Leorey N. Saligan, Ph.D., R.N., C.R.N.P., F.A.A.N.

Behind the Mask

August 13, 2021

Barr: Good morning. Today is August 13, 2021. My name is Gabrielle Barr, and I'm the Archivist at the Office of NIH History and Stetten Museum. Today I have the pleasure of speaking with Dr. Leorey Saligan. Dr. Saligan is a Principal Investigator in the Symptom Biology Unit in the Division of Intramural Research at the National Institute of Nursing Research (NINR). Today he's going to be speaking about some of his COVID-19 related research initiatives. Thank you very much for being with me.

Saligan: Thank you, Gabrielle, for this opportunity to participate and talk about our activities, especially those related to the COVID-19 pandemic.

Barr: Absolutely. As somebody who has treated cancer patients and has tried to address fatigue related to cancer therapies as part of your research, you co-authored “Risk for Coronavirus Diseases Among Cancer Patients from a Nursing Perspective” towards the beginning of the pandemic. Can you speak a little bit about your role in this product and what prompted you to get this information out there?

Saligan: That actually came about from my previous postdoc, who is currently an Assistant Professor at Johns Hopkins University. She has been a leading voice of nurses in the Asia region. Most of the nurses from developing countries don't have a lot of resources, or don't have a lot of access to current research, findings, or guidelines related to COVID-19. They've been reaching out to us and asking us to make it simple and easy for them to understand the current guidelines and research about COVID-19—from presentation of patients and clinical signs to management and plans for future directions of research and treatment. We put together that paper for that audience of nurses out there, particularly those that have had a really hard time accessing all this information. We wanted it to be very concise and very straightforward, collating all the information that is available to us related to these different areas of presentation, management, and future initiatives for COVID-19. This paper was put together during the very early part of the COVID-19 pandemic.

Barr: Would you think about revising it, because that was published very early on and so much has happened with the pandemic?

Saligan: Yeah, that's really a good suggestion to consider. I will reach out to my co-authors, particularly Dr. Nada Lukkahatai, who had taken the lead on this one. It’s really very important to have most updated information especially for nurses out there with limited resources.

Barr: Another project that you have been a part of is a study that looked at the role of resilience and gender in relation to infectious disease health literacy and anxiety during the COVID-19 pandemic, which on the surface is

very different than some of your other work. Can you speak about how you contributed to this study and how you got involved with that?

Saligan: Part of my role as a senior investigator is mentorship. At NIH, we've committed ourselves to mentor the next generation of nurse scientists. One of the students I mentored is in the graduate program of Johns Hopkins University and focuses on fatigue, but in patients with AIDS from China. She had a lot of data, especially during the pandemic, and she reached out to me and asked if I could help her put together and interpret a paper about the data she had collected. I looked at her analysis and then drafted a paper out of it, because this was very informative, especially at that particular time. Her sample size was really big—about 1,068. It was really very informative to show, especially with all the misinformation out there, how COVID impacts anxiety and, more importantly, building and developing resilience, and how that's different between gender categories. I thought that she has good information to share from her analysis. It basically showed that the relationship between resilience mediates association between health literacy, particularly for COVID-specific information, and that anxiety in individuals with good health care literacy, particularly on COVID, are more likely to acquire higher resilience and in turn reduce their anxiety. It makes common sense, but it's good to see that, especially during that initial surge of the pandemic. She found that males have benefited more from the mediation effect of resilience over time. These findings are very important to develop and establish gender specific and targeted interventions and information, particularly for public health.

Barr: It was a very interesting observation, but how do some of those lessons learned get applied in actuality?

Saligan: That's very important. Nurses are oftentimes tasked in patient education. We champion making sure that the patient goes home with the proper education related to their care. This information is very critical, particularly for those that are going home recovering from COVID. And also, for the general public, in making sure that information related to COVID prevention, management, and treatment are considered based on building resilience, but also making sure that they have adequate attributes to filter and digest the particularly varied multitude of information out there. Having that kind of educational program is critical—in particular, putting in the angle of gender in disseminating, but also in establishing, specific types of educational agenda.

Barr: As a nurse, and someone who mentors other nurses, how do you practice speaking to different populations appropriately about COVID-19, but also about a lot of other health information? Different people, as we just talked about, process information differently, and there are different amounts of information that should be conveyed in different ways, so how do you do that? That's probably very hard—every patient is different.

Saligan: Indeed. There are also different audiences, and there's a cultural component and access component. Of course, as a nurse scientist, I have a unique role and unique responsibility to make sure that when I talk to different audiences—whether colleagues, other nurses, other disciplines, or patients and their families—I need to make sure that all the information provided is evidence-based and strongly supported by data and science. That should be the driver of all information and presentations I do.

