Jason Anthony: Welcome to Proto, a new podcast that explores the frontiers of medicine.

I'm Jason Anthony.

Sarah Alger: And I'm Sarah Alger.

A terrorist attack by definition is meant to spread fear. And so the effects go way beyond those killed and wounded. We'll meet a forensic psychologist who has been studying the effects of terrorism on the population at large.

Samuel J. Sincl...: We didn't really have a good understanding of how terrorism impacted people. And following 9/11, there was just this absolute explosion of research.

Sarah Alger: Samuel J. Sinclair has developed a terror index and he has some surprising conclusions about how a generalized fear of terrorism affects the day to day behavior.

Jason Anthony: And we'll hear about the power of stories to heal and to help people come to terms with illness.

Catherine: You want to really be open to what's happening beyond your illness. And you have these poignant moments that keep reminding you about the goodness of people.

Jason Anthony: That's one of the many patients who spoke with Dr. Annie Brewster. She is the founder of Health Story Collaborative, a project to collect the stories of patients and put them to work, to help others.

Sarah Alger: Coming up on this episode of the Proto podcast, brought to you by Massachusetts General Hospital.

Jason Anthony: Terrorist attacks have unfortunately become a near constant presence in the news. This summer alone saw the death of more than 300 people in an attack, in Nice, and more than 50 at the Pulse nightclub, in Orlando.

Sarah Alger: And the lingering effects of these attacks radiate far beyond their immediate victims, their survivors, and even the communities in which they take place. Samuel J. Sinclair is a psychologist who has been studying the mental health effects of terrorism since 9/11. He spoke with reporter, Rachel Gotbaum.

Rachel Gotbaum: I asked Sinclair what we knew about the mental health effects of terrorism before 9/11.

Samuel J. Sincl...: When 9/11 happened, there really was no research out there. We didn't really have a good understanding of how terrorism impacted people. And following 9/11, there was just this absolute explosion of research. And what the research essentially showed is that immediately after the attacks, there were these spikes in different psychiatric disorders. So things like post traumatic stress disorder, depression, substance use. But that over time, rates of disorders essentially tended to normalize, but that really didn't jibe with how we were understanding it or thinking about it. People were still very scared and very fearful about a new terrorism happening.

Rachel Gotbaum: Besides your own experience with your patients and people that you knew, why do you say the research after the 9/11 attacks was incomplete?

Samuel J. Sincl...: There were a number of national polls that were coming out, as well as within the psychological research, people were still reporting. Large percentages of people were reporting that they were still very scared. 9/11 seemed like a game changer in terms of people having these significant reactions to this one specific event, but then moving forward in time, just worrying about new trauma happening. And so most traumatic experiences, whether it's a car accident or an assault, there's this isolated event that happens. People have varying reactions to it, and then over time they're able to work through those experiences in different ways.

With terrorism, the threat is ongoing, it permeates various aspects of our culture. It's constantly being thrown in your face in different ways, whether you're traveling on an airplane and you're going through TSA lines, or here in Boston, if you're riding the subway and if you see something, say something, warnings are going off. So it just has permeated our culture in so many different ways. And I think that's part of what perpetuates this underlying fear and makes it different than other threats that we face.

Rachel Gotbaum: Tell us how you went about understanding the fear of terrorism and its effects.

Samuel J. Sincl...: As I became more interested in this fear of construct, the first thing that I wanted to do was to figure out a way how to measure it, how to quantify it. And so I developed a measure rooted in a variety of different theories. It's called the Terrorism Catastrophizing Scale. And it basically conceptualizes fear as this multi-pronged process where one component is how much somebody may magnify or catastrophize with respect to some threats, so in this case, terrorism. And then also how helpless someone feels with respect to it. So that's essentially how the instrument itself was conceptualized and it essentially generates a quantifiable score that you can then use to see how fearful someone is and then use it to predict other things.

Rachel Gotbaum: So what did you find with your new measurement tool? There was no tool like this before. There was tools to measure depression and PTSD, but this was different.

Samuel J. Sincl...: This whole concept of terrorism and how people were affected, I think was so new and so not well understood that we felt like we were starting from scratch. In the samples that we looked at, it was somewhere in 2006 or so, there really were no people reporting no fear. But the other thing that we began looking at is what this fear predicted and looking at how people would change routines in their lives, like where they would decide to work or live in an urban area versus a more rural area. People were less likely to travel on public transportation or go into areas that would be perceived as higher threat. For example, going into a large, crowded urban area. Over time, I think this fear generally declined up until about the last year or two when things have seemed more active in terms of terrorist attacks or terrorist incidents going on.

Rachel Gotbaum: You basically have said that this new reality, this new fear has actually had an impact on policy, on government, on how people vote.

