## Lisa Dixon (<u>00:07</u>):

Welcome to our podcast, Psychiatric Services from Pages to practice. In this podcast, we highlight new research or columns published this month in the Journal Psychiatric Services. I'm Lisa Dixon, editor of Psychiatric Services, and I'm here with podcast editor and my co-host, Josh Berezin. Hi, Josh.

Josh Berezin (00:25):

Hi Lisa.

Lisa Dixon (00:27):

Today we have a real treat. We're going to be talking to two authors from Penn who have recently published an article on the use of patient generated digital data in mental health therapy.

Josh Berezin (00:41):

We are very happy to have Lauren Southwick, who is a research project manager at Penn Medicine Center for Digital Health, and also Dr. Sharath Guntuku, who's an assistant professor in computer information science at the University of Pennsylvania. And also a research scientist at Penn Medicine Center for Digital Health here to talk about their brief report effect of integrating patient generated digital data into mental health therapy, a randomized controlled trial.

# (01:05):

So, just before we launch in, we were talking a little bit before we started recording about just how much I enjoyed reading the paper and how thought-provoking I thought it was. To read through and think about things from different perspectives like, "Oh, how do I think about this as a researcher? And then how would I think about this as the patient and then how would I think about this as a provider?" And each of them are very generative for really interesting thoughts. So, I hope we'll be able to talk about some of that right now, but I'm curious before we start, how did you all get interested in this topic? Maybe Lauren, we'll start with you.

# Lauren Southwick (01:37):

Yeah, absolutely. Well, thank you so much for having us. So, Sharath and I, are very excited to talk through our paper. So, I got interested in this topic and that this was my first job after receiving my masters of public health.

# (<u>01:50</u>):

I concentrated in social behavioral sciences and health communication. And what drew me to this project was, how to enhance patient provider communication? I thought it was fascinating how we could leverage something that we all use every day to possibly inform and better our care delivery.

Josh Berezin (02:09):

And Sharath, how about you?

Sharath Guntuku (02:10):

So, I'm a computer scientist by training. So, I've been studying health behaviors using large dataset and something that got us from thinking when I joined Penn, my postdoc was... So, we might meet a

provider for about four times a year in the US but we spend over two to three hours a day on our mobile devices doing a lots of things.

# (02:35):

So, we post cat photos and we also post a lot of how we are feeling and so on. So, we wanted to look at can we go beyond survey measures of health behaviors? And is there any signal in these non-traditional data sources, say social media platforms, that can potentially provide insights into how individuals and communities are feeling? And specifically, about the mental health.

# Josh Berezin (03:06):

One of the first thoughts I had was reading about the study and a little bit of the background is, I was imagining myself, how would I come up with this study? And I was thinking about, when I am in a little bit of a dark place for some reason at 2:00 AM I start watching NBA highlight reels from the 1980s on YouTube.

# (<u>03:23</u>):

And I was like, "That would give my therapist a very different picture of myself and I offered to him." So, was there anything, as you were thinking about the study, that was brought your personal use of either phones or the internet or social media and sparked an interest about how that could be used in a clinical setting?

### Sharath Guntuku (03:45):

Maybe I can start and Lauren can chime in. We've been actually this built up over the years. So, we have a series of papers studying the online language of mental health. And specifically, we looked at, say, ADHD or depression and more recently loneliness. And what was so surprising was two things. One, the number of people who are open to share their mental health diagnoses and mental health states online is super high in a country like US. And number two, if somebody's depressed in our other data sites, we found that the biggest marker of depression is not necessarily the word depressed or depression, but being alone or lonely.

#### (04:37):

And none of these survey measures actually ask if somebody is alone or lonely when trying to diagnose depression. So, we found that social media sources or any naturalistic ecological sources can potentially have insights into how people are feeling that can go beyond the survey measures. So, we wanted to see if some of this insight could be deployed into a therapy session. So number one, can we even do it? And if we could do it, then will the therapists and participants even find it acceptable? So, we had a very simple ask, is this even feasible? And then we started building there.

# Josh Berezin (05:19):

So, you're not looking for signals of Cavs highlights from the '80s, but well maybe sometime that will come up for other people besides-

# Lisa Dixon (05:26):

Hey, Josh, We can just do a whole separate podcast on that. On the highlights. Yeah.

# Josh Berezin (05:32):

Very experienced. We could do a little bonus episode, but I think, you have a alluded a lot of the background and gives a flavor for what you're doing but could you just give us a 10,000-foot overview of what you were doing in the study? Who were the participants? What did you ask them and what was the intervention?

