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Behind the Mask

October 27, 2021

Barr: Good afternoon. Today is October 27, 2021. My name is Gabrielle Barr. I'm the archivist in the Office of NIH History and Stetten Museum. Today, I have the pleasure of speaking with Dr. Francis McMahon. Dr. McMahon is the Chief of the Human Genetics Branch at the National Institute of Mental Health [NIMH]. Today he is going to be speaking about some of his COVID-19 research, particularly focusing on two studies. Thank you very much for being with me.

McMahon: Happy to be here. Gabrielle my last name is pronounced McMann.

Barr: Okay, I'm so sorry.

McMahon: That's okay. Everyone has trouble with it.

Barr: Okay, so will you please speak about your role in the study that looked at the mental health impact on NIMH research participants and volunteers?

McMahon: We've been working with Amish and Mennonite communities in North America and South America for the last 10 years or so in an effort to understand how genetics influence the risk for disorders like bipolar illness and depression. The reason we work with those populations is that they have a special genetic history, which makes it sometimes easier to find genes that have a large effect on particular illnesses. There's a long history of Amish and Mennonite communities participating in medical genetic research for that reason.
The other very helpful thing is that they are some of the largest families that we can still find in the United States. For genetic studies, big families are very helpful, because families share genes, early-life experiences, practices, and home environment that we know are important in influencing mental health.

We've had a very productive relationship with the Amish and Mennonite communities over the last 10 years. Then when the pandemic started, in March of 2020, we had to suddenly change gears. As you may know, particularly the conservative Amish and Mennonites don't generally rely on electronic communication. So they typically won't have computers in their homes, maybe not even telephones. We rely heavily on our clinical team being able to go out in the field and visit people in their homes or in local clinics. We had to suddenly change that when the pandemic started.

One of the things that we realized is that many of our study participants didn't know what became of us because it was hard for us to communicate with them in the usual way. We started reaching out, generally via mail or by telephone. It became clear to us that the pandemic was also affecting those communities in ways that might be a bit different than in more urbanized parts of the United States. We thought it would be helpful to engage with our study participants with whom we had a long relationship in many cases and get a sense from them about how they were, how the pandemic was affecting them, how they were dealing with it. We decided to test the idea that people who already had mental health struggles might have particular problems in dealing with the changes and social isolation that the pandemic brought about.

Barr: How did you gather some of that information during the pandemic?

McMahon: That was our first big challenge. What we decided to do was come up with a series of mailings that we could send out to people in their homes that consisted of some questionnaires that measured things like mood and anxiety, and also asked people about the ways in which the change in the pandemic were affecting their daily lives. We used the questionnaire that has been used by a larger online study led by [Dr.] Joyce Chung [NIH Clinical Center]. We adapted it for paper-and-pencil use and also changed some of the content to be more appropriate to Amish and Mennonite communities. The important thing is that we had… [interrupted by interviewer]

Barr: How many communities do you have contact with throughout the world?

McMahon: Well, quite a few. It's often the case that people think of the Amish as one entity, but in fact there are hundreds of different Amish settlements all around the Americas, including areas in Canada and South America. And they all have different practices. Some are very conservative. They don't use electronics, don't use telephones, don't even have electricity in their homes. Others are very modern. If you were to see them on the street, you wouldn't realize that they were practicing Amish. So we've learned in working with these populations that there isn't one Amish community. There are many Amish communities.

The same is true about Mennonites. The Amish and Mennonites have a historical relationship having arisen during the early part of the Reformation in the 1500s. Generally, their genetic ancestry traces back to parts of Germany, Switzerland, and the Netherlands. So there are distinct genetic relationships between the groups. They often live together geographically in the United States, particularly. We've also worked with communities in Brazil who are primarily Mennonites. They have a somewhat different history. They call themselves "Russia Mennonites" and that's because when they left Western Europe, they settled in parts of modern-day Ukraine, where they lived for several centuries before emigrating around the time of the First World War. Many of the South American Mennonite settlements came from that origin.

Under the circumstances of having to rely on postal services, we didn't think it was practical to try and do the study with our Brazilian Mennonite participants. So we focused on the folks in Canada and the United States. Those are communities mainly in Pennsylvania, Ohio, Indiana, Ontario, parts of Michigan and Wisconsin, and parts of Iowa was well.

Barr: What were some of the findings from the study? Oh, continue. Sorry.

