

Human Rights in Crisis

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- Spijkerboer, T. (2004), Introduction to Reader: EC Directives on Immigration Law, prepared for "Gendered Borders, International Conference on Women and Immigration Law in Europe," *Vrije Universiteit*, Amsterdam.
- United Nations, Convention Relating to the Status of Refugees (1951), U.N. Doc. A/Conf. 2/108 (entered into force April 22, 1954) (UN 1951).
- United Nations, Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, Protocol to Convention Against Transnational Organized Crime (2000), G.A. Res. 55/25, Annex I, U.N. GAOR 55th Sess., Supp. No. 49, at 44, U.N. Doc. A/45/49 (Vol. 1), entered into force 29 September 2003 (UN 2000).
- United Nations, Population Trends Division, Department of Economic and Social Affairs (2005), Trends in Total Migrant Stock: The 2005 Revision; available at: <http://esa.un.org/migration> (UN 2005).
- United Nations Children's Fund (UNICEF) et al (2002), *Trafficking in Human Beings in Southeastern Europe*, xiii.
- US Congress, United States Trafficking Victims Protection Act of 2000, Pub. L. No. 106-386, 114 Stat. 1464, Trafficking Victims Reauthorization Act of 2003, Pub. L. No. 108-193, Reauthorization Act of 2005, H.R. 972, passed Dec. 14, 2005, signed January 2006.

Chapter 8

Doctors Without Borders and the Moral Economy of Pharmaceuticals

Peter Redfield

It is an old reporter's truism that not all deaths are equally significant or newsworthy. Although human rights and humanitarianism are by no means identical ethical genres – the first born from broadly legal assertion of principle and the second from a broadly medical response to suffering – in practice both oppose such media realism with a moral insistence on the equality of tragedy. Human rights groups and humanitarian organizations alike enumerate their claims through the violation and suffering experienced by the most ordinary of human bodies and lives, as presented in statistics as well as individual cases. Yet their efforts labor against a similar inertia to that of the newsroom, in that not all moments of human pain translate well to a given audience, and their comparison inevitably begs comparison to other examples present and past. Furthermore, both humanitarian and human rights movements fret over their own perceived relative state of crisis, occasioned by a combination of spectacular rhetorical success coupled with continuing practical failure. At the beginning of the twenty-first century claims to rights and humanitarian values have multiplied to the extent that even egregious violators commonly assert them, even as images of suffering only multiply.

This chapter addresses humanitarian parallels and alternatives to human rights discourse, focusing on the outspoken organization Doctors Without Borders/Médecins Sans Frontières (MSF). Founded three decades ago as an alternative French medical response to humanitarian suffering, MSF has since grown into a complex and transnational fixture of global crises. Along the way it has also expanded its operation to include a wider range of medical problems, addressing "neglected diseases" as well as emergencies in an effort to confront human suffering. Here I examine how MSF's efforts to distance itself from recent military actions conducted in the name of humanitarianism parallel its increased engagement in struggles to advance pharmaceutical equity on a global scale. My suggestion is that these developments mark a potential redistribution in the "moral economy" of suffering and humanitarian values, one that renders the larger global infrastructure of health and life more visible, even while still revealing the continuing limits of humanitarian sensibilities in effecting systemic change.

Death in Northern Uganda

By the summer of 2003, Idi Amin was dying. The man who embodied the madness of dictatorship for a media generation of the 1970's now lay in a coma, clinging to the final thread of life in a Saudi Arabian hospital. In the northwest of Uganda, Amin's home district, rumors flew about his condition, and the possible return of his body, dead or alive, to the land of his birth. Unlike elsewhere in the country, popular sentiment here ran strongly in favor of this idea, presented as a moment of reconciliation with a slight whiff of redemption. Amid a landscape of rural poverty and both national and international neglect, the fallen dictator retained an aura of magnificence; while people admitted that he may have committed some crimes, he remained a native son grown larger than life – simultaneously local and extra-local in his sphere of recognition. His was a most remarkable demise, extending well beyond a single body.¹

I was in northern Uganda for other reasons, however, visiting projects by Doctors Without Borders, internationally known as Médecins Sans Frontières, or MSF. One of these missions, an effort to combat sleeping sickness, was as dead as Amin for all except the most local adherents; the other, administering antiretroviral drugs to AIDS patients, was in full growth and flush with international significance. Both, however, focused on specific diseases and the medicines used to treat them, and traveling between the two in a matter of days offered a vision of the larger circulation of pharmaceuticals around the planet from the perspective of a Land Cruiser rather than a lab.

I will use this moment from the field (in its most classic composition) to frame a discussion about MSF's effort to launch a major new initiative targeting access to essential medicines and neglected diseases on a global scale. This effort has increasingly led the group into an advocacy role beyond its more historic field focus, as well as to a commitment to ambitious AIDS-related programs and even to the prospect of helping to coordinate and fund pharmaceutical research and development on behalf of less publicized diseases. In certain respects it has arguably brought the organization closer to the terrain of human rights issues, via legal issues of policy, intellectual property and international trade agreements.

Even while striking out in such new directions, however, MSF has also been fighting a rearguard campaign to defend its more traditional "humanitarian space" of action in emergency settings. The five years since the group first announced its medical initiatives have only witnessed new cycles of conflict and disaster, as well as conditions full of what are known in the soft euphemism of professional nonprofit discourse as "challenges." Chief among these was the reorientation of American foreign policy after September 11, 2001, which confirmed a longer trend of integration of humanitarian actors within military operations, and the incorporation of human rights rhetoric and humanitarian objectives into a larger geopolitical mission defined by national interest (Weissman 2004). Long iconoclastic, independent and outspoken, MSF has strenuously resisted this trend, first denouncing the association of food drops and bombing runs, then both criticizing efforts to deploy dire humanitarian

1 For a more comprehensive account of both the continuing crisis in northern Uganda and Amin's place in it, see Leopold (2005).

prophecy for antiwar ends on the one hand, and refusing to join any nonprofit coalition of the willing on the other. By the end of 2004 they had withdrawn from both Iraq and Afghanistan, the latter a particularly bitter retreat after over two decades of continuous presence following the murder of five staff members. At the same time they were deeply committed to projects in the Darfur region of Sudan (if wary of labeling that crisis genocide), and would soon halt fundraising for Tsunami relief in Southeast Asia in order to appeal for support for projects experiencing less publicity. In Uganda the disease specific missions now shared the billing with efforts to aid refugees from the country's shadowy northern war, which finally made it onto MSF-USA's annual top ten list of "underreported crises."