# Lauren Southwick (05:51):

Yeah. Absolutely. So, we conducted a randomized control trial on the effect of incorporating digital data into mental health therapy. So this study was a little different from other research studies I worked on, in that we recruited patients and their therapists together. So, we had to recruit dyads.

### (06:09):

And so, this was a learning curve for me in that we recruited a pair, we spoke at length with patients with providers, they both had their own informed consent document. We reviewed it, we really wanted to make sure everyone was on the same page of what this meant for them and what is expected, what they can expect from Penn.

### (06:30):

And so, recruitment actually was a lot more challenging than we intended. And we recruited both in person and remotely. And we would ask patients who would ask therapists. So recruitment was a big chunk of our study period, but once we recruited patients and their providers, everyone completed a baseline survey. So, we want to assess baseline measures of their therapeutic alliance, depressive symptoms, anxiety symptoms, and health related quality of life.

#### (07:02):

Once everyone completed the surveys, patient participants were asked to share at most three types of digital data. So, this is where it gets exciting. Over the years, we built a secure platform where patients can safely and securely share data with researchers. So, patients had the option to share Facebook wall posts, they could share Google searches, YouTube searches, or they could download a free app on their smartphone.

# (07:33):

And so, once patients shared the data, since it was a randomized controlled trial, 50% got up a dashboard and 50% did not get a dashboard for individuals who received a digital data dashboard, they received it every week for eight weeks. And then after the eight-week period was up, we administered more surveys to see if there was a difference in the measures and mentioned earlier, and yeah, that's basically it.

#### Josh Berezin (08:00):

So, what did you envision would happen in a therapy setting? So, a patient has been using the internet and you're collecting this information and it's something that's going to be shown in this visual representation that could be shared between therapists and the client.

# (08:27):

What did you think that was going to look like, both from the patient perspective, the therapist perspective, and then in the diotic perspective as well? Were you imagining discussions? Were you imagining that it would just inform the therapist about some things that they could bring up? What did you have in your head going in?

## Lauren Southwick (<u>08:46</u>):

That's a great question. So, we were very much cognizant of saying, "Hey, we want to give you supplemental information you might not have access to prior." And so, weren't saying you must discuss the dashboard every session or you must review it, you must do anything. Essentially, we just wanted to give both the patient and the provider more information and if relevant, they can discuss it in session.

### Josh Berezin (09:14):

So, it wasn't very prescriptive in terms of what they were going to do with the information it was they could do with it what they wanted.

## Lauren Southwick (09:19):

Exactly. Prior to receiving the first dashboard, everyone received a three to four minute training on like, "Hey, this is the breakdown of the dashboard and these are some suggested questions or prompts you could use this data with, but beyond that, we let individuals do what they wanted.

### Lisa Dixon (<u>09:39</u>):

So, if I understand this correctly, different people may have offered different amounts of data. Is that correct?

### Lauren Southwick (09:47):

Yes. And we had some folks who shared tons of data, so their dashboard was so rich and dynamic and they posted a lot. So. Every week it would change and it was really interesting, whereas other folks, their data didn't change it much. So, unfortunately, some of the dashboards were a bit more static each week.

#### Josh Berezin (<u>10:06</u>):

And so just to get a visual, what did the dashboard visually look like, if you can describe it over a podcast?

# Lauren Southwick (10:12):

So, each dashboard was tailored to each participant, and so the modules shown on the dashboard depended on the type of data the person shared. So, let's say, I shared all types of digital data that includes Facebook wall posts, Google searches, YouTube searches, and I downloaded a free app on my phone.

#### (<u>10:32</u>):

So, if I shared all that data, I would first see a module that is taken from the app, which includes late night phone activity. So, that would be a bar graph of the total amount of minutes I was on my phone during late night. The second module was about physical movement, and it included average miles walked during the weekdays and weekends, and it had call-outs on days that were most walked and lease walked.

# (11:02):

The next module included the top five most used words from Facebook wall posts, YouTube searches, and Google searches. We alluded to this before, but something really important we learned from our co-

design sessions is that patients wanted agency in what they share. So, in addition to the three data sources, we mentioned the fourth section included where patients could share anything else.

# (11:29):

And so, this is where folks can take screenshots of a Instagram story, a TikTok video, a tweet, an article, you name it. Folks could share anything that was relevant to them and something that they wanted to discuss and share in therapy sessions. And so, I found this last section to be most interesting because it really gave space for patients to be seen and heard.

