

Joseph, Paule 2021

Dr. Paule Joseph Oral History

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Dr. Paule Joseph

Behind The Mask

May 27, 2021

Barr: Good afternoon. Today is May 27, 2021. My name is Gabrielle Barr, and I'm the archivist for the Office of NIH History and Stetten Museum. Today I have the pleasure of speaking with Dr. Paule Joseph. Dr. Joseph is a Lasker Clinical Research Scholar at the National Institute of Alcohol Abuse and Alcoholism (NIAAA), and she has a joint appointment at the National Institute of Nursing Research (NINR). Thank you very much for being with me today.

Joseph: Absolutely, and my pleasure.

Barr: To get started, why does SARS-CoV-2 impair many people's senses of smell and taste? Does this occur with other kinds of coronaviruses?

Joseph: This is a great question. One of the things to put into context is that early in the pandemic, we started noticing a lot of people reporting they had lost their sense of taste and smell. Taste and smell are not necessarily one of those senses people pay as much attention to as they would their vision if it was getting blurry or if something really hurts in terms of touch—that [level of] sensitivity. When we started noticing increased reports, it was puzzling because other viruses—for example, the common cold and other coronaviruses—have these transient changes. If you have a cold, you will most likely have a change in the way food tastes, because you either have a runny nose or stuffy nose, but that goes away pretty quickly, and not everybody will experience that. But with COVID, it was very clear that something was different, because you had so many people around the world—it wasn't just one place—having this report. Why these things were happening was one of the questions I had, as well as many other colleagues [who work] in the chemical senses.

As of today, over a year later, we understand more about smell. We know that, for example, the supporting cells in your nose are affected by the virus, but not necessarily the olfactory bulb itself or the olfactory neurons. When it comes to taste, there's less we know about taste. Recently Dr. Josephine Egan from NIA [National Institute on Aging] published a paper that provides some evidence there is expression of H2 in the taste buds, which can be a potential mechanism by which the virus might be affecting taste cells. One of the other things we have learned so far is that the taste tends to recover faster than smell anecdotally, but we don't know exactly why. We can think about these two systems as a very plastic system: there's lots of plasticity. There's lots of changes that happen—renewal of cells and things like that. One of the other things we've been thinking [about] is the amount of viral load. The amount of viral load individuals have can vary; therefore, you may have differences in why some people lose their sense of taste and smell and then recover fast, and some people have not recovered. There's lots of things we're still trying to understand.

Barr: What percentage of patients with COVID have reported a loss of smell and taste? Have there been a range of experiences?

Joseph: That's another great question. It depends on what source you look at. During COVID, one of the challenges we had in terms of assessing taste and smell objectively was because a lot of the tools we use require proximity with patients and exposure of the nasal cavity and nose. With mask wearing, there's a lot of these things we couldn't really do. A lot of the reports we have in excess have been using subjective data—a lot of surveys and so on. We conducted a systematic review of meta-analysis. We see there are reports up to 80 percent—in some papers reports up to 90 percent. It really depends on where we're looking at those reports of losing their sense and smell—[some are] even transient. In terms of the experiences, they're very variable. Some people will have the symptoms and say they regained it two or three days later. Or you'll have people that haven't regained their sense of taste and smell. Even for those that have regained something, especially when it comes to their smell, their smell has been distorted—what we call parosmia. I don't know if you're familiar with reports of where everything smells like sewer all the time. It's not necessarily that there's sewer smell in the room, but that's the perception these individuals are reporting. That's more of what we're seeing with the long haulers.

Barr: That's terrible, but interesting. Is there anything that can be done to try to bring taste and smell back quicker for people who have had it gone for so long?

Joseph: That's another great question. That's one of the limiting factors here. Even before the pandemic, when it comes to treatment of chemosensory disorders, there's a lot more work that needs to be done in that area—in terms of developing effective treatments. There's a variety of things that have been tried. Steroids may or may not work. Olfactory training is something that's been tried by a lot of people with different results. The whole idea behind olfactory training is that you'll smell several substances every day and capitalize on that plasticity that I discussed when having some sort of regain. I'll send you something about olfactory training so you can understand a little bit more. Not everybody will be able to grasp that concept. I'll share some of that with you.

Barr: Okay, that'd be great. Have those who have lost their taste or smell had any subsequent effects, either biological or mental? It seems like it could be dangerous for someone to lose their sense of smell and taste for so long. It could make them very depressed. A lot of times people eat or smell things for pleasure.