Viewed from the perspective of this particular organization, then, and its shifting portfolio of specific projects, medical humanitarianism would hardly appear a single or uniform endeavor. Instead, it struggles in several directions at once, alternately demanding or opposing state action depending on the context. Although some humanitarian figures increasingly make explicit reference to human rights discourse in their opposition to suffering (e.g. Farmer 2003), MSF scrupulously tends to avoid it. Warning against the expansion of humanitarian dreams beyond temporary solace, the critic David Rieff (2002) would still find much to approve in the group's outspoken claims to limits. Indeed, in opposing the state version of any humanitarian "right of intervention" into crisis settings, MSF was countering a trend partly anticipated by its own early history, and endorsed by its most prominent founding member, Bernard Kouchner. This apparent contradiction is far from anomalous. Although sharing a common acronym and charter, the constituent sections of MSF sometimes interpret their doctrine differently, and quite frequently debate specific actions and positions.² Even within any given section views are hardly settled, but rather the latest word in a continuing, internal argument.

Rather than defending any rights *per se*, the varied announcements and actions of MSF followed perceived dangers to the health and dignity of ordinary people. Thus the group could effectively discover a language of economic and policy critique in pharmaceutical discussions while rediscovering a discourse of political neutrality amid emergencies. For this reason I will use the term "moral economy" as an analytic frame for my discussion of its activities, and particularly the concern over the availability of medicines within them. By moral economy I wish to imply the circulation and distribution of moral sentiment at two interrelated levels. The first, analogous to the historian E.P. Thompson's (2001) use of the expression in his

2 The MSF acronym incorporates a loose federation of national sections, the five most central being in France, Belgium, Holland, Switzerland, and Spain. Although based in its country of origin, each of these sections is quite international in terms of volunteers and staff. MSF prides itself on a relatively equalitarian ethos that favors individual initiative and fosters debate over bureaucratic hierarchy, to the extent that some could express concern that the most recent international summit (known as "La Mancha") produced too little in the way of dispute. For purposes of this chapter, however, I will gloss over internal divisions except where directly relevant. Beyond formal references, this work draws on the author's ongoing ethnographic and historical study of MSF. The reader is also directed to the following relevant websites: www.msf.org; www.doctorswithoutborders.org; www.accessmed-msf.org and www.dndi.org.

analysis of eighteenth-century English crowds upset by grain prices, describes the feeling in and beyond MSF that the availability of goods such as medicines should not be governed solely by motives of profit. The second, analogous to historian of science Lorraine Daston's (1995) use of the term in her analysis of values embraced by practitioners of early modern science, describes the systemic distribution of principles across MSF's varied stands and endeavors, producing the ethical ground for a humanitarian position. Alongside an idealistic commitment to altruism and independence, exemplified by the group's opposition to the political expediency of "the sacrificial international order" (Bradol 2004), and a realist focus on immediate suffering and present conditions, exemplified by its insistence on the calculation of medical benefit "one person at a time," MSF also exhibits an egalitarian sense of prioritization, exemplified by the motto of its spin-off drug venture: "the best science for the most neglected."

Although the different component sections of the larger MSF movement, not to mention individual adherents, may interpret these principles differently in particular settings and argue forcefully among themselves, they maintain sufficient cohesion to articulate a common moral vision constructed around a secular commitment to the value of human life. Since the group maintains a distinctly global ambition in its response to worldwide health crises, and has grown to enjoy significant public support both throughout Western Europe, as well as Canada, the United States and Australia, I suggest that its shifting rhetoric and activities reflect structures of feeling about human suffering well beyond its immediate members. In this brief chapter I will consider MSF's turn to advocacy for medical access and direct involvement with problems of pharmaceutical production and distribution with reference to the particular landscape of Uganda. My suggestion will be that these developments mark a potential redistribution in the "moral economy" of suffering and humanitarian values, rendering the larger global infrastructure of health and life more visible. At the same time they continue to reveal the limits of humanitarian sensibilities in effecting systemic change.

Institutions and Neglect

First let me offer some brief background on both MSF and its drug crusade. At the beginning of the 1970s, two small groups of French doctors and a few journalists working for a medical review came together to establish a new humanitarian organization. Calling it *Médecins Sans Frontières*, they hoped it would offer an independent alternative to the formally mandated Red Cross, engaging directly with populations in distress rather than filtering its activities through national governments. In addition to directly caring for suffering people, this new group soon came to reserve the right to speak out on their behalf, practicing a form of advocacy under the name of *témoignage* (witnessing).³ After a number of small

3 As I discuss and reference more extensively in other work (Redfield 2006), *témoignage* has been an expanding rather than static emphasis for MSF; while the spirit may have been present for some at its inception, the group's original charter was relatively modest on this score and, as Anne Vallaëys (2004) details, the question of whether not the group should take

emergency interventions and an eventual schism at the end of the decade, MSF grew through the 1980s, becoming both fully international in organizational terms and more technically proficient on the ground. The end of the cold war only increased MSF's scope and profile, as it and other non-governmental organizations played an increasingly central role in response to disasters and political turmoil. By the time the group won the Nobel Peace Prize in 1999, the acronym "MSF" designated a consortium of 18 loosely aligned national sections, with a collective annual budget over 300 million euros (the bulk derived from private, not institutional sources) and operations in over 80 countries. In human terms it included some 1500 expatriated volunteers and modestly salaried office workers, as well as some 10,000 national staff resident in mission sites. From a marginal and oppositional French group, the "doctors without borders" clearly had grown into an established transnational presence, no longer simply French nor simply centered around physicians.⁴

