Contents

Proem 00:52

Lately, I worry about the health and wellness of lab technicians. According to the NIH (National Institute of Health), managing COVID-19 depends on nationwide, easy-to-use, accurate testing. This especially means testing populations working in high-risk occupations, teachers and students, and nursing home residents and workers. But until we have widespread, reliable home testing, the more we improve access to testing, the more we rely on the limited number of burning out lab technicians. So, when my old crony, Mark Heyward Johnson, reached out to me to tell me about Project COPE (Chronicling healthcare prOviders' Pandemic Experiences), I said, 'tell me more.' He described a study of the moral stress and burnout of healthcare workers during this COVID-19 era. As a person involved with PCORI (the Patient-Centered Outcomes Research Institute), I'm familiar with the HERO registry (Healthcare Worker Exposure and Response). This research initiative seeks to engage healthcare workers to understand the impact of COVID-19 on their health.

Introducing Mark Heywood Johnson and Smitty Heavner 02:11

Health Hats: I asked if COPE was a study of doctors and nurses. He said, 'yes, and more. Anyone who self-identifies as a healthcare worker.' I asked if they included massage therapists, environmental services workers, family caregivers, and lab techs. He said, 'yes and more.' So, I set up this conversation with Mark and his compatriot Smitty Heavner Sullivan. I'll let them introduce themselves and tell you about Project COPE.

Health Hats: Welcome to Health Hats, the podcast. How about you introduce yourselves, so I don't have to.

Smitty Heavner Sullivan: I'm Smitty Heavner. My pronouns are he, him, his. I am a research manager with Prisma Health, a hospital system in Greenville, South Carolina, and a Ph.D. candidate at Clemson University. I am one of the co-PIs (Primary Investigators) on Project COPE. I study moral distress and burnout in healthcare workers.

Mark Heyward Johnson: And I'm Mark Johnson. I'm a registered nurse and Ph.D. student who recently joined the team at Project COPE. I live near Greenville, South Carolina, as well. I met Danny close to ten years ago, working together on the E-Connecting with Patients, a HIMSS (Health Information Management Systems Society) committee.

Health Hats: Yes, that was such an important moment for me. I met Jane Sarasohn-Kahn, Jonathan Wald, Jan Oldenburg, there. These are my peeps.

Mark Heyward Johnson: And Sherry Reynolds. I was among giants when I was on that committee.

Health Hats: I felt the same. I was like, 'what am I doing here?' Pretty much everybody told each other you're here for a reason. Get over it. Mark, you did consulting for a long time?

Mark Heyward Johnson: Yes. I worked for a software company for the last 13 years. I took a big dive here in 2020 and resigned from that position. I'm focused full-time on a Ph.D. in nursing science at the University of South Carolina in Columbia. A significant change for 2020, like everything else that's going on.

Chronicling with Project COPE 04:59

Health Hats: Why don't you tell us a little bit about Project COPE?

Mark Heyward Johnson: I'll let Smitty do that as one of the co-PIs. He and Dr. Ann Blair Kennedy are the principal investigators for Project COPE. Before he jumps in to talk about it, I will connect how I got involved with Project COPE. I heard a segment on our local NPR station here in South Carolina, educational television, and radio did a piece on Project COPE. And I was in the middle of doing my flexibility exercises in the morning, listening like I always do. And I said I need to reach out to these folks because what they are doing and how we're trying to connect with healthcare workers during this pandemic is very important. And it aligns with where I think I want my nursing science research to go at a population health level. But I just wanted to give that quick introduction to how I got involved with Project COPE, and I'll let Smitty tell us all about the genesis.

Health Hats: And I have; I'll put the link to that South Carolina public radio, It's Not About Superheroes episode. And I'll put that in the show notes.

Mark Heyward Johnson: And our new URL is ProjectCOPE.info for folks who want to find more information.

Smitty Heavner Sullivan: Yes, thank you, a little bit more about my background. I am a registered nurse, as well. I've been working in healthcare and nursing in some sense for 14 years, starting as a nursing assistant, working in Alzheimer's units, worked my way up. I was an LPN for several years, finished my RN. my bachelor's, and now working into graduate education. I've been very interested in healthcare workers' experiences because there's always been a lot of research about patients' experience, the healthcare that they provide, but not always as much about how healthcare workers feel about the situations here in the region. In the last couple of years, we've started to see more, but I and some other colleagues, including Dr. Kennedy, have been involved in some work looking at meaning in medical faculty. So, physicians who are also teaching medical students, and as the pandemic was coming to the United States in early March, Dr. Kennedy and I had a phone conversation where we started talking about what we see in our professions. Ann Blair or Dr. Kennedy is a licensed massage therapist.

