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**Infectious Diseases and Social Inequality in Latin America:  
From Hemispheric Insecurity to Global Cooperation**

**Lessons in the Time of Cholera**

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**Hidden Epidemics of Tuberculosis**

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**Rapporteur's Report: May 1, 1998 Conference**

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## **Preface**

**Charles L. Briggs**

When a devastating cholera epidemic began in Peru in January of 1991 and then spread throughout Latin America, public health officials, politicians, and development officials were caught nearly as much off guard as individuals who contracted the disease. After being free from cholera for nearly a century, the region was suddenly overrun by an illness associated with poverty and the pre-modern era. Coming toward the end point of the World Health Organization's drive to achieve "Health for all by the year 2000," the cholera epidemic suggests that health and medical care are now less accessible for many people than they were twenty years ago and that diseases are capable of crossing national frontiers with ease, producing terrifying epidemics. Cholera, which continues to be a problem in many Latin American countries, came in the midst of the AIDS epidemic, and it has now been joined by multidrug-resistant (MDR) tuberculosis, which continues to grow more dangerous in terms of extent, pervasiveness, and intractability in many regions.

This situation points to the critical need to identify the full range of factors that favor the rise of infectious diseases and to create coalitions of government institutions, community organizations, and non-governmental organizations capable of building bold initiatives designed to counter them. Unfortunately, the link between infectious diseases and poverty has more commonly prompted responses that stigmatize populations in which epidemics occur, such that developed countries reproach developing nations for their health problems and the latter, in turn, scapegoat their poorest and most marginal sectors.

While a Fellow of the Woodrow Wilson Center in 1997-1998, my research focused on a devastating outbreak of cholera in the fluvial rainforest area of the Orinoco Delta. As I describe in my contribution to this Working Paper, some 500 persons classified as "indigenous" members of "the Warao ethnic group" died from the disease in 1992-1993. Defending themselves in the face of the resulting criticism, public health officials fashioned time-worn stereotypes into characterizations of "indigenous culture," which were then construed as epidemiological factors responsible for having caused the deplorable levels of morbidity and mortality in the region and limiting the effectiveness of institutional efforts. This response paralleled the way that some international epidemiologists cited Latin American social and cultural patterns in explaining the depth and extent of the cholera epidemic as a whole.

In his contribution, public health authority, physician, and activist Paul Farmer focuses on the alarming spread of MDR tuberculosis and the way that Latin American and international officials have reacted to it. He argues that the "immodest claims of causality" that are made for assertions regarding the social and ideological foundations of poor populations in explaining the failure to contain epidemics ultimately delay the search for solutions, perhaps irreparably.

This process has profound negative effects on political and economic stability in the region. At a time in which more than half of the population in some countries lives in poverty, the failure to address crushing problems in such areas as health care, water and sewage

infrastructure, and malnutrition that target populations for these diseases promotes the feeling that whole communities have been excluded from the rights associated with citizenship and the institutions of civil society, exacerbating the search for survival strategies that lie outside the political system, including crime and violence. As Latin American countries perceive that the fear and stigma associated with cholera, MDR tuberculosis, malaria, and other infectious diseases will lead to economic and political repercussions, the desire to suppress information thwarts efforts to mobilize both institutions and the public. Ironically, by participating in this process and failing to take a leadership role in forging a global partnership, the United States and other wealthy countries promote the spread of diseases in the region and undermine systems of inspection and surveillance, thereby increasing their own vulnerability to domestic and imported microbes.

In spite of the scope of the problem and the fact that it affects all populations in the emerging global health community, discussions of infectious diseases in Latin America have largely been confined to technical forums in epidemiology and public health. While social scientists have extensively documented the impoverished urban and rural communities that have been severely affected by cholera and tuberculosis, they have been strangely silent with respect to these epidemics, with the exception of a number of medically-oriented researchers. As these diseases continue to exert serious medical and economic effects, there is a pressing need for multidisciplinary discussions of the factors responsible for epidemics and the range of policy decisions that will affect what happens in the years to come.

On May 1, 1998, the Wilson Center's Latin American Program organized a day-long conference, bringing together social scientists, public health experts, and specialists on development, political economy, and public policy to help formulate new ways of approaching connections between social inequality and infectious diseases in Latin America. The goal of the discussion was to place the question of new and newly emergent infectious diseases in Latin America in a broader context and to increase awareness of the scope of the problem, including its global roots and implications, in academic, policy, and public spheres.

Panelists discussed questions such as the following: In what different ways are epidemics of cholera, MDR tuberculosis, and other infectious disease tied to poverty and social inequality? How are recent political and economic transformations related to the rise of these epidemics? How have international diplomatic and economic relations both shaped and been affected by national responses to the epidemics? What sorts of policies in political, economic, and health arenas could be adopted in the United States and Europe in order to strengthen the ability of Latin American nations to eradicate endemic and epidemic conditions? In addition to the high level of engagement of the distinguished panelists, the discussion was greatly enriched by the active participation of audience members drawn from a range of fields and institutions. Both the formal presentations and the following discussion are reported in the summary written by Catherine A. Christen.

## LESSONS IN THE TIME OF CHOLERA

Charles L. Briggs

What can we learn from the Latin American cholera epidemic? This question has been raised in a number of publications by leading international epidemiologists with extensive cholera experience, Robert Tauxe (1992) and David Swerdlow (Swerdlow et al. 1992) among them. Posing the question within an epidemiological frame, many of the answers that have been given tie the incidence of cholera closely to questions of social inequality. Here differences between nation-states, particularly in the adequacy of infrastructures for providing potable water and disposing of sewage, and between populations within countries, especially living conditions and “cultural practices,” play a key role in attempts to explain why such a widespread epidemic emerged in a region that had been free of the disease for about a century.

At the same time that I take up the issue of the connection between cholera and social inequality, my goal here is to transform the manner in which researchers and policy makers in public health and other fields define and investigate the relationship between them. I wish to press for three sorts of reorientations.

First, characterizations of populations in which cholera cases are deemed to have concentrated often elevate powerful negative images of unwashed hands, unclean food, and fly-ridden sidewalk stalls to the status of social factors or even causal elements. Beyond the danger of evoking timeworn stereotypes, such accounts provide deceptively oversimplified ways of connecting social inequality and infectious diseases.

Second, this focus thwarts our ability to place the epidemic in a sufficiently global context. In accounting for the cholera epidemic, can we point to a sudden decrease in the extent of government’s concern with the health needs of their citizens or a sudden shift toward rejection of “modern” health-related concepts and practices in Latin American communities? I think not. Antiquated images of poverty and backwardness are less useful analytic tools than accurate assessments of the place of infectious diseases within this dynamic situation. Logics of stigmatization thwart identification of the full range of causal and contributing variables and render international cooperation more difficult, thereby exacerbating health problems. New points of departure are needed for conceptualizing the link between social inequality and infectious diseases.

Finally, systematic consideration of these issues have too seldom brought together epidemiologists and public health officials, social scientists who study Latin America, and specialists in development economics and other policy-oriented areas. Practitioners in all of these areas must grapple with social inequality, particularly in view of the precarious economic plight of so many Latin Americans at this moment; just as the issue can thus provide common ground, its complexities demand a multiplicity of perspectives. Beyond fostering a dialogue that draws on complementary points of view in epidemiology and other fields of public health, medicine, sanitation engineering, development, and the social and natural sciences, we need to be sufficiently bold and creative to question and change closely guarded premises—it is time to

work collectively toward building new approaches. The search for new perspectives that transcend perceived disciplinary and regional boundaries would also be greatly facilitated by building a new kind of partnership between North and South—between epidemiologists, other scientists, and practitioners employed by international agencies and by prestigious national public health agencies and schools of public health in the United States and Europe on the one hand and their counterparts in Latin America on the other. The conversation to date has centered on an older vision of international health, construed as the unidimensional flow of epistemologies, experts, and technologies from the “First World” to the “Third World.” The task of remapping our understanding of the connection between infectious diseases and social inequality provides a striking example of an area in which scientists and practitioners in the North are badly in need of the theoretical models and practice-based perspectives that have been developed in the South. In particular, interpretations of social and economic factors that related to questions of health and disease in the Americas written in the United States and Europe have too seldom drawn on a body of Latin American researchers and practitioners known as critical epidemiologists; these “epidemiologists of social inequality” have been pursuing this question for decades.

So let us ask what lessons we can learn from the cholera epidemic in a more global and incisive fashion. Cholera is a bacterial infection whose etiology, which has been known for more than a century, is relatively well understood.<sup>1</sup> Although the development of effective vaccines has been quite challenging, successful treatment modes have been available for decades. So why are we, at the close of the millennium, plagued by a malady that conjures up images of poverty, dirt, backwardness, ignorance, and the pre-modern era? Why is it the case that “In 1991, the pandemic of cholera El Tor which started in 1961 in the Celebes (Sulawesi), in Indonesia, finally completed its encirclement of the globe” (WHO 1992:253), precisely in the decade that preceded the Alma Ata goal of achieving “Health for all by the year 2000”? The Latin American cholera epidemic confronts us with much bigger and more troubling questions. And these questions also jump out at us from a host of other epidemiological quadrants; tuberculosis, malaria, and dengue come quickly to mind.

In focusing my discussion on cholera, I am not advancing the claim that it is the most pressing health problem in Latin America. Cholera was absent from Latin America for about a century prior to the beginning of an epidemic of *Vibrio cholerae* 01 biotype El Tor in Peru in January of 1991. The morbidity and mortality figures for Latin America published in the WHO Weekly Epidemiological Record for 1991-97 are as follows:<sup>2</sup>

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<sup>1</sup> This does not mean, however, that the microbiology of cholera offers no new surprises. Although scientists had believed that cholera strains that lack the 01 antigen lacked the potential to cause epidemics, a new type of cholera—which has been designed as *V. cholerae* 0139 Bengal—caused an epidemic in India and Bangladesh in 1992. Beyond questions that emerged regarding how it had evolved and why past infection with 01 El Tor cholera did not afford immunity, specialists were hard pressed to explain why the 0139 strain did not continue to displace the El Tor variety and lead to a new pandemic, as initially expected (see Albert 1995; Morris et al. 1994; Swerdlow 1993; Cholera Working Group 1993; WHO 1997).

<sup>2</sup>These figures are taken from the annual summaries of cholera statistics published in the *Weekly Epidemiological Record* (1992:258; 1993:151; 1994:207; 1995:203; 1996:159; 1997:231; 1998:203). For reasons

Year	Cases	Deaths
1991	391,192	4,002
1992	353,983	2,400
1993	209,167	2,437
1994	113,635	1,107
1995	85,783	845
1996	24,638	351
1997	17,756	225

Except in the most acute epidemic circumstances, more lives—particularly those of infants—are lost to other diarrheas each day than to cholera. Nevertheless, the continuing importance of cholera is summed up in an “Editorial Note” that concludes the WHO annual summary, “Cholera in 1997”:

Cholera remains a global threat and one of the key indicators of social development. While the disease no longer poses a threat to countries with a minimum standard of health living conditions, it remains a challenge to countries where access to safe drinking water and adequate sanitation cannot be assured. Almost every developing country is now facing either a cholera outbreak or the threat of an epidemic. [WHO 1998:208]

Beyond the continuing public health implications of cholera, the disease continues to constitute the lower limit of modernity, the dividing line between “developing countries” and their more fortunate counterparts. Cholera, in short, remains a key language for discussions of modernity and social inequality. Careful scrutiny of the Latin American epidemic can thus provide us with a range of insights into how social inequality and infectious diseases get connected.

I open this essay by detailing a cholera epidemic that took place in 1992-93 in the Orinoco Delta of eastern Venezuela, just south of Trinidad and West of Guyana.<sup>3</sup> The outbreak resulted in the deaths of some five hundred individuals, most of whom were classified as *indígena* (“indigenous persons”) and specifically as members of an *étnia* (“ethnic group”) referred to as “the Warao.”<sup>4</sup> Here race—the classification of individuals and communities into

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that I will outline below, I think that the published figures do not accurately reflect the extent of the epidemic.

<sup>3</sup> My investigation of the cholera epidemic was undertaken jointly with Clara Mantini-Briggs, MD, a Venezuelan physician; it was funded by the John Simon Guggenheim Memorial Foundation, the National Science Foundation, the Social Science Research Council, and the Wenner-Gren Foundation for Anthropological Research, Inc. I would also like to acknowledge the generosity of the Latin American Program of the Woodrow Wilson International Center for Scholars and the Center as a whole for the fellowship that enabled me to devote myself to this research. I would also like to thank Joseph Tulchin for supporting this conference and to acknowledge the active and persistent involvement of Allison Garland in bringing both the conference and this Working Paper to fruition.

<sup>4</sup> This estimate of cholera deaths in the Orinoco Delta during the outbreak of 1992-93 was produced in the following fashion: Dr. Mantini-Briggs and I traversed virtually the entire delta, visiting as many

indigenous people or Warao, on the one hand, and members of “the national society” or *criollos* (Creoles), on the other—structures daily life in pervasive and crucial ways. The manner in which public health officials linked race and cholera in the course of explaining the high morbidity and mortality in the region provides an illuminating example of the problems associated with prevalent means of connecting infectious diseases and social inequality. I then consider some of the ways that cholera was discussed in Venezuela as a whole and how international epidemiologists have described the Latin American epidemic.

### **Cholera in Delta Amacuro, Venezuela**

In the Orinoco Delta in eastern Venezuela, a fluvial region with an estuarial coastline that consists of about 40,000 sq. km. and a population of about 40,000 (OCEI 1992),<sup>5</sup> medical services are limited and transportation is difficult; the delta thus provided an ideal locus for the emergence of a cholera epidemic. The disease can kill an adult through dehydration in 24 hours, and death rates may be as high as 70 percent in untreated patients (Rabbani and Greenough 1992:217). Few communities in the fluvial region had received instruction on cholera symptomatology or knew that treatment was required immediately; the diarrheal diseases with which they were acquainted predominantly affect infants, children, and the elderly, and they do not kill so rapidly. In some small communities as many as a quarter of the adults died in a night or two. The epidemic thus compounded insecurity around issues of life and death in a region that has among the highest rates of malnutrition and infant mortality in the country. A study conducted in the 1950s-1970s by Miguel Layrisse, Johannes Wilbert, and their colleagues in one area (Winikina) placed prepubescent mortality at 50 percent (Wilbert 1980). Measles appears to have killed hundreds of children in the delta in 1993. Tuberculosis is so common that the majority of adults in some areas are symptomatic, and many die from the disease.<sup>6</sup>

The cholera epidemic continued to exert detrimental effects on living conditions after new cases had slowed to a trickle by the middle of 1993. As insecurity surrounding everyday health conditions was transformed into terror by the outbreak, thousands of delta residents fled to the mainland, and groups began living as mendicants on the streets of the capital, Caracas, and other major cities. When this exodus drew the attention of the press, the national government and

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individual communities as possible. (These range from groupings of several houses to communities with several hundred residents to principal towns, such as Curiapo, Guayo, and Pedernales.) Since our research was conducted in 1994-95, it consisted of retrospective interviews with community leaders, asking for details regarding each death associated with cholera symptoms that occurred between 1992-93.

<sup>5</sup> These figures are taken from the 1990 census figures as published by the Central de Estadística e Informática, OCEI. The population figure is for all rural residents of the state. Although this total thus includes some rural residents who do not live in the fluvial region of the delta, it also excludes delta residents who live in neighboring Monagas State.