MSF was also a movement in partial transition. While maintaining (and periodically reaffirming) a core commitment to emergency operations in impoverished countries, different MSF sections had also experimented with a variety of other missions addressing an expanded conception of crisis, including efforts to address the health needs of marginal populations in Europe and elsewhere and longer-term efforts to address specific diseases in contexts where they were endemic. By the late 1990s MSF had dropped its earlier resistance to HIV/AIDS work and increasingly involved itself in campaigns to combat that spreading epidemic. And within some quarters of the organization, particularly the French section, momentum had been building for a new initiative to address the perennial problem of unequal access to medicines on the part of afflicted populations, together with an increasing lack of pharmaceutical products to combat unprofitable conditions.⁵ On the eve of the Nobel

public positions constituted its first internal struggle. For additional descriptions of MSF in English see Bortolotti (2004) and Fox (1995). Brauman (2000) provides a broader background overview history of humanitarianism and Barnett (2005) outlines its current tensions.

4 By 1999–2000 only about a quarter of the volunteers were doctors, and fully 45 percent of field postings non-medical. For this and all other figures see MSF (2000), 82–85. The number of national staff that year was 9,570; however it would rise above 12,000 by 2001. The percentage of private funds within the budget came to 74 percent in 1999–2000; it too would rise to over 80 percent in the following years before dipping again. In 2004–5, total international income was up over 450 million euro (MSF 2005). While different national sections vary in their fund-raising abilities (not to mention sensibilities, the combination of which has at times produced as much conflict as cooperation), overall MSF has achieved remarkable success in deriving most of its income from private citizens rather than institutional donors, an economic strategy it sees as essential to maintaining operational independence.

5 In the early 1990s, MSF largely saw HIV/AIDS as falling outside its particular expertise and best left to others. The small projects by MSF Switzerland in Uganda constitute an exception (field notes 2003). The spreading impact of HIV/AIDS into other health concerns, along with the advent of antiretroviral therapy precipitated a reappraisal by the end of the decade. Another step towards MSF's eventual pharmaceutical epiphany occurred in 1995, when the manufacturer of a meningitis treatment known as oily chloramphenicol abruptly decided to cease production just after the organization had successfully lobbied the WHO to recognize the treatment. The scramble to fashion an alternative supply source put drug issues on the group's agenda (Rankin 2005, 93–96).

award, MSF launched a "Campaign for Access to Essential Medicines," denouncing global inequities in biomedical supplies, and demanding new measures to address the problem. The subsequent award of the prize, together with the publicity and funds it generated, would fuel the rapid growth of MSF's advocacy work over subsequent years. As a number of those involved with the campaign have noted to me, the timing of the Nobel produced a fortuitous conjuncture for the new initiative.

Thus far the Access Campaign appears a relative "success" within the orbit of MSF's projects, although an ever incomplete and potentially troubling one to some within the organization. Over the short span of its existence it has played a role in the larger advocacy struggle to reduce drug prices in contexts of poverty. During this time issues of pharmaceutical production and pricing achieved a measure of media prominence with political effects; a WTO conference held at Doha, Qatar, in 2001 produced a grudging declaration about the right of states to consider Trade-Related Aspects of Property Rights (TRIPS) relative to public health concerns, and a few specific struggles showed signs of partial resolution. Most notably prices for antiretroviral drugs (ARVs) used to treat AIDS patients fell precipitously, due to a combination of generic production in Brazil and India, a legal struggle in South Africa, and concerted pressure on the part of activists and non-profit organizations (Hoen 2002). Yet the overall imbalance has remained little changed; corporations found ways to circumvent the Doha declaration in negotiating with weak states, and despite a remarkable shift towards the provision of ARVs by states and international organizations, the majority of people with HIV/AIDS remain without access to the drugs, and are unlikely to receive them in the near future (MSF 2003, 2006). At the same time the Access Campaign has expanded MSF's commitment to advocacy into extensive lobbying activities, frequently conducted in concert with other nonprofit and advocacy organizations, and aimed at an audience of state and institutional actors. Such activities sit uneasily with some in the organization, as they conflict with its historic focus on field operations, as well as its independent and generally rebellious, anti-bureaucratic ethos. MSF continues to depend on its global array of medical missions as a source of legitimacy for its testimony about pharmaceutical issues, even as the Access campaign stretches it into more rarified, and potentially complicitous ground.

From its inception the Access campaign included an even more daring departure for the MSF movement: a collaborative effort to directly fund and coordinate the research and development of drugs for "neglected" diseases. Surveying the greater terrain of human afflictions, MSF distinguished four categories of conditions relative to the pharmaceutical market (MSF 2001a). The first is that of "global diseases," maladies such as cancer or cardiovascular disorders that affect all populations, including wealthy ones where profits can be made. Unsurprisingly, the focus of pharmaceutical corporations rests here. The second category is that of "neglected diseases," maladies such as malaria and tuberculosis that occasionally strike people who live in wealthy countries, but largely affect poorer ones. Such conditions are generally marginal to pharmaceutical profits and hence to research. The third category is that of "most neglected diseases," maladies such as sleeping sickness and leishmaniasis that exclusively affect populations in economically marginal environments. Because they offer no real opportunity for profit at all, these conditions fall almost completely outside the market and corporations pay virtually

no attention to them. The fourth and final category is that of conditions "other than purely medical," defects such as wrinkles, cellulite or baldness that obsess wealthy populations and constitute a significant and growing area of pharmaceutical research (MSF 2001a, 11).