Barr: That makes sense. Now we're going to turn to your own protocol that you have been working on. Can you speak about the premise of the study you're leading that's looking at COVID-19 and fatigue?

Saligan: The protocol that I'm working on currently is with NINDS [National Institute of Neurological Disorders and Stroke]. That is related to what I've been doing in the cancer arena, which is really understanding the symptom of fatigue. We all know, especially with the current literature, that a lot of COVID recovered patients complain of persistent fatigue over time. Most often, the long-term symptom they report is fatigue that's also associated with cognitive impairment. We all know, and I know from my field of cancer, that fatigue is such a nebulous construct. The premise of the study is really to understand, because if we don't disentangle the experience of fatigue, we won't go anywhere. If we disentangle it, and really understand the dimensions of it, we'll be able to offer targeted rehabilitative services. For example, fatigue can be physical. That's especially burdensome to the patient. Any form of fatigue management needs to be patient-centered. Oftentimes patients complain that their fatigue is physical, so we can offer some physical rehabilitation like exercise. Some patients complain that it's more cognitive, so the intervention and the management should focus more on cognitive training and improvement in memory—all those kinds of areas. For some it may be affective, and it can be depression related or anxiety related. Those also require a different type of management. There are others that complain that the fatigue is mostly motivational. That's also a different type of management, particularly of the behavioral coaching type. The premise is really to understand those different phenotypes of fatigue, so we can better serve our patients.

Barr: That's really interesting because I wouldn't have ordinarily thought of mental health as part of fatigue. I just thought of it as being either mentally or physically really tired.

Saligan: Yeah, and that's unique because we mix it with so many other symptoms, because often times it presents with clusters of symptoms, and it gets muddled. We say fatigue is just being tired and to just take a nap and get better. Fatigue is more than that. Fatigue has so many dimensions. Oftentimes, it's not even related to your physical activity. Those are the areas that we can separate—being tired from being fatigued. There is also some cultural implications, because a lot of different cultures have no term for fatigue—they're all clumped up together with other terms like being tired. And that's where most of the issues are. Even in English, there's a lot of association between fatigue and depression or lack of sleep. Those are the different types of areas that we really need to understand—what type of fatigue is being presented or experienced, so we can help.

Barr: Do you think a lot of it is because when you say "fatigue," it's kind of stigmatized, especially in Western culture, like you're being very lazy and you should be working, or you should be better.

Saligan: Yeah, there's a component of that, and there's also a cultural and gender history that need to be considered. In some cultures, you don't have time to complain. You have to get up and do things. In some cultures, the male role is associated with being a provider or being 'macho'. So, if you are male, you are not expected to complain. We've seen from the fatigue questionnaires we have administered on patients with prostate cancer that Puerto Rican men who are receiving the same treatment for the same disease have lower fatigue scores than Caucasian males. There's a lot of literature out there about differences in symptom severity

among cultures and genders. Cultural backgrounds and gender role expectations have, over time, influenced our experiences of symptoms, particularly in fatigue.

Barr: When did you begin beginning conceiving of this study for COVID-19? Can you talk a little bit about your methodology—how you're going about it, how many participants you hope to recruit, as well as some of the metrics you are using to assess your study?

Saligan: When the pandemic started, we knew that in the first wave, we had to take care of the acute phase. But we saw that, as the disease transitions to the chronic stage, the issues of fatigue and cognitive impairment are becoming common. That's why a group of us here at NIH have come together and said we really need to plan for a platform where we move from acute to subacute to chronic to maintenance to improve health outcomes of these patients. That's how we planned to see patients post-COVID, when they've recovered from the acute and subacute phases, to capture their chronic lingering symptoms—particularly fatigue and cognitive impairment. Once we've identified patients that have this chronic fatigue, rehab medicine developed an exercise study to manage their COVID-related chronic fatigue. They call it the "COVID Care Study." In that study, our lab is in charge of collecting the blood samples to analyze the types of processes and mechanisms that may explain their symptoms and/or response to the exercise regimen. Oftentimes it's prolonged inflammation that we've seen in our fatigue patients from our previous studies. So far, we have collected about 22. Some are participants that have completed that protocol, and some are actively enrolled. The COVID phenotyping protocol that NINDS is leading has completed most of the survey piece where they virtually ask patients about their experiences, and they're going into the second phase of that study. We are part of those two studies at the moment—particularly with the lab component in processing and analyzing the blood. We have more studies that are coming up. I have an ongoing ketamine study to look at the effect of ketamine in rapidly reversing fatigue symptoms. We're hoping we can apply that to COVID patients who have chronic fatigue.

