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FEATURE ARTICLE

Saving the World, or Saving One Life at a Time?

Lessons my Career with Médecins Sans Frontières/Doctors Without Borders/MSF has Taught Me

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It is a double honor to address you today. First, this is because my team and I are aware of, and grateful for the significant contributions that student and faculty members of the University of Pennsylvania's academic community have made, and are making to the advancement of global health and medicine. We feel fortunate that Médecins Sans Frontières/Doctors Without Borders (MSF) has attracted a steady flow of health professionals educated at Penn, who have undertaken medical assignments with our organization.

Second, it is also an honor to have this opportunity to deliver the seventh annual Renée C. Fox Lecture in Medicine, Culture and Society. Renée is well known in MSF for the many years during which she has conducted first-hand sociological research among and about us, which has included a much appreciated analysis of our distinctive culture – including the many contradictions in it.[1] We in MSF, and I personally, have great respect and admiration for her sharp, non-complacent, ethical, and humanistic understanding of our ethos and our complex work.

As I am about to take a leave of absence from my work with MSF, this talk gives me the opportunity to reflect on my 22 years with this organization, and to share with you the highs and the lows that my colleagues and I have experienced. It is not an easy thing to reflect on two decades of intense – sometimes painful, but always vibrant – humanitarian endeavor. But I will try my best to convey to you both the positive passion, commitment and achievements that such action to try to alleviate suffering on this earth involves, and the outrage and at times despair that it entails.

Humanitarian crises are a window on the world's history. They make you a witness and an actor in this history as it evolves. In these roles, I have been a part of a quarter of a century of disasters, most of them human-made. From the mid-1970s that coincided with the Cold War, to the fragmented, universal (dis)order that we face today, MSF has fought for, and stood by those who are harmed by crises, and have been simultaneously ignored. In the aid system we call them target groups or beneficiaries—terms that sadly, will never catch the extent of the suffering and the personal values of each of the individuals who are caught up in large-scale tragedies. Having had the privilege of meeting and helping these individuals directly, observing their strength and their dignity, has been a lesson and a driving force. This is what protected me from seeing them as numbers, which can become dizzying. Just think of the more than fifty million persons displaced in the world today—equivalent to the whole population of the United Kingdom. Remember the trepidation with which established nations like the United States and Spain barely managed to deal with just a few cases of Ebola; and imagine having to cope with fifteen thousand Ebola patients, surrounded by fear, panic, and untenably high temperatures. Or think of the hundreds of thousands of Nepalese whose lives have been smashed by the recent earthquake. Of course we in MSF are aware of these massive statistics; but we've also made the conscious choice of addressing individuals' needs, one by one. We do not claim to fix health systems. We try to fix patients – one at a time. It is a daunting task when you are dealing with large-scale outbreaks of violence or disease.

[0] See, Renée C. Fox, *Doctors Without Borders: Humanitarian Quests, Impossible Dreams of Médecins Sans Frontières*. Baltimore. Maryland: Johns Hopkins University Press, 2014.

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It is even more challenging when you are under increasing pressure for cost-effectiveness, impact, accountability, and performance. Then the risk of reasoning and acting on numbers increases, instead of going for more individualized complex care. Last year, one of the many rating agencies that guide donors in the United States decided to downgrade MSF from the previous year. When we reached out to them to understand why they did so, here is what they answered:

> We love your organization, but we think that you are less cost-effective than some other organizations. You report more surgical activity in 2014. Surgery is far more expensive and reach[es] less patients than other types of services like mental health. We think it is more cost-effective to focus on primary health care than on secondary health care.

As a matter of fact, programs depend on needs and vary from year to year. With conflicts and violence booming in recent years in South Sudan, the Central African Republic, Syria and Yemen, our provision of secondary health care had naturally expanded, on top of our existing primary health care programs. This was both the result of increasing demand, and because the few remaining health organizations that exist in those countries today are focused on primary health care services. Even though more costly and complex, MSF's surgical activity was deliberate. Since safe and affordable surgery saves lives and is out of reach for ninety-three percent of people in sub-Saharan Africa and for many in the Middle East today, we consider it to be very cost-effective to deploy our means and resources for this type of care.