Facing this constellation of diseases only partially addressed by commercial drug development, MSF first assembled a working group to study the problem, and then decided to join with several partner organizations and launch an effort known as the Drugs for Neglected Diseases Initiative (DNDi).⁶ Incorporated as legal entity in Geneva in July, 2003, DNDi began the task of identifying both shorter and longer-term projects that would modify or enlarge the arsenal of medications available to combat neglected diseases, especially the most neglected. Early examples of potential products suggested by DNDi included an oral dose of efloornithine (used to treat sleeping sickness), and fixed dose artemisinin-based combinations for chloroquine resistant malaria. Rather than plunging directly into comprehensive research and development itself, the initiative was designed to operate as a virtual drug development organization, eliciting, supporting and coordinating a portfolio of projects within existing infrastructures. The goal was to circumvent the marketplace by focusing on medical need, and treating drugs as "public goods" (DNDi 2004).

The eventual relative success of DNDi, along with parallel ventures such as One World Health (a nonprofit organization in San Francisco funded by the Gates Foundation), remains to be seen. But like the related drug campaign, DNDi has already proved internally controversial for MSF, generating much debate within sections about the plan to devote five percent of their respective budgets to its funding. The Dutch section of the organization in particular opposed participation in the venture, arguing that it strayed too far from MSF's traditional focus on crisis intervention, and its operational expertise on frontline medicine. Certainly drug development involved a far different timeline than most humanitarian projects, with projects estimated in terms of years, even decades at the outset. And like the related advocacy initiative, involvement in pharmaceutical research and development required new forms of knowledge, considering medical compounds in terms of policy documents and international treaties regarding intellectual property.

Taken together, the Access Campaign and DNDi represent MSF's most explicit venture into the economics of suffering. Whereas the group classically denounces political failure and frequently calls for political responsibility in the form of state action, here MSF is seeking to shift market economics into a moral equation, one where life is never fungible. In the words of the head of the Access Campaign: "This inequality is incompatible with the concept of humanity. Fighting the fact that millions of lives are considered of less value than a fistful of dollars, is about preserving the basic morals of human civilization for the future" (quoted in MSF 2003). The effect

6 In addition to MSF, founding partners in DNDi included the Oswaldo Cruz Foundation in Brazil, The Indian Council of Medical Research, the Institut Pasteur in France, the Malaysian Ministry of Health and the Kenyan Medical Research Institute. The new organization also worked in association with the UN-World Bank-WHO program known as TDR (Research and Training in Tropical Diseases). For further details see MSF (2003) and the DNDi website (www.dndi.org).

of this reorientation of MSF's already global frame from populations to drugs, I suggest, is to extend humanitarian defense of life into the moral economy of suffering at a deeper technical level, repositioning neglect beyond particular bodies and into the apparatus of treatment itself. It also suggests something analogous to a right to healthcare, understood less as an abstract principle than as a material practice.

Small Happenings in Local Communities

Imagine the outcry in North America or Europe if a drug for, say, congestive heart disease didn't work in one-third of patients, and killed up to 10% of those who took it. Yet those are the shocking statistics for a 50-year old drug called melarsoprol, used to treat sleeping sickness – MSF website, 2003.⁷

Here I will return to a specific landscape of neglect, in this case northern Uganda, and small happenings in local communities. MSF first sent a mission to Uganda in 1980, just after the fall of Amin, and continued with various emergency interventions through the long years of ensuing chaos. After Yoweri Museveni came to power in 1986 and the country grew relatively stable, MSF had to decide whether to leave or develop a different sort of mission. As it happened, the field director for MSF-France of the time had written a thesis about sleeping sickness, then reaching epidemic levels in some areas of the country. Following his initiative and the efforts of many successors, a sleeping sickness program emerged, one that would continue in successive sites in the north until 2002. This program would not only become MSF-France's first long-term, disease-specific mission, but also play a background role in its later development of the Access Campaign and the DNDi. Slowly, over the years, MSF developed a degree of expertise in the treatment of sleeping sickness, conducting epidemiological studies of its programs and experimenting with different courses of treatment its clinics.

Sleeping sickness (African trypanosomiasis, in this case *trypanosomiasis brucei gambiense*) easily provides a paradigmatic example of MSF's "most neglected disease." A neurological disorder, it is transmitted by an insect vector – the tsetse fly – that infests marginal areas near vegetation and water across a central swath of Africa, and consequently mostly bites poor people.⁸ Fatal if untreated, the condition has nonetheless enjoyed little in the way of pharmaceutical research, and the

7 Declan Butler, "Raiding the Medicine Cabinet," MSF website, information July 7, 2003 (<http://www.msf.org/countries/page.cfm?articleid=F64F06F1-E7A7-44CF-87B9DAE4057D981F>).

8 "Poor" here designates poorer people within already poor contexts. In complaining about lack of state funding for the sleeping sickness program members of the team joked that the only way to get attention for the disease would be to release tsetse flies outside the houses of the elite. Lyons (1992) underscores the role of the sleeping sickness in regional colonial history, covering an epidemic that struck Uganda in 1899–1905 amid a study of northern Congo/Zaire and suggesting that ecological effects of colonial policies themselves contributed greatly to outbreaks of the disease. This suggests a larger pattern of interventions and counter-interventions interacting under the divergent desires for wealth and health: in effect a greater colonial pharmacopoeia. For further discussion of colonial medicine in Africa see Vaughn (1991).

dominant first line treatment for the second stage of the disease remains melarsoprol, a compound derived from arsenic first developed in 1949 that is notorious for its painful application and sometimes-fatal side effects. The mixed results of this quintessential pharmacopoeia led MSF to favor treatments with eflornithine (DFMO), first licensed in 1990. However, in 1995 the manufacturer, Aventis, announced it would no longer produce eflornithine, which was proving unprofitable despite its high cost. An extensive lobbying campaign by MSF and others, coupled with the appearance of VaniqaTM, an eflornithine-based product marketed by Bristol Myers Squibb as the solution to wealthy women's unwanted facial hair caused Aventis to shift course, and agree to restart production in 2001. Moreover, Aventis and other manufacturers committed to direct some resources to humanitarian ends.⁹ For a moment, at least, MSF's moral claim had helped sway the market. And yet the triumph was limited, given that the \$40 million estimated to launch a truly comprehensive sleeping sickness program at a global scale remained nowhere to be found.