I forget exactly how many years she has practiced, but quite a few, more than 15. She also has a doctorate in public health, and she is faculty at our med school. We were talking back and forth about what we were seeing in our communities, our professional organizations. We heard many conversations about people having anxiety about the unknown, about being in your workspace knowing that there's this pandemic coming that's going to impact how you conduct yourself; how you interact with your patients. There were several factors about not knowing how to prepare yourself for it. They felt like there's not a clear way for them to express their concerns into state, federal, or professional leadership and then feel like there's no centralized plan. We started thinking about these two groups of people as people who are locked into a system. If you're an emergency room nurse, you could quit your job, but short of that, you're stuck in a workplace that maybe has a plan, but perhaps it doesn't. But if there's no larger plan and you just have to sit there and wait for the pandemic to come. Whereas, if you're an allied or complementary and integrative healthcare provider, you're on the outside saying, I've got skills that I could offer to help, but no one wants to have them. Some of the previous research has shown that around burnout and moral distress, massage therapy is something that's recommended to a lot of people. Many firefighters from 9/11 were treated with massage therapy to help them deal with their trauma and stress. Then there's a whole body of research about the other part of their treatment being psychotherapy, where all those therapists that had secondary trauma from listening to those stories from those providers. But no one assessed how the massage therapist felt about it. So, we started conceptualizing this project.

Mixed methods research: Interviews and surveys, numbers and experience 09:19

If we get into the technical terms, it is a mixed-methods ethnography. In science, we love to make things more complicated than it needs to be. That means that we wanted to collect some survey data, which gets you some good comparability. Especially if you have a validated measure, it's a question that's been studied, and we know what it's asking, and we know how people respond. We can say this is representative of a group. We can repeat that same measure with another team. But it doesn't give you a whole lot of depth, right? So, if one of the questions to be asked is a single item or one question that

assesses a person's level of burnout, and we can get a level of burnout that is on a scale. We can say, look in our survey, this person's experiencing more or less burnout than this other person. And over time, we can say, Oh, their level of burnout increased or decreased, but we can't understand the why. We can ask other questions and say, okay, so people who felt like they didn't have enough PPEs or protective equipment didn't have enough masks and gloves. These people tended to have higher levels of burnout, but we don't know why. And that's where the mixed methods come in. All of that is quantitative data. That's surveys and things you can measure. Things you can count. In qualitative data, you listen to someone talking, and you try to develop a theory about what they're experiencing. So, you would apply codes to the words they're using to see if similar ideas show up in other people's data and see if you can form a large picture that describes the whole group. In Project COPE, that qualitative portion is a five-minute video blog that we invite our participants to submit. A wonderful thing about that video blog is the act of just recording can be cathartic for you - help you process some of what you're dealing with - it also gives us rich data so we can look at the words and the way they talk, the candor, their speech, we can also look at their body language. There's a big difference between someone who's sitting upright, eyes clear, no puffiness under their eyes, feeling like this is difficult talking about the ways they're coping. Someone else is using the same words, and they're slumped and speaking softly, looking a little disheveled. You can tell that person isn't having the same experience. So, with quantitative and qualitative data together, ultimately, we're trying to describe this experience. In previous disasters, the SARS outbreak, Hurricane Katrina, 9/11, warzone healthcare workers get information after the fact. We interview them, and we debrief and try to get an understanding of what that experience was like.

Mark Heyward Johnson: Because it's so quick.

Vlogging: Video blogs 11:36

Smitty Heavner Sullivan: Yes, because it's often quick, but also isolated. Here we have this ability to look at the experience while it's happening. We have participants give us a video blog every couple of weeks, and we can look at them across the whole timeframe and see when they started dealing with different pieces, how they coped with other effects. Then we can also get a sense from their survey responses.

That survey platform tells us what area they're in. We can narrow it down to a couple of counties, and we can see this is what was happening in the pandemic at that time in that location. We were hoping to end up with this rich data source that tells these stories. In the newspapers and on social media, your ER nurses, ICU doctors, paramedics, and stories are told repeatedly. These are important stories to be told, but massage therapists, allied health professionals, like radiology technicians, phlebotomists, athletic trainers, audiologists, chaplains, and there's not as much attention paid to their stories and what they went through. We can help represent those stories. So, to-date, we have over a thousand participants representing twenty different healthcare professions from thirteen countries across the globe. The majority of them are in the United States, of course. Still, we could get this sense of some of the unifying experiences that people are having regardless of what profession they're actually in, being motivated to help people and having all these barriers that keep you from actually providing the care.

Including who? Self-identified healthcare worker 13:53

Health Hats: Let me ask you a couple of questions to understand your pool of people better. So, you're looking at licensed healthcare workers? Say more about your inclusion, exclusion of the people who are in the study.

