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Behind the Mask
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Interviewed by Gabrielle Barr, Archivist, Office of NIH History and Stetten Museum, NIH

Barr: Today is June 7, 2023. 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. Nirali Shah. Dr. Shah is a Lasker Clinical Research Scholar, and the Head of the Hematologic Malignancies Section of the Pediatric Oncology Branch with the National Cancer Institute (NCI). Today, she's primarily going to speak about how treatment of her patients was affected by the COVID-19 pandemic. Thank you very much for being with me.

Shah Thank you so much for having me.

Barr: Definitely. While this interview will focus on how COVID-19 affected your research and treatment of patients, will you briefly discuss your areas of interest, as well as what led you to pediatric oncology as a specialization in the first place? And what are some of the unique challenges in treating patients within this age demographic that are still growing and developing?

Shah: At first, I didn't know about pediatric oncology as a child. But a fundraiser for a school project that I was doing—it was called a Math-A-Thon and it was for St. Jude Children's Hospital—was the first time that I ever came across St. Jude Children's Hospital and learned about pediatric oncology. I think ever since then I have been drawn to the field. I knew from a very young age that I wanted to be in medicine, that I wanted to take care of children. I actually found a book when I was visiting my parents in my childhood home. It's my fourth-grade book and it says, "I want to be a pediatrician," and the pediatric oncology part came in shortly thereafter.

In terms of the unique challenges in treating patients in this age demographic—in the context of my work, I treat children, adolescents, and young adults. I trained in both internal medicine and pediatrics. I think that each population presents its own challenges. For the younger pediatric patients, it's a lot more supporting the parents, really being part of that family, knowing how to interact with the child, and support the child. For adolescents, its already hard enough being a teenager, and that's even without having cancer. Trying to navigate independence in the context of the cancer diagnosis is really challenging. I think that we try hard to preserve the patient's autonomy, while keeping in mind that they are very reliant on their caregivers. And then young adults, I think, can be increasingly more complex depending on the age of the patient and where they are in their lives. We've had some young adults who were diagnosed as children who have continued to not be able to reach some of the normal milestones. We have other young adults who are parents. It's a very, very interesting and challenging dynamic in terms of the work that we do.

Barr: Can you talk about some of your research in broad strokes, which includes the development of targeted immunotherapy approaches to treat various blood cancers, your work on the prevention and treatment of relapsed disease after allogenic hematopoietic stem-cell transplantation, your work on exploring and improving chimeric antigen receptor T-cell-based therapies, and your efforts to try to find solutions to reduce toxicity and late effects on cancer therapy?

Shah: I'll start with the target immunotherapy. Basically, in pediatric B-cell ALL [acute lymphocytic leukemia], with current treatment approaches using standard chemotherapeutic-based strategies, we anticipate that 85% to 90% of children with standard-risk ALL are going to be cured. But B-cell ALLs are the most commonly diagnosed childhood cancer. And even that 10 to 15% of patients who have either relapsed or refractory [disease], that still makes ALL one of the leading causes of cancer-related deaths in children. Older patients who get ALL tend to have biologically higher-risk B-cell ALL that doesn't respond well to chemotherapy. Additionally, certain cytogenetic risk-factors found in the leukemia are also less likely to respond. So, our goal is to try to overcome chemotherapy resistance and find ways to make the immune system able to target cancer cells.

CAR T cells, or chimeric antigen receptor T cells, are where you are taking a patient's T cells outside of the body, engineering them so that they're able to target certain markers that are found in the leukemia, [and] you give them back to the patient. You have in essence, given them a living drug, because once those T cells see the leukemia, if it's working, they should grow, expand, and kill the leukemia cells. CAR T-cell therapies in pediatric patients have now been used for a little over a decade. Now that there are patients who are getting to have long-term cures, I think that this new modality of therapy warrants further study in terms of thinking about late effects. In some regards, if you're able to use CAR T cells and prevent patients from getting additional chemotherapy (which is associated with its own side effect), that may be your very best outcome. But we don't know what the long-term outcomes are. I think that we need to start to compile that in a very systematic way.

Barr: Yeah. Well, that's very interesting and hopefully, we'll have a chance to talk about this more in depth at a later time. When the pandemic struck, what were your first thoughts as a medical practitioner for your patients at NIH?