On the ground in Uganda, MSF itself decided to close its own program in Omugo in 2002. Local prevalence of the disease had shrunk to an unremarkable 0.3 percent, and after more than 15 years of operation in a series of sites the group felt it was time to hand over responsibility to the government. MSF's new mission in nearby Arua focused on HIV-AIDS, and that program was expanding to offer ARV drugs to several hundred patients, part of a new global initiative begun in 2000. For all of the organization's impressive resources, it could not do everything, everywhere, all the time. By the time of my visit to the area, only a small Ugandan team working for MSF's research affiliate Epicentre remained devoted to sleeping sickness, finishing off the last epidemiological studies. The program was clearly dying: no government funding had appeared for salaries, equipment or fuel, the only regularly operating vehicle was the last MSF land cruiser and the now expiring drugs on clinic shelves still all bore that organization's logo. While hoping that someone would arrive to pick up the pieces, the local staff and other medical personnel also recognized this collapse as indicative of a norm rather than an aberration. "Our limitations are national limitations," the director of one hospital told me, standing in front of a largely barren supply room. Waves of international aid come and go; the training of the sleeping sickness assistants might now go to waste, but at least they still had their donated bicycles.

Here we find the familiar shadow of poverty behind MSF's drive to address suffering infrastructural inequities in access to medicines, as well as the limitations of its ever-impermanent field missions. By moving beyond the immediacy of suffering bodies to focus on the commodification of medical materials, the Access campaign produces a different humanitarian configuration. At the same time, however, it also leaves some individuals and populations behind. Places like northwestern Uganda

9 See MSF (2001). As an article in 2002 noted, eflornithine is effective only against the gambiense variant of trypanosomiasis and remains expensive at \$400–800 for a 14 dose treatment. Resistance to melarsoprol also appears to be rising. While the pentamidine prescribed for stage one of the disease is relatively safe, most patients only seek treatment when in the more debilitating stage two of the disease, which requires a treatment compound that can cross the blood/brain barrier (Ssemakula 2002).

run a regular surplus of neglected suffering, and one can die there from many things beyond either AIDS or sleeping sickness.

The Ugandan projects devoted to sleeping sickness and AIDS mark different points on MSF's trajectory into pharmaceutical activism, as well as some of the essential tensions of its sweeping endeavor. Whereas HIV-AIDS is a global pandemic threatening people in many walks of life, sleeping sickness is a regional disease limited to the marginal poor. Whereas many seek fame (and some also fortune) in searching for new treatments for AIDS, few researchers give much thought to sleeping sickness. With its drug campaign, MSF tries to address both the needs of the neglected and those of the "most" neglected. AIDS, however, often ends up at the rhetorical spear point of the effort. Given its greater media visibility, the vast advocacy coalitions constructed around it, and the sheer weight of medical need this is hardly surprising. DNDi, by contrast, concentrates more strictly on the "most neglected" diseases. Rather than changing pharmaceutical availability through policy, it focuses on extending pharmaceutical reach by creating more "public goods" beyond the market.

Taken together, MSF's drug efforts and the two Ugandan projects also echo an observation made by Veena Das about the different resonance of expert knowledge and democratic desires in poor countries:

The issue in this context is rarely that of our stake in "humanity" or "the human condition" as many have supposed, but rather how we can make institutions concerned with large issues of "human dignity" or "human rights" responsive to the small happenings in local communities far away from the eyes of the media or of new technologies – happenings that could nevertheless have vast consequences for our experience of the body, nature and society (Das 1999, 126).

The ambition of MSF's drug advocacy presents a precise corollary to Das' observation in biomedical terms: to render large-scale institutions responsive to "small happenings in local communities." Following the campaign and the initiative thus promises to illuminate not only this latest phase of humanitarianism, but also the distribution of global neglect, mapped with material exactitude by pathogens and medicines. In an era where "drugs for life" may well reflect a new biomedical orientation (Dumit 2002), we should recall that such a slogan can echo differently in different medical settings, particularly those where life finds its measure in existence rather than fulfillment.¹⁰

Expanded ambitions notwithstanding, however, MSF's move to address structural inequities of global health at the level of pharmaceutical access encounters the same general limit of capacity as its emergency programs. Geographically mobile and staffed by a fluid and partly volunteer mix of amateurs and experts, the organization

¹⁰ Dumit deploys the phrase to address a remarkable reconfiguration of contemporary pharmaceutical understanding at the centers of biomedical productivity, such that conditions like depression can be understood as a chronic state of an inherently ill (or suboptimal) body. Viewed from the margins of biomedical consumption, however, the phrase "drugs for life" just as easily suggests current anti-retroviral therapies for AIDS, where the course of treatment is literary conceived to be life-long, and measured directly in miniscule and uncertain supplies.

is neither a state nor a corporation. The group has sufficient collective resources to run small programs and make some larger noise, nothing more and nothing less. The very values that produce MSF's moral authority also restrict its action: it will not yield its independence, nor sacrifice lives in the name of a greater good, nor settle on a single priority amid the vast sea of the neglected. In a humanitarian time frame, future and past can never eclipse the present, embodied as it is in the immediacy of suffering, and evoked in the urgency of crisis. News from the latest front holds clear social appeal inside as well as outside the organization, as reflected in the pages of both its newsletters and fundraising brochures. Even AIDS, the most prominently publicized and moralized of contemporary afflictions, produces only a partial sense of urgency when viewed from the routine of a specific program; more than one volunteer at the ARV program in Uganda referred wistfully to the drama of emergency interventions elsewhere. Less remarkable conditions that only affect marginal populations – such as sleeping sickness – are even harder to cast as happenings with "vast consequences," and remain beyond the focus of most local, let alone international media. They might, however, present the sort of limited problem that a nonprofit pharmaceutical venture can address, thereby positioning them on the horizon of new technology.

