

Center Core Faculty Member, <u>Charles Jonassaint</u>, <u>PhD</u> is an Assistant Professor of Medicine, Social Work, and Clinical and Translational Science at the University of Pittsburgh. A practicing clinical health psychologist, he aims to reduce health care disparities using multimedia technology to deliver evidence-based interventions to underserved populations.

The <u>Center</u>'s Julia Holber had the opportunity to talk with Dr. Jonassaint to learn more about his work.



Julia: Tell us a bit about your background.

Charles: I grew up in Canada, and I actually came down to the states to play football. Going into academics and psychology was never on my radar. When I went to college in North Dakota, though, I ended up double majoring in psychology and broadcasting. I went on to get a PhD in Health Psychology at Duke. I got married, and it was actually marriage that brought me to Johns Hopkins. That was the best thing that could have happened to me, because previously, I was focused on the mechanisms of stress interaction with gene environment. But when I started Hopkins' Internal Medicine fellowship, I was working very closely with physicians, and I realized that, while they think the work on mechanisms is interesting, they care more about things like which of my patients is going to get sick, and more importantly, how do I help them? That shifted the focus of my research to understanding and improving medical outcomes for patients, and I began researching healthcare utilization and patients with sickle cell disease.

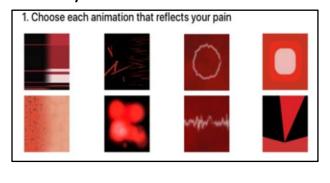
Julia: What brought you to Pittsburgh?

Charles: While at Hopkins, I was introduced to <u>Bruce Rollman</u>, who had been working on <u>delivering online collaborative care</u> <u>interventions for depression and anxiety</u>. I had a strong understanding of cognitive behavioral therapy from my clinical psychology background. I also had broadcasting experience and had always been interested in multimedia. I realized that this was exactly what I wanted to be doing, and here I am!

Julia: Well we're glad you're here! How did you start working with patients with sickle cell disease?

Charles: While I was at Duke, I started working with Christopher Edwards in Behavioral Medicine. He was a black clinical psychologist, and I had never actually met a black psychologist before. Being in North Carolina and hanging out with this group from Duke was really encouraging because it showed me that there were people that look like me who were doing this cool, geeky work. I was always interested in studying vulnerable populations, specifically African Americans with low socioeconomic status (SES), and Christopher Edwards began to collaborate with a group doing research on patients with sickle cell disease. My father who was a nurse actually ended up doing research with the sickle cell group, too. One thing led to another, and soon I was hanging out with them. In the sickle cell community we say "you don't choose sickle cell, sickle cell chooses you." As I began to work with these patients, I learned that they were mostly black, young (since their life expectancy is 30 years fewer than their non-sickle cell counterparts), and they experienced a lot of morbidity, like acute and chronic pain, organ damage, and frequent hospitalizations. I realized that the only thing that separated them from me was that they had sickle cell disease and had to live with this hard condition.

Julia: Your work with patients with sickle cell has incorporated quite a bit of technology. Can you tell us about the role of digital health in your research?



Charles: Like I mentioned, patients with sickle cell disease suffer from chronic pain. For a while, we were giving them paper and pencil to take home and keep track of the level and location of their pain and the medications they were taking. Patients would bring back the diaries totally blank and fill them out quickly in the waiting room. This was a common phenomenon, and most studies using paper and pencil diaries found that the majority of patients weren't filling them out regularly. So in 2009, we developed the SMART app to track pain in patients with sickle cell in addition to their interventions and medications. It was a new way to monitor and manage pain. That initial work

was preliminary, but fortunately, <u>Nirmish Shah</u> and my father actually continued with it after I left Duke. That opened the doors to using mobile technology in my work. I went on to create a tool called <u>Painimation</u>. It's a simplistic idea that uses animations to measure pain. Pain is the number one reason people enter into the medical setting. Why do we still use a 0-10 scale to measure it? We have the most basic assessment, we aren't even that great at it, but we continue to use it. Incorporating pictures and animations could completely transform our understanding of our patient's pain.

Julia: You clearly have a lot of experience working with vulnerable populations and racial minorities. What advice do you have for clinicians and healthcare providers who want to do more for these populations and address health disparities?

Charles: Relationships are so important. Unfortunately, in the ivory tower, in high-powered medical institutions, we don't tend to have great relationships with the community. There are a lot of things that separate us, whether it's because the Hopkins and University of Pittsburgh's of the world buy up all the property and make living more expensive for these vulnerable populations or that there's just a big power differential. Ever since the days of <u>Tuskeegee</u>, there's been mistrust between minorities and lower-income communities and high-powered medical centers. To do good work, we have to get in there and be part of the community. At the very least, we have to make people realize we care about them, not just about their data. We can't make them feel like a lab rat. We have to partner with the community and care about what people think. That's often lost when we're doing work with vulnerable populations because it's challenging and our funding agencies don't directly support that type of work. If I went to my Chair and said, "I don't have any publications or grants, but I've been spending the last year hanging out with these community-based organizations and working in the neighborhood to get to know people," that would not go over well. That's not anyone's fault, but it's the reality of what we do. I think creating ways to support the formation of partnerships between medical institutions and these communities is really important.

Julia: Thanks for that great advice. In addition to working with vulnerable populations and patients with sickle cell disease, you are also involved in multiple organizations and active on Twitter (odrigonassaint). Are there any organizations or societies you would encourage people to join?

Charles: I want to give a shout out to <u>Society of Behavioral Medicine</u> (SBM). I specifically work closely with the Behavioral Informatics and Technology Special Interest Group and the Digital Health Counsel. <u>Sherry Pagoto</u> is the current president, and <u>Gary Bennett</u> was the previous president. The leadership for Society of Behavioral Medicine as a whole is thinking about ways we can bridge the divide between academia and private industry. We're looking at how we as scientists can lead the narrative on behavioral medicine and behavior change. It's interesting

SOCIETY of
BEHAVIORAL
MEDICINE

we have so many health apps that manage anything from cancer to diabetes to autism, but few of these apps are evidence-based. App industry companies are able to produce these programs without any regulation and without seeking expertise on behavior change techniques. I think society is realizing now that this is a major issue. We have the expertise that this area in digital health needs. SBM is working to make sure we can lead the narrative the development of these interventions.

Julia: Where do you see digital health going in the next 5-10 years?

Charles: First, I think virtual reality is a cool tool people are dabbling in and tweaking. Right now it's like the internet in the 90s. As the technology becomes smoother, I think there's going to be a huge explosion of virtual reality used in the healthcare realm. I think it will be a powerful approach, and we on the academic side need to keep up with the technology and make sure that our projects are compatible with virtual and augmented reality. We need to anticipate the move away from pencil and paper scales when we do assessments. We need to always be thinking out-of-the-box, one step ahead, or else we will be left behind.



Overall, in the next few years, I believe there's going to continue to be a push toward making everything automated and trying to remove the human component. We already have chat boxes that are able to interact with you as though there's a real person on the other end of the line and virtual assistants that can provide human responses. There's definitely a place for this automation. But I think within 5-10 years, we'll realize that we've gone too far with removing the human component, and that we'll need to bring that back. All digital health tools are not meant to remove human touch, but rather to enhance it and make our interventions more effective.

