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I'll Show You What a Woman Can Do

Françoise Barré-Sinoussi

My mustrious lordship, I'll show you what a woman can do.

Artemisia Gentileschi

The first cases of AIDS date back to 1981. Only two years later, together with your mentor Luc Montagnier, you isolated the human immunodeficiency virus (HIV) causing AIDS. For this achievement, the two of you won the Nobel Prize in Medicine in 2008. Almost thirty-three million people have died from AIDS-related conditions worldwide, and more than seventy-five million people have become infected with HIV.⁴ Professor Françoise Barré-Sinoussi, when you discuss HIV/AIDS with people who don't suffer from this disease, what are the things they don't know or are misinformed about?

A good proportion of people think that HIV isn't a problem anymore, there is a treatment for this chronic condition and there is nothing much to worry about. As a consequence, a significant proportion of young homosexual men are taking risks again. In France, my country, we've seen an increase in the incidence of the infection in the last years in the young homosexual population. I know there is a similar situation in the United States, Australia and other countries. The first point probably is that communication is not as intensive as it was in the past and is not as good as it should be. Some people think there is a cure: however, we know that the treatment is a life-long treatment; it's not a cure. There's a lot of work to be done regarding information about HIV.

There is also a significant proportion of people who are affected by HIV, but they don't know it because they have never asked to be tested. Thousands of them are infecting others, which is, of course, not optimal for ending the HIV epidemic. This is the situation in many countries around the world.

The general public also thinks that this is now mostly a disease of sub-Saharan Africa. They're not interested because they think they can't be affected, which is wrong because the

⁴ www.who.int; www.unaids.org

virus travels all over the world. If the effort regarding access to prevention, care and treatment for everyone in the world doesn't continue, I would be worried about the future re-emergence of an HIV epidemic.

You've been to African and Asian countries many times. Your first visit to an African country was in 1985, when you went to Bangui for a World Health Organization workshop, and the Nobel call surprised you when you were in Cambodia. What were your emotions during these visits? What are the moments that stick in your eyes and your heart after over thirty years of travel there?

That's a difficult question. The first time I went to Bangui in the Central African Republic in 1985, the participants of the meeting visited the hospital in the capital. We saw that many people in the hospital were in terrible, awful conditions. In 1985, there was no treatment for HIV, and not even medications for helping patients to die. It was a shock for me and for many of us at that meeting. We realized we had a responsibility and a duty to try to improve the clinical situation in those countries via lots of interventions, including training and transfer of knowledge. That's how I became involved in resource-limited settings.

I was trained at the Pasteur Institute in Paris. At that time, I fully understood what Louis Pasteur had in mind when he decided to implement the Pasteur Institute in different countries in the world. Part of the activities was about transferring our knowledge and working *with* them, not just *for* them. This involved implementing research and intervention to improve the lives and dignity of people in resource-limited settings. There are plenty of things to be done. However, we can see some progress in resource-limited settings and in terms of the research done directly on site by African colleagues or colleagues from South-east Asia. The results of implementing these structures and strengths benefit the population locally in terms of HIV and other diseases.

Many medicines are still not widely available in every country worldwide. What actions need to be taken to make access to healthcare universally available and to improve global health systems?

The so-called first-line treatment for HIV is and can be available everywhere. In principle, all patients can have access to first-line treatment in developing countries. If they don't, it's because they have not been tested for it. In most resource-limited settings today, when the patients are diagnosed, they're already at a very late stage of the disease. They arrive at the hospital and have infections: we know this is not the best situation for the treatment to be efficient. For me, the first priority is to test people in resource-limited settings.

It's easy to say, but not so easy to do. There are many obstacles: often people say it's a question of money and funding, but it's not just this. It's a question of testing for HIV: in small villages, they haven't got the professionals to do this. This means that we have to organize community-based activities for the communities themselves to be trained and to do the testing. We have tools that are very easy to use, for example rapid tests or first testing that can be used in small villages. If we have communities involved, we can improve the situation. We also need to have political weight: there are countries without access to medication because the politicians think that people affected by HIV don't deserve any treatment or medical care. They belong to what we call the 'key affected population': they are homosexual or drug users. Such politicians think they don't have to spend any money on this.

We have more than seventy countries in the world that have repressive measures against these populations: against homosexual people, drug users, sex workers, transgender people. And we know that repressive measures oppose accessing prevention, care and treatment. The list of obstacles is quite long.