Joseph: You have really gathered lots of great questions. In terms of long-term consequences and effects, we've only been through it for a year. Based on some of the data and information we have from prior to the pandemic, many individuals that are anosmic [having no sense of smell or being unable to smell certain things] or have had acquired anosmia—because we have both, congenital and acquired—there have been associations of change alterations with depression and with different types of other mental illnesses. However, it's going to take a little bit of time to really start digging through some of this data and really understand. We probably need to do long-hauler studies—especially for people who have had long-term effects of chemosensory symptoms—to assess and try to really understand not only their mental health in association with this, but also what is happening in terms of nutrition. What is happening if they're eating more of something or less of something because of pleasure? You could think about what risks that could have in terms of weight, in terms of maybe drinking more when it comes to alcohol—things like that. We need to look at it, but the whole concept of long-haulers is pretty recent in comparison to where we were a year ago. It's really trying to understand what the long-term consequences are of COVID overall, not only with these symptoms, but on the mental health as well for individuals with these long-term symptoms and for those that are at risk for other disorders. Where are we going to be in two years, three years, and five years?

Barr: Have there been any reports of people hurting themselves because of a lack of smell or taste—eating food that's too hot or burning their mouth?

Joseph: I haven't really read many reports on that. I have seen a couple of tweets around, especially of individuals that have said they've let their food burn because they couldn't smell it, or things like that. I haven't read anything in terms of injuries in particular. The risk could be there, but in terms of specific reports, I'm not aware.

Barr: When did you and your team begin investigating the links between COVID-19 and chemosensation? You've worked in this field in the past, so how have you leveraged some of your past studies and experiences for tackling this new disease?



Dr. Paule Joseph in her

laboratory at NIAAA.

Joseph: Chemosensation is the bread and butter of my lab. This is something that I was very passionate about—even before it was cool. Early in the pandemic, people in my lab who are very cognizant and aware of this issue of taste and smell, as well as many colleagues from across the world, have noticed those reports [of loss and taste and smell] in particular. I'll tell you what happened. There was a lot of uncertainty here in terms of how to operationalize some of the work. One of the things that I did, together with other colleagues, was develop the Global Consortium for Chemosensory Research (GCCR). It was early in the pandemic, so most of the reports we were seeing were happening in social media—just different people having this report [of loss of smell or taste]. This consortium now has over 600 people from across maybe 62 different countries. The goal of the consortium, even though it started during COVID, was to help unite chemosensory scientists from across the world to answer a question that was important during a public health crisis. We developed tools—a survey that was deployed in 36 languages across the world. This is how we started tackling this, especially because it wasn't just a survey asking if you have COVID taste or smell loss, but really trying to understand the qualitative and quantitative changes that were occurring. That led to several papers that we published as well as some more papers happening [not yet published].

Although the consortium studied COVID, it's also doing work outside COVID. It pushed us to be creative in a time where we can't do chemosensory research the way that we would traditionally do it—in the lab—because it requires proximity with people, and the tools we use to be able to obtain objective data were not feasible at the time, especially on a global scale. We wanted to really understand this across different countries and different groups. That in itself was the best way we could use STANA [The Smell and Taste Association of North America]. It was 600 scientists, clinicians, and patient advocates. The consortium also had patients in it—so it's not just researchers—from 63 countries, dedicated to collecting and analyzing data regarding taste and smell dysfunction with COVID. We're still going strong from that survey. We developed other tools, like the taste and smell check and other things that help people collect more—to help them understand on a daily basis how their senses are varying.

One of the things that I think is very important is that we have a smelling chart. We have this for 20/20 vision. That's a good standard. You're clear, you don't need glasses. We don't have that for taste and smell. We don't have those standards. We don't have routine assessments for taste and smell, even clinically. One of the goals, especially for me as a clinician and others in the field, is I would like to see these things—develop good tools that can be implemented in clinical practice, can help us get normative numbers, and help us assess these senses over time. Even when people are discussing that their sense of taste and smell is recovering, the issue is determining what stage they are recovering from. We don't know where you were or what your baseline was prior to COVID. We don't even know where you were during COVID, so when you are recovering, are you recovering back to your baseline or are you recovering to a lesser degree. Understanding these things is important because we know these senses get diminished with age. Are we seeing a population right now that, as they age, will have a faster decline—a more pronounced decline? These are things that we're not going to be able to answer unless we follow people over time.

Barr: Definitely. How long did it take you to compile your questions for your surveys and your checks? What kind of considerations did you make in terms of formation of the questions because it would go out to so many different kinds of people?