Human Rights, Humanitarianism and the Practice of Virtue

Contemporary anthropologists tend to approach human rights less as an abstract set of defined principles to be supported or contested, and more as a dynamic discourse embodied in practice, and deployed by particular human groups within specific struggles (e.g. Merry 2006; Riles 2006; Wilson 1997). In this sense human rights claims constitute a potential basis for social exchange, in which the gap between legal ideals and daily realities can itself serve as a representational resource, one calculated in terms of suffering. From such a perspective, any "crisis" in human rights can only indicate a state in which the meaning of terms like "human rights violation" have become altered through their frequent deployment, and the strategies developed to respond to them. Similarly, from an anthropological perspective, humanitarianism designates not only a moral adherence to the alleviation of suffering, but also what people do while pursuing that good.

The fact that MSF has ventured into addressing pharmaceutical topics during a period of perceived crisis in humanitarianism suggests that this development marks a potential reorientation or redistribution within humanitarian sensibility, whereby economic factors contributing to suffering become newly tangible in the absence of medical materials. The forms of response that MSF has generated to further its goal of greater pharmaceutical equity – the Access campaign and DNDi – involve operations on a different time scale than those of its field operations: policy analysis, public advocacy and scientific research. These activities in turn involve MSF in alliances and coalitions with other groups and institutions pursuing similar ends, testing its historic value of independence even while the organization seeks to reassert autonomy in the face of military cooptation of humanitarian rhetoric.

Thus the actual practice of virtue grows complex and contradictory when examined at the level of ethnographic and historical detail. Within a regime of value focused on human life, an individual death can constitute a personal tragedy, a symbolic reference or an organizational opportunity. In certain cases it becomes all three. Although humanitarian organizations have long focused on the suffering of ordinary individuals, they have usually mobilized in response to extraordinary conditions, such as famine and displacement. By concentrating on global inequities in pharmaceutical availability and research orientation, the drug initiatives widen the scope of what counts as a humanitarian crisis. Deaths from unprofitable diseases have acquired additional moral weight in this sense, and are no longer "ordinary." In these practical terms one edge of humanitarianism now overlaps with international efforts to promote social and economic rights. For all of MSF's continued avoidance of human rights rhetoric, its efforts to address the problem of neglected diseases, along with HIV-AIDS, have effectively positioned the group to assert something analogous to a universal right to healthcare. The focus remains restricted to specific and quite tangible problems related to pharmaceutical access. At the same time, however, that goal is implicitly expansive; in identifying structural deficits in the global supply of drugs, MSF has recognized poverty, a condition for which it offers no cure.

Pharmaceutical issues emerged as a significant topic of international treaties amid the dramatic spread of the AIDS pandemic. As well as altering local conditions, debates and advocacy surrounding AIDS produced new configurations within the broader politics of international health and the moral framing of disease. At a moment when antiretroviral therapy promises survival, access to drugs defines an important attribute of public welfare. Thus scholars can speak of "biological" or "therapeutic" citizenship, as well as "pharmaceutical" governance (Petryna et al. 2006; Biehl 2006; Nguyen 2005). Such matters are hardly contained within individual nation states, but rather intimately connected to transnational networks and international organizations. When MSF altered course and launched into the provision of AIDS treatment, it hoped to spur state action. By the end of 2005 it was supporting well over 50,000 patients with its own ARVs, and faced problems of governance of its own (Calmy 2005). AIDS care ultimately involves social dimensions well beyond the physical treatment of individual bodies (Heald 2003; Kleinman et al. 1997; Whyte et al. 2006).¹¹ Nonetheless, it continued to agitate for increased attention to less-publicized conditions, particularly those restricted to marginal settings. Issuing briefings on topics such as "What to Watch for in Free Trade Agreements with the United States" (MSF 2004), and launching efforts at nonprofit, need-driven drug research, the organization countered claims to intellectual property rights with an alternative conception of pharmaceutical products as a public good.

11 HIV-AIDS represents a particularly clear instance for the general anthropological emphasis on social aspects of suffering (Kleinman et al. 1997). Delivery of quality care requires quality health infrastructure, and antiretroviral therapy is a continuing, indefinite form of treatment. Moreover, it only restores bodies, not social relations, which MSF generally perceives to lie beyond its purview. For further anthropological work addressing the global life of pharmaceuticals see Lakoff (2006); Laplante (2003); Petryna (2005); Van der Geest et al. (1996); and Whyte et al. (2002).

What I wish to suggest is that something like a rights claim can emerge in practice as well as from principle. In the case of MSF's ventures into pharmaceutical advocacy and research, it does so in between legal treaties, laboratories and suffering bodies. Such human rights would necessarily address the material state of populations as well as states and legal persons, and they would redefine the circulation of goods in moral terms. Human dignity would now involve molecular reactions (Rabinow 1999). Whether or not these developments prove "successful" in the sense of achieving their initial aims, they mark a shift in humanitarian sensibility. Faced with the tension of states appropriating aspects of their moral discourse for their own ends, a humanitarian organization expands its focus to address market failure. Along the way it strives to highlight the suffering of victims of unprofitable diseases, and exposes the structural inequities of global health. Once ordinary forms of death can thus be recast as potentially extraordinary.