Shah: Oh, goodness. So, I have three kids and I work full time. Basically, one day they were in school, and the next day they were home. My nanny was sick, and everybody was worried that it was COVID. My husband also works full time, and I had active patients that were here at the NIH Clinical Center. It really disrupted the normal flow of how I separate out my day, personally. Because now you're trying to do everything all at once. It really became not humanly possible. There were a lot of strategic things we had to do at home, which included my husband transitioning working from home full time, which happened with the pandemic. In the meantime, I was here (at the NIH CC) nearly every day, at least at the very beginning.

I think what was particularly challenging is that while there was a certain workforce that converted to [being] completely remote, those of us who had active patients, like I did—my patients are primarily inpatient who had active ongoing needs, we continued to do the work that we were doing to provide optimal care to our patients in need, as we did every other day while we watched the world change all around us. I think that discord was particularly challenging as you tried to figure out how it was going to work. But I often told my patients that leukemia doesn't stop for COVID. For some of the therapies that we have at the Clinical Center, that therapy may be that child's only hope. And so, while certain non-intervention clinical trials did close—our program stayed open. So, we had to also navigate how patients traveled. Keeping in mind these are immunocompromised patients. We had one patient who drove here from Chicago because flying seemed too risky. We basically charted out what hospitals were on the way in case an emergency evolved in the course of traveling to get here. They subsequently came here, had a good response, and went to another center to seek further therapy. But we really had to do a lot of interesting navigation to get through this.

Barr: Can you speak about some other examples of having to think outside the box in order to get your patients the treatment they need, but keep them safe?

Shah: I think the one thing—and this actually isn't outside the box, this was us staying in the box. I think that we tried to adhere to the highest standards and principles of clinical research and conduct so as not to compromise anything that would to impact their outcomes. When you have a research infrastructure that has all of a sudden shrunk, and you don't have the normal people who are usually inhouse—a lot of us took on additional responsibilities. So yeah, I had to ship samples. We all took on additional responsibilities, because there was now a group of folks who were there usually that were no longer coming in. We all had to step up. I think [it's] not to say that we worked harder. I think it was equally challenging for those who weren't coming in. Because for some people, they were told explicitly not to come in. I think that also made it really challenging because we have a group of care providers where we know that the work that they do is so important. It might be supportive care, it might be child life, it might be social work, but they are essential to the clinical workflow. Having them work remotely was also challenging because it sort of tugs at your heart to not be able to be there at the patient's bedside when that's all you know how your work is. Right?

Barr: Definitely.

Shah: I think it was challenging for many, many people.

Barr: Can you speak a little bit about how some of your processes changed in terms of the pandemic, in terms of caring for the patient? I know the treatment must be the same, but any of the other precautions before or after?

Shah: We did have to do definitely separate precautions. Everybody had to do COVID testing before they came [and] COVID testing before procedures. So, we had to this additional time and element of their care [and] we just have to be extra, extra cautious about things. I think it was probably to the patient's benefit because you're dealing with immunocompromised patients. Just to give you a sense, pre-pandemic, even when there's a high flu season, we'd sort of functioned like it's a pandemic. Now all of a sudden, everybody's experiencing the pandemic. That one patient that I had mentioned who drove from Chicago, his family put it the best, and it just made me think about things so differently. I remember talking to him, and I apologized to him. I'm like, "I'm so sorry, that we're taking all these extra precautions. I know that it sort of seems crazy that we're doing all of this." We could only have like one parent in the room and things like that. He said, "Dr. Shah, we've been living the last couple of years like it's a pandemic, the rest of you are just catching up." I was like, "All right. That is a very good point." All of a sudden, it just made me think a little bit differently.

Barr: Yeah. Did you worry that you or others, like your co-workers, could be exposing these patients to COVID-19? How did you deal with that?

Shah: Yeah, so I would say that that was really hard. And I think many providers felt really differently. For some people, I think that the COVID experience was extremely isolating. Not being able to travel was hard. When you did travel, you had to worry about the rest of your work team and how comfortable others were being around somebody else who had traveled recently.