Joseph: Great question. In terms of considerations, this was a group effort, especially since we became a consortium. All of us had input in terms of the most appropriate questions, especially when it comes to chemosensory assessments—asking people about their taste and smell prior to the pandemic, during the disease, and after. We captured the range of the experience of the disorder. We also needed to find out if people had been tested via PCR tests, whether they were diagnosed, and, especially early in the pandemic, whether they were diagnosed by clinical symptoms because tests were not available for everybody across the world equally. We had a lot of these things to consider as we were asking these questions.

Barr: Some kind of surveys are using a lot of CDEs [common data elements] when they form their questions. Are there any for your type of research, and did you use them for the surveys that you created?

Joseph: The traditional CDEs that exist right now; there's not a lot of those on chemosensory assessments. We really focus a lot on that chemosensory experience, but it would be a great idea to have common data elements associated with chemosensation. Many years ago, assessments of taste and smell were added to the NIH Toolbox. If we can maybe even capitalize on that and use that as a battery of tests that already exists, it can be used by scientists across different places to create common data elements associated with chemosensation. That would be fantastic. We would have data across different populations and so on and so forth. Maybe this is an opportunity for us to really think about adding this through the traditional common data element platform.

Barr: How long did it take you to formulate your questions? How did you distribute these surveys to all these various people?

Joseph: It was a big group effort. The survey was launched April 7th. We started noticing these symptoms March 19th, so early. By April 7th we already had the survey developed and translated into ten languages. It was all hands-on deck. It was a lot of work, especially for the leadership team of the consortia, which I'm part of. We met every single day—long hours—just really refining. Members really pitched in to develop the questions and translate. All that effort took a lot of hours as well. You can create magic when you bring people together searching for the same answers, having a great cause, and a common research interest. That's really what we saw here.

Barr: That's really wonderful. Can you talk a little bit about some of your other COVID research initiatives?

Joseph: In the intramural program, we collaborated with Dr. Blake Warner from NIDCR. We added taste and smell measures within the protocol he initiated collecting saliva. We have that collaboration going. We also have a collaboration with Dr. Nancy Diazgranados and Dr. Vijay Ramchandani of NIAAA. We deployed a protocol to really understand the impact of COVID during alcohol consumption so there's more subjective measures. Again, you cannot really bring all these participants in, especially during the pandemic, to collect objective measures. Although, there might be some ways in which we can think about maybe mailing some things to people as more measures are being developed across the world. There might be some other ways in which we can collect these things.

Barr: Do most of your participants access these surveys and these diagnostic checks online?

Joseph: All of this is online. It's all on the website. There's also a Twitter account and a Facebook group that has been created. All these things are pretty much available for people to do, and people continue to answer. It's May 27th [2021], but people are still being affected, and we can see the data even for India.

Barr: It's probably interesting for you to see what it is now.

Joseph: It's been an interesting experience for me in particular—the ability to work with people from across the world in areas that I probably would not have gone so quickly on the traditional path. I think this has really opened doors and windows of opportunities to really extend collaborations in corners of the world where we probably could not have gone as a unit. Having great colleagues, we can make things happen, so that's been really great.

Barr: You said you had some patients that were part of your consortium as well as some advocacy groups. How did those groups help with distributing these different tools that you created to test chemosensation and COVID?

Joseph: Even in the leadership team there is a patient advocate. At the end of the day as a clinician, you know that the patient voice is critical. We really need to understand what the patient experiences. What are some of the questions they would love to have heard? We can open more opportunities for research. They play a lot of different roles, even looking through the questions before we finalize them and just making sure they're clear. The patient advocates are, again, not only U.S.-based, they're across the world. Many of the advocacy groups, for example in the U.K., did a lot of work in trying to get taste and smell symptoms with COVID recognized in the U.K. Through this gathering, STANA [The Smell and Taste Association of North America] has also been developed, which is the patient advocacy group for the U.S. That was recently developed because there was not an equivalent here in the U.S., so that's newer. I would say it's good to have a place where patients can congregate and really understand their experiences, especially those that have been having these symptoms with COVID. But we also cannot forget the people that were here before COVID having taste and smell disorders. As I said, there's many people who had congenital and acquired anosmia. There's so much work going on in that area—patients that would lose their sense of taste and smell after traumatic brain injury and other conditions.

Barr: Do you think COVID has highlighted this situation? How are you using this common situation of people losing their sense of smell and taste to advocate for more research in the field in general?