# Josh Berezin (11:56):

All right. And I want to include this, but it was all static. If they posted a video, they would [inaudible 00:12:01]-

# Lauren Southwick (12:00):

Yes, it would be a screenshot. So, we had some patients who would send in links and it was a static dashboard. So, unfortunately, we took a screenshot, but we would include the link. If the therapist was so interested in then clicking it. Yeah, but to that point, seeing a link raises some privacy concerns, some boundaries that might be blurred. So, we really focused of screenshots only make it very much one item.

# Josh Berezin (<u>12:31</u>):

So, I think, if we could talk all day about some of the thought behind the and background, but we should probably get to the results, right? You're looking to see if this sharing of this digital data dashboard with the therapist had effects on the outcomes that you were mentioning before. So, what did you find out?

#### Sharath Guntuku (12:51):

The biggest result for us was it is feasible to take patient's data into the therapy session, right? So far, there have been a number of studies that we're looking at generating insight from these digital data sources, but none of them necessarily try to implement some of that into the session and give both the patients and therapists access to the data and see if they will find any use for it.

#### (13:18):

So, number one, we were very thrilled to see that it is doable. And number two, both patients and therapists found it acceptable. So they were not like, oh, this is useless, but they were like, yeah, this made sense. And secondly, did it improve a patient's quality of life, not statistically significantly. And did it improve therapeutic alliance? Again, not significantly.

#### (13:43):

The biggest takeaways for us were it is doable, it is acceptable, but there are also a lot of other learnings that we have had through this exercise. For instance, as we've just come for different patients shared different amounts of data. So, that could have potentially affected our primary and secondary outcomes.

# (14:03):

Even the dashboards themselves might not have reflected the most relevant digital information because of the restrictions that different platforms offer or that the time enroll in therapy by different participants might have been different. So, there are several reasons why the intervention might not

have had an effect, which we could potentially look at a use study, but the overall takeaway was we were pretty excited by the overall takeaway.

# Josh Berezin (14:30):

It's a fun study if you're excited by an null result on your primary outcome, and it really is. So, it was just like, well, that's interesting too, that it didn't have this effect, but it must have changed the content of the therapy discussions, for sure.

# (14:48):

And then the other thing that kept on coming to mind as I was reading it, I was like, "Oh my God. Well, it must be that this is changing people's behavior." If they know that they're going to find out that your therapist is going to find out that you're on your phone at 2:00 o'clock in the morning and be like, "Okay. I'm going to put my phone down at 1:59 and stop using it.

### (15:06):

And of course, I was like, "oh, this is a good criticism of the study" but of course there's a name for it, which you mentioned in your discussion called the Hawthorne Effect. How did you think about that? That just the act of recording, the act of knowing that you're going to share results is likely to change behavior?

# Lauren Southwick (15:25):

Absolutely. So, we definitely thought about the Hawthorne effect throughout our entire study design period. And so we've been collecting social media data for years, and so we've analyzed it, we've gleaned insights, but never before we gave it back to the individual who shared the data, let alone share it to a new person, their therapist.

#### (15:46):

And so, throughout the study preparation period, we are very much aware of that people were probably likely to change their behavior due to new type of awareness, but in fact, we actually viewed this as a strength in that our dashboard was a type of measurement-based care where we wanted to share back this information and we wanted individuals to act on it.

#### (16:09):

And so, awareness of one's digital activity was a major aspect of our dashboard design, and that's why we gave it back to the patients. And interestingly, after we finished the randomized controlled trial, we conducted interviews with patients and therapists to really better understand how was their experience? Was it weird? Was it creepy? Was it interesting?

### (<u>16:32</u>):

All we know from our surveys is that the therapeutic alliance didn't change, depression symptoms didn't change, but there's so much more than that. And so, we're actually working on this analysis now. So, very, very much top of mind, but a common theme throughout some of the patient interviews were that patients actually liked the accountability.

#### (16:53):

And so, there's one quote that comes to mind in that a patient said that the late night phone activity graph was really in fact helpful because it created awareness and they now could associate unproductive dates to when they stayed up late the night before.

# Josh Berezin (17:11):

It's a real cognitive behavioral therapy intervention that's built into the design of the studies.