McMahon: Yeah, no problem. I should say that at this point the way we designed this study was to have four waves of data collection. The first went out as soon as possible during the pandemic. Then the second wave went out about six months later. We're now in our third wave of mailings. We plan ultimately to do a fourth wave of questionnaires in the happy days when the pandemic is declared over.

When we initially started the study, we thought that two years would be a very safe time to say the pandemic was over. Now, we're realizing we're probably going to have to push that back a bit in order to really get a measurement of how people have been able to resume their normal lives after the pandemic has really gone.

I should also say that, at this point, we have not formally analyzed most of these data, but I can give you some qualitative impressions of the questionnaire we got back in the first wave. These are folks who were

experiencing the initial lockdowns and disruptions in the first year or so of the pandemic. One of the things that really strikes me the most about looking at these data is how variable their responses were. Many people said that, yes, the pandemic had affected them in economic ways. They weren't able to open their retail operations or to work in places that required on-site labor. So there were economic disruptions that came from that.

Many people talked about social isolation that came on account of the pandemic, although they also noted—since most of our participants live in extended families—that they were able to continue to maintain contact within their immediate family units on a day-to-day basis, which we think probably will help buffer some of the mental health impacts when we finally analyze the data. We also had a number of people tell us that they found that the pandemic was really very anxiety provoking. Probably anxiety was the biggest complaint that we saw in these data—anxiety about how their lives were going to be affected going forward, anxiety about the illness itself, and whether it would infect them or their family members. Unfortunately, some folks reported to us that they did have members of the community who died of the illness. [They had] anxiety about how they could access medical services, because a lot of the Amish and Mennonite communities we work with are in fairly remote rural areas in the United States. So their access to health care, particularly mental health care, is very limited. They also had anxiety about the how the pandemic was going to affect their ability to make a living.

Barr: How is the virus spoken about? I know, it's probably very variable across the community since they don't have as much technology as maybe those outside of those communities. We see it all the time on TV and on the computer. How is the virus spoken about in their communities, both in terms of tone as well as the medium for the messaging?

McMahon: Yes, that's actually one of the things that we asked about in our questionnaires—where most people were getting their information from. Most people said they were getting it through word of mouth. Despite that, it seems that many people were quite well informed about the virus and how it was affecting their communities at various times. We don't yet have information back on our participants who experienced the pandemic once the vaccine became available. It'll be interesting to see, first of all, whether vaccine uptake has been widespread in these communities or not, and how much the barriers to accessing health care may affect that.

Barr: I had some other questions. I have heard that in some Amish communities, there was a very high percentage of that community that got sick, and some of them even achieved herd immunity. I've also heard that in some communities, they don't embrace modern health care. So they don't take tests and they didn't embrace the vaccine, and they did return to normal life sooner than maybe those outside. How has that been seen in your research in terms of affecting their mental health in in comparison to those in the English population?

McMahon: I should say we don't have any firsthand information on that since we haven't been out there observing what's going on in the community. Our sources of information are probably similar to yours in that regard, but what people tell us, in their responses to the questionnaires, is that things did start to return to a fairly normal life, probably about in the springtime of this year. That was a welcome change, because that's often the time when planting and auctions and other activities that require groups of people to work together, get underway. One open question is whether that return to a normal lifestyle will have a protective effect on the mental health impacts. We don't yet know that, but the data we got from the first round of questionnaires suggest that a lot of people, in addition to anxiety, felt socially isolated. There were increases in depression and a lot of concern about whether things would ever return to normal after the pandemic ended. Questions we all have, I think, even in the broader society.

Barr: That is very interesting. What are you hoping to find out in your fourth wave of questionnaires?

McMahon: In our fourth wave, we're trying to get a sense of how long it takes for people to return to their baseline not only in terms of daily living, but in terms of their mental health. Now we have measures on our study participants that go back several years before the pandemic, so we can actually compare a baseline state of mental health. Many of our participants, at baseline, struggle with mental health symptoms. That's why they're in our study. Then we have measures during the pandemic, the initial phase, as things started to return to normal. Then we finally want to get a measure of when things really seem entirely back to normal. Our hypothesis is that some people will have a harder time resuming their previous level of daily function. We plan to look at whether genetic risk factors for depression and anxiety play a role in that, as well as other factors that may be protective, such as strong community bonds, family support, and religious practices.

