Wafaa El-Sadr: A “Genius” AIDS Research Pioneer

Dr. El-Sadr shares with AIDSmeds how her innovative AIDS and tuberculosis research in Harlem, New York, and sub-Saharan Africa made her a MacArthur Fellow.

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Every year the John D. and Catherine T. MacArthur Foundation awards at least 24 “creative individuals who inspire new heights in human achievement” each with a $500,000 grant (commonly referred to as a “genius grant”) to further his or her work. This year, one of the recipients is Wafaa El-Sadr, MD, MPH, a noted HIV physician and researcher at Columbia University.

Dr. El-Sadr has been treating people living with HIV in Harlem, New York, since the beginning of the AIDS epidemic in the early 1980s. She pioneered an innovative model to treat and prevent tuberculosis in New York City in the early 1990s and became the director of AIDS research in Harlem for the Community Programs for Clinical Research on AIDS (CPCRA). Dr. El-Sadr also established and directs the International Center for AIDS Care and Treatment Programs (ICAP), overseeing the efforts of 400 health care workers around the world to combat HIV and tuberculosis.

AIDSmeds talked with El-Sadr about her MacArthur Fellowship and her work in Harlem and sub-Saharan Africa.

Your biography says that you went to medical school in Egypt; is that where you grew up?

Yes. I grew up in a family of doctors. I guess in a way it felt familiar to me, and I liked what they were doing and trying to do.

What year did you begin working in HIV?

From the very beginning of the epidemic actually. If you think back, very early on in the epidemic before we knew about the virus or cause of AIDS, it was an enigmatic disease that affected people in very devastating ways. I was a very young infectious disease doctor at that time, and I just wanted to be a part of it, taking care of people with HIV, and trying to understand it better.

In the early 1990s, many researchers told AIDS activists that women and people of color were too difficult to recruit and maintain in clinical trials. Did you have to fight against that kind of prejudice in setting up the CPCRA site in Harlem?

Yes, very much so. At that time I felt that my patients in Harlem could not yet advocate for their own care, or for getting new treatments or research in their communities. People who are affected by HIV anywhere and everywhere should have access to clinical trials and be part of trying to find the answers to the scientific questions—and hopefully seeing the benefits of those answers.

I wasn’t naïve. I also appreciated that there were major challenges in accomplishing this, but I didn’t believe that they were insurmountable. I felt that there was a high level of mistrust of research in the community, but I was very cognizant of the reasons for that. I felt it was our responsibility to build that trust again, and work with the community and people who were affected to garner their trust, so that they would feel comfortable and knowledgeable and informed when they participated in research.

I also thought that the whole issue about follow-up and adherence was really our responsibility. We had to shape the research programs in a way that was appropriate for the patients, so that they would feel compelled to be part of it, and to come back, and to continue with the research and to undergo everything that is necessary to conduct rigorous research. So in a way, it was about building a partnership.

Some scientists have the attitude that research participants should adjust their lives and who they are to conform to the demands of the study, whereas it seems that you’ve always had the perspective that scientists must adapt the research to conform to the needs of the participants. What led you to that philosophy?

If you want to shape a study so that it is completely artificial and overwhelming and completely inconsistent with the lives or the practices of the people you are going to treat, in the end that’s not very useful. So I felt that it’s actually a part of doing good research and not something special to shape research to the needs of the participants. It’s not less rigorous to do participant-friendly research.

I also felt all along that the best thing one can do is to listen very carefully to what your patients are saying, and if what you want to do is not something that makes sense to them, then I think that in the end you are not going to succeed.

The MacArthur Foundation gave you the award, at least in part, because of the creativity you showed in developing a family-based model for tuberculosis (TB) prevention and treatment. Can you tell us a little bit about that and what it’s been like to take that model from Harlem to Africa?

In the early 1990s, if you remember, there was a resurgence of tuberculosis in New York City, and in Harlem the ability of patients to complete treatment was very limited. I think it was only about 11 percent of patients with TB completed treatment. I remember trying to really understand why that was. I realized that many of the patients with tuberculosis also had HIV. They often had very weak social support systems. They had no one in their lives to support them through the arduous treatment for TB.

So we came up with the idea for what we called the “surrogate family” model. Rather than going out into the community every day and trying to find people with TB and watch them take their treatment—which is so difficult because people were in homeless shelters or moving from one person’s house to another—we instead transformed the clinic into a family or home-like environment where they would want to come every day. This is because there would be people there whom they could relate to almost as their surrogate families.

We trained the staff and recruited people. Obviously many of the people we recruited came from the community. Many had been infected with TB or had been homeless, and they became a family to the patients. It was phenomenal. I think in just one year the rate of treatment completion went up from 11 percent to almost 95 percent completion.

That’s amazing!

Yes. And then we thought that this model should fit well in HIV. I follow women with HIV, and sometimes the women didn’t come back to see me, but they would take their kids to the pediatrician. I would sometimes see the pediatrician in the hallway and ask, “Have you seen such and such a person?” and the pediatrician would say, “Oh yeah. She brings her kid in all the time.” I think that’s when we thought of using the family-focused approach to HIV, realizing again that HIV is a family disease.

Then we started having a joint clinic, where moms and babies could be seen together and then the support system would take the family into consideration. More recently, I expanded my work into sub-Saharan Africa. In many ways the lessons I learned in Harlem really helped guide the design of the programs we now have in Africa. And what I learn in Africa is shaping what I do here in Harlem as well.

What has it meant to receive an award like this?

Well, it’s quite a shock! I’m completely stunned. I really never, ever suspected it or thought of it or even considered that it could happen. And I feel like it’s not an award for me personally; in all honesty, it’s for the wonderful teams I work with here in Harlem, at ICAP and the [Columbia University Mailman] School of Public Health. We try to think of ways of tackling an issue and letting ideas kind of emanate from the people who are experiencing the challenge. I feel that maybe this is an acknowledgement of the space that we try to provide to let innovation thrive and flourish.

The award also offers me an opportunity to think about some little ideas I’ve had along the way, that have not been the kind that are very attractive to funders, you know, or a priority for funders, and maybe now I have the resources and the space to pursue some of them.

It seems like you’ve consistently chosen to tackle some of the most seemingly insurmountable problems in HIV, in terms of the people you’ve worked with and the challenges you’ve take on. That can be an inspiration for people living with HIV, for whom just living with the disease sometimes feels like an insurmountable challenge. Why do you think you’ve been drawn to these challenges, and what’s given you the strength to overcome them?

Honestly, it’s the people, the patients I take care of, and the people I encounter wherever I go, in the villages and towns. I feel that’s really where it’s all rooted. I’ve never had one genuinely new idea. Instead it’s from listening carefully to something my patients or staff have said. It’s really just listening carefully and trying to think of creative ways of responding to a challenge, or tackling a new problem, or trying something new or different. It’s rooted in the people.

And then I very much enjoy working with teams. I really feel like that’s where I draw my energy. Having the opportunity to sit around with people who are very committed, innovate, creative and devoted. Really just working together is such an incredible privilege.

Any parting thoughts that you’d like our readers to know about your work or the award?

Although HIV has been a huge health and societal challenge for all of us, sometimes I feel that maybe there’s a silver lining. Maybe HIV is pushing all of us, whether it’s a person with HIV to overcome the day-to-day prejudices and challenges, or whether it’s clinicians needing to overcome our own preconceived notions about our roles and responsibilities, or whether it’s society and what is our responsibility for people here and overseas. I know it’s kind of hard to say that there’s a silver lining when there’s such a horrific epidemic, but sometimes I feel like we have to keep trying to utilize the opportunities we have to shape a better future.