By the end of 2014, three billion US dollars had been pledged worldwide in response to the Ebola outbreak (only one-third of which was actually paid). That same year MSF spent less than fifty million dollars to care for five thousand confirmed cases of Ebola—a third of the total case load in the West African region. To date, I consider our response to be pretty cost-effective.

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But now, let me share with you some of the lessons that I have personally learned over the past 20 years. I have experienced the best and the worst of humankind, which won't surprise anyone in this medical auditorium.

- I have learned that flexibility is a key element of our ability to conduct humanitarian assistance.
- I have also come to admit that even though we've won a few battles, we certainly haven't won the war—particularly in the field of drug development.

Let's start with the most rewarding experiences. The dramatic advances that have taken place in the fight against AIDS is one of them. In 1992, I was in Thailand, where HIV/AIDS was decimating hundreds of lives every month. Care was mostly palliative, and the stigma against AIDS patients was at its highest. MSF was partnering with Buddhist monks who were at that time the only community willing to support dying HIV patients. Georgio, one of our drivers and friends, became sick and tested positive for HIV. Although MSF salaries are modest, the health care with which we provide our staff is always a top priority. But what to do when a cure does not exist? At that time, zidovudine (AZT) was being introduced as a promising drug, but it was unaffordable. We could have had Georgio enrolled for free in a randomized control trial conducted by a Thai university hospital, which meant that he would either receive a free treatment or a placebo. The dilemma that this posed prompted us to start paying for available HIV drugs for our staff, which in the late 1990's expanded into a big campaign for access to affordable HIV treatment in affected countries. Although we still have no cure for HIV, millions of individuals now have access to HIV drugs, and live healthy lives.

We've also had tremendous success in the field of malnutrition. We have been able to change the protocols and practice in dealing with malnourished children in low resource settings through the introduction of ambulatory care, and the use of Ready-to- Use Therapeutic Food, (RUTF), a magic-like instant food. In addition, with the mobilization of a coalition of actors, we have also greatly influenced the quality of regular food aid. And finally, a couple of years ago, the United States—the world's largest food aid donor – stopped sending food to children in Niger that we would never feed our own kids here.

No less remarkable is the outstanding mobilization and courage demonstrated by international volunteers and local communities during the Ebola epidemic. Despite the high risk of infection, and despite the fact that for the first time in our history we could not guarantee that our international volunteers would be repatriated if they became sick, because we had no guarantee of medical evacuation, finding a willing workforce has not been the chief obstacle in responding to the Ebola outbreak. Instead, the main challenge has been the lack of available skilled individuals to deal with this highly infectious environment. Members of our international staff have undertaken numerous assignments to the Ebola stricken areas of West Africa because they are among the few people in the world with the expertise to deal with hemorrhagic fever settings. Equally remarkable is the incredible generosity of the public, particularly in the United States, which led us to exceed our fundraising goals at the end of 2014 by sixty-seven percent.

Teams of national staff in Liberia, Sierra Leone and Guinea have worked around the clock for months in order to contain the disease, while dealing with the risk of infection, fear, stigmatization, and grief over the loss of family and friends in their communities. Twenty-five of the twenty-eight MSF staff

who became infected with Ebola were members of the national staff, and there were fourteen deaths among them. And yet, while this was happening, and Ebola was killing hundreds in their communities, when the American physician Craig Spencer became infected with Ebola and was hospitalized in New York, his Guinean colleagues sent him messages, pictures and videos of support. It sometimes takes a tragedy of this magnitude to realize how compassionate and supportive people can be.

Over the course of the 22 years that I have worked with MSF, I have met amazing, dedicated, smart individuals who have assumed the lion's share of the risks associated with humanitarian work. Outside of MSF, it is not sufficiently realized that ninety percent of our staff are hired locally. For those like me who come and go, we are acutely aware and deeply appreciative of the fact that they are the ones we leave behind when we go back home, and they are the ones who keep the shop running.