I think monitoring for mental health and those considerations were so critical. Making sure that everybody was feeling okay and doing okay was really challenging. I will say that everybody's experience on the team, during the height of the COVID pandemic, was so individualized. But it did impact the team. I think that our approach was just to be mindful and supportive of everybody. If somebody felt that they needed to be more restrictive, and not be exposed, we wanted to be maximally accommodative and supportive. I think that was really important for the team.

Barr: As a manager, how did you go about doing that, with everyone having such individualized experiences and perspectives on how to handle the outbreak?

Shah: I made sure to check in individually with folks but also with the team collectively. We instituted times where we would try to virtually connect. We would do these team check-ins and sometimes they would just be like, “What are the things we’re looking forward to?” or “Give me what are your three favorite books that you’ve read recently.” We came up with different strategies to stay connected, so that that sense of isolation was not there as much.

Barr: Yeah. Did your patient load remain the same as pre-pandemic?

Shah: We treated as many patients during the early years of the pandemic as we had in other years. I have to say that I’m really proud of being able to do that. The easier route would have been to not do that, but we would never do that.

Barr: That was terrible with the children being so sick. That’s sad. What were some of the challenges [with] fewer people so the team had to take on more responsibilities? Can you speak about some of the other challenges that you and your co-workers faced due to the pandemic?

Shah: Oh. I think the work-life balance. I sort of alluded to that at the beginning, I think that was really hard, right? I would say there’s a balance. I sort of have a flowing approach of what I need to do when. But that completely got disrupted. All of a sudden, on the days that I would work at home, I now had a four-year-old at home. I would be on a virtual call and she would just plop herself in my lap and take the headpiece and join the call. [pantomimes taking the headset] I’m like, “All right, I guess that’s just how it’s going to be.” But I think that also there was a silver lining that came out of that in that we were able to learn how to work from home sometimes and learn that some flexibilities might be nice, and that you are able to do things virtually. I think we became a lot more accommodating of other families who were struggling with kids. I use kids because that’s my personal concern. But if it wasn’t kids, it was eldercare. Right? I mean, there was always something that people—I think everybody on my team, and I think that generally, you either have somebody who depends on you, or vice versa. And I think trying to navigate that was particularly challenging.

Barr: Yeah. Can you speak about any other opportunities that the pandemic brought, which you’ve already spoken a little bit about—new opportunities in terms of attending to the logistics of running a group, but also maybe in terms of evaluating your research, writing papers, or just looking at how you treat patients?

Shah: I am very proud of the quality of care that our team provides. I think that our goal was to maintain that and never to compromise that. I feel that the thing that we did best was that we figured out ways to maintain the highest level of care that we could provide and not compromise the integrity of the research studies. I think that we do that on a day-to-day basis. Like I said, it felt like you were doing the same job while you watched the rest of the world change around you. But I think we needed to be able to do that. I think that we definitely became more accommodating of one another and what other people’s needs are. I think that that’s a change in the field, that’s for the good. A particular change that I do really [like], it’s a little bit outside the day-to-day, but, for travel and work conferences, I think that people realized that you can do these conferences virtually. I go back to thinking about times where I had was an invited speaker, and I couldn’t go because I was pregnant, or had just had a baby, or something like that. Do you know what I mean?

Barr: Right.

Shah: All of a sudden, we made things possible. So, I think the world learned to become a little bit more accommodating, which I think was nice. Now, don't get me wrong. I think we also learned that it is absolutely important to be able to interact in person. Getting that balance all of a sudden going from a norm where you had to be in every single day, to say, "I'm still getting my work done, [but] in a slightly different way." I think that was really important.

Barr: Yeah. You said that it was very surreal being doing the same job, but watching your world shrink around you. Can you share some of your perceptions or memories from that time of being on campus when so many others were working at home?

Shah: So right when the pandemic happened, I had a really sick patient at the time. As I mentioned, I also had little kids at home. So, balancing my husband's and my work, and with our nanny being sick that first couple of weeks, it ended up such that one of my colleagues and I, we swapped. I would go in in the evenings, or she would go—she also had kids—in the evenings. We would round, and we would sit, and we would have these profound, deep conversations about end-of-life issues with this patient.