<sup>6</sup> This statement is based on clinical examinations and observations made by Dr. Mantini-Briggs in the course of her work in the delta. In many areas, tuberculosis patients are only examined by physicians when they are severely ill, and many die in their communities without ever being seen by a medical practitioner. We accordingly lack reliable estimates of the extent of tuberculosis morbidity and mortality in the delta.

officials in others states reacted by rounding up the refugees and sending them back in military transport to the delta; the cycle is still repeated frequently. The constitutional rights of persons who looked “indigenous” were violated for a time by confining them to the delta region. Both the cholera epidemic and the exodus of refugees prompted criticism of the Delta Amacuro State government by national officials, other state governments, and opposition politicians: deeming “the Warao” to be a political liability, politicians and administrators subsequently turned an even deaf ear to conditions in the delta, responding to petitions presented by “indigenous persons” for improvements in medical services, political representation, human rights, land expropriation, and environmental degradation with a mixture of disinterest and contempt.

The national publicity that focused on the epidemic threatened the legitimacy of public health institutions in Delta Amacuro State, and some accounts characterized the epidemic as evidence of major shortcomings on the part of the state government as a whole in terms of its “indigenous policy.” The stigma attached to the emergence of a disease that conjures up visions of backwardness, lack of hygiene, poverty, inadequacy of health infrastructures, and negligence on the part of public health and other authorities led to the dismissal of the directors of the Ministry of Health and Public Assistance, the Office of Indigenous Affairs, and other agencies. It also seems to have contributed to the replacement by voters of the Acción Democrática party with the Movimiento al Socialismo in the state government in 1993. Official embarrassment in the Delta Amacuro was exacerbated when it became apparent that no serious efforts had been made to prepare for an epidemic—some of the rural clinics neither had physicians in residence nor more than minimal quantities of medicines when the outbreak began.

Government institutions responded in two primary ways. First, an unprecedented avalanche of resources was mustered to control the epidemic. Additional physicians were sent to rural clinics, and temporary treatment centers were established in areas where the greatest concentrations of cases were emerging. These efforts are clearly to be commended. Second, officials produced and circulated accounts of the epidemic that deflected the blame away from government institutions and onto the cholera victims themselves. The most pervasive feature of these representations was the racialization of cholera in the region. The social and political power of the opposition between “the Warao” and “the criollos” (or “the national society”) was mobilized to the task of depicting the epidemic as an indigenous problem, thereby rendering cholera, the space of the delta, and the Warao population synonymous.<sup>7</sup> Conversely, cholera cases among criollos in Tucupita and in the delta were virtually erased in public commentary on the epidemic. Drawing on extensive interviews with public health officials, medical practitioners, and politicians conducted by Dr. Mantini-Briggs and myself and on public pronouncements published in newspaper articles, I detail the explanations they offered of the

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<sup>7</sup> In the remainder of the text, I bow to editorial policy and refrain from placing “Warao,” “the Warao,” “the criollos,” and similar expressions in quotation marks. I ask the reader to bear in mind, however, that my use of these terms does not imply that they refer to bounded, discrete social groups; my analysis suggests that dividing delta residents into discrete and non-overlapping “indigenous” and “non-indigenous” categories is less a reflection of a pervasive and elementary social difference than a tool for *imposing* racial categories and the forms of social inequality that go with them. Thus, please bear in mind that my use of these terms refers to the categories as they are employed in statements by public health practitioners and others.



causes that led to high cholera morbidity and mortality, thereby presenting a rather dramatic example of how questions of health and social inequality get linked.

The concept of “cultural idiosyncrasy” provided a rhetorical foundation on which to build explanations of why cholera affected the Warao in the delta and not criollos. “Warao culture” was characterized as a set of *costumbres* (“customs”) or a “millenarian cultural pattern”; food preferences and modes of preparation and consumption were cited as key elements of the “customs” that rendered delta residents highly susceptible to cholera. When he visited the region at the beginning of the outbreak, the Minister of Health, the highest-ranking public health official in Venezuela, announced that the high rates of cholera infection were due to eating habits in the delta. Just as the consumption of ceviche, a dish prepared with uncooked fish, became the leitmotif for the cholera epidemic in Peru, “the consumption of the blue crab, a millenarian ancestral tradition” (*Notidiario*, 17 August 1992) was often cited as the leading mode of transmission in the delta. The regional epidemiologist went beyond blaming the diet and mode of food preparation of the Warao in creating a totalizing image of the domestic space inhabited by them:

The Indian is accustomed to living in conditions of very bad environmental hygiene, that's why [there was so much cholera]. We know the situation of these people: They eat on the floor, and they defecate—or let's say, they don't have a system of defecating discretely. They do it in the open air. The flies, which land on food, land first on the feces and then on the food and then on the bottle, the pacifier of the child, and then they give it the bottle. (Interviewed by CLB, 14 January 1994)

Going far beyond scientific descriptions of possible routes of transmission of cholera, such statements evoke stereotypes of the Warao as ignorant, unsanitary, and backward.

These “millenarian cultural patterns” were deemed to be too deeply ingrained ever to be changed. By locating the causes of high morbidity and mortality in the minds of the patients and their communities, these officials erased the possibility that political-economic and institutional structures that limit access to adequate schooling, potable water and sewage facilities, health education, and medical treatment might have played a role in creating conditions that are highly hospitable to cholera. In attempting to identify the cultural core complex that prompted such high morbidity and mortality, the director of the Regional Health Office characterized the way that the Warao (and Warao mothers in particular) view issues of health, life, and death:

The Indians—they're people who accept death as a normal, natural event in their lives. And when an Indian dies, it's not anything transcendental: an Indian dies and nothing happens. There isn't this fondness for life, this affection for life among them. “It's all the same: a child dies and I have another tomorrow and it dies.” Okay, maybe it's because it's always been like that—they have their children and they die. So then this—well, they will think that when a disease comes along that decimates them, it's because one of those evil spirits is getting even with them... In their case, we have to teach them to take care of their lives, because they don't love their lives. [Interviewed by CLB, 31 March 1995]

In this statement, the highest public health official in the Delta Amacuro State at the time of the epidemic argued that the absence of an “affection for life” among Warao mothers constituted an almost insurmountable obstacle to the delivery of health care, and particularly to programs of health education. She pins responsibility for the high mortality in delta communities, both during the cholera epidemic and in general, specifically on Warao mothers.

Here is an area in which social scientific research can provide insights into the creation and political uses of the image of the defective mother. The woman who is callous to the death of her own children is not only a widely dispersed image but seems to be deployed frequently and with especially powerful effects in areas in which infant and child mortality are high. Visions of poor, incompetent mothers juxtapose dimensions of gender and class in generating the sense that the objects of these representations exhibit unnatural emotional and behavioral dispositions. Nancy Scheper-Hughes (1992) suggests that supposedly universal norms of motherhood reflect the political-economic position of white, middle-class women; poor mothers thus seem to be defective or unnatural deviations from these norms. Marilyn Nations and Linda-Anne Rebhun (1988) argue that the image of the mother who is indifferent to the illness and death of her own children has been widely used as a political tool for covering up the structural factors that lead to high infant mortality in Brazil. These constructions of poor women in South America echo a Euro-American pattern that depicts the sexuality of women of color quite differently from that of white women (see Crenshaw, 1989; Wyatt, 1982). In the Delta Amacuro, race joins gender and social class in creating these powerful images. The allusion is less direct in this passage, but the director is also drawing on a common stereotype of “indigenous” women as lacking respect for and control over their own sexuality, wantonly (and perhaps promiscuously) having babies one after another. Women who appear to fail so miserably at such a “natural” task as loving their children, nurturing them, and mourning their loss, seem less than fully human. The fall from complete humanity can easily be extended to the “group” or “race” as a whole, thereby legitimating racist practices.

Women who are classified as “indigenous” are subject to multiple forms of subordination, in Kimberle Crenshaw’s (1989, 1991) terms, which makes them particularly vulnerable to acts of violence and simultaneously deprives them of access to most forms of legal protection. The step from moral and medical to legal culpability follows easily. In the opening days of the cholera epidemic, a young Warao woman who was working as a domestic for a criollo family in Tucupita was convicted of homicide in the death of her newborn. Flagrant acts of labor exploitation, medical malpractice, and police violence—as well as the common understanding that she had been raped by her employer—only figured as evidence in the case against her and never became the subject of legal proceedings in their own right. This highly visible criminal case was read by many persons who consider themselves to be criollos as proving that Warao mothers are incapable of learning how to protect their families from cholera or other diseases (Briggs 1997; Briggs and Mantini-Briggs, forthcoming).

### **Lasting Effects of the Epidemic**

Although morbidity and mortality in connection with epidemics is clearly of vital interest to epidemiologists, the long-term impact of epidemics on health conditions and social life in

general is seldom documented by researchers and practitioners in epidemiology and other areas of public health, or by social scientists. The research that I conducted jointly with Clara Mantini-Briggs, MD, suggests that the impact of the epidemic hardly disappeared when the reported cases slowed to a trickle in mid-1993.

The fear and uncertainty generated by the cholera epidemic was exacerbated in September and October of 1993 by a virulent measles outbreak that took many lives; although young children constituted relatively few of the cholera fatalities, measles took its toll primarily among this group. Life was further complicated by a subsequent outbreak of malaria in several areas of the delta. Requests for additional medical services abounded; during a time of economic crisis, the Ministry of Hygiene and Public Assistance was unable to meet many of them.

One of the most tangible effects of this fear and uncertainty was migration. A continuing sense of the precariousness of life and the inexplicability of death should, of course, come as no surprise—pervasive and lingering perceptions of disorientation and insecurity are common in the wake of epidemics and disasters. In the delta, this process was exacerbated by deplorable everyday health conditions. The experience of the people who were living along the Mariusa River near the coast at the beginning of the epidemic provides a case in point. Abandoning the region entirely after a few days, some went to a nearby area, creating friction with residents. Most, however, traveled to Tucupita and Barrancas, small cities on the edge of the delta. They lived under sheets of plastic, surviving by begging on the streets and looking for odd jobs. The hostility that marked their arrival was exacerbated by fears that they would spread cholera into areas inhabited by criollos. Although many Mariusans returned to their homeland three to six months later, others decided to remain permanently in Barrancas del Orinoco in order to escape the precariousness of health conditions in Mariusa and to obtain greater access to medical and educational services. In a bitter irony, their lives seem to be no less at risk as they live on the immediate periphery of “civilization.”

A second effect of the outbreak was a partial undermining of the authority accorded vernacular healers. People quickly saw that the individuals charged with defending the health of their communities were powerless in the face of cholera. Most non-institutional practitioners freely admitted their impotence; one of the most respected healers in the delta, Manuel Torres, echoed a prevalent sentiment among healers in November of 1992: “What could this disease be? We still don't know.” This powerful sense of uncertainty with respect to the effectiveness of lay medical practices was acutely exacerbated in many communities when the healers themselves contracted cholera after treating patients—and particularly after many of them died. At the same time, people were amazed at the success that institutional practitioners achieved through the use of rehydration and chemoprophylaxis. Patients whose skin hung limply on their bodies, whose limbs were twisted with cramps, and who were nearly unconscious were suddenly brought back to life when hooked up to three or four IV's. But once the epidemic was officially declared to have ended and the emergency allocations of medical resources disappeared, many clinics had to turn away patients for want of even basic medical supplies. Disillusioned, many delta residents remarked that “When they want to save our lives, they do; but when they don't want to, they let us die.” Institutional medicine thus also lost a great deal of its legitimacy as well.

Dr. Mantini-Briggs and I noted in the years following the epidemic a pattern in which delta residents would visit both the clinic and local lay practitioners, sometimes with a visit to a criollo or Trinidadian healer in town thrown into the mix. Rather than combining the potential benefits of these contrastive therapeutic techniques, patients often fall through the cracks. Moving rapidly between practitioners in a desperate search for help, patients often fail to follow a full course of treatment prescribed by any one, and no practitioner enjoys a great deal of confidence.

Dr. Mantini Briggs's and my research suggests that one of the most serious implications of this delegitimation is an increase in the difficulty of promoting productive relationships between institutional and lay medicine. Some patients believe that supernatural pathogens must be removed before Western medicines will prove to be effective. Once non-institutional healers believe that they have assisted the patient to the fullest extent of their ability, they often send them to the doctor, thereby enhancing confidence in Western medicine. Similarly, if they deem an illness to be a criollo rather than a Warao disease, healers frequently refer the patient to an institutional physician. When confidence in vernacular medicine or in both systems is undermined, however, non-institutional practitioners cannot play a strong role in referring patients for treatment. Facing strong challenges to community leadership on issues of health, many lay practitioners feel that their power and prestige are threatened; they are less likely to promote the use of medical practices if this step is likely to further undermine their position. When institutional physicians and other individuals exploited the failure of vernacular practitioners to assist cholera patients as a means of ridiculing and attempting to delegitimize "indigenous" medicine, they helped increase the likelihood that lay healers would see their institutional counterparts as powerful competitors rather than allies. By deriding *piaches* ("shamans") as "quacks" and refusing to cooperate with them, physicians ran the risk of eroding confidence in both systems. Thus, while the epidemic may have promoted medical pluralism, it has ironically rendered relationships between different modalities more fragile and less complementary.

Third, self-medication through the use of prescription drugs has, according to our observations, risen considerably. Cholera control techniques often included visits to the home communities of patients who appeared in the clinics and the distribution of substantial supplies of antibiotics; unfortunately the use of antibiotics generally seemed to be stressed over oral rehydration. One of the explicit goals of these campaigns was to promote a greater sense of medical security—and thus to prevent a great influx of health refugees onto the mainland. The former director of the Regional Office of Indigenous Affairs recounted that "They asked us if we took [antibiotics] and we, so that they would keep taking them, told them that yes, we were taking them. And in front of them we took one or two tablets." And this is exactly the pattern that continued: when anyone felt sick, particularly with any sort of intestinal or stomach pain, they took one or two tablets. When the antibiotics handed out during the epidemic were gone, many people used cash that could have been allocated for food purchases to buy antibiotics at pharmacies in town. Beyond increasing the amount of time that people sometimes waited before bringing seriously ill patients to the clinic and directing attention away from oral rehydration and from prevention-related practices, reliance on self-medication through small doses of antibiotics

increased the risk of developing drug-resistant strains; when a third outbreak emerged in the delta in late 1998, the antibiotics used in 1992-93 were no longer effective.<sup>8</sup>

Finally, the cultural logic invoked by public health officials increased the stigma attached to being Warao. The way that public health officials and politicians attempted to “explain” the cholera epidemic bears a double relationship to social inequality. At the same time that official responses *reflected* race-based patterns of stratification, statements and actions also *augmented* the depth, sense of concreteness, and social power of racial formulations by constructing the epidemic as a categorical and transparent confirmation of the intractability of “Warao culture” to modern hygienic norms and an unbending resistance to extensive involvement with medical practitioners. Cultural reasoning provided a language for recasting these assertions in a pseudo-scientific language of cultural difference, a distinctly modern rhetoric that seems to replace the politically suspect character of bald racism with a liberal tone (see Balibar 1991). Angered by the collapse of tourism in the region and the strident criticisms that were sparked by the epidemic, politicians and government officials grew even less willing to invest in programs that would improve economic and other conditions in the delta. The overall result was thus an increase in malnutrition, an erosion of resources available to rural clinics, and a decrease in the availability of the motorized transport that is needed to get patients to the clinic in time.