Barr: Have you encountered any challenges to date, and has anything stood out for you, in particular with what you've seen so far with your COVID study?

Saligan: Of course, all of us have had a lot of challenges, particularly with the restrictions. Now we've started to come back. My staff has been back in the lab to help with the processing of samples. But initially, when we all started figuring out what to do, we had to go through, like anybody else, challenges and restrictions. Staff got sick and all that. Those were the main challenges. But otherwise, we're so lucky to be at NIH and to have the very systematic and science-driven guidelines on how to move forward with our activities. Right now, all is well.

Barr: Has anything about what you've seen so far with the data stood out for you, or is it too soon to say?

Saligan: It's still too soon to say, but it's interesting that it has the same picture and the same aura as presentations like chronic fatigue syndrome. There are very similar presentations, symptom reports, and clustering of symptoms. We are exploring similarities and differences between the fatigue experiences of patients with COVID-recovered fatigue and those with myalgic/encephalomyelitis/chronic fatigue syndrome. We're hopeful we can find some answers to that, especially in their biology, so we can really target the causes.

Barr: Are there differences amongst the variants? Is one of the variants causing more fatigue than others or for longer or different kinds of fatigue?

Saligan: That's a really good question. We haven't looked that far yet. But that would really be a good question to follow up on. That makes unique sense because of what we're experiencing at the moment.

Barr: Do you worry that some of the medication given to COVID patients is leading to the fatigue? You work a lot with chemotherapy—so it could be not just the cancer, but also the therapies that cause some of these issues.

Saligan: That's really a good point to consider in our analysis. In particular, we use any comorbidity or medications that they take as a covariant for our analysis.

Barr: Are you involved in any other COVID-19 related activities or initiatives, either at NIH or outside of NIH?

Saligan: Being an active-duty officer with the Public Health Service, I've been involved in several mission responses. For COVID specific missions, I was deployed in Minneapolis, for example, to help with those responses.

Barr: What did you do in Minneapolis? What did you do on some of your COVID missions?

Saligan: This is to help the state take care of their COVID patients at that time. Those are the other roles that I am obligated to do as part of being a Public Health Officer.

Barr: Were you in a convention center or were you stationed in a nursing home or a hospital?

Saligan: We were in a long-term facility, so I was taking care of the long-term residents.

Barr: As a person, not just as a scientist and a clinician, what are some of the opportunities and challenges that COVID has presented for you?

Saligan: Oh, definitely. Like everybody else, the social element of not seeing your family for a while [has been a challenge]—especially for me. I cannot travel internationally. My dad is old and has a lot of medical issues. I have not been able to see him, of course, and the rest of my family back home. But thanks to technology, I'm able to Skype or video call with them often and regularly to make sure they're okay. More importantly, [a big challenge has been] the disparity in vaccine distribution, particularly in developing areas. I come from the Philippines, a very developing area. Availability of vaccine and the distribution itself has had some challenges. Those were the concerns and issues that worried me a lot during the pandemic—especially making sure my aging dad is able to get vaccinated.

Barr: Has he been able to get vaccinated yet?

Saligan: He's bed bound, so it's very hard to bring him. We're working with the local government to see how they can come over to the house and get him vaccinated or how we can bring him to a facility.

Barr: That's very hard. I wish him the best in that. What do you think COVID-19 has done for nursing?

Saligan: It really emphasized the critical role of nurses in public health. This is a very commonly repeated theme over time with every pandemic and every emergency public health response. The 1918 Spanish flu, for example, and now the COVID pandemic, show that nursing is central. In every health care system, whether acute care settings or in the community, nurses are very critical. They make sure that there is delivery of acute care for patients who are sick, but more importantly, make sure that they're healthy once they leave—or make sure those that are not sick remain healthy. Our frontline workers and providers make sure that that happens, and that critical role of nurses cannot be dismissed and downgraded.

Barr: Definitely. Is there anything else that you would like to share about your COVID-19 experiences and work?

Saligan: There is definitely a lot of work and research to be done related to the COVID-19 pandemic. As you can see, there's going to be a long-term effect, not just on patients and families, but communities and health care systems. There's really a lot to be done in all different aspects. We definitely need all the hands and all the minds that we can get to make sure that we address this, because this will change our experiences. It's already changing our experiences. More important is making sure that kids and the next generation are ready in case a global medical crisis happens again. We hope it doesn't happen, but it’s important to make sure we have all the framework necessary to prevent it from happening.

Barr: I wish you and everyone you work with—and your family—all the best of luck and success and continued health.

Saligan: Alright, you too, Gabrielle. Thank you for this opportunity.

https://pubmed.ncbi.nlm.nih.gov/33324062/