I always work odd hours anyways, getting other research done, but in terms of patient care, I had to navigate when I was going to be able to come in to do what I needed to do. So, I think that that was definitely sort of a unique challenge and trying to figure that out. I'm also really grateful that our patients were so understanding of everything that needed to happen. I also think that there is also the sense of, "Are you doing enough?" Because I think what we were also sensing, as we kept our day jobs, we were doing what we needed to be done. But we're not frontline workers. I work in this very unique specialty position. And while we maintain our jobs, I think that there was also the concern, "Are we doing enough?" All the frontline workers, they were getting hit so hard. I would ask myself, "Should I be doing more? Is there something different? Is this the best I can do?" So, it's also that aspect of it.

My dad is an internal medicine doctor. And he's in his 70s. We're like "Dad, there's a global pandemic, you should retire. If there was a time to retire, it's probably now. We don't want you to get sick." And I remember him telling me, "But I feel like I should be there." And I was like, "Well, what do I say to that?" I get it, I totally get it. But then, I'm worried about my dad who is a frontline worker, who's in his 70s. Do you know what I mean?

Barr: Yeah.

Shah: You know, I was so proud of him, but also worried. And then you just see what people are going through at different hospitals. I think there was a struggle, and then, not to mention, there was this huge political divide. As scientists, you want people to just follow the facts and science. And I think that was really hard, too, because it felt like the world was—the country was—sort of torn. [Gesturing with her hands.] And you're like, "I just want people to do well, and to think about it."

I had the opportunity to write a protocol for treatment of patients with cancer, who developed COVID. When the trial opened, I just felt so blessed [puts her left hand over her heart] that I was like, "Okay, I'm doing something for the pandemic. I'm contributing in some way. I'm using my expertise to make a bigger difference than that." I think that ended up coming at a time that was really valuable. It felt like it gave me purpose in helping what was going on—even though the trial ultimately ended up treating just 1 patient.

Barr: Yeah. Going back, can you speak a little bit more about your connection with patients during this time? Were you able to engage with them in the same ways? Do you feel that you had a deeper relationship with them? Things of that nature.

Shah: Yeah, I don't know that it was a deeper connection. We are very, very connected to our patients. The work we do is really so compelling. Our patients have been through so much. I don't think that changed. And I don't think we wanted that to change.

Barr: It's nice that you are able to be with your patients. In so many medical settings, they couldn't have so many people in a room. It was a challenge. Did you do anything…? [interrupted by Shah]

Shah: I'll give you an example of what was hard. We had brought this patient in. And this is like, I don't know, seven weeks into the pandemic—a new patient, young adult. I put my hand straight out to shake his hand [extends arm as if to shake hands]. We shake hands. And like, literally everybody's looking at me like I've done something horrible [holds up both hands as if in surprise]. It's just like the most natural thing. Like, "What did I do, guys? What did I do? Did I do something wrong?" And it was just like, you couldn't shake somebody's hand. I think that was really hard, now that I think about it.

I had this other patient where they got amazing news. Her daughter was in remission. I got to tell her. We hugged. Normally we would hug. She drops down to her knees, praises the Lord [holds arms wide]. I gave her a big hug [pantomimes giving a hug]. And I was like, "You know what, I don't care if people yell at me, because this is what the situation calls for." But like, you had to be all of a sudden, "I'm totally going to get in trouble for this, aren't I?" Even like touch—touch is so important to the work we do. We had to still maintain distance unless it was absolutely necessary. So, you're having these conversations, and you want to lean over and put your hand on somebody and comfort them. I will say that that part of it was really, really hard. Because it's like this natural tendency that you learn that all of a sudden, you're like, "Oh, shoot, I just did something wrong. Oh, shoot, I just did that again." I forgot about that. That was very odd.

Barr: Yeah, definitely. Is there anything else that you'd like to share about your pandemic experiences? And what your ideas are going forward?

Shah: I think the pandemic was an experience for all. I look back on it with a lot of mixed feelings. I think everybody does. I am very much hoping that the silver linings that came from the pandemic are here to stay and that the lessons we learned from it are that we can continue to provide high-quality care [and] maintain the integrity of our studies in the best way possible, no matter what the circumstances may be.

Barr: Well, I hope that continues to be and I wish you and your team, and of course all your patients, only the best.

Shah: Sounds good. Thank you so much for taking the time to talk with me.