### Responses at the National Level

To be sure, the Delta Amacuro provides a rather extreme example of the way that public health officials and others connect social inequality and infectious diseases. Nevertheless, these two elements were also linked in the perspectives expressed by *national* public health officials and the media. Statements that were made between January of 1991 and late November of that year, when the first cases were reported in Venezuela, provide a case in point. As a cholera epidemic in Venezuela seemed more and more likely, Minister of Health and Public Assistance Pedro Páez Camargo asserted in August of 1991 that “Cholera spreads slowly like an oil stain (*mancha de aceite*), and there are no methods that enable us to know when it will arrive; but the proximity to Colombia where cholera cases have been detected obliges us to take preventative measures” (Bracamonte 1991:7). A leading Caracas newspaper, *El Nacional* (1991), spoke of a “national alert” and a “declaration of war on the Colombian-Venezuelan border” even as it described binational cooperation between public health authorities. Cholera was thus enmeshed in a nationalistic rhetoric long before it arrived, becoming a threat not just to the health of individuals but to Venezuelan citizens, institutions, and the nation-state as a whole.

Even as cholera was cloaked in the language of nationalism, particular social groups were singled out as potential bearers of the disease. Before it entered Venezuela, cholera was closely linked to social inequality. In an address to a conference entitled “Cholera is Everyone’s Problem,” Dr. Francisco Aráez paradoxically asserted that “Cholera is an infection that typically and almost exclusively affects very poor people” (*El Mundo* 1991). The term Aráez uses, *gente miserable*, is loaded, as it is also commonly used to designate individuals who are “villainous.” Zulia State, where cholera was first reported, contains the largest population of persons who are deemed to be *indígenas* in Venezuela; they are generally referred to as “the Waayú” (also spelled

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<sup>8</sup> Interview with the current Regional Epidemiologist, Tucupita, Delta Amacuro, 21 December 1998.

Guayú). Health Minister Páez Camargo brought “the Waayú” into the national cholera story even before the first cases were reported. When pressed to take action aimed at preventing a cholera epidemic in Venezuela, Páez Camargo stated that “closing the border makes no sense because the Guayú indigenous ethnic group, which is the one that has been affected by the disease, is geographically and culturally a single entity, which feels the same in Colombia as in Venezuela and has no concept of physical border” (Zambrano 1991). The “physical” border—which was the locus of not only political but also intense medical concern for other Venezuelans at the time—is characterized as being of no relevance to “the Guayú.” This statement was made by a cabinet-level official during an epoch in which the Waayú, the Warao, and other *indígenas* were pressing for recognition of their political, territorial, and human rights. The logic that racializes populations affected by cholera in Zulia and the Delta Amacuro asserts that “they” have no concept of—and thus no concern for—politics. Here public health officials echo the common assertion that it is the *indígenas* who have excluded themselves from the political sphere—and thus from full, substantive citizenship—rather than being excluded through the operation of policies of the nation-state or institutional racism. Senator Lolita Aniyar de Castro went on to link “the Waayú” and cholera more directly:

With the entrance of cholera in Zulia State, there is a serious risk of an epidemic of considerable proportions among the members of the Waayú indigenous group, since the great majority of those who live in Sinamaica and Paraguaipo don’t have the most elementary sanitary services in the region, in addition to which they drink water from springs (*jagueyes*), where the animals drink, they don’t have latrines, and their hygienic habits are primitive. (Gómez 1991)

She used this powerful image not only in asserting that “the Waayú” were destined to become the bearers of cholera but why. Interestingly, Aniyar, a sociologist who later became the governor of Zulia, claims to have “Waayú blood” on the basis of her Zulian ancestry.

Statements by public health officials, politicians, and the press in the course of the epidemic extended a logic that views the poor and *indígenas* as natural targets of cholera. Rather than going on to detail how these images continued to develop after the first cases were reported in Venezuela in late November of 1991, I want to ask what we are to make of the ways that cholera and social inequality were linked there. It would be easy to condemn Venezuelan public health authorities and other officials by suggesting that they should have invested more energy in discovering how cholera exposes the weak links in their own institutional structures, practices, sanitation infrastructures, and the like rather than in blaming the victims of cholera for their plight. But I will devote most of the remainder of this paper to suggesting two reasons why blaming Venezuelan public health officials and politicians is inappropriate and why it is unlikely to be productive in breaking up these sorts of links between infectious diseases and social inequality.

### **Cholera and Social Inequality in International Epidemiology**

The first reason that leads me to deem it inappropriate to blame Venezuela in this regard is that social inequality was a recurrent theme in work by international epidemiologists—including some of the most distinguished cholera researchers in the world—from the early days

of the Latin American epidemic. As the quote from the World Health Organization report on "Cholera in 1997" suggests, distinctions between industrialized countries, the United States and Europe, and developing countries and portraits of impoverished populations in Latin America are highly recurrent in this literature. The opening lines of an article on "Cholera in the Nineties" that appeared in the *CDC Briefs*, an official publication of the Centers for Disease Control in Atlanta, characterized the epidemic in the following terms:

"When one thinks of cholera, images of pre-twentieth century sanitation come to mind...sewage in the streets, children suffering miserably. Does this sound like a plague from long ago?"

Not so. After an absence of nearly a century, epidemic cholera has reappeared in the Americas. Hundreds of thousands of cases of cholera have been reported in the past year in many South American countries. The death toll is estimated to be around 4,000, but officials have concluded that the numbers would have been much higher if modern treatment had not been available. (Anderson 1992:1)

Here John Anderson, Editor of the *CDC Briefs*, calls up images of poverty, filth, suffering, and backwardness with which cholera is associated historically—and then connects them to contemporary Latin America. Since his field is public relations, we might surmise that Anderson enjoys more freedom to incorporate images of poverty, filth, and suffering associated with cholera than do specialists in public health. But this process of dislocating contemporary Latin America in cultural, political-economic, and historical terms is also apparent in the way many leading international experts represent the epidemic. Robert Tauxe, chief of the Epidemiology Section of the CDC<sup>9</sup> and one of the world's foremost cholera researchers, provided this description in an article that appeared in *Atlanta Medicine* and was subsequently reprinted by the CDC:

The explosive spread of cholera in Peru and other countries occurred in large, poor urban populations. Millions of people in the urban slums of Latin America lack safe piped water and sewage disposal. They live crowded together, in primitive circumstances, eating "fast food" from street vendors and storing their drinking water in whatever buckets can be found. (Tauxe 1992:41-42)

Such statements conjure up two sorts of stereotypes about Latin America. First, people in the North often believe that Latin American governments lack the same sense of obligation for providing modern services for their citizens that is felt by the United States, Canada, and countries in Western Europe. Engineer Fred M. Reiff of the Pan American Health Organization suggests that the "rapid dissemination [of cholera in Latin America] is due to many years of neglect in the environmental health sector" (quoted in Marwick 1992:1314). Although infrastructural problems are generally blamed on municipal and national governments, Swerdlow, Mintz, and Rodríguez et al. (1992:29) assert that "illegal connections to major water

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<sup>9</sup> The Epidemiology Section is part of the Enteric Diseases Branch of the Division of Bacterial and Mycotic Diseases of the National Center for Infectious Diseases of the CDC. The CDC itself forms part of the Public Health Service of the U.S. Department of Health and Human Services.

lines break the integrity of the distribution system," thereby shifting part of the blame to individuals and neighborhoods.

The quote from Tauxe contains another powerful image, that of Latin American poverty. Epidemiologists draw attention to the "health-related behaviors" of communities in which cases were concentrated. Failure to boil drinking water is emphasized, along with such practices as storing water in open-mouthed vessels, washing one's hands in drinking water, and making contact with water while scooping it out of the container (see for example Swerdlow et al. 1992). The failure to wash one's hands with soap prior to handling food or water is often cited. "The food habits of the population" (Tauxe and Blake 1992:1388) are also frequently marked as suspect. A leitmotif is provided by the popularity of such foods as raw or partially cooked fish and shellfish; ceviche, a popular dish consisting of marinated fish, is the prime example. The consumption of food sold by street vendors is similarly scrutinized. A study conducted by researchers from the CDC and Peruvian health professionals published in the prestigious British medical journal *The Lancet* also blamed attendance at fiestas for increasing the consumption of contaminated food and drink (Swerdlow et al. 1992:31).

These individual elements get connected in a number of ways. Collecting individual factors in a global metaphor, Tauxe and Blake argue in the *Journal of the American Medical Association (JAMA)* that in explaining the "extreme vulnerability" of the Peruvian population to cholera, "the urban fabric itself appears to be a major contributing factor" (1992:1388). Dunn and Janes (1986:8) suggest that contemporary epidemiologists favor models that focus on the interrelations of persons, places, and times. In representations of the cholera epidemic, these linkages are created not through statistical techniques alone but through the use of powerful and widespread images of Latin Americans that circulate in a wide range of popular and scholarly contexts in the United States, Europe, and elsewhere. I quoted above the description published by Tauxe in which he relates "the explosive spread of cholera in Peru and other countries" to poverty, population size and density ("millions of people...crowded together"), infrastructural shortcomings, and practices associated with food and water in creating an image of "primitive circumstances" (1992:41-42). Such discussions seem to transform popular stereotypes into "factors" that are deemed responsible for the scale of the epidemic and raise them to the level of scientific description.

*JAMA* published an article by Charles Marwick (1992) entitled "Like Attacker Probing Defenses, Cholera Threatens US Population From Elsewhere in This Hemisphere" that contains a wealth of such images. The article is constructed as a series of quotations from cholera experts. Marwick quotes Tauxe as contrasting Latin America's failure with the United States' success: "good drinking water systems and proper sewage control are the main reasons that the disease hasn't established itself" in the United States. He paraphrases Tauxe in projecting this basis for cultural differentiation into the past; although Latin America is headed downhill with regards to sanitation, "cholera was the principal impetus driving the reconstruction and modernization of sanitary systems in Europe and the United States." Fred M. Reiff is then cited in declaring that such improvements enabled North America to "essentially" eliminate cholera in the early 1900s (ibid.).



Many international epidemiologists project both inadequate sanitary infrastructures and cholera well into the future for Latin America. The *JAMA* article quotes Tauxe in creating a sense of how the story of the epidemic unfolded: "At first, there was some hope that the outbreak would not last long. But it clearly is persisting" (ibid.).<sup>10</sup> In an article that appeared in the same issue of *JAMA*, Tauxe and co-author Paul Blake (also of the CDC) suggest that "In the 19th century, the sanitary reform movement in Europe and America was largely spurred by fear of recurrent epidemic cholera and ultimately conquered the disease. Now is the time for Latin American countries to make a similar transformation" (Tauxe and Blake 1992:1390). Glass, Libel, and Brandling-Bennett (1992:1525) estimate needed "investment" in water, sanitation, and health services in the region over the next twelve years at over \$200 billion. Tauxe and Blake (1992:1390) note that these expenses lie "beyond the means of some Latin American countries."

Marwick's *JAMA* article juxtaposes depictions of Latin Americans, the global contrast between the premodern South and the modern North, and the lexicon of war and violence in characterizing cholera as a new "threat" to the US population. Tauxe (1992:41) argues that even though water and sewage infrastructures in the US will shield it from the "fury" of the epidemic, the likelihood that more cases will be imported and could even spread suggests that "cholera will no longer be a remote and exotic disease for some Americans and their physicians." CDC reports and other publications thus warned health care professionals in the US to be on the lookout for cholera cases crossing the border from the south. Tauxe and Blake (1992:1390) suggest that "our advanced sewerage and water treatment systems are not available to the entire US population, and cholera could be transmitted in the United States among a homeless, destitute, or migrant farm labor population." Tauxe (1992:42) includes "the immigrants in 'colonias' along the U.S./Mexican border" as being a potential locus for a cholera outbreak.

Linking infectious disease and social inequality tightly, Tauxe notes that "cholera is a disease of poverty" (1992:42), as did Anderson in the *CDC Briefs* quoted above. A problem with this logic is that it tends to erase the particular historical, social, and economic circumstances in which the epidemic is taking place in favor of creating the impression that certain populations are natural targets for "ancient scourges," such as cholera, just as "they have long been known to have high rates of hepatitis, tuberculosis, and typhoid fever" (Tauxe 1992:42).

In short, the Latin American cholera epidemics of the 1990s point to the need to reflect on the images that get linked to biomedical phenomena as the "social factors" that shape health and disease. Just as we saw for public health and epidemiology in the Delta Amacuro and Venezuela as a whole, cholera gets connected in international epidemiological research with time-worn stigmatizing images. My goal in saying this is not to suggest that any of the practitioners I quoted or their colleagues *intend* to stigmatize poor populations or deepen the forms of social inequality that they face. To the contrary, these individuals sought to mobilize public health and other institutions to the task of saving lives under difficult circumstances. It is

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<sup>10</sup> Tauxe echoes this pessimistic assessment in an influential article he co-authored with Eugene J. Gangarosa: "It seems likely that in parts of Latin America, epidemic cholera may persist for years to come. Hopes that the epidemic will end spontaneously are likely to be in vain as long as the circumstances for transmission are ripe" (Gangarosa and Tauxe 1992:353).

rather precisely the manner in which stigmatizing images find their way into even the most praiseworthy public health research and practice that should prompt us to think more broadly and critically about how health and social inequality intersect.

## **Oil and Economic Chaos in Venezuela**

It seems ironic that researchers would downplay the importance of the context in which the epidemic is emerging, since the present circumstances in many Latin American countries are striking and strikingly relevant. Once again, Venezuela provides us with an illuminating case in point.

The epidemic that began in 1991 can be considered the death knell of what has often been referred to as Venezuelan exceptionalism. During most of the second half of the twentieth century, Venezuela was deemed to be the exception to generalizations made about Latin America by politicians and social scientists in the United States and Europe. Although some governments were authoritarian, Venezuela has been governed by a constitutional democracy for much of the twentieth century. The national identity of Venezuelans accorded tremendous weight to their status as democratic citizens. While the economies of other nations were characterized as chaotic and collapsing, Venezuela enjoyed a prosperity that was based on substantial revenues from petroleum exports, and income was distributed in a relatively equitable fashion. Seen from abroad as a bastion of stability and democracy, the United States often placed Venezuela in the position of speaking for the region and of mediating US-Latin American relations. In spite of its location within the “Third World,” Venezuela could claim a place on the threshold of the “First.”<sup>11</sup>

This image began to erode in the face of an economic crisis that began in the 1980s and continues through the present. Venezuela generally directed over 90 percent of its exports to the world petroleum market; the collapse in oil prices and OPEC restrictions on production thus cut deeply not only into export income but into government revenues as well (Hausmann 1995:1). After Venezuela abandoned fixed currency exchange rates in 1983, the Bolívar fell from about Bs. 4.5 to the dollar; it currently stands at nearly Bs. 600 to the dollar. The drop in oil revenues and the value of the currency turned service payments on \$30 billion worth of foreign debt, largely accrued during the flush 1970s, into a major problem. The rentier economy sustained by oil exports had bankrolled a large public work force, making public salaries a substantial problem in the 1990s. The economic crisis was exacerbated by capital flight and a decrease in private investment. In 1989, inflation reached 84 percent (Morley and Alvarez 1992:4). Some areas were hit much harder by inflation; medicines, for example, rose 513 percent in price between 1989 and 1991 (Fajardo 1992:41).