Smitty Heavner Sullivan: The inclusion is simple. The first question of the survey if someone signs up and goes to look is, 'do you consider yourself to be a healthcare worker or a student in a healthcare field?' We leave that entirely up to the person. We have respondents in supply chain and supply chain management, a few that are public health professionals. Still, we also have a few EV technicians that have responded, EVs environmental services, Housekeeping.

Healthcare workers providing family caregiving 14:49

Health Hats: Do you keep track of whether any of these health workers are also family caregivers?

Smitty Heavner Sullivan: Not directly, though we do have a question that asks if they've had people that have gotten sick in their family, and then there's the second question about the level of impact. But we decided not to ask directly are you the sole provider of care for a family member because it becomes harder to measure, and it might be harder for someone to give that information.

Health Hats: I would quibble with the 'sole business' because one of the challenges of people who are healthcare workers, in general, is that a large cohort of people who work in healthcare also provide some caregiving at home for family members. That's becoming an area of interest in science itself.

Mark Heyward Johnson: That's a good point, Danny, because the pandemic isn't centered in the hospital or the clinic, it's pervasive, and it affects healthcare workers while they're quote-unquote offering the care as part of their profession, as well as when they get back home. We used to be able to seal it off. Now it's everywhere. I think that's an important distinction everywhere.

Health Hats: And people still have dementia, chronic diseases, and developmental illness. I can imagine that being a healthcare worker in a pandemic impacts that. It's a factor in mental health and satisfaction with life.

Smitty Heavner Sullivan: Absolutely. One of the wonderful things about doing mixed methods is when you have this qualitative component, one of the prompts that we give for those videos is to ask about how it's affecting their life. So, that can be an opportunity for someone to give that extra information, to give that context, It becomes hard to try to add. We didn't want to make an exhaustive survey that would take hours to fill out. Yeah. We tried hard to keep it short.

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Answering what questions? 18:00

Health Hats: You're creating a data source? What's the research part of it? Do you have a hypothesis that you're proving or disproving, or is it comparative effectiveness, that A is more likely than B to be effective? Tell me about that.

Smitty Heavner Sullivan: In the original study, we had nine different research questions that we were asking. Some of the questions were to what extent do essential healthcare workers feel prepared and supported as they head into the pandemic? We also asked to what extent do those quote-unquote non-essential healthcare workers (The unfortunate reality is that our system is labeling people as essential or unessential). Still, we all know that community health workers that home health caregivers are every bit as essential as the ER nurse or the ER doctor, as a resident or a surgeon keeping the whole system working. There's a series of questions like that we'll be answering with a combination. Some questions can specifically be answered with the survey data. For example, looking at this is a question of preparedness, we have a question that asks, 'does your facility, your practice have a plan?' Or does the organization that supports you have a plan for how to make sure you have masks and gloves? Do you feel like you understand the policies? Have you been given a chance to ask questions?

Health Hats: Then your dependent variable is something like stress level or burnout level? You're looking at if you have all the equipment you need, are you more stressed or less stressed? I'm trying to understand the dependent variable.

Smitty Heavner Sullivan: Yes. The independent variable will be these questions about, do you have access to these things? Do you feel like you've received the training? Our dependent variable in the regression analysis will be these validated measures; the Maslach Burnout Inventory perceived stress scale. There was a survey that was developed during the SARS pandemic that we've also included.

Scared and exhausted 20:12

Health Hats: So, what have you learned so far?

Smitty Heavner Sullivan: The biggest thing that we've learned is that people are scared. We're seeing these powerful videos of people that are exhausted, they're drained. Especially the people who have been actively working the whole time and haven't stopped seeing patients. The sense of overwhelmed and fatigued. We're seeing increasing burnout rates as time goes on. We're amid some of our initial analyses to try to quantify the exact increase of those. But interestingly, we're seeing similar increases in people's levels of burnout, regardless of whether they're part of that quote, unquote essential or quote-unquote non-essential group of workers. We see it every bit as much in the dentist as we are in a surgeon.

Quadruple Aim: Healthcare workers matter 21:08

Health Hats: What change do you hope that the results of this study will motivate? What's going to happen? Research is ink on paper until it motivates somebody to do something. What do you hope this will motivate?

Mark Heyward Johnson: We don't think this is the last pandemic or the last natural disaster we're going to have to deal with, right?

Smitty Heavner Sullivan: Absolutely. In the mid-2000s, there was a big push to move from a triple aim to a quadruple aim, adding healthcare providers' wellbeing as part of the core measures around quality health care. It wasn't very well adopted. A couple of health systems did a good job, but by and large, the US health system hasn't done this. I hope that we'll be adding more evidence and more language to how important it is to care for those healthcare providers first to make sure that they are well-equipped make sure they are safe, make sure they're able to deal with all the things that they're seeing and experiencing, so they can continue to provide high-quality evidence-based care.