Samuel J. Sincl...: Yes, so one of the studies we did was published in 2010. We looked at whether fears of terrorism predicted trust in government. And we found that the more fearful people were, the more likely they were to trust government to make decisions on their behalf and put in place sound policy.

Rachel Gotbaum: When you say trust in government, what do you mean by that?

Samuel J. Sincl...: So in our study, we basically administered people our fear scale, the Terrorism Catastrophizing Scale. And then we also asked people how much they trusted their government in general and how much they trusted their government to keep them safe from terrorism. The more fearful someone was, the more trust they also reported in government for protection. So as this fear increased, they were more likely to trust their government to make decisions on their behalf.

Rachel Gotbaum: And why is that important to know?

Samuel J. Sincl...: I think the idea is when there's an outside threat that's perceived, I think people look to people of authority to keep them safe. And I think that's essentially what happened after 9/11, when we were making decisions as a country about whether to go to war. I think people felt very unsafe. I think the prospect of new terrorism was on the forefront of many people's minds. And I think it moved people again to go to greater lengths to feel safe. And that's one example of many. We had gone for a period of time, years, where it wasn't as prominent and present as it had been. And then with the attacks in Paris, the fact that it was on the news constantly again, the attacks in California, the attacks in Brussels, I think it thrust it all back onto people's plates to the extent that it skews one's perspective, or it takes away from objectively evaluating government and holding government accountable. I think it can become dangerous.

Sarah Alger: That's clinical psychologist, Samuel J. Sinclair. He spoke with reporter, Rachel Gotbaum, for Proto magazine and for this podcast.

Jason Anthony: Something that's interesting for me in this research is what Sinclair is looking at are the reactions of people, not at the site of a terrorist attack, but people who might be hundreds or even thousands of miles away.

Sarah Alger: So now I wonder, what will be the use of this scale?

Jason Anthony: I think Sinclair... As I understood from the piece that we produced for the print magazine, the primary phase of Sinclair's research had been behaviors, almost from a sociological point of view. But one way that some psychologists had been using it, is to look at people who might be candidates for treatment. I believe in Israel, there was a study using something like the Catastrophizing Scale, where if people scored high on the scale, that they were in fact deeply effected by terrorist attacks and lived almost in a panic about future terrorist attacks, that maybe this test could tell psychologists whether these people might be a good candidate for psychological services for treatment of PTSD or treatment for anxiety.

Sarah Alger: That's interesting. It's interesting work.

Jason Anthony: Our next story is also about fears and the psychological tools that can help to counter them. One of those is storytelling. Sarah met up with the founder of Health Story Collaborative. It's a program that explores how a patient can make sense out of a tough diagnosis or a personal loss just by telling their own story.

Sarah Alger: Annie Brewster works here at Massachusetts General Hospital. As a physician, she collects vital signs and the details that a trained physician's eye picks up. But in 2010, she began collecting something more. Patients' stories. And it's not just about giving patients a chance to sound off. Illness, Brewster writes, "Can give us perspective, depth, compassion, empathy, wisdom, resiliency, and strength." So the listeners have something to gain as well. One of the Collaborative's most recent programs is called the SharingClinic, an audio listening kiosk that lives at the Russell Museum here at Mass General, where I serve as Director.

Dr. Brewster, how did Health Story Collaborative get started?

Dr. Annie Brews...: So it was a long evolution and it developed over a lot of years. I'd say between 2001 and 2010, the idea was brewing. And it really came out of my personal experience, both as a patient and as a provider. As a patient, I was diagnosed back in 2001, with multiple sclerosis. And I found myself in the beginning, after my diagnosis, craving stories of other people who'd been given a diagnosis like mine, but had found ways to move forward in positive ways. And I wanted to hear narrative and I couldn't hear these... I couldn't find these anywhere. So I started to think about what can I do that might help other patients or other people that are given a diagnosis like me. And then coming at it from the doctor side, I was working in Primary Care at that time. And I was struggling with some of the limitations of the healthcare system today, namely the time crunch that we face as Primary Care doctors.

So coming at it from both those directions as a patient and as a doctor, I really started to believe wholeheartedly that we needed to make room for the stories and bring back the stories of people's lives. And that led ultimately to the formation of Health Story Collaborative.

Sarah Alger: Before this interview, you selected for us some of your favorite audio clips that you've gathered over the years. And I figured we would listen to two of them together, and you can talk a little bit about why those were two of your favorites.

Robin: When I think of Nick, I think of just this brilliant soul. I know pot made him feel more comfortable. And I think his curiosity, while that made him feel okay, so what else would these other pills do? But he didn't want to be addicted. He knew when there was a problem. He only did one semester at URI and came home. And he came to us and said, "I have to tell you something. I'm addicted to heroin." The emotion that he showed at that moment and the vulnerability of not being in control and not being able to help himself was... It was very hard to see. And then he was clean for seven months. He was on a good road to recovery. We said to ourselves, "Oh, he's going to be one of these kids that makes it."