Barr: That will be really interesting to see. What was it like for you guys, you said that you mailed these questionnaires? What was the process? That's a lot of manual labor to address all these envelopes, send them out, process the information, and put it into some kind of spreadsheet for you to later analyze. Can you talk a little bit about what that process was like for you all?

McMahon: That was a big logistical challenge, I must say. I'm very grateful to my clinical team, particularly to our postbac [postbaccalaureate] fellows, who did a lot of that manual labor and made sure that the mailings got out and are still making sure that they get out. We had to deal with things like how do we do large-scale printing and packing of envelopes when we couldn't access the campus resources? How do we make sure that when mailings are returned, that we don't lose track of them somewhere in the mailroom? One thing that initially we hadn't anticipated, which proved to be quite significant, is how do we respond in real time when people tell us on their questionnaires that they're in real distress? What we decided to do was to institute a protocol where as soon as an envelope is received, a member of our clinical team reviews key questions that relate to safety, and whether someone is actively feeling suicidal, for example. Individuals who answered yes to those questions, I was immediately notified. We reached out to them by telephone when possible, or by mailing when it wasn't, to make sure that they were hooked up with additional supports and mental health resources. We didn't anticipate that there would be many such responses at the beginning of this, but it turned out there were quite a few. We probably reached out to over 25 of our study participants who had endorsed thoughts of suicide. The other thing that was really interesting is that when we did that, the overwhelming response to that was gratitude. I was worried that people might feel that we were intruding in some way, but almost everyone that we contacted was glad to hear from us and was glad to actually have the support of a friendly voice at the end of the phone, and some help in getting hooked up with mental health services. We were glad to be able to provide some help and support to the community in that way. A small return for all the work they've put in for us over the years in the study.

Barr: Yeah. Did you ever feel like because it's by mail, that perhaps maybe you were too late in contacting a person because you didn't get that information in time?

McMahon: We worried about that and discussed it with the IRB [Institutional Review Board] to make sure that we all felt comfortable with the kind of timeframe that was necessarily involved here. We also worried about whether—because the pandemic really peaked at different times in different communities—we would be able to really capture the impacts of the pandemic in real time. We're still not sure whether we're going to be able to do that, but we're hoping that the COVID questionnaire that went out with mental health measures will allow us to correct for, if you will, the degree of the pandemic at the time in each community.

Barr: Have you been involved in other COVID-19 research initiatives?

McMahon: Not directly. We were indirectly involved in Dr. Chung's study. That's how we learned about the COVID questionnaire. We were able to adapt it for our study.

Barr: Have you done anything else on campus in terms of services to your fellow NIH colleagues?

McMahon: I have not.

Barr: In addition to being a scientist, you're also a person yourself living through the pandemic. What have been some challenges and opportunities that COVID-19 has presented for you?

McMahon: That's a big question. It was actually an enormous challenge for us to be able to reconfigure our day-to-day operations on relatively short notice. We were really fortunate to have a lot of support through our Scientific Director's office in getting everyone online, making sure everyone had enough laptops, having a system for allowing people to safely come into campus, because we also have a laboratory operation with growing cells and things that need to be maintained on a day-to-day basis. We have to do that while maintaining safety and social distancing, etc. We worked out a system where we met every day via Zoom and made sure that we were keeping track of all that needs to be handled. We also made sure that members of our team had the opportunity to let us know what challenges they were going through. We had a couple of folks test positive. Fortunately, no one was severely ill. But that also was something that we had to deal with as we moved through this. Now that we're finally to the point where we are able to have most people return to campus on a semiregular basis, we really have a sense—this sigh of relief, sort of holding their breath—waiting for this to improve. Now there's a real sense that we see light at the end of the tunnel. I'd say the biggest challenge really was communication. One of the things that happens almost automatically when everyone's working together in the same space is we tell things to one another, we read one another's body language, we see facial expressions, we observe somebody carrying out a procedure. All of that was much much harder. Most of our communication was via Zoom. It was hard, even for our fellows, to go into the lab and learn procedures by standing next to a more experienced lab member.

Barr: Have you guys gone back to some of the research that you were engaged in before the pandemic? What is that been like balancing both your COVID research and some of your other research?

