



Kessler Foundation Podcast Transcript: Moving research forward while staying home:

The past, present, and future of rehabilitation research

Recorded April 2020. [Listen to it here.](#)

EKATERINA  
DOBRYAKOVA : 00:05

[music] We're already seeing a lot of medical appointments actually switching to something that is called telemedicine.

ANNOUNCER: 00:14

Welcome to this COVID-19 special edition podcast brought to you by Kessler Foundation, moving research forward while staying home. The past, present, and future of rehabilitation research. CarolAnn Murphy, senior writer at Kessler Foundation and host of this podcast interviews three foundation scientists. Together, they will explore the changing face of rehabilitation research during the COVID-19 pandemic. Let's listen in as CarolAnn Murphy introduces our guests and begins the discussion.

CAROLANN MURPHY:  
00:46

Dr. Olga Boukrina, research scientist in the Center for Stroke Rehabilitation Research. Dr. Nuri Erkut Kucukboyaci, associate research scientist in the Center for Traumatic Brain Injury Research, and Dr. Ekaterina Dobryakova, research scientist also in the Center for Traumatic Brain Injury Research. These scientists have a special interest in this topic as the authors of an opinion piece in the International Journal of Psychophysiology. In that commentary published prior to the pandemic, they detailed the scientific challenges of rehabilitation research in terms of study design and data analysis. The pandemic, however, presents a host of different challenges to researchers, especially those implementing clinical studies in vulnerable populations such as people with disabilities. In this podcast, the team regroups to discuss innovative ways of adapting ongoing studies and how some of these adaptations may influence how future studies are conducted. First, we will hear from Dr. Boukrina, who will describe the types of rehabilitation research typically conducted at Kessler Foundation. Dr. Boukrina.

OLGA BOUKRINA: 01:59

Typically, Kessler Foundation is engaged in a number of ongoing rehabilitation research studies and each study goes through a kind of a life cycle. It begins with an institutional review board approval which ensures that the study is ethically sound. Then the research staff engage in participant recruitment which ensures that interested candidates are eligible to take part in a given study. And once participants are consented into the study, we begin data collection. This typically involves in-person visits during which participants complete surveys, cognitive testing. We also sometimes collect neurophysiological data by recording brain, spinal cord, or muscle activity and we use a variety of different techniques such as magnetic resonance imaging, transcranial magnetic stimulation, electromyography or electroencephalography. At this point, patients may also receive an intervention. After we complete data collection, we begin data analysis to determine if there are group differences or a given intervention had an effect or if some behavioral variables are linked with neurophysiological ones. And lastly, we prepare the results for publication in peer-reviewed scientific journals or for dissemination to other scientists and to consumers. Most of our studies are in person or involve in-person visits with only a handful of studies that are phone-based or computer-based. For example, one



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study on medication management that is currently funded by the New Jersey Commission on Brain Injury Research is aimed at providing people with brain injury medication reminder-- I'm sorry. People with brain injury medication reminders by voice goals or text messages.

BOUKRINA: 03:52

So another study that is still ongoing that involves mostly phone interviews of participants is the TBI model systems grant and Kessler Foundation together with Kessler Institute for Rehabilitation are one of the few recipients of this prestigious grant, and this grant is still able to continue forward because it is based on phone interviews of participants. So that's kind of the overview of how our studies are conducted.

MURPHY: 04:23

Thank you, Dr. Boukrina, for outlining the usual approach to research studies at the foundation. Next, Dr. Kucukboyaci will tell us about how researchers have responded to the sudden and dramatic changes imposed by the measure required to contain the spread of COVID-19. Dr. Kucukboyaci, what does rehabilitation research look like today at Kessler Foundation?

NURI ERKUT  
KUCUBOYACI: 04:47

It definitely has not stopped but the current coronavirus crisis has, of course, impacted what we are doing significantly. With the order from the state governance, we have limited our person to person interaction starting in March and we have been very careful about making sure we don't add any health risks to anyone's life that we work with. Research participants Kessler Foundation works with, most of them have also been part of the Kessler family for many years and we have a long standing relationship with them and we've been very careful about making sure that we keep them healthy as well. For that reason, all in-person data collection has stopped as of March 20th and even the week leading up to that, we had slowed down all our in-person data collection. And as Olga pointed out, the life of a scientist actually involves multiple aspects of project administration and project management. So currently, we were also able to work on our re-budgeting, write annual reports that we have to give back to our funders in terms of our progress today, and we are also writing some request to extend certain timelines. That said, there are certain aspects of the research cycle, like recruitment, that we have also been able to continue thanks to some of the novel and supportive approaches that Kessler Foundation has also undertaken since the social isolation period began.