I will close this chapter with the image of a second body, this one fitfully inhabited by a departing mind. Idi Amin, after all, was not the only Ugandan to die in the summer of 2003. On my last day visiting the sleeping sickness program, I met a patient in the latest stages of the disease in a dilapidated regional hospital not far from the Sudanese border. Wearing a green T-shirt with the name "Versace" printed across the front, she exhibited signs of dementia when awake, dancing slightly and chanting phrases only she fully understood. She had recently given birth, and her own mother now attended both her and her child, since she herself was beyond any such maternal duty. The nurse accompanying me explained loudly (presumably for the benefit of others in the ward as well as me) that no drug could reverse the neural damage now, and so this patient was beyond the reach of cure. On seeing me the woman in the Versace T-shirt shouted two remaining words with foreign significance – "America!" and "Entebbe!" – before returning to her song. Along with Amin she lingered at the edge of existence, although the close of her life would inspire far less moral commentary. Both the staff and other patients around her seemed to recognize this woman as already departed; it was only a matter of time before her body followed behind. Her madness and impending demise lent her a degree of fleeting visibility within the ward, quickly erased by the continuing flow of human misery. Unlike the former dictator, this woman cast no long shadow of notorious excess and several hundred thousand bodies, only the slight shadow of a tragic, but unprofitable disease. Even in this corner of Uganda, sleeping sickness was far from the only health problem, and neither a national nor international priority. The very unremarkable nature of her fate, however, reveals both another horizon of humanitarian ambition, as well as the recognition of its continuing frustration.

Works Cited

- Biehl, João (2006), "Pharmaceutical Governance," in Adriana Petryna, Andrew Lakoff, and Arthur Kleinman, eds, *Global Pharmaceuticals: Ethics, Markets, Practices*, Durham, NC: Duke University Press, 206–239.
- Barnett, Michael (2005), "Humanitarianism Transformed," *Perspectives on Politics*. 3: 4: 723–740.

- Bortolotti, Dan (2004), *Hope in Hell: Inside the World of Doctors Without Borders*, Buffalo: Firefly Books.
- Bradol, Jean-Hervé (2004), "Introduction: The Sacrificial International Order and Humanitarian Action," in Frabrice Weissman, ed., *In the Shadow of Just Wars: Violence, Politics and Humanitarian Action*, Ithaca, NY: Médecins Sans Frontières and Cornell University Press, pp. 1–22.
- Brauman, Rony (2000), *L'Action humanitaire*, Paris: Flammarion.
- Calmy, Alexandra (2005), "Alive at Five: Lessons Learned from AIDS Treatment in Resource-poor Settings," *Access News* 12 (November): 1.
- Das, Veena (1999), "Public Good, Ethics and Everyday Life: Beyond the Boundaries of Bioethics," *Daedalus*, 128: 4: 99–133.
- Daston, Lorraine (1995), "The Moral Economy of Science," *Osiris*, 2nd Series, 10, *Constructing Knowledge in the History of Science*, 2–24.
- DNDi (2004), "An Innovative Solution," Informational brochure, April 2004.
- Dumit, Joseph (2002), "Drugs for Life," *Molecular Interventions* 2: 3 (July): 124–127.
- Farmer, Paul (2003), *Pathologies of Power: Health, Human Rights, and the New War on the Poor*, Berkeley: University of California Press.
- Fox, Renée (1995), "Medical Humanitarianism and Human Rights: Reflections on Doctors without Borders and Doctors of the World," *Social Science and Medicine*, 41(12): 1607–1616.
- Heald, Suzette (2003), "An Absence of Anthropology: Critical Reflections on Anthropology and AIDS policy and practice in Africa," in George Ellison, Melissa Parker and Catherine Campbell, eds, *Learning from HIV and AIDS*, Cambridge: Cambridge University Press, 210–237.
- Hoen, Ellen 't. (2002), "TRIPS, Pharmaceutical Patents, and Access to Essential Medicines: A Long Way from Seattle to Doha," *Chicago Journal of International Law*, 3: 1: 27–46.
- Kleinman, Arthur, Veena Das, and Margaret Lock, eds (1997), *Social Suffering*, Berkeley: University of California Press.
- Lakoff, Andrew (2006), *Pharmaceutical Reason: Knowledge and Value in Global Psychiatry*, Cambridge: Cambridge University Press.
- Laplace, Julie (2003), "Le Médicament aux frontières des saviors humanitaires et autochtones," *Anthropologie et Sociétés*, 27: 2: 59–75.
- Leopold, Mark (2005), *Inside West Nile: Violence, History and Representation on an African Frontier*, Santa Fe, NM: School of American Research Press.
- Lyons, Maryinez (1992), *The Colonial Disease: A Social History of Sleeping Sickness in Northern Zaire, 1900–1940*, Cambridge: Cambridge University Press.
- Médecins Sans Frontières (MSF) (2000), *Activity Report, 1999–2000*, MSF International.
- Médecins Sans Frontières (MSF) (2001a), "Fatal Imbalance: The Crisis in Research and Development for Drugs for Neglected Diseases," MSF Campaign for Access to Essential Medicines/Drugs for Neglected Diseases Working Group Report.
- Médecins Sans Frontières (MSF) (2001b), "Supply of Sleeping Sickness Drugs Secured," Press Release, New York/Geneva, May 3, 2001.