At the urging of international lenders, the World Bank, and the International Monetary Fund, newly elected President Carlos Andrés Pérez attempted upon assuming office in 1989 to adopt a number of neoliberal policies aimed at stabilizing the economy, restructuring it

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<sup>11</sup> See Martz and Meyers (1977) and Goodman et al. (1995) for studies respectively of the image of Venezuelan exceptionalism and its eclipse. Coronil (1997) presents a detailed history of the Venezuelan oil industry and how it shaped the course of modernization in Venezuela.

through privatization, and enhancing competition. The changes included eliminating exchange-rate and interest-rate controls and restrictions on prices in the private sector. Price constraints and supports for basic commodities, the *cesta básica*, were gradually removed. A new value-added tax (VAT) of 10 percent was placed on most goods and services, and the price of gasoline was raised, resulting in a steep rise in bus fares. Efforts to balance the budget included substantial cuts in public services, including the elimination of some social services and the privatization of others. Clearly, the availability of health services was affected by these cuts. Based on figures provided by the government Central Office of Statistics and Data Processing (OCEI), it has been estimated that the percentage of the population living in poverty increased from 24 percent in 1981 to 59.2 percent in 1990 (Márquez et al. 1993:146, 155). Morley and Alvarez (1992:38) suggest that nowhere else in Latin America, with the possible exception of Chile, has structural adjustment signaled such a radical increase in poverty (see also Mamalakis 1996).

The announcement of the acceptance of debt-reduction measures recommended by the IMF and an increase in bus fares led to an explosion of popular discontent that was most clearly evident in the looting and rioting that broke out across the country on 27 February 1989. At the same time that the response by police and the military augmented the uncertainty of daily life in poor neighborhoods, fear of a more violent and better organized “descent” from the barrios limited the government's ability to impose neoliberal policies more swiftly—and, increasingly, even to govern (see Coronil 1997; Coronil and Skurski 1991). Economists suggest that the opening years of the 1990s marked a decided improvement in the economic situation. The extent to which these benefits reached poorer Venezuelans is less clear, however, and they do not seem to have muted the perception on the part of many that the country was in crisis. The political ramifications of economic problems came into sharp relief on 3-4 February 1992 in the face of a coup attempt led by Lt. Col. Hugo Chávez Frías; although both it and an attempt in November 1992 failed, Chávez was lionized by large segments of the working class. President Pérez was indicted in May of 1993 on charges of corruption and removed from office. Even though the presidential elections of 1993 returned a seasoned politician to office, former President Rafael Caldera, the authority of the two political parties that dominated Venezuelan politics since democracy was reestablished in 1958 has been sharply challenged.<sup>12</sup> New evidence of the complexity and dynamism of the political climate emerged with the election of former coup leader Chávez as president in December of 1998.

A very different type of exceptionalism has now come to characterize life in Venezuela. Argentina, Brazil, Chile, and a number of other Latin American countries have moved from military rule to claim the status of newly emerging democracies. A number of economies that had become international symbols of inflation and instability were declared to be in recovery. At the same time, democracy seemed to be becoming more fragile in Venezuela (see Goodman et al. 1995). Venezuela has often been chided from abroad for failing to embrace neoliberal policies as quickly and systematically as some of its neighbors. But imagine the sort of misery and discontent that are generated internally when a country slides into economic free fall, going from one of the most prosperous in the region to a country where most of the population is in poverty and the middle class is precarious.

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<sup>12</sup> See Serbin, et al. (1993), Tulchin with Bland (1993), Goodman et al. (1995), and Coronil (1997).

Enter cholera. Even before cases were reported in Venezuela, cholera was deeply woven into the fabric of the crisis. A major concern was economic—politicians were afraid that news of a cholera epidemic would cripple tourism and lead to export sanctions. The worry about tourism was quite real; Victor Gamboa, president of the government's office of tourism (Corpoturismo) estimated that international tourism dropped more than 40 percent in the first half of 1992 (Escalante 1992); clearly, the February coup attempt and "popular disturbances" played a role here as well. The impact on the export economy was minimal—few corporations are going to worry that the oil, iron, bauxite, gold, or diamonds they buy will be contaminated by cholera. But an unstated fear seems to have been more important and better grounded. Venezuela's national image, long and successfully cultivated on the international stage, had been roughed up in the wake of international coverage of the political and economic crisis. Enter cholera, a disease that reeks of poverty, dirt, backwardness, and ignorance, a symptom of deep and perhaps irredeemable antimodernity. Venezuela was flung alongside Peru, Ecuador, and Colombia into the recesses of "The Third World."

The impact of the epidemic on Venezuela's national image prompted a diplomatic scuffle between Venezuela and the United States. The Consular Information Sheet for 1994 (the old "Travelers Advisory Bulletin") that the US Department of State releases to travel agencies and US citizens warned of cholera—along with dengue, malaria, crime, cross-border violence with Colombia, kidnappings, and "sporadic political demonstrations" (US Department of State 1994). Antonio Ledesma, the vice-president of the Venezuelan Senate, lodged a protest to the US Embassy, accusing it of an "attempt to soil Venezuela's prestige in keeping with certain economic interests" (*El Universal*, 18 April 1995); Ledesma characterized the document as "depicting Venezuela as a branch of Hell, which only stopped short of saying that we eat our children here" and as "speaking of Venezuela as if it were the last country in the line of nations in the Third World."

President Carlos Andrés Pérez is said to have remarked prior to the point at which the first cases were announced that "we will never tell the truth about cholera."<sup>13</sup> The Office of the National Epidemiologist reported 2,842 cases of cholera and 68 deaths in 1992 to the Pan American Health Organization, and these figures were published in the benchmark *Weekly Epidemiological Record* of the World Health Organization (1993). Since these statistics represented less than 1 percent of the cases in the Americas as a whole and were dwarfed by the 212,642 reported by Peru, Venezuela never became an important focus of cholera in the international press or in international public health circles. But these figures more directly reflected concern with possible effects of the epidemic on tourism, economic activity, and the country's image than the realities of the epidemic.

The Regional Epidemiologist for Delta Amacuro officially reported 823 cases of cholera and 12 deaths in the state in 1992 and 1993.<sup>14</sup> Nevertheless, both he and the Director of the

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<sup>13</sup> This statement was reportedly made in the course of a radio interview. I have been unable to locate any recordings or written reports that document Pérez's comment.

<sup>14</sup> This information is contained in a typescript report that is available in the Office of the Regional Epidemiologist, Ministry of Health and Public Assistance, Tucupita, Delta Amacuro.

Regional Office of Health informed a newspaper, *El Diario de Monagas* (1993:1), that 1,701 cases of cholera and 49 deaths had been recorded as of 26 January 1993. In an interview that I conducted with him, the Regional Epidemiologist stated that he had initially compiled statistics for all cholera cases that came to the attention of medical personnel. Informed by the National Epidemiologist that the total was far too high, he was instructed to count only cases for which a laboratory confirmation was available—even though no laboratory was available in the state at the beginning of the epidemic and the tubes for taking samples were largely unavailable at the rural clinics in which most patients were treated. Based on systematic interviewing conducted in the delta in 1994 and 1995, Dr. Mantini-Briggs and I estimate that some five hundred people died in the fluvial area in 1992-93.

### **Toward New Perspectives on Social Inequality and Infectious Diseases**

I hope that my reasons for discussing the way that social inequality and cholera got connected in the course of the epidemic that took place in the Delta Amacuro, in Venezuela as a whole, and in international epidemiology are becoming clear; the logic is similar in these three contexts even if the specific ways of representing cholera patients and their communities may differ. In each case, the link between social inequality and cholera is portrayed as natural—as if intrinsic and timeworn features of populations in which cholera cases are concentrated have preordained them as targets for the disease. When official (either scientific or administrative) accounts accord a central role to dimensions of the culture and behavior of patients and their communities, they lend themselves to efforts to deflect the blame away from the more powerful, including both individuals and institutions, and onto the less powerful. In doing so, public health officials, researchers, and policy-makers conflate structural violence with cultural difference, as Paul Farmer argues in his essay. As a result, groups that already enjoy less access to resources and political decision-making can become further stigmatized and accordingly further marginalized. When a population that is characterized as fundamentally different in racial or cultural terms, such as “the Warao,” gets closely linked to cholera, medically useless quarantines and cordons sanitaire can be more easily justified. The people from the Mariusa River area of the delta were forcibly confined, first in a high school in Barrancas and then on an island that offered them little shelter and no means of subsistence, even after they had received a program of chemoprophylaxis and were declared to be free of the disease. As the aftermath of the cholera epidemic in the delta so strikingly suggests, this stigmatizing process can have long-term negative effects on health conditions and access to medical care. In other words, naturalizing links between social inequality and infectious diseases can contribute to the deterioration of health conditions in precisely the populations that physicians and public health practitioners are trying to help. These claims go beyond conflating structural violence with cultural difference to actually extend and deepen structural violence and the racism on which it relies.

Incorporating cultural reasoning in this way goes against the grain of epidemiology for two reasons. First, epidemiology generally rejects anecdotal evidence, calling for systematic research that is empirically verifiable. To be sure, epidemiologists would not accept the assertion that an epidemic was taking place or that it was caused by a particular pathogen on the basis of hearsay or casual observation. Nonetheless, assertions regarding the medical beliefs and health-related practices of the poor that enter into the depictions of the cholera epidemic in the

delta and in Latin America as a whole are often derived from superficial observations—rather than in-depth, systematic research, or are simply taken from anthropological, sociological, or popular discourses. Moreover, they incorporate images that are tied to time-worn stereotypes that have been invoked in characterizing poor populations around the globe for more than a century. Studies of nineteenth-century cholera epidemics in the United States (Rosenberg 1962) and India (Arnold 1993) suggest that images of poverty and difference were used in explaining and organizing responses to epidemics then too, long before *Vibrio cholerae* had been discovered. It seems bizarre to make what Farmer refers to in his paper as “immodest claims of causality” on the basis of the least systematic and empirically adequate facet of one’s research. In the cases that I am citing, cultural reasoning is not deployed primarily by anthropologists or other social scientists—it has rather been incorporated into statements by public health officials, politicians, and others. It has, in other words, become part of everyday institutional perspectives and practices in public health agencies.

Second, one of the central tenets of the critical epidemiology<sup>15</sup> that is practiced in many areas of Latin America is that epidemiological accounts must be historically sensitive, that is, that they must deal with the specifics of what is taking place at the particular historical juncture in which the phenomenon in question emerges (see Laurell et al. 1992, 1994). Critical epidemiologists also reject what is often referred to as medicalization, the idea that health issues can be explained as purely biomedical phenomena without reference to social, political-economic, or historical dimensions; to the contrary, researchers must explore the full range of factors that may be of importance in producing the health conditions in question. The uses of cultural reasoning that I have analyzed fail on these two criteria as well. Cultural images that have a wide distribution in time and space provide poor tools for explaining the particular parameters of an epidemic. This mode of explanation overlooks the obvious—the deep and pervasive changes that have taken place in Latin America during the last two decades through the profound economic crises associated with globalization, neoliberal policies, and debt restructuring programs. The result, as I noted for Venezuela, is not simply more pervasive and rapid transnational flows of capital, information, goods, people, culture, and microbes but widespread poverty and heightened social inequality in many regions. It would be unfair to say that epidemiologists are unaware of the broader political-economic situation, and some of the sources that I cited do allude to it. It is, however, far different to make passing reference to the political-economic and historical context in which the epidemic emerged and continues to reappear in many areas of Latin America than to analyze systematically how the two are linked, to see what causal factors may lie beyond local culture and national political goodwill.

This point bears in crucial ways on policy development as well, in that stigmatization has negative consequences for cooperation in public health programs. When a stigmatized identity is imposed on an individual or an entire population, self-esteem and a sense of agency (the capacity to formulate plans and bring them to fruition) are likely to suffer. This process can diminish both

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<sup>15</sup> The term “critical” is often used by proponents of a “critical epidemiology” in opposition to “academic,” “official,” or “hegemonic” epidemiology. Breihl suggests that while the latter links social and biological factors “by way of a simple, external association” (1994:31, translation mine), the former seeks to build new theoretical, methodological, and statistical models that challenge the epistemological and political-economic roots of inequality and exploitation.

the ability and the willingness of groups and individuals to collaborate with medical professionals, public health officials, and others in taking steps to prevention and treatment. The urge to resist the imposition of such stigmatized images can thwart cooperation by leading people to reject everything that is associated with such images. Marilyn Nations and C.M.G. Monte (1996) point to the effects of stigmatizing health education campaigns that targeted cholera in Brazil. Marcos Cueto has argued that the government used anticholera campaigns “as a means of drawing attention away from the gaps in the sanitary infrastructure and attributing the blame to individuals” (1997:221, my translation). Julia Paley (1999) describes how residents of a poor community outside Santiago, Chile, countered shortages of public services and denigrating rhetorics by organizing popular cholera campaigns that sought to empower rather than denigrate poor communities.

The cases from Brazil, Peru, and Venezuela suggest that stigmatizing rhetorics exert powerfully negative effects on the material conditions of the poor by increasing discrimination (as based on class and gender and often on race as well) and legitimating the structural underpinnings of social inequality, including differential access to infrastructures, services, education, employment, and legal protection. Blaming the victim also excuses international financial institutions from reversing the application of neoliberal policies to the health sector that result in cutbacks of public services and privatization schemes which decrease the access of the impoverished to health care.

Public health officials in the Delta Amacuro commonly use cultural reasoning in asserting that the Warao are “unwilling” to visit clinics and hospitals due to lack of information about institutional medicine (i.e., that they are ignorant) or that their belief in nonbiomedical theories and practices leads “them” to reject doctors and physicians. Medical “resistance,” rejections of physicians’ explanations and instructions, as well as attempts to avoid contact with institutional practitioners altogether has accompanied cholera epidemics since the nineteenth century in a wide range of settings (see Arnold 1993 and Rosenberg 1962 for examples). Physicians and public health officials generally attribute this resistance to the “ignorance” and “backwardness” of poor communities and as evidence of the difficulty—or even impossibility—of “changing their habits.”

The effects of stigmatizing rhetorics used in governmental health education campaigns in Latin American cholera epidemics suggest that something else is going on here. In such cases, contact with health authorities vis-à-vis cholera, whether it be through media campaigns or visits to clinics and hospitals, can lead to experiencing institutional sexism, racism, and class-prejudice. If an individual makes negative statements about you that you believe to be false, you are not likely to believe much else that he or she says or to go out of your way to repeat this painful experience. I do not mean to suggest that persons who contracted cholera in the Delta Amacuro and their relatives accordingly avoided medical facilities due to the denigrating images of the Warao that they encountered there. Drawing this conclusion, which is utterly false, might warrant a new brand of “blame the victim” rhetoric, and it would certainly gloss over the inadequacies of health care infrastructures in the region. But paying attention to the experience of racism in health institutions can help account for the nature of many interactions with medical personnel during and after the epidemic.

The data from Venezuela as well as from Brazil, Chile, and Peru suggest that medical resistance might be better accounted for through investigations of the way that stigmatizing images are produced, disseminated, and woven into public health services than by drawing on timeworn rhetorics of ignorance, backwardness, and the incompatibility of medical science and “superstition.” Similarly, forging more productive relationships between marginalized populations and health care professionals would seem to involve changing the attitudes and practices of the providers more than those of the patients.