There are also political issues, stigma and discrimination. When people are stigmatized, they don't want to have a test because they're afraid of being rejected by others, of being put in jail, of being rejected by their friends and family. Everyone can be affected by a disease like HIV. We have seen that for Ebola: populations were escaping and going into the forest because they were afraid of being considered to potentially carry Ebola. It is a process of education, organization of the health system and political will.

Stigma and discrimination are often associated with diseases, and they're constantly associated with HIV/AIDS and mental health. In 1996, for around a year, you didn't attend HIV/AIDS-related conferences.

In 1996 I wasn't going to conferences anymore because of the evolution of these conferences. I was at the first one in 1985 in Atlanta and at the second one in Paris in 1986, which I organized. Then, I went to the conferences in Washington, Stockholm and Montreal. At some point, these conferences became much more oriented towards political issues, the media and communities, but very little towards science. For these reasons, I stopped going for a while. Then, in 2000, the conference was organized in Durban, and there was a call from the international community saying: please come to Durban because in South Africa there's a terrible issue with the President, Thabo Mbeki, who doesn't recognize that HIV is the cause of AIDS. As a consequence, the magnitude of the epidemic in South Africa was enormous. And it was continuing to grow in some regions with more than fifty per cent of people affected by HIV without any access to care and treatment. When I decided, I said, 'OK, they're right, we should go there and put pressure on the government to change their policies.' I realized that those conferences could put pressure on governments to change their policies. Since 2000, I have been to these conferences every two years.

Mental health issues in academia still seem to be taboo. A study at the University of California, Berkeley found that forty-seven per cent of graduate students suffered from depression, following a previous work that showed ten per cent had contemplated suicide.⁵ Have you ever experienced depression in your life, and, if yes, how did you go through it? I have experienced depression, but it wasn't related to my research in academia as such, but rather to the field I was working in, HIV. I went through a terrible period, and I wasn't the only one. Even as a scientist, it was the first time in my life that I'd been in contact with the patients. I saw patients in terrible, awful conditions, dying from the disease on which I was working. Some of them became my friends and, unfortunately, died. As a human being, it was a very painful experience. As a scientist, it was very stressful because I felt responsible for trying to find a solution as fast as possible. But as we know, science takes its time. There was a discrepancy between my feelings as a human being and my feelings as a scientist. In 1996, data from the retroviral treatment showed, for the first time, that patients treated with a combination of drugs could live with HIV. After that I had depression myself – probably because it was the end of this terrible pressure on our shoulders.

Thanks for this. I'm sure this answer will be of help to many people suffering from mental health diseases. Next question: there have been almost thirty years of legal issues ...

[Françoise interrupts me.] Not thirty years ...

About twenty-five?

[She laughs.]

⁵ S. Jaschik (2015). The Other Mental Health Crisis. www.insidehighered.com/news/2015/04/22/berkeley-study-finds-high-levels-depression-among-graduate-students; The Graduate Assembly (2014). Graduate Student Happiness & Well-Being Report 2014. http://ga.berkeley.edu/wp-content/uploads/2015/04/wellbeingreport_2014.pdf

[Dear reader, a brief recap. In 1984, Robert Gallo and his laboratory, with whom Françoise was, at that time, exchanging research samples, isolated the virus causing AIDS. However, it was the same virus that Françoise and Luc Montagnier had isolated one year earlier. Over the years, Gallo has kept contributing to HIV/AIDS-related research, but was not awarded the Nobel Prize in Medicine in 2008 that Françoise shared with Luc Montagnier for the 'discovery of human immunodeficiency virus'.⁶ The third recipient was Harald zur Hausen 'for his discovery of human papilloma viruses causing cervical cancer',⁶ – something unrelated to HIV/AIDS. Let's come back to the question.]

Almost thirty years of battles and disputes have taken place, including a joint declaration from the US President Ronald Reagan and the Prime Minister of France Jacques Chirac, mostly about the priority of discovery and the patents related to the test to detect the virus. How have you managed not to be distracted by these issues and to stay focused on your life and your research?

I stayed out of this story as much as possible because I wasn't interested in it. I'm a scientist, and as a scientist – and as a human being – I could see what was going on with the patients. My priority was to continue working and doing my best to enable progress for people affected by this disease. It's a sad story, in my opinion. I went to a meeting on the history of HIV in the US, at Cold Spring Harbour, with Bob Gallo: we were together without any problem. Indeed, I was invited by Bob Gallo himself, so the story is over. I said to a journalist who was asking why I didn't mention the conflict between the US and France, 'Why should I mention it? Why? Tell me – has that story affected the progress of science?' No. I'm a scientist and I'm only in charge of science.