I paid a visit to our Liberia program last March. I was delighted to see Victor again, who is one of the local staff members there. Victor is a Liberian logistician who worked with MSF throughout the entire civil war in that country. For 15 years he negotiated on our behalf with war lords and child soldiers in order to help us gain access to impoverished areas in Liberia. In 2006, after the war, when I was conducting an assessment of one of our maternity hospitals in Liberia, he had introduced me to local leaders in a meeting that was being held to prepare them for MSF's eventual departure. I was so impressed by the way he talked about our work that I remember saying to him: "You are the best and most eloquent MSF ambassador I have ever met." You can imagine how moved I was to see him again during my last visit—all the more so because after leaving the country for several years, MSF had returned to Liberia in response to the emergence of Ebola in that country. There was Victor, who had found his way back to work with us again.

Our international staff exhibits the same passion. Montserrat Serra and Blanca Thiebaut were kidnapped in Kenya in October 2011, and detained in Somalia for 22 months. When they were finally released we decided to shut down our programs in Somalia, having no faith in the security guarantees we were receiving from Somali authorities and opposition leaders. Despite the suffering and trauma that Montserrat and Blanca had endured, they were the first to beg MSF to stay in Somalia and not abandon the Somali people.

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I could go on and on with many stories of great human kindness to those in need, and deep empathy for them. But I'll stop here and will now share with you some less glorious experiences.

Every person in MSF has his/her stories to tell about the most traumatic events they have ever faced. Among the worst I experienced was in Rwanda at the beginning of 1995, following the genocidal murder of Tutsis and moderate Hutus that had taken place there from early April to mid-July1994. The birds in Rwanda were as fat as pigs after feeding on dead bodies for months. People were barely looking at one another. Prisons and displacement camps were populated with skinny zombies. And my Rwandese friend told me in tears how she had had to abandon her handicapped brother on the side of the road 6 months earlier when they were fleeing an attack. I also found it terrible to hear North Korean refugees recounting monstrous stories about extreme deprivation and torture in labor camps.

Currently, it is deeply disheartening to recognize that what finally triggered the intervention of foreign governments—including the United States—in the Ebola outbreak was the realization that Ebola was at their doorstep. It had nothing to do with solidarity, the common good, or international and transnational political will. And it is also shocking to know that there is no political solution in sight for the millions of Syrians, Central Africans, or Somalis who are subject to daily violence and abuse. But, one could argue, this is precisely what makes humanitarian aid indispensable.

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Another kind of general observation that I would like to make about some of the attributes and concomitants of humanitarian action is that maintaining a form of mental and physical agility is essential to navigating its environment that calls for dealing with a huge amount of competing and conflicting interests. MSF is a principled organization, but at times we can be incredibly pragmatic and opportunistic if it serves our purpose. This starts in the field and from there spreads through the organization.

For example, in the late 1990s, I was working in China. One of our programs was to provide medical care to North Korean asylum seekers. The Chinese authorities never granted us official permission for this, but they were aware of our presence and tolerated us. Fleeing North Korea was considered a criminal act by the Chinese, so for the safety of the refugees we had no fixed shelters on the Sino-Korean border. Instead, we would arrange medical consultations with refugees in hotel rooms and we would change hotels every day.

One of my MSF colleagues, like me, was a French woman with blonde hair. We were in our thirties at the time. One day, a Chinese receptionist who had seen us spend the whole day taking men to our room, asked me if we were Russian. This is when it clicked. They thought we were Russian sex workers, who were quite present on the scene, and operating freely in the region. We did not deny it, and for three full years we were able to operate under this perceived identity, which happened to be the greatest cover we could ever have thought of.

At the level of the organization, principles and pragmatism are constantly oscillating. In 1998, when MSF received the Nobel Peace Prize, not only did we debate at length about whether or not we should accept it, but we also looked for a

way to leverage our new visibility to highlight some of our concerns. At that time Grozny, the capital of Chechnya, was being subjected to repeated bombings by the Russian army. In the acceptance speech that James Orbinski (then MSFs International President) delivered at the Nobel award ceremony in Oslo, he denounced the bombings, declaring that "we don't know if speaking out will save lives, but we know for sure that silence can kill." This was a clear affirmation of one of our fundamental principles the impeative to speak out and bear witness.