- Médecins Sans Frontières (MSF) (2002), "AIDS: The Urgency to Treat," Supplement to Messages, 123. December.
- Médecins Sans Frontières (MSF) (2003), "Access: Three Years On," *Access News*, 8 (February).
- Médecins Sans Frontières (MSF) (2004), "Access to Medicines at Risk Across the Globe: What to Watch out for in Free Trade Agreements with the United States," MSF Campaign for Access to Essential medicines Briefing Note (May).
- Médecins Sans Frontières (MSF) (2005), *Activity Report, 2004–5*, MSF International.
- Médecins Sans Frontières (MSF) (2006), "Too Little for Too Few: Challenges for Effective and Accessible Antiretroviral Treatment," Briefing document, XVI International AIDS Conference, Toronto, 2006.
- Merry, Sally Engle (2006), *Human Rights & Gender Violence*, Chicago: University of Chicago Press.
- Nguyen, Vinh-Kim (2005), "Anti-retroviral Globalism, Biopolitics and Therapeutic Citizenship," in Aihwa Ong and Stephen Collier, eds, *Global Assemblages*, Malden, MA: Blackwell, 124–144.
- Petryna, Adriana (2005), "Ethical variability: Drug development and globalizing clinical trials," *American Ethnologist*, 32: 2: 183–197.
- Petryna, Adriana, Andrew Lakoff, and Arthur Kleinman, eds (2006), *Global Pharmaceuticals: Ethics, Markets, Practices*, Durham, NC: Duke University Press.
- Rabinow, Paul (1999), *French DNA: Trouble in Purgatory*, Chicago: University of Chicago Press.
- Rankin, Johanna (2005), A New Frontier for Humanitarianism? Médecins Sans Frontiers Responds to Neglected Diseases, unpublished Honors Thesis, International Studies, UNC-Chapel Hill.
- Redfield, Peter (2006), "A Less Modest Witness: Collective Advocacy and Motivated Truth of a Medical Humanitarian Movement," *American Ethnologist*, 33: 1: 3–26.
- Rieff, David (2002), *A Bed for the Night: Humanitarianism in Crisis*, NY: Simon & Schuster.
- Riles, Annelise (2006), "Anthropology, Human Rights, and Legal Knowledge: Culture in the Iron Cage," *American Anthropologist*, 108: 1: 52–65.
- Ssemakula, John Kiwanuka (2002), "No Longer Asleep: African Sleeping Sickness is Back," *Medilinks* 31 May, 2002, <http://medilinks.org>.
- Thompson, E.P. (2001 [1991]), "The Moral Economy of the English Crowd in the Eighteenth Century," in Dorothy Thompson, ed., *The Essential E.P. Thompson*, New York: New Press, 316–377.
- Vallaëys, Anne (2004), *Médecins Sans Frontières: La biographie*, Paris: Fayard.
- Van der Geest, Sjaak, Susan Reynolds Whyte, and Anita Hardon (1996), "The Anthropology of Pharmaceuticals: A Biographical Approach," *Annual Review of Anthropology*, 25: 153–178.
- Vaughn, Megan (1991), *Curing Their Ills: Colonial Power and African Illness*, Stanford: Stanford University Press.
- Weissman, Frabrice, ed. (2004), *In the Shadow of "Just Wars": Violence, Politics and Humanitarian Action*, Ithaca, NY: Médecins Sans Frontières/Cornell University Press.

- Whyte, Susan R., Sjaak Van der Geest, and Anita Hardon (2002), *Social Lives of Medicines*, Cambridge: Cambridge University Press.
- Whyte, Susan R., Michael Whyte, Lotte Meinert, and Betty Kyaddondo (2006), in Adriana Petryna, Andrew Lakoff, and Arthur Kleinman, eds, *Global Pharmaceuticals: Ethics, Markets, Practices*, Durham, NC: Duke University Press, 240–262.
- Wilson, Richard, ed. (1997), *Human Rights: Culture and Context* (London: Pluto Press).

Notes

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Conclusion

Alice Bullard

The historian’s perspective on human rights is perhaps best conveyed in *Human Rights and Revolutions*, a book that documents the fitful pursuit of human rights via violent upheavals as much, if not more than, via the rule of law (Hunt, Young, and Wasserstrom 2000). Such a broad historical perspective might induce us to view the present crisis with equanimity. If enemy combatants are detained without right to trial or adequate protection, nonetheless their number is much lower than the Japanese Americans interred in camps during World War II. If dissent is currently stifled, nonetheless the courts are asserting their power more robustly than they dared in previous war situations (Stone 2004; Lessig 2004). If human rights law is partially eclipsed today, a future era will undoubtedly usher in a climate more favorable to such claims.

Such arguments suggest a long term evolution of rights culture. Nonetheless, an evolution, with inevitable setbacks and partial eclipses, cannot remove the haunting fear produced by US government agents engaged in torture. Nor can it redeem the suffering, the lives lost and destroyed, by reckless actions. Advocates of international human rights law such as Mary Robinson, moreover, are less than sanguine about the current situation. Speaking at the International Rule of Law symposium in Chicago in 2006, Robinson lamented the “balance that was lost in the aftermath of 9/11,” as she described the deterioration of guarantees and freedoms and the targeting of human rights advocates as terrorists (Robinson 2007). Writing with a characteristic restraint, Robinson remarked how the Eminent Jurists’ panel to which she belongs, “was taken aback by the testimony” in their hearings in Washington D.C., noting with dismay and deep concern “the extent to which fundamental rights and freedoms [have] been undermined over the past five years” (Robinson 2007, p. 8; for a wide-ranging discussion of US infractions, see UNHCR 2007).

Robinson’s words echo the message of Barr’s contribution to this volume; the Eminent Jurists’ panel’s on-going examination of human rights during the Global War on Terror has found much cause for worry in societies around the globe (Eminent Jurists’ Panel 2007). Writing about the United States, this panel reported that the moral leadership of the United States had been seriously undermined by treatment of unlawful combatants and prisoners from the Iraq war and in Afghanistan. Perhaps not surprisingly, the panel decried the post 9/11 erosion of the rule of law both in the United States and overseas (Eminent Jurists’ Panel 2006).

In this collection the culture of crisis is bound up with the culture of human rights. “Human rights in crisis” can mean both human rights threatened and human rights defended. Indeed, the culture of human rights is bound intimately to the culture of crisis. In the first and most prominent instance, the crisis centers on a