⁶ www.nobel.prize.org

Do you think Bob Gallo should have been awarded the Nobel Prize as well?

It's not for me to say anything about that. It's a question and a decision for the Nobel Committee. I respect their decision, and I have no opinion at all.

I know you've spent many Saturdays in the lab.

Not only Saturdays, but also Sundays and nights. [She laughs.]

On your wedding day, a Saturday, your fiancé had to call you in the laboratory to make sure you were joining him for the celebration. Well, that is dedication!

My fiancé knew me very well, obviously, and he wasn't surprised at all. He used to say, 'I know very well that the first priority in your life is your work, secondly your parents and then your cats, and I'm in fourth position.' He was very conscious of this when he married me and not surprised at all to have to call me in the lab on our wedding day. He knew that my dedication was mostly to the work I was doing. I have some difficulty in calling it 'work' because it's been a real passion for me.

In August 2015, you had to retire from active research. Were you looking forward to this or, as I can imagine, would you have never retired? Were you prepared for that stage of your life?

I was very well prepared – at some point in your career you have to retire. But that doesn't mean that you have to stop all your activities. My agenda is terribly full and, except that I don't have a lab anymore, I still have exactly the same activities I had before. I'm not doing science by myself anymore, but I still have relationships with scientists, I'm still coordinating and sharing a tour of the HIV Cure Project in many cities worldwide. If I had to totally retire and stop having any relationship with the scientific and HIV community, that would be difficult, but it's not the case. My former

collaborators are continuing their works. We prepared for my retirement for more than five years. I know they're producing very good science. It makes me happy to see my former collaborators at a very good level internationally. That was part of my job: to train a new generation of scientists. By looking at their results, I think I did that successfully. You shouldn't always think about yourself: as a scientist, you should be a leader, but you should also have the leadership to facilitate training and development of a new generation of scientists. I believe I did my job.

I completely agree with you. Do you think there is a right moment to take a step back from active research?

It's something that is progressive throughout your scientific life. As a young scientist, you work on the bench to find an answer to scientific questions. Initially, most of these questions are those your mentor asked you to work on. After your PhD, you start asking yourself scientific questions. Then, you start to supervise students. When you become a senior researcher, you also have an administrative role and make grant applications for the lab and for the young scientists working with you. It's a progressive process. The more bureaucracy and administrative work you have, the less you're at the bench: you can't do it all. The senior people become coordinators of the research in their lab, ensuring that everyone is working in a common direction, even if different models and approaches are being used, and also developing a collaborative network. Communication about research is important for their lab to be recognized and to have more access to funding. The public shouldn't think that a scientist is always in the lab with a lab coat on. The career of a scientist evolves from a student to a senior researcher in charge of laboratories.

A flashback to the beginning of your career: before completing your PhD, you started seeking advice from senior scientists at the Pasteur Institute. One of them told you that, as a

woman in science, it would have been better for you to choose a different career, as, he said, women are only good at caring for the home and babies. What is your message for the men who still behave and think in this awful way?

My message is that they're totally wrong, and there are plenty of examples that have shown that this kind of statement is totally false. We're talking about almost forty years ago, when this kind of mentality was everywhere, not only at the Pasteur but in many research organizations in France and outside France. Fortunately, it has evolved. When I started at Pasteur, there were fewer than five women as professors. Now, about fifty per cent of professors are women. Such progress has been possible because women demonstrated to men what they were capable of doing and, fortunately, are recognized today.

It's not easy to be recognized. For young female researchers, being recognized will probably be twice as hard as it is for men. But they should be persistent.

Any other thoughts or advice for the female scientists still suffering from sexist issues?

My advice to female scientists is to become a scientist because of their passion, as it has been for me, for giving to others. Because giving to others, and giving to patients in the field of biomedical sciences, is so important for *your own* life. If you live for yourself and just do science to produce publications and to have a wonderful CV, it's not enough.

The most important thing is to try to give as much as possible to others. In the field of medical sciences, this means to improve the life of patients suffering from diseases, whoever they are and wherever they are. If they have this passion, they should just keep going, because they will receive so much in return from the people they'll meet all over the world. In my case, I'm quite happy in life because I've tried to give the best

of myself. When I go anywhere in the world – Africa, Cambodia, Vietnam – I'm so accepted by the populations, and *they* make me happy. To see a person affected by HIV, for example, who is alive, smiling, playing, dancing – that's the best gift for someone who, like me, has worked for so many years on this disease.