Ten years later, MSF conducted research about the way we were implementing our sacrosanct principles of impartiality, independence and neutrality, and our double mandate of providing assistance and speaking out. The analysis showed that, in fact, our presence systematically involved negotiation and a high degree of compromise with regard to these principles. It also showed that "silence can heal,"as well as kill – for example, that after a series of expulsions from Niger and Darfur in 2009, MSF had refrained from speaking out in places like Somalia, Pakistan and Sri Lanka, because of its concern about being expelled, and that this had enabled us to continue our medical missions there. This is to say that every single context has forced us to accommodate. And when we have considered that the medical benefit to our patients was worth compromising some principle, we have adapted.

But what is true for field operations and our medical practice is much less so for our institution. Actually it is quite the opposite. When it comes to change and adaptation of the organization itself, we are our own worst enemy. As the organization grows, it becomes harder to manage, and requires some structural changes that are incredibly difficult, if not impossible to implement. The associative nature of MSF, composed of members who all feel entitled to express their opinions and challenge decisions, is at odds with the size of our now $1.5 billion organization. We face an enormous tension between our need to professionalize our management and organizational structure, and the fear of losing our culture of debate, spirit of initiative, and our reactivity. We can move mountains if we decide to experiment with a new approach to care, but 2 years of exhausting governance reform have produced very minimal change.

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My last point is less about MSF and more about the system—particularly the drug development system. It is clear to me that we have won no more than a few battles, and that the system continues to suck. Seriously! Take malaria.

As I said previously, my life with MSF started in the early 1990s in Thailand. In addition to assisting HIV/AIDS patients, MSF was providing medical care for Burmese refugee camps along the Thai-Burmese border. Malaria was the main cause of morbidity and mortality among the population. It was resistant to most available drugs, to the point that young children and pregnant women had become untreatable. Every year, during the rainy season, epidemics would occur. Then some patients came to us with a Chinese drug smuggled into Thailand through Burma from China. The drug was based on artemisinin derivatives. This family of new drugs was poorly known outside of China. In fact, during the Vietnam war, malaria was a real burden for both the American and Vietnamese forces, which kept large numbers of their soldiers out of combat. The Vietnamese asked their Chinese ally to provide them with better treatments. Chinese academics first screened the plants used in their traditional medicine. This is how the artemisinin derivatives were re-discovered. Meanwhile, Western laboratories, especially U.S. military research institutions, identified several new molecules, among them mefloquine and halofantrine. The Vietnam war was over before this new generation of drugs had any impact on the military balance of forces. Nonetheless, the two U.S. drugs were developed, and we used them in our programs. But, subsequently, the parasite rapidly developed resistance to both these drugs.

Looking at epidemiological data, it was obvious that there was a crucial need for a new treatment for malaria in other parts of the world as well. At the end of the 1990s, the situation was worsening in sub-Saharan Africa. Chloroquinine and Fansidar, the drugs we were using to treat malaria, had become useless. Quinine had maintained a good level of efficiency, but it was necessary to preserve this drug as a second line to treat severe cases.

This is where the story starts for us, and when we turned to the Chinese version. With the Chinese drugs, three main difficulties quickly emerged. First of all, these drugs had not been studied in keeping with international scientific standards. Second, they were not economically attractive because they were not patentable by Western pharmaceutical companies, and therefore profits were not guaranteed to anyone potentially interested in producing them. Third, politically and psychologically, Western institutions had difficulty in recognizing that Chinese medical institutions had won the medical battle and found an alternative to outdated malaria drugs.

The first step out of this deadlock was to carry out clinical trials using alternative treatments. This was absolutely necessary if we were to have a chance of developing an effective treatment for one of the world's most common and deadly diseases before it became completely untreatable. It was clear that neither the World Health Organization nor most academic institutions had any plan to study these Chinese drugs. So the question arose: should we do it ourselves? For us, several ethical dilemmas immediately emerged because the studies we had in mind were to be conducted among Burmese refugees living in camps. Clinical trials in humanitarian situations raise very specific ethical dilemmas: Is it truly possible for refugees to choose whether or not to participate in a trial when the study is carried out by the very same aid organization they depend on for their survival? And when the reference treatment is totally ineffective and patients are at risk of dying, is it

acceptable to continue using it to compare it to a new therapy? There were other ethical dilemmas; but these were the ones that mainly concerned us.