Similarly, it is not just poor lay persons who resist stigma. When treatment, education, and prevention programs proposed by international public health agencies incorporate negative stereotypes to reinforce hierarchies between “industrialized” and “developing” countries, even potentially beneficial forms of assistance are likely to meet with resistance. If national epidemiologists perceive that reporting accurate statistics will only result in stigma, the loss of tourist dollars, and a threat to national prestige, the motivation to underreport will be strong. Since international public health agencies depend on the willingness of national officials to compile accurate statistics and address health problems in as open and vigorous a manner as possible, naturalizing links between social inequality and infectious diseases is counterproductive here, too.

The work of critical epidemiologists or epidemiologists of social inequality in Latin America points to an alternative. As Breihl ([1979]1986, 1994) argues, the social side of epidemiology must be expanded beyond discussions of isolated features of populations. Critical epidemiologists have argued for years that the question is not one of inherent characteristics of impoverished populations but of the social, economic, and political relations that produce both social inequality and health crises. Naomar de Almeida Filho (1997) suggests that epidemiologists must become much more cognizant and critical of their own discourse, of the way that epidemiological concepts are defined and used and how these schemas shape conceptions of and interventions into health and disease. Scholars and practitioners working in Brazil, Mexico, Ecuador, and elsewhere have argued that recent epidemics and other health crises cannot be seen apart from severe economic downturns and increases in income disparity that have taken place in many countries in the region. It seems naive to focus discussions of health and development entirely on the responsibilities of Latin American governments to fight poverty and reform health care systems, as is evident in the World Bank’s 1993 Annual Report on *Investing in Health* (1993).<sup>16</sup> While the World Bank recommends selectively targeting the delivery of health services, the ability to successfully prevent and treat cholera depends upon broad-based, widely accessible health infrastructures (including health education, clinical services, and the provision of potable water and sewage disposal) that will already be in place whenever and wherever cholera cases might be reported.

Suggesting that health-related problems are simply to be expected during the “temporary” periods of hardship that accompany adjustment programs, as does the World Bank report, would seem naive even in economic, let alone in political and public health, terms. The Venezuelan example points to just how painful and lingering such “transitional periods” can be. As I have

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<sup>16</sup> See Laurell (1994) for a critique of this report from a variety of critical perspectives on public health; also see Burkett (1991).



argued, epidemics have a range of effects that extend beyond the immediate loss of life from the pathogen. The inroads made by cholera, tuberculosis, malaria, and other infectious diseases during such temporary periods may long outlive the economic circumstances in which they emerge. As Paul Farmer argues in his essay in this working paper, the rapid spread of tuberculosis and the emergence of drug-resistant strains can be controlled by relatively modest investments now but may be nearly unstoppable later. Beyond the economic effects of epidemics on the work force, the psychosocial impact of high morbidity and mortality due to preventable and treatable diseases can thwart willingness to participate actively in economic reforms, political processes—and in civil society in general. Just as we may not know the full extent of morbidity associated with cholera, tuberculosis, and other infectious diseases in the region, economists may be seriously underestimating the economic effects of health crises as well.

It would also be naive to suggest that globalization and structural adjustment are “the cause(s)” of epidemics. Nevertheless, when international agencies and industrialized countries engage in finger pointing and prove unwilling to examine their own roles in shaping economic conditions that may foster epidemics and other health crises, they seriously thwart their ability to discern the full range of causes and effects. Even self-interest alone would seem to discourage this sort of myopia. When disease burdens exacerbate social and economic instability, the effects—like the diseases themselves—are not easily contained within national borders. We need to promote more open discussion among political scientists, economists, public health specialists, and social scientists (including researchers and practitioners in all three groups) that can provide new bases for examining the relationship between infectious diseases and social inequality. Just as no discipline should be privileged, neither should there be any one-way arrows drawn in exchanges between North and South or between international, national, and regional institutions.

I could be rightly criticized for letting social scientists off the hook, for failing to direct the sort of (hopefully) constructive criticism at members of my own professional club that I have leveled at epidemiologists, public health officials, politicians, and development specialists. The cholera epidemic certainly does not warrant any sort of privileged treatment here. While epidemiologists may invite criticism when they utilize weak models of social and cultural processes in characterizing the epidemic, social scientists bear responsibility for being largely silent. Many people have been infected with cholera and many have died in the very communities in Latin America that have been studied intensively by anthropologists, sociologists, and folklorists for decades. Academic meetings and publications have been largely silent on the question of cholera; I think that the same could be said, *mutatis mutandis*, for tuberculosis and malaria. Except for a vigorous group of medical anthropologists, sociologists, and other researchers, very few social scientists have returned to these sites to study what is happening and to engage public health officials and community leaders in discussions that center on saving lives.<sup>17</sup> Social scientists would do well to heed the critical epidemiologists’ call for broad and critical study of the social, cultural, and historical dimensions of infectious disease—including providers, patients, communities, and other players—if they are to contribute

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<sup>17</sup> Notable exceptions are provided by the work of historian Marcos Cueto (1997) on the 1991 cholera epidemic in Peru and anthropologist Julia Paley (1998) on cholera prevention and social movements in Chile.

productively to transforming the way that links between infectious diseases and social inequality are perceived and experienced. Exploring these connections would yield important insights into the way that Latin America in general and poor communities in particular are being placed within—and often excluded from—the (post)modern world.

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## HIDDEN EPIDEMICS OF TUBERCULOSIS

Paul Farmer

So long as those who suffer have no other protection than the self-interest or the benevolence of those better situated, disease and hardship inevitably persist.

William Allen, *Civics and Health*, 1909

What does it mean to “hide” an epidemic? The holocaust of deaths that followed 1492 was certainly not hidden from the New World’s indigenous population, but its true causes and dimension were often masked to serve the purposes of the conquistadors: “The early historians were much more likely to cast their eyes skyward and comment on the sinfulness that had called down such epidemics as obvious evidence of God’s wrath than to describe in any detail the diseases involved” (Crosby 1972:43).

Even if we are asking about the close of the fifteenth century, the specific questions are likely to be more fruitful: From whom were these epidemics hidden? With what intent? What claims of causality were made regarding differential susceptibility? Indeed today, as five hundred years ago, the visibility of epidemics is more a social than biological question, as the powerful have occasionally found it in their interest to make epidemics disappear — or else to bring them into relief, exaggerating their dimensions. In the United States and many other countries, anti-immigrant sentiment may be purposefully fanned by such exercises; contagious diseases were and are common causes of exclusion of immigrants (see Kraut 1994). Thus may we also ask, with what intent are increased burdens of disease brought to the attention of the broader society?

Answering these and related questions leads us to draw on a broad range of disciplines. History, political economy, epidemiology, and the sociology of knowledge are all indispensable to such analyses, especially if the answers happen to run counter to the claims of officialdom. And they often do. Hiding epidemics can serve larger political goals; the purpose may be not only to fiddle with data, but with vulnerable people themselves. In his classic study *White Plague, Black Labor*, historian Randall Packard refers to the decline in apartheid South Africa’s tuberculosis incidence as the “great disappearing act,” since forced relocation amounted to removing TB cases from view “with the stroke of a pen.” Packard writes of the mass removal of millions of urban and rural Africans to the already overcrowded reserves, alternately labeled “bantustans,” “homelands,” or “national states.” The incidence of the disease was in effect not so much diminished as displaced, moved from the urban and industrial centers of the country to the rural dumping grounds—to which the Nationalists had relegated an ever-growing portion of the country’s impoverished African population (Packard 1989:252).

At the close of the twentieth century, hiding epidemics is an even more complex affair; the fecklessness of the powerful, however, seems to be a constant. Advances in information technology have led to much more rapid dissemination of information about all sorts of

calamities, including epidemics. Indeed, the very notion of “emerging” or “resurgent” infectious diseases is tightly tied to increased surveillance activities and to novel technologies of communication, including the Internet.

One of the diseases held to be “resurgent” is tuberculosis. Dramatic local shifts in epidemiology aside, however, global analysis does not reveal a major increase in deaths due to this disease. Tuberculosis has retreated in certain populations, maintained a steady state in others, and surged forth in still others—remaining, as of this writing, the world’s leading infectious cause of preventable deaths (Bloom and Murray 1992).

Generalized ignorance of such facts is of course another way to hide epidemics. If at mid-century, tuberculosis was still acknowledged as the “great white plague,” what explains this killer’s invisibility by the 1970s and 1980s? Again, one must look to the study of disease *awareness*, that is, of consciousness, publicity, and their relation to power and wealth. “The neglect of tuberculosis as a major public health priority over the past two decades is simply extraordinary,” wrote Murray in 1991. “Perhaps the most important contributor to this state of ignorance was the greatly reduced clinical and epidemiological importance of tuberculosis in the wealthy nations” (1991:150). Thus tuberculosis has not *emerged* so much as *surfaced* from the ranks of the poor. An implication, clearly, is that one place for diseases to “hide” is among poor people, especially when the poor are socially and medically segregated from those whose deaths might be considered more significant. Katherine Ott (1996:158) puts it sharply: “Tuberculosis is not ‘resurgent’ to those who have been contending with and marginalized by it all their lives.”

This is not to argue that there’s nothing new under the sun. On the contrary, it is easy to discern novel developments. We live in an era in which new myths and mystifications about tuberculosis proliferate. We are living in a global economy with its own rapidly changing “geoculture,” a transnational social phenomenon that interacts in novel ways with local cultures, themselves rapidly mutating.<sup>18</sup> The degree of travel and the volume of trade are unprecedented.

Parallel to these changes in society and human behavior, *Mycobacterium tuberculosis*, the organism that causes tuberculosis, has adapted and changed. Multidrug-resistant tuberculosis (MDRTB) is a relatively recent development, emerging only in the past two decades as a frightening concomitant of improvements in the dissemination of pharmaceuticals. Nobody can dispute the fact that MDRTB is a genuine “emerging infectious disease.” But regarding MDRTB’s seriousness there is dissensus. Examining the same epidemiological survey of resistance to antituberculous drugs, one specialist terms rates of drug resistance “low,” while the World Health Organization (WHO) regards the phenomenon to be “ubiquitous” (Cohn, Bustreo, and Raviglione 1991; WHO 1997a).

Other discrepant claims abound. With scant data in support, it is argued that MDRTB is less infectious and less virulent than drug-susceptible tuberculosis. Some contend that attention to MDRTB is drawing resources away from the much less costly treatment of drug-susceptible tuberculosis. In fact, expert opinion from the WHO has argued that it is not even necessary to treat MDRTB, since such treatment was not part of the DOTS (directly observed therapy, short-

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<sup>18</sup>The term “geoculture” derives from Immanuel Wallerstein. See, for example, Wallerstein (1991).



course) strategy, which insists that everyone, everywhere, should be treated with the same doses of the same drugs.<sup>19</sup> If only DOTS were to be implemented universally, goes this line of argument, then MDRTB would disappear.

In this essay, I will explore an epidemic of drug-resistant tuberculosis in a setting where DOTS has been fully implemented. It is by no means the largest outbreak of this deadly disease—the prison-seated epidemics in Russia no doubt take this honor—nor is it the best hidden. The outbreak is instructive, however, because it occurs precisely where it was held to be impossible—that is, in a country with perhaps the best DOTS-based tuberculosis-control program in the world.

This epidemic of MDRTB is significant less because it is being concealed by government officials, than because it belies claims that policies now in place will make this plague disappear. While onlookers await another “great disappearing act,” those sick with MDRTB continue to suffer, passing on their drug-resistant strains as they do so. But because such suffering is currently concentrated in the densely populated urban slums, it may be hidden—until the day MDRTB “emerges” into the ranks of the nonpoor. What does it mean, from the sufferer’s point of view, when MDRTB goes “underground?” To give a sense of the interplay of economic pressures, expert opinion, and the dynamics of transition, I will begin by introducing a family afflicted by this unacknowledged epidemic and then explore briefly the epidemiology of drug resistance in urban Peru. Finally, I will turn to a reexamination of the immodest claims of causality staked by health-policy experts and other authorized voices. By the end of this exercise, another constant should be revealed: that the true costs of error and delay are inevitably borne by the powerless.

### **Blanca, Andrés, and the *Familia Tebeceana***

As subtle as her initial symptoms may have been, Blanca Pérez had little doubt about what was coming when, in July, 1995, she began having fever, chills, and a productive cough. Blanca and her husband, Andrés, both then 22 years old, were living in her mother’s house with Blanca’s six siblings, two of whom were being treated for active tuberculosis. But they alone were not the reason that the Pérez family had been labeled a *familia tebeceana*—a tuberculosis family. Blanca was in fact the fifth in her family to be diagnosed with the disease—from which two of her nine siblings had already died.

It all started in 1987, when Blanca’s older sister Sonya tested positive. Sonya received numerous treatments, all unsuccessful despite what she described as “religious” compliance. Because tuberculosis treatment in Peru is supervised, there is a high likelihood that Sonya had primary drug-resistance: that is, she had been infected with a drug-resistant strain from the start, which is why her treatments failed. In any case, she remained smear-positive for years, living in a small house in the hills of Carabayllo with her mother, nine siblings, and a changing cast of spouses, partners and children.

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<sup>19</sup>And this is put none too subtly, as a 1998 article in *TB Monitor* (15(5):53) suggests. Its subtitle: “Bumgarner defends non-treatment of MDRTB.” Richard Bumgarner is the associate director of the WHO’s Global TB Programme.

It was only a matter of time before others in the household began to cough. Pablo, the family's only son, was diagnosed with tuberculosis in 1990. Pablo was a teenager at the time, but was already the main breadwinner in the family. He worked as a street vendor, which entailed a predawn ride to Lima's central market to collect old limes from the trash, then returning to sell them in the Carabayllo market. The trip in a crowded bus took almost two hours each way. Responsible for feeding his siblings, Pablo often missed his medications on days when he was unable to leave work. For years, he was in and out of treatment and was considered a classic "problem patient" by the health center. As more and more of his lungs was destroyed, Pablo became increasingly short of breath. Eventually, he was unable to work. In late November, 1994, Pablo was referred, at his repeated request, to a pulmonologist. Although he eventually did see a specialist, and was diagnosed presumptively with MDRTB, Pablo was never able to follow the pulmonologist's advice. He died the following day, still receiving first-line antituberculous drugs.

In 1991, Sonya's husband Raúl was also diagnosed with tuberculosis. Sonya continued to have positive smears throughout her directly observed therapy, but it was not until 1993 that she was recognized to have MDRTB; Raúl's resistance was not confirmed until mid-1996. Sonya and Raúl made heroic efforts to buy second-line drugs, but they could do so only intermittently, since their work as street vendors could barely feed them and their daughter. Both remained smear positive for years, and Sonya was terrified by life-threatening episodes of hemoptysis.

Luisa, another older sister, was also diagnosed with tuberculosis in 1991. She followed the same pattern of unsuccessful treatment and retreatment as her siblings. After she saw Pablo die, Luisa gave up hope, and refused any further treatment. She often said to Sonya: "Why do you go through all that to get those pills, when you know we're both going to die just like Pablo?" Luisa died one year after Pablo, in November of 1995.