Including healthcare workers in design 22:20

Health Hats: So, how have you included healthcare workers in this study's design and implementation?

Smitty Heavner Sullivan: That's a great question. Our team of co-investigators started out with an interdisciplinary team of thirteen - me as a registered nurse and Dr. Kennedy as a licensed massage therapist as co-PIs. We have another researcher who is an expert in massage therapy. We had a physician, a psychologist, an evaluator, and a few organizational psychology professionals. Then we included a team of medical students and graduate students to make sure that we are getting an idea of what questions might be more relatable to some newer people in the profession. We've also done some

stakeholder engagement with nurses at my own practice and a community paramedics program. We've engaged some to ask them the questions that might be relevant for their work. And then we've also worked hard to make sure that those people who don't have all that fancy training to do the actual analysis can be involved in the way we're interpreting the data. And that's a part of what I'm excited about because we have medical students watching the videos, watching the blogs that are part of the research team. We ask the medical students to think about what hashtags they would use if this was posted on social media? That is essentially a proxy for developing themes. They're an integral part of our qualitative analysis as we move forward.

Including patients in design 23:51

Health Hats: How about patients? How do you involve patients in the design and execution and analysis of this data?

Smitty Heavner Sullivan: I'm so glad you asked that. One of Dr. Kennedy's other roles is the director of our patient engagement studio. The studio seeks to make sure that patients' voices and experiences are used to help interpret research and help to form that design. We did have an informal engagement with that group early on. We are working to secure some funding to get some dedicated time from that team to develop some patient-specific measures that we can help triangulate and add another level of understanding of what's happening in the pandemic.

If you could do it over? 24:35

Health Hats: I have two more questions. If you were to start over, what would you do differently?

Smitty Heavner Sullivan: That's a great question. I probably would have spent a lot more time recruiting early in the pandemic. Now everyone's bracing for everything, and we put it out in the ether. But we didn't try to hound any groups to get them to participate. We did that because we didn't want to add to people's stress, but we have missed out on some people's stories by not doing that. I am concerned that there may be parts of the story that we're not able to tell, but that's always a limitation with research. The only thing we can do going forward is to keep recruiting, trying to gather more perspectives, more stories so that we can tell to describe the experience of all healthcare workers when we get closer to the end, whenever that is.

Follow, join, learn 25:35

Health Hats: If people either want to follow this or participate in it, how would they get hold of you?

Mark Heyward Johnson: We have social media channels on Facebook, Twitter, and Instagram. The website is Project COPE.info.

Health Hats: What should I have asked you that I didn't. Or what should we have talked about that we haven't?

Mark Heyward Johnson: I want to echo what Smitty said earlier about the therapeutic value of that opportunity for our participants to express their lived experience. I think that's unique. Because we are going through this in slow motion, it seems as healthcare providers and those folks who are dealing with this moral distress, giving them an opportunity to articulate that lived experience and those frustrations where they might not otherwise have that opportunity to pull it out of themselves. I think that's unique

here, and I think that's the value. It goes both ways. We can help the participants, and they can help us with this research. Then we can help the healthcare system at large by doing that.

Health Hats: I appreciate this conversation. Thank you,

Mark Heyward Johnson: Danny. Thank you.

Health Hats: Mark, wonderful to see you again and to do something together. What a hoot.

Mark Heyward Johnson: Absolutely. I've enjoyed watching the evolution of your podcast, your blog now to, podcasts. I was there at the genesis when you were kicking that idea around.

Health Hats: Yes, you were. Thank you, Smitty. Nice to meet you.

Reflection 27:28

Healthcare workers matter. Anyone who self-identifies as a healthcare worker - Lab techs, family caregivers, massage therapists, housekeepers, morgue attendants, food service, community health workers. We all matter. We need each other. We need each other as healthy as possible.

I first heard about mixed methods during my second statistics class in 1989. (I didn't begin to appreciate statistics until my third class in 1991) I didn't appreciate mixed-methods until I became a Merit Reviewer for PCORI in 2014. A scientist/statistician sitting next to me explained it as 'Numbers alone say little. Mixed methods give the numbers life.' I explained it to someone recently as 'numbers and stories.'

I fear our limited capacity to care for each other during COVID-19. It's not a limit on beds or equipment. It's a limit of caring people with expertise. All sorts of expertise. Experts in the care of me and you, experts with lived experience, experts in maintenance, experts in testing, experts, experts. It's a finite pool that we need to invest in and support for the long term – two weeks, a month, a year. I know many burning out expert healthcare workers ready to throw in the towel. Check out Project COPE. Enroll.