Joseph: That's one of the things that COVID has done. It has really highlighted the importance of the chemical senses. It's what I sometimes refer to as the "forgotten senses"—the neglected senses. Overnight they were not neglected anymore. People had heightened awareness that their taste and smell was not the same. It just really highlighted the importance of continuing to do work on this, especially to develop an understanding of what happens from a mechanistic perspective, what happens in terms of patient experiences, and what can lead us to advanced treatment. Maybe there will be more that we could have done if we can have potential targets for treatment, that can help not only those that lost their sense of smell with COVID but also those that existed prior to COVID and will continue [to exist]. If we take the average number of people that have been affected now with the average number of people that were affected before, we're looking at a conservative estimate of about three million people who have lost their sense of taste and smell. That's a lot. Again, thinking about long-term consequences, what does that mean for those individuals in the long-term? Those are some things to think about.

Barr: Do you have any studies in the works to look at some of those issues or not yet?

Joseph: Not yet. There are some ideas floating around. Right now, at least within the intramural program, I have partnered with Dr. Avindra Nath from NINDS [National Institute of Neurological Disorders and Stroke] and Dr. Brian Walitt with NINR [National Institute of Nursing Research]. We'll be running a long-hauler study, so we actually have objective chemosensory testing. We need that protocol.

Barr: That's great. I was going to ask if you're going to look at the long-haulers.

Joseph: That's a great opportunity because that long-hauler protocol really has a very rich battery of assessments. If I have learned anything through COVID, it's that engaging in these collaborations is very efficient because they're bringing so much expertise together to really study this long-hauler population. It will provide data specific to the chemical senses, but also other data, like the mental health piece and other questions they're asking. We can look in association with these symptoms and see differences between groups, so we can see a little bit more of what happens here. I'm very excited.

Barr: That's really exciting. When is this study going to be launched?

Joseph: Right now, I think it's being reviewed, so we should be hearing pretty soon. I'm very excited to get that rolling. That should provide some very exciting data over the years.

Barr: Definitely. We're going to switch from you as a scientist to you as a person who's been living through the pandemic. What have been some personal challenges and opportunities for you during the pandemic?

Joseph: Challenges? Let's start positive and start with opportunities. I like the idea of starting with opportunities. I think on a personal level, it gave me more time with my family. It's just kind of renewed that experience—being together as a family. I just really loved that a lot. I'm originally from Venezuela, so I remember being little and always coming home, running to my family and all of that. Then you grow up and get into a routine and mode and you take for granted all of those opportunities sometimes.

Barr: How many children do you have?

Joseph: Two boys. 6 and 9 years old.

Barr: That's nice that you got to be with them.

Joseph: Yes, they are fun. It's just in general great—time with my parents—just time with family overall. That was really great and refreshing. My family is very close so that was a great time and opportunity for all of us. The other thing is in terms of reflection time. Just reflecting on the things that are important in life—the meaningful things that you consider meaningful for yourself. [Having] time to really think about what matters, and just putting all that in context. Personal plus career. Reflecting on that to make some informed decisions in the future. COVID provided a pause, not only on the material things, but just a pause in general—to grow. Especially, for me, spiritually, which is a big part of my life.

Barr: That's nice! What has been something that you enjoy that has helped you cope with the stresses of the pandemic?

Joseph: Oh, that's right, the challenges and stress! There's been so many challenges in terms of changing from the routine of coming to work every day and now the routine of working in your office at home—just creating that balance between [work and home]. Now you're right there at home and it's like, "Okay, how do I make all these things happen?" Getting adjusted to a different tempo was different—I don't know if it was necessarily a challenge as much as it was different. I always embraced change, so it was something new to do. How do I cope with a lot of these things? I have coped with a lot of challenges in life. I'm big, big into meditation practice and yoga, so those are very much part of my life and my daily routines. That's how I cope with change—I kind of distance and separate myself into just diving into meditation and reflecting as to why things sometimes happen the way they happen. I like reading a lot, so I've found more time to read—and other things than science.

Barr: What's your favorite book that you've read lately?

Joseph: During the pandemic there's been... I've read so many. One of my favorites that I've been reading is a book called "Karma" from Sadguru, which was very, very interesting. I've been reading a lot of that and it's a very, very fascinating book. I kind of have a very broad range of readings that I do.

Barr: That's nice, it's a good break from your career.

Joseph: Yeah, absolutely. Those types of things, but just embracing the moment and living in the moment, and just acknowledging that it is what it is. There are certain things we just don't have control over, and this has been highlighted with COVID.

Barr: Definitely. This is a fun question. What do you hope to do, now that the restrictions have relaxed, that you couldn't do last summer, as we're approaching Memorial Day?