So we decided to overcome these challenges and engage in our own clinical trials. Between 1996 and 2004, MSF enrolled twelve thousand patients in forty- three efficacy tests in eighteen countries. Our studies were conducted in keeping with scientific standards, published in peer-reviewed journals, and provided evidence on the efficacy of most drug regimens containing artesunate. Beginning in 2002,we also supported the Neglected Diseases Initiative (DNDI)—a foundation whose goal was to fast-track the development of drugs for neglected diseases. In addition to assisting in the development of new regimens to treat sleeping sickness, visceral leishmaniasis and Chagas, DNDI helped to create two single dose combination treatments for malaria that include artemisinin: namely, artesunate and amodiaquine. They are both in widespread use in Africa and Asia today. However, two decades later we are back to square one, because resistance against artemisinin is emerging, and there is no alternative, drug resistance-free treatment.

Other challenges loom as large. After 50 years without any research on tuberculosis, we finally have a few potentially TB-relevant drugs coming to market. But none of them have been tested together to form a regimen against multi-drug resistant tuberculosis, which is a rampaging problem in an increasing number of countries. Without a proper regimen, we face a fifty percent mortality rate among our drug-resistant TB patients. Because of the culture of secrecy and the competitive mentality of the drug manufacturing environment, no one is willing to test these drugs together, and we have to conduct our own clinical trials to figure out what regimen would work against tuberculosis in its multi-drug resistant form.

And take Ebola. Ebola has been known for 40 years, and over twenty outbreaks of it have occurred, giving ample time to experiment with new medicines. Yet we have faced the most recent Ebola epidemic with no vaccine, no treatment, no rapid diagnostic test, which would have been game changers in the management of this outbreak. Ebola is not an anomaly in this respect. It is a symptom of a drug development system that repeatedly fails to consider health as a public good, address research priorities, and make innovations that are adapted to, and affordable for patients.

And finally, when we experience a breakthrough, as we did recently with the development of sofosbivir for the treatment of Hepatitis C, the cost of the drug is out of reach for most people. In the United States, a 24 month-long treatment is priced at eighty-four thousand dollars, or one thousand dollars per pill.

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As I prepare to step down from my current position, I don't know what MSF will be tomorrow. But I do know its strengths and its weaknesses. Both are the reasons why I love this organization and its members dearly.

I hope I was able to convey the sense that for me and my colleagues assistance goes far beyond the simple programmatic delivery of medical care. Care is first about caring about others as if they were oneself, or those we love. Care is about taking the risk of rejecting the status quo when it seems unacceptable. MSF is one among many actors in the field of humanitarian action. And each of us plays a specific role. We don't claim to be the ministry of health of the world. We don't claim to restore peace. We feel okay about just keeping alive and healthy as many individuals as possible every year, and about showing a face of humanity and solidarity to communities when their worlds fall apart. We understand that other organizations may embrace other ambitions and differ from us in their approaches, be they human rights groups, or development organizations. Each contribution to humanitarian crises is as valuable as the other, as long as we don't claim to be what we are not.

Today's ongoing debate about how to respond to the hundreds of thousands of refugees from countries in the Middle East and Africa who are arriving in Europe, desperately seeking asylum, is vivid proof that in the end, not caring is far more harmful (and less cost-effective) than the imperfect offerings of the aid system.

Sophie Delaunay is the former Executive Director of Doctors Without Borders/Médecins Sans Frontières (MSF), USA. This lecture, the seventh annual Renée C. Fox Lecture in Medicine, Culture and Society, took place on May 5, 2015, at Medical Ground Rounds, in the Flyers/76ers Surgery Theatre of the University of Pennsylvania Perelman School of Medicine, Philadelphia, Pennsylvania. Dr. Delaunay's present work at MSF involves the promotion and establishment of a coordinated network of biobanks for Ebola specimens and a data sharing platform for Ebola-related information and knowledge.