Rosa was diagnosed with tuberculosis in the first months of 1995. While receiving her antituberculous treatment, she became pregnant but miscarried. Since completing her treatment, Rosa has been symptom-free. Blanca's mother was also treated for tuberculosis last year, and her symptoms have also disappeared.

For all of these reasons, then, Blanca suspected she, too, was ill with tuberculosis when she began coughing in July, 1995. Initially, however, she did not seek either diagnosis or treatment. But one morning in August, about a month after her symptoms began, Blanca had an episode of massive hemoptysis. Blanca's sisters, by this time experts, rushed her to the local health post, where her sputum was found to be abundantly positive for the tubercle bacillus. In spite of her known MDRTB contacts, Blanca began receiving the *esquema unico*, the standard six-month tuberculosis treatment regimen sanctioned by the Peruvian national tuberculosis program.

In patients with fully susceptible tuberculosis, directly-observed therapy with these four drugs leads to rapid response; patients usually feel better within a couple of weeks. Most are usually smear negative—and thus noninfectious—within the first month of treatment. By mid-

September, a full month into treatment, Blanca's symptoms had failed to improve. Her chest X-ray looked worse, and her sputum smear remained positive. In fact, during every month of treatment, Blanca had a repeat smear; every month, it was positive.

During this entire period, the local health workers who gave Blanca her daily medications were concerned that she might be resistant to these drugs. They knew about her family history: it was they, in fact, who coined the term *familia tebeceana* to describe the Pérez and other families decimated by tuberculosis. Fearing MDRTB, the health workers collected a sputum specimen from Blanca in November and sent it for culture and susceptibility testing.

In early January of 1996, Blanca's drug-sensitivity results finally revealed that her tuberculosis strain was, like that of her sister, resistant to isoniazid and rifampin, the two most powerful antituberculous drugs. Despite these laboratory results, and to the dismay of the health workers who visited her each day, Blanca was told by the health authorities that she must complete the *esquema unico*, even though it consisted, at that point, of precisely the two drugs to which she had confirmed resistance. Discouraged, indeed frightened, Blanca did as she was told. Her symptoms worsened.

In late January, after completing the daily six-month regimen, Blanca's sputum continued to show abundant tubercle bacilli. She was wracked by fevers, cough, and had experienced life-threatening hemoptysis; she now weighed less than 80 pounds. In keeping with the rules of Peru's national tuberculosis-control program, Blanca was evaluated by a program pulmonologist, who placed her on an "alternative" three-drug regimen approved by the national program. In addition, this physician prescribed Blanca two third-line drugs, ciprofloxacin and ethionamide, explaining that if she could obtain these drugs, her treatment would be even stronger. Blanca recognized the names of these drugs, as they had been prescribed to Sonya and Raúl, too. Since these drugs were not part of the standard public-health program's regimen, Blanca knew that she would have to buy them herself. But the \$200 a month that would be necessary to buy the drugs was well in excess of her entire family's monthly income.

The extended family pulled together enough resources to purchase one week's worth of the drugs for Blanca. This only made her feel worse, she recalled, since she could see that it was not possible for her family to sustain this economic burden and survive. Blanca announced that she would find another way of getting the drugs. Desperate for effective treatment, and thinking of her small children, Blanca changed her name and moved to another catchment area in order to be accepted by another health center. Under an alias, she began a standard retreatment regimen in February of 1996—despite the laboratory documentation that she was resistant to the most powerful of the drugs she was receiving. Her symptoms improved, but she remained smear-positive throughout this second treatment as well. After completing this regimen, Blanca's symptoms returned, then worsened. Without further treatment options, she spent the next two months bed-ridden, losing weight, and coughing blood—the classic picture of galloping consumption.

Just when things seemed as if they could not get worse, Blanca's husband fell ill. Andrés worked as a street vendor, selling books, but he had also assumed all the cooking and housekeeping as well. So the increased fatigue and myalgias he felt were initially attributed to

overwork. In August, 1996, he began coughing, and soon he too was diagnosed with tuberculosis. Given his multiple MDRTB contacts, Andrés was reluctant to begin standard therapy with the drugs to which his wife, sisters-in-law, and brother-in-law were resistant. But he, too, was pulled into the official algorithm; he, too, remained smear-positive for most of his treatment.

In October, Blanca's 19-year-old sister Ana was diagnosed with tuberculosis. She was in the first trimester of her first pregnancy. She was the sixth Pérez child to fall ill with tuberculosis.

The Pérez family did receive some good news, though: in October, Blanca, along with Sonya and Raúl, began receiving a treatment regimen with drugs to which their isolates had demonstrated susceptibility. These drugs were being provided, along with nutritional support and daily community health worker visits, by *Socios En Salud*, a community-based organization. On November 18, Blanca's sputum test was negative for the first time since she was diagnosed with tuberculosis. Raúl and Sonya were also soon smear-negative.

By the end of 1996, Andrés and his family were sure that he, too, had MDRTB, and he was angry that he was being forced to complete the standard regimen. The advent of therapy for MDRTB had engendered a certain amount of tension in the local "tuberculosis community," since many of the patients who had failed the official regimen understood, as did some of their providers, that they may have "knocked off" other potentially effective drugs in the process—Sonya, for example, had become resistant to five drugs, although she had initially been resistant only to two; the same was true of Blanca. Still other patients had died while waiting, as one patient put it, "to be liberated from *esquema unico*." Finally, the drugs made her nauseated: "Why should I take drugs that make me sick if they're ineffective?"

Laboratory studies done by the community-based organization revealed that Andrés did, in fact, have resistant disease. In January 1997, a few days shy of completing *esquema unico*, Andrés refused to take his medications. He was forced to sign a statement acknowledging that he was "abandoning treatment." For this reason alone, Andrés will never figure in national data as a case of primary MDRTB. Instead, he will be mislabeled, as were all the Pérez family, as having acquired MDRTB through erratic compliance. They were "problem patients."

DNA fingerprinting of Andrés' infecting strain shows, of course, that he is sick with the same strain that almost killed his wife. He too is now improving on appropriate therapy, which he began in late January of 1997.

## **A Hard Look at Epidemiology**

The history of antituberculosis drug resistance in Peru is only now coming to light. In 1984, Hopewell and colleagues estimated the overall rate of success in treating 2,510 patients diagnosed in 1980 at only 47 percent, due largely to the fact that 41 percent of patients failed to complete more than ten months of treatment. But even among those who completed more than ten months of fully supervised therapy, greater than 21 percent had treatment failure, relapse, or death. The authors concluded that these unfavorable outcomes among the treated were the result

of “many years of poor chemotherapy resulting in a high prevalence of patients with drug-resistant organisms” (Hopewell, Sanchez-Hernandez, Baron, and Ganter 1984:342). In 1985, the same team evaluated outcomes in 2,669 TB cases diagnosed in 1981 (76 percent of all patients receiving treatment in the fifty-three facilities visited). Again, therapy was supervised, but now the team was able to compare two different regimens: a “standard” twelve-month regimen and a shorter course regimen including two months of rifampin (RIF). Again, success rates were low: only 70 percent of those receiving the eight-month and 53 percent of those receiving the twelve-month regimens were presumed to be cured, by bacteriologic or clinical criteria. Since rates of cure were higher in Lima, where the eight-month regimen was more commonly used, the study also compared outcomes within the city and found that “in patients who did not abandon treatment the major determinant of outcome was whether or not there had been prior treatment rather than the current treatment regimen employed” (Hopewell, Ganter, Baron, and Sanchez-Hernandez 1985:738). Although much of the resistance was assumed to be acquired, the report also cited a study of tubercle bacilli isolated from eighty-three consecutive previously untreated young patients from Lima; 25 percent of them were found to have primary drug resistance (Black, Ganter, Grzybowski, Sanchez-Hernandez, and Hopewell 1985). Both studies led the authors to conclude that the degree of resistance in Peru was significant and should figure in decisions regarding national TB policy.

Peru still has high rates of TB, with prevalence estimated at 216 cases per 100,000 population in 1994 (Peru 1995), but a great deal has happened in the decade since Hopewell and colleagues presented their overview of the Peruvian experience. Following World Health Organization (WHO) guidelines, the government of Peru reorganized its National TB Programme (NTP) in 1991. In the past several years, the program can point to significantly increased rates of therapy completion, in large part because of the adoption of directly observed therapy with a short-course, four-drug regimen that includes six months of RIF (DOTS). Recent unpublished data also suggest a decrease in acquired resistance—a laudable trend often registered where directly observed therapy is used. Furthermore, the NTP has recently increased access to TB services in regions of the country previously underserved.

Peru’s NTP has been singled out for special praise from the international TB community. But what happened to the “treatment failures” described by Hopewell and colleagues in 1985? Many have no doubt died. But many others, it is clear, became persistent shedders of drug-resistant bacilli: approximately 50 percent of the patients who abandoned treatment were defined as having positive sputum at the time of abandonment. In our experience in three of the poorer districts of northern Lima, cases of suspected drug-resistant disease (patients persistently smear-positive throughout DOTS) have been reported from almost all area health centers. Furthermore, some of these patients had long had culture-confirmed MDRTB, even though none was receiving effective therapy. In fact, many continued to receive first-line drugs to which their isolates had demonstrated resistance; several had been prescribed “INH (isoniazid) for life.” Our own culture and susceptibility testing of specimens from these patients has confirmed resistance, most often to all four first-line drugs, and has also revealed resistance, in certain patients, to ethionamide, kanamycin, the fluoroquinolones, and capreomycin (Farmer et al. 1997). Even with passive case-finding, we have discovered that prevalence of *active* MDRTB is at least 30 cases per 100,000 population in the district. (As prevalence of TB is estimated at about 300 per 100,000 for the district, cases of active MDRTB accounted for about 10 percent of prevalent TB cases in

1995.) Resistant strains plausibly account for an even larger fraction of *new* infections, since patients with drug-susceptible TB are treated effectively by the NTP, while patients infected with MDR strains are not.

Contact tracing and ethnographic research reveal that the MDRTB epidemic is by no means contained in this region of the city. Many Peruvian patients with active MDRTB work (and commute) as long as they can, usually to pay for the second-line drugs they know they need but can only intermittently afford. They also continue to frequent clinics and hospitals for their TB-related symptoms. Hospital- and clinic-based spread continues apace: 10 percent of our patients are former health care workers. The northern Lima epidemic has been felt beyond Peruvian borders as well: at least three cases of TB resistant to all first-line drugs, all acquired in Lima's northern cone, have recently been reported in Boston, suburban New York, and Puerto Rico. MDRTB may also be a problem in other poor areas of Lima. Gilman and co-workers recently reported that, of the isolates obtained from 109 hospitalized patients with TB at one hospital in central Lima, 29 percent demonstrated resistance to at least two drugs, with fully 13 percent resistant to INH and RIF.<sup>20</sup>

Other sampling methods confirm the impression of significant rates of MDRTB in Peru. In a WHO study of ten Latin American countries, the highest levels of drug resistance were from a cluster in Peru: fully 54.5 percent of samples from Callao, Lima's port, exhibited resistance to at least one drug (Laszlo and de Kantor 1994). The Peruvian NTP recently reported that, among a sample of 1,500 patients who had never been treated for TB, 15.4 percent had isolates demonstrating resistance (by definition, "primary") to at least one first-line drug, while 2.4 percent had isolates demonstrating resistance to both INH and RIF. Among 458 patients previously treated for TB, 36.0 percent had isolates resistant to at least one antituberculous drug, and 15.7 percent had isolates resistant to both INH and RIF (Peru 1996). The true dimensions of this problem may not be reflected by these figures, as TB case-finding is passive, isolates are not tested for all patients who fail to improve on first-line drugs, and TB services, though greatly improved since 1991, remain inaccessible for some.

What does the WHO, a key architect of the Peruvian NTP, say about these troubling developments? In large part because of the worldwide problems of "therapeutic anarchy" and lack of access to any therapy at all, the WHO has, until recently, focused all of its energies on the promotion of DOTS through well-managed national TB programs. In materials recently published in anticipation of the 1997 World TB Day, the Global TB Programme noted only that, in Peru, "TB is being defeated by a model DOTS program" (WHO 1997b). As for MDRTB, the same publication argues that "DOTS makes it virtually impossible to cause a patient to develop the incurable forms of tuberculosis that are becoming more common. Other treatment strategies are actually causing multidrug-resistant TB and may be doing more harm than good" (ibid.).

Unfortunately, it is untrue that DOTS makes it "virtually impossible" to cause a patient to develop MDRTB. Through an important but understudied mechanism—the enrollment of patients with primary resistance to INH and RIF into standard, short-course algorithms—those resistant to only two drugs may become resistant to PZA (pyrazinamide) and (EMB) ethambutol

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<sup>20</sup>R.H. Gilman, Lecture delivered at IX National Congress of Internal Medicine, Lima, Peru, 1996.

as well. Since empiric retreatment regimens are often based on the same four drugs plus a short course of streptomycin, patients initially resistant to two drugs may become resistant to as many as five. We've termed this the "amplifier effect of short-course chemotherapy," and have documented its contribution to the MDRTB outbreak in northern Lima.

In this scenario, the "time bomb" of which Michael Iseman warned in 1985 has already exploded (Iseman 1985).

To its credit, the Peruvian NTP has recently acknowledged the importance of treating patients with resistant strains. In the future, those who fail standard regimens will be evaluated by a team of specialists who will recommend regimens tailored to each patient's susceptibility pattern (L. Portocarrero, personal communication). We are also working with the Peruvian NTP in order to treat the more highly resistant patients in Lima's northern cone. What is needed now, then, is for other public health authorities to follow Peru's lead in confronting MDRTB sooner rather than later. To postpone this reckoning will mean continued transmission and a larger explosion tomorrow.

### **Social Science and Immodest Claims of Causality**

Clearly, there is a great deal of confusion regarding MDRTB, although various, discrepant hypotheses about its causes and management tend to be advanced with great assurance. Let us examine a sample of studies of tuberculosis published in the sociomedical or anthropological presses. Each of these studies was conducted in a poor country, and each, faced with a frustratingly high failure rate, makes certain "claims of causality" in attempting to explain why tuberculosis remains a major cause of death in the setting under study. Often enough, the studies echo trends in the clinical literature by attempting to lay the blame for tuberculosis mortality on non-compliant patients. Why do patients fail to comply with medically mandated regimens? Here culture is often invoked as the decisive factor.

In important research conducted in southern Haiti and published in *Social Science and Medicine*, Weise devotes most of the discussion to the "health beliefs" of tuberculosis patients and their families. This is certainly a legitimate preoccupation for an anthropologist, especially one who has given us the most detailed study of the experience of tuberculosis in rural Haiti. She argues that the failure of a tuberculosis control program in the region was largely the result of "the clinic's lack of knowledge about the local culture and consequent failure to operate within it" (Weise 1974:359). Weise, however, assumes a linkage between culture and outcome that is simply not automatic. It could more easily be argued that tuberculosis control programs in Haiti have failed not through cultural insensitivity but rather through a lack of commitment to the destitute sick. As noted, I interviewed one hundred tuberculosis patients from 1989-1991 regarding their own understanding of their illness, which almost all agreed to be tuberculosis. The majority of patients felt that sorcery might have caused their illness. Both the medical anthropological literature and the Haitian physicians queried predicted that these individuals would be those most likely to abandon antituberculous therapy. We found, however, that holding the belief that sickness might be caused by sorcery did not predict half-hearted compliance with chemotherapy in Haiti's central plateau. What, then, did predict adherence to therapy? Among patients offered free and convenient care, compliance and outcome were

strongly related only to whether or not patients had access to supplemental food and income. We were led to conclude that cultural, political, and economic factors, although inevitably important, cannot be of equal significance in all settings. Similar disjunctions between anthropologists' expectations and treatment outcomes are reported elsewhere in the literature. For example, Rubel and Garro reported high rates of compliance among migrant tuberculous Mexican farm workers in California, who attributed their symptoms to disorders ranging from bronchitis to "folk illnesses" such as *susto*: "Interestingly, interviews with these patients show a continued denial of their diagnosis of tuberculosis despite faithful adherence to lengthy treatment regimens and extensive education by clinical staff members" (1992:629).