Joseph: That's a great question. There are so many things I had planned for last summer including a silent meditation retreat that I couldn't do. I'm hoping I can do this now, at least towards the end of the summer. Although, I do have a Board of Scientific Counselors site visit pretty soon, so I'm probably going to have to schedule that [meditation retreat] a little bit after that or before [the site visit]. Those are things that I consider fun for me. I love just taking a break. I like going out a lot, in terms of outdoors and just exploring. I had this whole entire trip planned to Bali which I wish I could have finished last year. We could have gone last year but I didn't get a chance to. I'm thinking about what I'm going to do—just being able to just go outside and enjoy things. I'm still wearing my mask so I'm still "behind the mask." One of the great things with the mask is this is the first year I haven't had terrible allergies so I'm keeping my mask probably forever! It's been good to know that restrictions have been relaxed, but we're still learning a lot about what's coming next, so I'm still behind the mask and I will stay behind the mask to decrease my allergies.

Barr: I don't blame you. Is there anything else that you want to add as an NIH scientist but also as somebody dealing with COVID-19 as a human being in the world?

Joseph: Let's see if I have anything to add. I think that COVID gives us a time to renew energy, renew sense of self, at least for me. Where do I want my science to go? How do I want to contribute? I have appreciated having that time to really think and ponder on those things, but also just to embrace continuous change, because life is always changing. Nothing is ever stagnant. We went through a very difficult situation, but we are emerging through it. I'm just very grateful for science and to be a scientist and to be able to contribute during a very difficult situation—a global health crisis. I could really see my contributions as a clinician because I had the opportunity to really volunteer, especially at the NIH through COVID Response and OMS [Occupational Medical Service] and so on and so forth.

Barr: What did you do with that? Were you a greeter or in the car line or a vaccine person?

Joseph: I was on the car line, and I was in the call center. When we were in the car line, we were doing the testing. When I was in the call center, I was just doing a lot of the screenings.

Barr: What did you do in the call center? What did they have you do?

Joseph: In the call center we do a lot. I'm still in the call center now. I do most of the work over the weekends and in my volunteering time. Employees call when they needed to be screened, so we can assess whether they need to be tested or not. That was a really rewarding experience. For me as a nurse, clinician, and scientist, that was an immediate place where I could contribute during the pandemic, to really use my skills and be there. We were noticing the chemosensory symptoms early on. There were discussions I was having with others in the call center, [suggesting] we probably needed to be watching for these symptoms. Later, this was added to the questionnaire. I was very excited to see that. That opportunity to use my skills in different settings is one of the reasons I really love working here at the NIH. It allows me to be a clinician, it allows me to be a scientist and to use those skills to really contribute to the betterment of public health.

Barr: Did you volunteer in the vaccine center giving vaccines?

Joseph: I didn't get a chance to go volunteer in the vaccine units. I did sign up for it, but I didn't get a chance. Things got a little bit complicated during the time I was going to do it, but I'm grateful that the opportunity was there for us to volunteer.

Barr: What was it like to be in the car line? I didn't know that you all did these things.

Joseph: I did a lot of things. It was very early. I think it was March or April when we started. I can't even remember the timeline. It was interesting because there were a lot of policies that were implemented quickly to keep us safe—to keep everyone safe. Another great experience was really seeing how different people at NIH came together, whether it was the fire department fellows volunteering, PIs [Principal Investigators] volunteering—everyone was just wanting to help and keep everyone safe. That was great. You collected a sample, and the sample was being taken over to the other side of the building to get tests run. It was just great to see everyone really involved and contributing their skills and just being able to help. For me the quite clear thing was that we take an oath to help and to do well, so I wanted to be able to contribute.

Barr: That's really impressive and it's nice that you're able to combine your skills as a nurse but also as a scientist!

Joseph: Yeah, that's great. It's been a great experience. It's been a hard year, but it's been a "growing" year, so I think I have grown as a person, on a personal level. I have grown as a scientist just because it really required a lot of adapting to really advance the science, but also keep the public safe. I'm the person that—at least within my family—people are looking to for answers to questions. In my circle of friends, people are asking for answers to questions, so it was great. I was glad that I had that knowledge and that ability to really put things into perspective in lay terms.

Barr: That's a lot of pressure to be asked all those questions.

Joseph: Yeah, well when your grandmother is trying to figure out whether she should be vaccinated or not, and you can explain why, it just really makes a difference. I'm just glad that I could do that for friends and family. That was really great.

Barr: That is really great. I wish you and your staff and family all the best as you continue, and I hope that you all continue to stay safe.

Joseph: Thank you so much.