He became an EMT because he wanted to help people. He was loving his job. He had 16 hour days and just couldn't wait to go to the next one. He would come home and talk about people he had saved and all these great things he had done and how proud he had felt to be an EMT. And it just... Everything was clicking right. And he relapsed once and passed away. I love him and I miss him so much, but he knows that because I live every day trying to do something and I do it in his memory. So everybody knows about Nick and knows about Nick's story and that it can happen to that boy next door.

Dr. Annie Brews...: That was Robin who lost her son, Nick, to an opioid overdose. I love that she spoke so honestly, and I think there's so much shame around addiction. So I think one of the benefits of SharingClinic is that it is not only for the storytellers, but it's for the listeners. And in this case, I think other people listening who might have someone who's addicted, might feel less ashamed listening to that. So I think that is a real benefit. I think also what she does a beautiful job with, is showing us who Nick was beyond just an addict. So it brings the human out rather than just the addict and I think decreases stigma around the illness as a result. So all of those are benefits.

Sarah Alger: Are you ever astonished by the vulnerability that people show you and just how much they're willing to share about themselves?

Dr. Annie Brews...: I don't think it astonishes me because I trust in me that we all have that within us, but I think it's so hard to touch that in our culture. But if people are given the opportunity in a safe place, they often want to do that, and I think find tremendous power in doing that. And then really, that's been my experience throughout this whole process of collecting stories, is that people are really yearning to connect in that way and to share really vulnerable parts of themselves if they're invited to do so in a safe setting.

Sarah Alger: Can you tell us about what a storytelling session is like with a patient or a provider or a family member?

Dr. Annie Brews...: Sure. So, just to back up and say a little bit about what SharingClinic is. So it is a collection of audio clips, audio stories, really from patients and from patients' loved ones, and from healthcare providers that live in this touch screen, computer program kiosk. And the goal for SharingClinic is really to make these accessible to people who are in the hospital or in this case, in the Mass General Museum, which is on the hospital campus, so that people ultimately feel less alone. So these are usually between two and four minute clips and they are theme-based. So for instance, you might hear clips about end of life or about gratitude or about parenting. And you can search for these clips by either theme or by diagnosis or by perspective. So is it a patient sharing a story or a provider or a family member or a loved one? So that requires sitting with someone usually for about 30 minutes and asking them the questions, but it's more like a conversation. And then we just find the themes within. And I edit myself out, so it's just their voice.

Sarah Alger: That's really fascinating. I think maybe we'll go with the second clip.

Catherine: I feel that if you go into an experience like being in the hospital, you want to really be open to what's happening beyond your illness. And you have these poignant moments and they keep reminding you about the goodness of people. One is, I was in terrible pain. I was in the hospital. The nurse came rushing in. She was very hassled that day I would imagine and she was in a rush. And she was going to do a quick hit medication dispensation and be out the door. And so she did her stuff and she was headed out the door and she looked at me. And all of a sudden she just stopped and she came over and she brushed the hair out of my eyes and she put her hand on my face and she stroked my face. And I just thought, "Oh." It didn't take the pain away, but it changed the whole day.

Dr. Annie Brews...: So this is Catherine, who has end stage renal disease and has been ill for a long time. And I think what I loved about this clip is first of all, her perspective. Catherine is able to see the beauty in things in a really impressive way, given that she's in the hospital and ill, but she does not want her illness to consume her. In fact, it gives her, I think, more wisdom and more of an ability to tune into what is beautiful and valuable. SharingClinic is in a hospital setting and I want providers to hear this. To remember that those little moments can be so important to patients.

Sarah Alger: Is there anything else that you would like to add about your aims or your goals with SharingClinic?

Dr. Annie Brews...: A lot of my goal is around trying to respond to what I think is lacking in healthcare now. And we have an amazing medical system in so many ways in that we are curing diseases and coming up with amazing new technologies and doing so much good in that way. But we're really losing so much or have lost so much over the years in terms of the human side. So there is an individual side of trying to heal individuals, but there's also a system side of trying to transform and heal our healthcare system through the stories.

Sarah Alger: Dr. Brewster, thank you so much for joining us.

Dr. Annie Brews...: Thank you very much for having me.

Sarah Alger: To hear more compelling stories or to hear about recording your own, come to the Russell Museum or visit healthstorycollaborative.org.

Jason Anthony: We hope that you'll join us for the next Proto podcast. We'll talk to Mike Jay, a medical historian who's explored the history of laughing gas and its surprising legacy in both the literary and medical worlds.

Sarah Alger: You can find us on iTunes or wherever you get your podcasts, and at protomag.com, where you can sign up for a free subscription to our print magazine. I'm Sarah Alger.

Jason Anthony: And I'm Jason Anthony. Until next time, thanks for listening to the Proto podcast.