To take once more the example of South Africa, where blacks of all ethnic backgrounds have much higher rates of tuberculosis than do whites, a recent anthropological study identified several reasons for the high default rate seen among Xhosa-speaking patients with tuberculosis. Chief among these were the "deep-seated mystical beliefs" of the people under study. These beliefs include the understanding that tuberculosis may be caused by witchcraft and is thus best treated with the help of a diviner who can explain *who* caused the sickness. The author listed several other reasons as well, from the side effects of the medications to the "carelessness" of certain patients, but nowhere was there any mention of the poverty of South African blacks or of apartheid and its effects on the delivery of services. Small wonder, then, that the investigator's conclusions focus so exclusively on patients' cognitive profiles:

As an anthropologist it is therefore possible to plead that health care personnel who treat black patients with tuberculosis be aware that their patients' perceptions of the disease may differ from their own, that the patient may already have consulted a non-western practitioner, or that they are merely seeking time before they embark on a different strategy for seeking a solution for what troubles them. (de Villiers 1991:72)

This is eminently sensible, but one could as readily argue instead that the proximate cause of increased rates of morbidity and mortality among South African blacks is not their "mystical beliefs," but rather lack of access to resources, as a study by a team of physicians recently concluded: "Poverty remains the primary cause of the prevalence of many diseases and widespread hunger and malnutrition among black South Africans. The role of apartheid in creating and maintaining this poverty has been well documented" (Nightingale et al. 1990:2098).

Even here, a more extensive social analysis is necessary. Poverty and apartheid are not to be discounted, but high rates of tuberculosis in South Africa are closely linked to a "racial capitalism" far older than apartheid itself. Randall Packard has shown that institutionalized apartheid alone is inadequate to explain the skewed incidence of the disease. Indeed, differential patterns of onset and outcome were emerging well before the enactment of apartheid laws, which are merely decades old:

It is not enough to invoke apartheid, racial discrimination, and black poverty, for they themselves are symptoms of more fundamental political and economic transformations that have been associated with the rise of industrial capitalism in South Africa. Ultimately the answer to why TB remains such a serious problem



in South Africa lies in understanding the history of these transformations.  
(Packard 1989:xvi)

Packard has since been proven correct, because tuberculosis is an even greater problem in South Africa than in many of the poorer countries on the continent. What's more, the inequalities formalized in the South African economy have fostered rising rates of MDRTB, just as forced removals to "homelands" may have "ruralized" the tuberculosis epidemic more than in other settings.

Turning to Latin America, another region characterized by high grades of inequality, similar conditions obtain. But again these features of society escape commentary even in the social science literature on tuberculosis. Another study, set in Honduras and published in *Medical Anthropology*, begins with a telling vignette:

One day, in an important health center in Tegucigalpa, the capital city of Honduras, Central America, the general practitioner identified ten patients suffering from symptoms of tuberculosis. He asked them to go up to the laboratory, which was one floor above, to get the authorization for laboratory exams. Only five of them arrived at the laboratory; of those, only three brought the sputum sample the following day. Only one of them returned to pick up his result: it was negative. The results of the other two, who had given false addresses, were positive. They were suffering from tuberculosis. They were never located. (Mata 1985:57).

A team of investigators set off to interview some five hundred Hondurans to uncover the reasons for this noncompliance; the study began with the formulation of six hypotheses that might explain it. None of these hypotheses linked treatment failure to a failure of the public health system, or to Honduran society at large; none of these hypotheses mentioned poverty or social inequality at all, although those surveyed, in contrast, correctly associated tuberculosis with "extreme poverty, filth, and malnutrition" (ibid.:59).

The researchers found the patients and public to be full of strange "knowledge, attitudes, and behaviors" as well as a "great lack of education about the disease." When patients were interviewed, many "maintained a careful distance when speaking to the investigators, and seemed fearful and distrustful" (they had, speculates the author, "feelings of isolation...accompanied by guilt"). Above all, of course, the patients were noncompliant, "refus[ing] to accept [TB's] existence, and attempt[ing] to remedy the symptoms with self-prescribed medications." Some of the patients were downright refractory, "and obstinately refused the visits of health personnel." "Even when the patient can no longer ignore the evidence of his symptoms," adds the author, "he is willing to die rather than undergo treatment" (Mata 1985:62, 60, 61, 58).

Fortunately, consultants like the author were able to remedy the situation. They designed a flip chart explaining "the measures that should be taken by the patient and his family," and had sputum cups "printed with attractive and clear illustrations." Sadly, though, "the Ministry [of Health] had not yet improved its tuberculosis program services, and the necessary sample cups

were not available in time,” nor were the flip charts. But a series of radio spots, posters, and a pamphlet served to “clear up the patient’s immediate confusions about the disease” (ibid.:62, 63). The author seemed confident that Honduras—which in his account sounds more like Sweden than one of the poorest countries in Latin America—is well on its way to solving its tuberculosis problem.

Even in a more thoughtfully conceived investigation, with more robust data, the same circular logic is easily discerned. Working in Wardha District in central India, Barnhoorn and Adriaanse compared 52 compliant with 50 noncompliant patients in an effort to determine what factors might be responsible for failure to take medications. They found that “three socioeconomic variables, i.e., the monthly income per capita in a family, the type of house in which a family lived, and the monthly family income” were the strongest predictors of compliance with antituberculous chemotherapy. “It is noteworthy,” the authors add, “that the highest ratings were followed by three additional socioeconomic variables, i.e., place of residence, fuel used and education” (Barnhoorn and Adriaanse 1992:296).

Etiological beliefs about tuberculosis did not correlate strongly with adherence to therapy. A number of “health beliefs” were, however, felt to be strong predictors of compliance—but these “beliefs” also sound much more like indirect socioeconomic indicators: “Compliers also tended to clean their body, ate good foods, visited a Primary Health Centre, whereas noncompliers tended to isolate themselves and prayed to God for a cure.” Similarly, other items classified under “family attitudes” included having someone to prepare meals and “eating breakfast regularly.” If such habits were purely a matter of “attitudes,” the fight against TB in the Third World would be easily won (ibid.:299, 302).

In essence, the researchers found that the strongest predictors of compliance were economic, not cognitive or cultural. However, their conclusions lead in the opposite direction: “Concerns with the determinants of [noncompliance] might improve the care of tuberculosis patients by giving directions for educational interventions.” And although Barnhoorn and Adriaanse insist that socioeconomic obstacles to treatment do exist and are fundamental, they become, in much of the discussion, secondary: “before obstacles to a treatment regimen can be cleared away, patients have to develop health beliefs and social norms consistent with it.” When investigators call for the patients to be “liberated,” it is not a revolt against the structural violence that creates and sustains a significant and growing tuberculosis epidemic among the world’s poor. Instead, they propose that “future health education programmes aimed at the public at large should be focused on the liberation of the masses from false thoughts and burdens” (ibid.:291, 301, 303).

In another paper published in *Social Science and Medicine*, a prominent anthropologist reported that, in one city in the Philippines, children’s respiratory symptoms are often attributed to *piang*, a folk illness best treated by traditional healers: “Such a lay diagnosis *leads* to long delays before tubercular children are brought to a physician” (Rubel and Garro 1992:630, referring to a paper by Lieban 1976; emphasis added). If this claim is true, then little short of changing the culture should lead to a change in compliance. But Valeza and McDougall, working in a nearby area, were able to double compliance with antituberculous medications merely by making drugs readily available and easy to take. (Cited in Sumartojo 1993, p. 1314).

In East Africa, another region characterized by extreme poverty, weak medical infrastructure, and high rates of tuberculosis, “attribution of tuberculosis symptoms to witchcraft or other folk illnesses is associated with delays in seeking professional treatment as well as remarkably high rates of default once treatment has begun” (Rubel and Garro 1992:630). As noted, similar claims are often made in Haiti, where we found no association, except in the minds of most physicians surveyed, between belief in sorcery and tuberculosis outcomes.

These discrepancies bring us back to the sociology of knowledge. What is it, exactly, that medical anthropologists are expected to say and do? For many physicians and public health specialists, anthropologists are expected to “do the cultural piece.” We are expected to elicit the local beliefs and customs that hamstring sensible efforts to treat or prevent illness; we are supposed to reveal what it is that makes the natives tick. This role is crystallized in the “knowledge, attitude, beliefs, and practices” surveys that crop up so often in AIDS research. These surveys are not designed to reveal the messy contingencies of everyday life or the large-scale forces that may at times render cognitive considerations irrelevant to outcomes; nor are funders looking for such information, which is often regarded as useless or worse. They are looking for “rapid ethnographic assessments” with distilled kernels of cultural wisdom. And very often, we have been willing to fill this restricted role, even if it means not talking about the forces and structures that ultimately determine tuberculosis outcomes.

It is inappropriate, of course, to generalize on the basis of such a small number of papers. But a more thorough review of the sociomedical literature on compliance with antituberculous therapy does little to gainsay the impression left by the articles cited above. Such research tends to be conducted in settings—called “cultures” in these studies—characterized by high rates of tuberculosis and by extreme poverty. The fact that the cultures involved are so various calls into question the impact of culture on treatment failures. These patients do not share culture or language. What they share is tuberculosis and poverty. They also share, often enough, spectacularly bad tuberculosis services, such as those described by Friemodt-Möller, working in rural India:

The treatment began when a sufficient number of patients had been collected to justify sending out a drug-issue team the long distances. To begin with, there was an interval of 2 months from the time the sputum was found positive until treatment began. Forty-seven patients died before the treatment could begin, 14 left the towns, 20 refused treatment from the beginning, 26 stopped after the first or second drug issue, two preferred to take their own drugs. (Friemodt-Möller 1968:22)<sup>21</sup>

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<sup>21</sup>In most studies, improving the quality of services inevitably results in drastic improvements in outcomes. In discussion of tuberculous meningitis in urban India, where access to care was significantly better, one large study found that “default was not a very serious problem, despite the fact that about half the patients come from outside Madras City. Patients attended punctually on 90% of occasions. Furthermore, in 95% of the remaining unpunctual occasions, drugs were missed for less than a week which, as there was no proper retrieval action, is very commendable. All those who attended late had valid reasons for their unpunctuality” (Ramachandran and Prabhakar 1992:173; see also Grange and Festenstein 1993).

Strenuous insistence on the causal role of culture or personality in explaining treatment failures runs the risk of conflating cultural (or psychological) difference with structural violence, leading to the immodest claims of cultural causation evident above. In theory, it would be necessary to remove obstacles to full and ready access to medication before ascribing treatment failure to complete treatment to shortcomings in the patients' beliefs or sense of responsibility. But in none of the places in which the above-cited research was conducted is full and ready access assured. On the contrary, these settings crying out for measures to improve the quality of care — not the quality of the patients.<sup>22</sup> Throughout the world, compliance is lowest among those least *able* to comply.

In each of the sociomedical studies critiqued, a well-intentioned effort to incorporate the patients' points of view has served, paradoxically, to shift the blame onto the sick-poor by exaggerating their freedom to act. In so doing, researchers have echoed the received wisdom of many physicians and other providers. Their explanations, as noted, tend to focus on local actors—most notably, on patients—and local factors. Curiously, many of these studies take it as a matter of faith that educational interventions are what is required to significantly reduce rates of tuberculosis in a particular population. No one, as far as I know, has ever shown this to be true. Historical reviews, such as that by McKeown (1979), would suggest that, in England and Wales, at least, death rates from tuberculosis have varied quite independently of patients'—and healers'—understandings about the disease.<sup>23</sup>

Sociomedical research shows not only the expected divorce between patients' and healers' conceptions of the causes of tuberculosis, but also great dissensus regarding the reasons for treatment failure.<sup>24</sup> Collando reported that when Mexican district health officials were asked “To what do you attribute the problematic nature of tuberculosis control in your jurisdiction?,” those surveyed “overwhelmingly laid the blame at the door of their patients' shortcomings: ‘poverty,’ ‘lack of education,’ ‘poor motivation,’ ‘superstition,’ and ‘failure to comprehend the importance of compliance with treatment recommendations’” (cited in Rubel and Garro 1992:627). A similar pattern was described in a San Francisco chest clinic, where in the 1960s up to 34 percent of patients failed to keep their appointments. Again, providers and the patients had strongly discrepant ideas about this failure. The physicians and nurses tended to focus on the patients' shortcomings—“the social and cultural characteristics of the user population”—

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<sup>22</sup>Chaulet puts this sharply in an editorial castigating health care professionals for their noncompliance: “It is only after these general measures have been applied that we can turn our attention to improving compliance” (Chaulet 1987:23).

<sup>23</sup>Note, however, that McKeown's position lends itself to the Luddite position criticized throughout my recent book, *Infections and Inequalities* (University of California, 1999).

<sup>24</sup>For sharply divergent interpretations of TB control, see the disturbing essay by Steven Nachman (1993), an anthropologist who briefly worked among Haitians detained by the U.S. Immigration and Naturalization Service. Nachman offers compelling ethnography without making immodest claims of causality. For a review stressing the importance of patients' perspectives, see Conrad (1985). Too few of the papers reviewed underline the enormous difference between failure to adhere to an isoniazid prophylaxis regimen and failure to adhere to treatment for active disease.

while the patients listed structural barriers ranging from the inconvenience of the clinic's hours and location to a failure to treat affected families as a unit, with adults and children seen on different days and by different physicians (ibid.:632). Addressing these structural problems by moving the clinics to more convenient times and places, as well as "an improved attitude on the part of the professional staff," led to a drop in missed appointments from 34 to 6 percent after five years (Sumartojo 1993:1316). The social and cultural characteristics of the user population were not altered.

Anthropologists and other social scientists have long complained that their perspectives have not been incorporated into tuberculosis control efforts. Although it is true that physicians and their biomedical colleagues have long disregarded the social forces at work in the changing epidemiology of tuberculosis, a review of the recent biomedical literature suggests an increasing willingness to incorporate social factors in their explanations of why tuberculosis control has failed. Indeed, specialists from the CDC and from academic departments are all likely, these days, to speak of social and economic determinants. But this is not an unmixed blessing: ethnography may be valued because it is an effective excuse. Medical anthropologists have often been less willing to take account of basic biomedical insights, including the following: among their poor informants, untreated tuberculosis disease may have a case fatality rate of over 80 percent; in drug-susceptible tuberculosis, at least, over 95 percent can be cured with appropriate therapy. However, drug-susceptible tuberculosis will kill tens of millions in the coming years, and it will kill them slowly, during which time they will serve as culture media for the induction of resistant strains. This, and not a failure to incorporate the concept of culture in efforts to prevent or treat the disease, is the obscenity of late twentieth-century tuberculosis.