### Lisa Dixon (<u>17:18</u>):

Yeah. It makes me think of maybe there are certain types of individuals who might benefit more or less. So, is it helpful for some groups and not others? Are there ways to improve or personalize what's in the dashboard and how it's presented? And whether more training or some real orientation that the therap for the therapist actually for both regarding how to use it.

### (17:47):

There's so many next steps. Every researcher needs to have a no difference finding study, at least one. I mean, it's just part of the work, but I think then the key is what we do with that information and how we glean and learn what we can with the idea that this cannot be a completely neutral intervention in my view. I mean, it's a mystery maybe what and how, but I think it's all very engaging and compelling for us as the reader.

#### Josh Berezin (18:23):

Along those lines, there's just a million next studies that I could imagine. You've mentioned that you've done a qualitative section, but what was generated for you in terms of a research program from this finding? Because there's so many different variables.

### (18:39):

Just off the top of my head, I'm like, "Well, if you did this in young adults versus people who were older, would you find a different... Would the age of the therapist matter if you, and is it moderated by the social media use of the therapist as well? If they're on social media a lot, can they better interpret it? There's so many different questions that could come up here? What were the ones that you think you're going to tackle next?

#### Lauren Southwick (19:07):

You're absolutely right. There are so many potential confounding factors. We try to control for some, but our sample is pretty small. We had 115 patient participants and about 65 therapists. So, unfortunately, our sample is small, so we couldn't do a lot of subgroup analyses, but I completely agree and that there's the ways the individual uses social media data, the way the therapist uses it.

# (<u>19:36</u>):

I think, just anecdotally, folks who are interested in this study or more likely to be willing to incorporate or to be open to talking about digital data, I will say in our co-design sessions we had some people who were just like, "There's no utility in this" or "This is private." Where other folks were like, "Yeah, if therapy is holistic, sure, let's bring in some digital data."

#### (20:04):

So, it really depends on the person, but I will say people who are willing to sign up to say, "Yes, I want to share my data, let's do it might be different from others who wouldn't enroll. But to your question, in terms of next steps for research, I think, we're very much interested in exploring how best to use digital data in a therapeutic setting. May it be therapy maybe with your primary care physician or your

cardiologist at the Center for Digital Health. We're exploring all different disciplines to see how this data could enhance communication or information exchange.

### Josh Berezin (20:46):

So, I just want to say I was impressed that you got 115 diads. It maybe seems small to you, but I was like, "That's a lot of people who agreed to do this very new thing."

### Lisa Dixon (20:57):

And actually just asking about that in terms of the clinicians, what was the background and training and what did you learn about the clinicians who signed up?

# Lauren Southwick (21:09):

Well, first of all, thank you. 115 was a lot. Recruitment was really challenging. So we were thrilled that we met our goal within a year. In terms of thinking about table one right now, and most were CBT providers, I think, were between 30 and 40 a lot were academics.

So, I think, they were not new to research. Research was part of their training. And I will say we recruited across all different types of platforms. We used, Penn Medicine has this great patient clinical trial registry that we used to connect with patients, and then they brought it to their providers. So, we enrolled some private practice therapists as well.

#### Lisa Dixon (22:05):

So, it sounds like you had a really nice mix?

# Lauren Southwick (22:07):

Yes, for a relatively small study. It was relatively mixed.

# Josh Berezin (22:13):

And makes sense that you'd get a lot of CBT providers as well. This is in line with something that A CBT provider might do naturally to say, Hey, why don't you track your social media use? Come in and we'll talk about the results using this worksheet. But you just made an awesome worksheet for,

#### Lauren Southwick (22:31):

We tried to make it super easy. And actually that's a great point in our co-design sessions when we said, Hey, does this work, we also asked a question of, have you talked about digital data in therapy before? Are we bringing something totally new to your workflow? And in fact, a lot of the therapists we spoke to said, "Yeah, I would ask what's going on online? Or asking about a friendship like, oh, that happened on Instagram. So, it wasn't completely new to talk about how someone's online and social media activity affects their wellbeing.

#### Lisa Dixon (23:03):

Yeah. It reminds me of a lecture I heard of a colleague saying that one of the things he does is teach clinicians how to take a history of online use of these websites and online interactions. How do you ask what is the clinician who's trying to understand their patient's behavior? What are the questions?

## Josh Berezin (<u>23:29</u>):

I wanted to also just bring up a couple of interesting timing details of one of which you noted in the paper that this is all also happening during Covid when I think people's interaction with digital media, social networks. And we were just talking about how Lisa and I would do this podcast in person until Covid, and now we're doing it on Zoom and it's much easier.

