a pleasure, and thank you so much.

BANKS-SMITH: 18:11

To learn more about our current or former research assistants or career opportunities at Kessler Foundation, be sure and check out the program notes for links. Tuned in to our podcast series lately? Join our listeners in 90 countries who enjoy learning about the work of Kessler Foundation. This podcast was recorded during the spring of 2016, was edited and produced by Joan Banks Smith, creative producer for Kessler Foundation. [music]