KUCUBOYACI: 06:36

We want to thank the Kessler Foundation IRB, for example, for being very responsive to amendments to existing upfront IRB protocols and allowing fund consent in ethical ways so participants can still be recruited and involved in studies. If we're able to identify them and if the study is able to get the fund recruitment and consent form approved, we are able to bring on new participants on board for our studies. The other interesting aspect of some of our work is that Kessler Foundation has always invested in exploring new technologies and how they work with our rehabilitation population. To that end, we have multiple studies that focus on computer-based or telehealth phone interventions and we even have some virtual reality interventions that are part of our research portfolio. Some of those projects are able to go forward if you're able to have participants. The phone interventions, we are still able to provide those. And also in other news and in terms of the larger scope of the support

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we are getting, the funding sources namely some of the ones that we work with including NIH, NIDILRR, New Jersey Commission on Brain Injury, Spinal Cord Injury Resources, and National MS Society. They've all been very accommodating in terms of what we can do in this period.

KUCUBOYACI: 08:24

Many of these funders, I can speak for NIDILRR, for example, because I have an active project with NIDILRR at the moment, they allow locals extensions through request through the project manager, the program officers and we are also able to submit annual reports with some delays if we need to. That said, most funders have not extended grant application deadlines which is also understandable and we also feel like, as researchers, we can also now focus on some grants writing and grants publishing as well and keep up with our business schedule the way it already has been. Olga and Kat, I know you might also have some other projects ongoing. So if you want to mention how you're also enjoying some of the flexibilities from your funding resources, please feel free to pitch in.

BOUKRINA: 09:21

We have an ongoing project with the American Heart Association. We've received communication from the American Heart saying that they understand that there may be some delays in projects and that they will provide up to 60 days of salary support on funded grants without actually any data collection happening because they understand that data collection may be delayed at this time. For example, the study on medication management funded by the New Jersey Commission on Brain Injury Research which is aimed at providing people with brain injury medication reminders via voice calls or text messages and that study is still ongoing.

S1: 10:01

I can add that the New Jersey Commission for Traumatic Brain Injury and Spinal Cord Injury as well as the National MS Society, of course they're also being understanding and will allow no-cost extensions to the ongoing projects that are funded by these agencies.

KUCUBOYACI: 10:20

Another thing that our foundation has been doing really well is to keep engaging with our participants. With a lot of our studies being longitudinal studies, we do tend to work with our participants over the course of many months and some projects were right in the middle of their intervention period and there were multiple sessions cancelled. To that end, Kessler Foundation research assistants and project supervisors have been keeping in touch with them by phone calls and we were also able to provide gift cards to the participants thanks to an initiative led by our research coordinators. We were able to send a little thank you gift card for the sessions that were cancelled. And also just in case some of these participants are also out of jobs or in need of any kind of support and as a way of also thanking them for their continued engagement with us. That's been a nice touch that our foundation has provided.

MURPHY: 11:27

So clearly the impact has been tremendous on our research staff and our research participants as well as on our IRP and the agencies and institutes that fund our research. They've had to adapt to these crisis conditions. There are lessons to be learned from this experience and some may fundamentally change our approach to rehabilitation research. Dr. Dobryakova will share her perspective on this changing face of research. Dr. Dobryakova.

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S1: 11:56

With COVID-19, we're already seeing a lot of medical appointments actually switching to something that is called telemedicine and this might be the future for a lot of research, including rehabilitation research too. So in terms of scientific conferences, for example, we also see now a lot of scientific and consumer conferences switching to a virtual format so that participants can still present their research and hearing about new findings and mentions of telemedicine or telerehabilitation which is basically a format where a medical appointment or rehabilitation session is conducted over the internet or over the phone instead of the patient or participant being in the same room with the doctor or investigator. So there already have been several telerehab studies out there that were particularly geared towards situations where a participant and a researcher are far away from each other, and certainly studies that involve surveys have been relying on surveys that can be filled out on the computer rather than using a paper and pencil questionnaire. So I think this can be received sort of as a silver lining in terms of telerehab where this format can be boosted such that we can improve and perfect that technology and approach. The research that I am involved in at Kessler Foundation currently requires a lot of standardized neuropsychological assessments that are usually administered while one is sitting with a participant face to face.

S1: 13:47

So the challenge here and moving forward is to see whether we can administer these assessments in an online fashion and that means collecting data remotely from a large number of participants, assessing validity and reproducibility of the findings. So I think there are a lot of interesting and exciting projects that can be done moving forward with this approach.

MURPHY: 14:16

Thank you, Dr. Dobryakova, for this perspective. As the research landscape changes, we are seeing the stakeholders come together to maintain momentum despite the need for most of us to stay at home. Applying creative solutions is critical to continuing the work we do here at Kessler Foundation which is now more important than ever. In closing, I'd like to thank our scientists for joining me to share their view of moving research forward during this time of unprecedented challenges.

ANNOUNCER: 14:49

[music] Tuned into our podcast series lately? Joined our listeners in 90 countries who enjoy learning about the work of Kessler Foundation. The new episodes are experts weigh in on the impact of COVID-19 on people living with disabilities and they talk about research that changes lives continues at Kessler Foundation. Check back soon to listen to more COVID-19 podcasts that are listed on our playlist. Listen on iTunes, SoundCloud, Spotify or wherever you get your podcasts. This podcast was recorded on Thursday, April 9th, 2020 remotely and was edited and produced by John Bank Smith, creative producer for Kessler Foundation. [music]