People are telecommuting. There's just a whole different landscape. And I'm just wondering how you thought about that as you were, as the study was going on because it sounds like you were designing it prior to Covid and also maybe a lot of these interactions I just realized probably happened over telepsych and not in person, which is interesting as well.

### Lauren Southwick (24:15):

Yeah, our study very much coincided with Covid. We, in fact, were supposed to start recruitment March 2020, so for obvious reasons that didn't happen. And so we delayed it till October 2020, but originally we were going to print dashboards. We bought nice paper and really cool envelopes to make sure they were totally opaque. All of that went out the window. So then we said, all right,

### Lisa Dixon (24:44):

Nice envelopes. Yeah, no longer really valuable in the post Covid universe?

### Lauren Southwick (24:48):

Nope, nope. So, we emailed, we texted, so we changed our entire dashboard delivery. And so, personally, I think obviously it is for the better in that we were able to reach more people. And so to your first question, yes, during the early phases of Covid, the amount of time spent online increased dramatically, and people's depression and anxiety symptoms got worse.

In addition, therapists were completely overwhelmed. And when we were trying to figure out a date to launch a study, we met with a lot of stakeholders to say, is this even feasible? Therapists were dealing with so much that we couldn't bear to ask them to like, "Hey, you want to talk to your patient about a research study?" It just wasn't a good time.

And so, we waited a bit of time and met with a lot of folks to make sure that it was actually feasible to ask people to say, to take on another obligation during a really challenging trying time.

#### Sharath Guntuku (25:51):

But at the same time, I think, the timing was also super crucial because for instance, I think, right around the start pandemic, both CDC and Gallup rolled out a survey measures to understand how Americans are doing in terms of depression, anxiety, and stress. And all of those showed a very significant increase in the mental health prevalence. I think, it was more than anything that Gallup had seen in the last 10 to 15 years in the data anyway.

And we saw similar increases on our Twitter collection, which is about 5 million tweets a day. And we've, we've been seeing the mentions or poor mental health increasing and the county level. So, we wanted to see if some of this digital data source can be brought into the therapy session because the timing was super crucial, but also we wanted to do it right.

Josh Berezin (<u>26:50</u>):

And then the other interesting timing thing is I've been binging on coverage of ChatGPT and some of the new buzz around the AI large language models. I'm just wondering either to do with this paper or in some of your other work, how you've all thought of it, and I'd imagine it might change with... As you read more and more about what some of the answers the chats are giving back but I'm just curious, as long as we have you on the line about what you all have been thinking about some of the new AI buzz.

### Sharath Guntuku (27:27):

Yeah, so ChatGPT is an excellent writing assistant. So, it can help you edit your responses. It can help you tone down your responses. It can help you even make your email sound harsher or stronger, but can it replace a therapist? No. Right. We are first thinking of ways and how to test the feasibility and usability of conversational agents or chat bots in promoting health behaviors.

And there are a lot of ethical challenges around how it's deployed and tested, because often if you deploy this as a text messaging service, a lot of participants will likely want to talk to a human, especially in these sensitive contexts. But now if you say, oh, here's a chat bot which will likely do the first set of screening, then we need to be a lot more rigorous in how that can be presented and how that can be deployed. So, there's a lot of potential which we are still thinking of how to deploy this, this, and violated this in the context of understanding mental health and potentially promoting health behaviors.

# Josh Berezin (28:43):

So as I mentioned at the beginning, this was reading the paper was very generative and fun and interesting, and talking to you both has been similar. There's just like a million ideas and at least can tell you that I'm often excited about the research studies that we show, but this one particularly, I think, is just fascinating and very timely as well, and really encourage folks to go check out this study and other research from your group. So, thank you so much for all of your time, and I'm really looking forward to hearing what's next.

Sharath Guntuku (29:16):

Thank you so much. It was a pleasure talking to you, Josh and Lisa, thank you so much for having us.

Lauren Southwick (29:22):

Thanks for having us.

Lisa Dixon (29:23):

This is so interesting and I'm so eager to see what comes next from this research group. We invite you to visit our website, ps.psychiatryonline.org, to read the articles we discussed in this episode. As well as other great research, we welcome your feedback. Please email us @psjournalpsych.org. I'm Lisa Dixon.

Josh Berezin (29:44):

I'm Josh Berezin.

Lisa Dixon (29:45):

Thank you for listening. We'll talk to you next time.

# Speaker 5 (29:48):

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