McMahon: Yes, we've gradually been able to resume some of our work. We have focused on participants who are able to interact by telephone. So we've been doing some of our mental health interviews by telephone. And we've been using a contract phlebotomy service for collecting blood samples. That's allowed us to resume at about half the rate that we've had been going before, at least in in North America. We've also had to move all of our data-management into an online system. That's taking some adjustment. We used to meet face to face once a week to review our mental health assessments, medical records, and other information, and discuss each case among our clinicians. We've had to work out a way to do that on a virtual platform. We've also had to suspend our more far-flung operations until we can have a larger portion of our staff being able to travel. We had been planning, for example, to start some new collections down in South America, places like Paraguay and Belize. And of course, we had to suspend that until after we're able to resume normal travel.

Barr: That's quite that's a lot of adjusting.

McMahon: Yes, it is. I won't say that there hasn't been some friction. There certainly has been from time to time. But by and large, people have been able to adjust very well and managed to work together under pretty extraordinary circumstances.

Barr: Yeah. Do you have any tips on how to cope with all this adjustment for other people who are also struggling to adjust?

McMahon: Yes. I'm not sure that we have a solution to it, but one thing that that we've tried to do as much as possible is make sure that everyone feels as connected as they can to the research team. We've had fellows who are still living at home while doing their fellowships. We make a particular effort to reach out to them and make sure that they have regular meetings with me and other members of the research team. We've increased our joint meetings, journal clubs, seminars, things like that, just to give everyone a chance to get together online. We encourage people to turn their cameras on during the Zoom calls so we can see one another's faces. And we've done our best to celebrate events like comings and goings in open Zoom meetings where people can sit down and have lunch together through the computer, but it's not the same. I think everyone is very ready to be able to resume one-to-one interactions.

One thing that I've particularly missed is the ability to interact with my colleagues in the Porter Center [John Edward Porter Neuroscience Research Center]. That building is a terrific place for people who are working on a broad range of neuroscience problems to get together informally at the coffee shop or over lunch. I missed that kind of informal hallway-type interaction. When everything is reduced to an hour-long Zoom call, it really changes the nature of the interactions.

Barr: Definitely. Is there anything else that you would like to share either about your research in the Amish community, or about your COVID-19 experience?

McMahon: Well, one of the things I will say is that, as we have shifted more toward doing our work online, we realize that there may be ways that we can maintain these sorts of structures going forward. So it hasn't been all bad. It's really important with genetic studies to have large sample sizes. Computerized methods of reaching out to study participants, doing assessments, etc., save us a lot of time in travel. We've actually started to rethink ways in which we might be able to work with other communities to expand our research. For example, we have been reaching out to Mormon communities.

Barr: I was going to ask you about that.

McMahon: Again, because they are large families and… [interrupted by interviewer]

Barr: How about the Orthodox Jewish community? Do you have any interest?

McMahon: That would be another possibility as well. We been spread as thin as we can go at the moment. But I think the Orthodox Jewish community also has a long history of active participation in medical genetics research, and we would love to work with them.

Barr: I was wondering, within Mormon and then occasionally within the Orthodox Jewish community, you have people from the outside that join that community, so their genetics is not the same necessarily. Is that the case with the Amish? What is the rate of people joining that community?

McMahon: So as I understand it, among the Amish, there's relatively few people who come into the community from outside. That's different in Mennonites. The Mennonite community often grows through evangelism and proselytizing. Mennonites are actually one of the fastest growing religions in the country right now, as I understand it.

Barr: I didn't realize that.

McMahon: A lot of that is by recruiting people into the Mennonite Church. We have genetic tools that allow us to sort all that out pretty easily. What we do see is that among the conservative Amish communities, we see a very particular set of genetic markers. Some of them are very local, so that we can place an individual within Pennsylvania or Ohio or Indiana, based on those genetic markers. Whereas for many of our Mennonite participants, there's a distinct set of genetic markers. That's also different for the Mennonites in Brazil who emigrated from Ukraine.

Barr: That is really interesting.

McMahon: It's a very clear delineation. Now, in practice there are, as I understand it, some Amish who decide to not be baptized as Amish, but to join the Mennonite Church. They're often neighbors and have a similar lifestyle. So we also see within our self-described Mennonite groups, individuals who are genetically more similar to the Amish.

Barr: That's very interesting. Well, thank you very much for sharing your research with me today. And I wish you continued health and continued success.

McMahon: Thank you very much. Thanks for your interest. I appreciate having the chance to talk with you today.