If we social scientists of disease are to be other than academic Cassandra, we would do well to acknowledge the largely structural causes of persistent tuberculosis and ask why we have not had much influence in past attempts to treat it. In other words, the research tasks before us might more likely be accomplished if we can avoid the traps of the past. As I examine my own field—similar exercises would be welcome in each of the sociomedical sciences—five such pitfalls come quickly to mind:

### ***1. Conflating Structural Violence with Cultural Difference***

Each of the sociomedical sciences—medical anthropology, medical sociology, health economics, etc.—has tended to stake out its specific "turf." Representatives of these fields have then tended to claim that their disciplinary focus is of paramount importance in explaining the phenomenon under scrutiny—regardless of what that phenomenon happens to be. In medical anthropology, regularly enough, *culture* is held up as the determinant variable. Because culture is merely one of several potentially determinant factors, anthropologists and other researchers who cite cognitivist "cultural" explanations for the poor health of the poor have been the object of legitimate critiques:

Medical anthropologists and sociologists have tended to elevate the cultural component into an omnibus explanation. The emphasis is on cultural determination. Even when social relations receive more than reflexive recognition, medical social scientists restrict the social relations to small

‘primary’ group settings, such as the family, and factions at the micro unit... Little or no attempt is made to encompass the totality of the larger society’s structure. (Onoge 1975:221)<sup>25</sup>

One of the side-effects of such cognitivist approaches to culture, as noted, is a conflation of structural violence and cultural difference. Related trends are easily discerned in medical psychology, where personality attributes—the turf of that discipline—are held to explain risk for such disorders as AIDS, alcoholism, and addiction to drugs.

## ***2. Minimizing the Role of Poverty and Inequality***

Many anthropologists, regarding their turf to be the “cultural piece,” have also tended to underplay economic barriers to effective care. Poverty has long been the chief risk factor for both acquiring and dying from tuberculosis, and this was true long before MDR strains appeared. It was true when the likes of Lord Byron and Keats died from tuberculosis, for even then “the white plague” found the great majority of its victims among the poor. Dramatic shifts in local epidemiology aside, a global analysis does not suggest major decreases in the importance of tuberculosis as a cause of death. In fact, it is only in terms of visibility that tuberculosis may be said to be an emerging disease.<sup>26</sup>

Almost unexamined has been the relationship between the social reproduction of inequalities and the persistence of tuberculosis. To my knowledge, there have been no studies of the mechanisms by which steep grades of inequality might elicit resistance to antituberculous drugs—though two mechanisms, poor nutrition and suboptimal treatment spring immediately to mind. The paucity of research on the political economy of TB contrasts with the overrated emphasis (in my view) on the influence of culture. It is time that such imbalanced analysis is reassessed.

## ***3. Exaggeration of Patient Agency***

The praiseworthy effort to incorporate the patients’ points of view can serve, at times, to obscure the very real constraints on agency experienced by most, but not all, patients with

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<sup>25</sup>Medical anthropologists are not the only ones who lend importance to factors that cannot be considered central in the shaping of TB pandemics. Although René Dubos was at times tough-minded in his assessments, calling TB “the first penalty that capitalistic society had to pay for the ruthless exploitation of labor,” he saw TB as a reflection of the human failure to adapt harmoniously with the environment. This failure was most obvious in the “anonymous gloom of the industrial cities” of the nineteenth century, and had replaced the more sensible pastoral lifestyle that had reigned prior to industrial revolution: “The most destitute villager in his native land had learned to adorn the dullness and drudgery of existence with bright ribbons and jolly tunes, and with the pageantry of his church” (Dubos and Dubos, 1992:207, 202). René Dubos tended, at times, to adopt what has been termed above a “Luddite stance,” even after the development of effective antituberculous chemotherapy. As regarded smallpox, he once noted “eradication programs will eventually become a curiosity item on library shelves, just as have all social utopias” (in Oldstone, 1998:41).

<sup>26</sup>For a review, see Porter and McAdam (1994).

tuberculosis. As noted, clinicians are often the first to endorse such immodest claims. One influential editorial in *Chest* declared patient non-compliance to be “the most serious remaining problem in the control of tuberculosis in the United States” (Addington 1979:741). Assumptions regarding human agency are readily discerned in most discussions of treatment failures and noncompliance. In tuberculosis clinics throughout the world, patient-related factors top providers’ lists of explanations for treatment failures. These lists, as Sumartojo politely and acutely notes, reflect providers’ “observations and experience, but exclude environmental, structural, and operational factors that are beyond the patient’s control” (1993:1312). Calls to change “lifestyle and behavior” are often made to precisely those persons least able to do so. Similar exaggerations took place in earlier eras, as historian Barbara Rosenkrantz has noted in examining the elaborate treatment protocols of the turn of the century: “The disease-oriented hygienic regimen dictated by bacteriologic research came to grief when a patient’s poverty made it unlikely that such advice would be followed” (see her excellent Introduction to Dubos and Dubos 1992:xxi).

Exaggeration of patient agency is particularly marked in the biomedical literature, in part because of medicine’s celebrated focus on the individual patient, which inevitably desocializes him or her. Strong behaviorist trends mar much of the psychological literature on tuberculosis. Similar critiques of modern epidemiology have also been advanced (see McMichael 1995). But it is social science that has underlined the importance of contextualization; if we have failed to complement clinicians’ views with more robustly contextualized ones, we have not given a good accounting of our discipline.

Who is better qualified than social scientists to find sad irony in the fact that a rhetoric of patient “agency” emerges only *after* populations have been subjected to a series of external attacks, of which contagious disease is only one? As far as the risk of contracting TB is concerned, the poor have no option; tuberculosis is merely one feature of a hostile environment. For most populations, as we have seen, the chances of acquiring infection, developing disease, and lacking access to care are structured by a series of systemic forces. In South Africa, say, these forces include poverty and racism; in other settings, gender inequality conspires with poverty to lead to higher incidence of tuberculosis in poor women (Margono, Garely, Mroueh, and Minkoff 1993).<sup>27</sup> Throughout the United States, increased indices of economic inequity seem to favor epidemics in blighted inner cities, already ravaged by related epidemics of AIDS, injection drug use, homelessness and racism. Such chronic inequalities amount to a condition of structural violence. Overt political violence and war—themselves usually a reflection of long-sustained structural violence—have well-known associations with increased rates of tuberculosis.

#### **4. Romanticism About “Folk Healing”**

A strong vein of commentary in medical anthropology depicts folk healing as somehow superior—perhaps by virtue of its deeper integration with local cultures—to biomedical

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<sup>27</sup>Although biological universals are important—cell-mediated immunity wanes during pregnancy—TB is strikingly patterned even among pregnant women. Poor, urban women of color are disproportionately affected among U.S. women. See also Snider (1992). It is important to note, however, that in recent years the majority of U.S. cases have been men.

therapies. Although these claims have been called into question by some within the field, they have since assumed importance far beyond the boundaries of anthropology (see, for example, Patel 1987). Sad to say, nonbiomedical treatments for active pulmonary or extrapulmonary tuberculosis have thus far proven to be spectacularly ineffective. They do not change case fatality rates. If folk healing were so effective, the world's wealthy would be monopolizing it. When the privileged do use folk healing and other nonbiomedical modalities, it is as adjunctive therapy, often for chronic illnesses refractory to biomedical intervention. (I have personally treated dozens of Haitian folk healers for tuberculosis, malaria, and typhoid.) We live in an increasingly interconnected world. Folk remedies no longer justify themselves as the only remedies known in a given setting. Robert David's use of herbal remedies to treat tuberculosis is emblematic not of his cultural integrity, but of the unfair distribution of the world's resources.

### ***5. Persistence of Insularity***

We medical anthropologists, like other subspecialists, are usually familiar with the arcane debates in our own field. Yet we are too often unwilling to learn the basics of infectious disease or epidemiology, even when they are related to our chosen arenas of intervention. This sectarian approach to research can be costly when examining pandemics with demonstrable relation to both biological and social forces—which is to say all pandemics, as far as I can tell. Why, for example, have anthropologists been generally ignored in the AIDS pandemic? Perhaps because we too loudly and too insistently made immodest claims of causality: in the first years of the pandemic, as noted, the refrain at many of our professional meetings was that anthropology had “special knowledge” about the “cultural practices” then held to be related to the high incidence of AIDS in certain areas where we worked (Farmer 1991). Regarding Haiti, for example, there was much talk of the role of voodoo. Long after “exotic” cultural practices proved irrelevant to the spread of HIV, red herrings of this sort continued to figure prominently in our professional meetings. Meanwhile, important multidisciplinary research faltered or was based on slipshod social theory.

### **Conclusion: Future Research on MDRTB**

The emergence of MDRTB is a terrible vindication for those who predicted earlier in this century that a social disease would not be eradicated without social action. But their clairvoyance is no reason for celebration. MDRTB is a biologically and socially complex development. To check it, we must understand the forces promoting and retarding its advance. How, more precisely, might anthropology (and the other social sciences) contribute to efforts to control the new scourge of MDRTB?

Several research tasks come to mind. First, who is better qualified than social scientists to discern the precise mechanisms by which social forces (ranging from racism to political violence) promote or retard the transmission or recrudescence of tuberculosis? Since several patent mechanisms have already been brought forward, it will be incumbent upon us to offer a hierarchy of factors and understand how, in different settings, these might be differentially weighted. New research technologies, such as the DNA fingerprinting techniques mentioned above, promise new insight into transmission dynamics, but will also lead to new social



dilemmas that will demand innovative responses (see, for example, the review by Small and Moss 1993).

Second, ethnographic research will be important in identifying and, again, ranking the barriers preventing those afflicted with MDRTB from having access to the best care available. The best available care, regardless of the etiologic beliefs of the patient, seems to consist of multiple-drug regimens, accompanied by adequate nutrition, applied for at least eighteen months and probably longer. It is insufficient, though important, to adopt a patient-centered approach. "The challenge to researchers is to acknowledge that adherence is influenced by a complex array of factors, many of which are beyond the patient's control, and to begin identifying and describing these factors" (Sumartojo 1993:1318).

Third, social scientists should become more engaged in multidisciplinary research and trials. We have much to offer those seeking to design programs that will increase access to optimal therapies. Comparative trials, not just of directly-observed therapy, but also of simpler, more dignified and "user-friendly" regimens, have yet to be widely initiated. In settings in Latin America, where effective therapy is urgently needed, we must critically examine confident claims that treating MDRTB is not "cost-effective." Outcomes research on community-based MDRTB treatment efforts must be linked to innovative research on the transmission dynamics of this disease. Such explorations will link ethnography to both conventional and molecular epidemiology.

Fourth, research that exposes—and deplores—the precise mechanisms by which entrenched medical inequities are buttressed may help to redress these inequities. In so doing, we would no doubt also be exposing the real co-factors in this emerging epidemic of "social disease."

These suggestions are more crassly utilitarian than those usually heard in calls for social science research, but it is clear that we should act quickly to make common cause with those on the side of the sick-poor, regardless of profession—whether we are community health workers, or folk healers, or physicians, or bench scientists. Certainly, some of these will be stop-gap measures, but such measures matter a great deal to those sick with tuberculosis. "It is useful to remember," remarks Rosenkrantz, "that a 'social disease' typically affects the socially marginal, who can ill-afford to wait for the fundamental insights and social transformations that challenge the well-established associations of disadvantage and disease" (Dubos and Dubos 1992:xxxiv).

I have sought in this essay to adopt the sufferer's view as far as possible, and not the administrator's or the grant officer's. I believe that the interests of those who suffer from tuberculosis are not served by attempting to hide the dimensions of this pandemic, or by masking the mechanisms through which it has been aggravated. Sick people are certainly not served by labeling them "untreatable," or declaring the strains that infect them to be less virulent or less infectious than is, in fact, the case. If the first step in alleviating their suffering is to acknowledge its dimensions, then the second step must be to develop meaningful treatment strategies. As Michael Iseman has eloquently noted, history will stand in judgment of our collective response to drug-resistant tuberculosis, determining in the process "whether we

deserve the appellation 'sapient' or whether anthropologists will have to find another designation for our species" (Iseman 1995:139).

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# **Infectious Diseases and Social Inequality in Latin America: From Hemispheric Insecurity to Global Cooperation**

**Catherine A. Christen**

## **Introduction**

On May 1, 1998, the Latin American Program hosted an afternoon session on "Infectious Diseases and Social Inequality in Latin America: From Hemispheric Insecurity to Global Cooperation." The two paper presentations, subsequent commentary by four invited panelists, and a concluding audience-speaker interchange principally addressed the nature of epidemiological theories and practices regarding infectious disease situations among poor populations in modern Latin America. The participants considered how present epidemiological approaches sometimes stigmatize poor populations, thereby rendering programs of prevention and treatment less effective. The participants also explored means of overcoming obstacles to North-South dialogue and to the disciplinary barriers that separate epidemiologists and other public health practitioners, development specialists, and social scientists. The participants represented all of these types of institutions and disciplines.

Dr. Charles Briggs, conference organizer, Wilson Center Fellow, anthropologist, and Professor of Ethnic Studies at the University of California, San Diego, provided the session's first featured paper presentation. Dr. Briggs spoke about "Lessons in the Time of Cholera," opening his address with the deceptively simple question, "What can we learn from the [contemporary] Latin American cholera epidemic?" Briggs suggested that insofar as standard epidemiological approaches to this question have focused on Latin American government shortcomings and on the incidence of risk-enhancing "cultural practices" of local populations, their accounts of the social factors that underlie the epidemic have been misleading and inadequate.

Briggs asserted three principal shortcomings of most epidemiological research to date. First, epidemiological studies of Latin American countries and populations often mention certain stereotypical images—such as unwashed hands, unclean food, and fly-ridden sidewalk stalls—thus conveying oversimplified connections between social inequality and infectious diseases. Second, these studies fail to address the significance of the past decade's broad global transformations in political and economic relations. Third, the discourse on epidemic cholera is too narrow: epidemiologists, public health officials, social scientists, development economics specialists, and other policy-oriented practitioners do not engage jointly in systematic consideration of the issues. Briggs's paper elaborated on these concerns, with particular reference to his research (in collaboration with physician Clara Mantini-Briggs, MD) on perceptions and realities of epidemic cholera in modern Venezuela.

The second paper was presented by Dr. Paul Farmer. Several years ago, as a health care provider in Haiti, Paul Farmer first became familiar with Multidrug-Resistant Tuberculosis (MDRTB). Farmer, now a Harvard Medical School professor and Director of the Institute for Health and Social Justice, Partners in Health, described how his Haiti experiences raised his

concerns about the "immodest claims of causality," both structural and personalist, used to explain widespread failures in tuberculosis treatment. Such claims have contended that MDRTB deaths are consequences of structural causes, such as impoverished or overlarge families, or of personalistic causes, including patients' belief in sorcery or their noncompliance with medical regimes.

In a study conducted in Peru that was designed to explore these discrepant claims, Farmer's team discerned no relationship between patients' explanatory models (regarding how they got sick) and disease outcome. What mattered was whether the population under study, landless Peruvian peasants, received sustained help—in particular, access to health care, nutritional aid, and financial assistance—throughout a complete course of treatment. Too often, Farmer emphasized, when international public health authorities make claims that a disease is "untreatable," they actually mean that treatment is not cost-effective, given the present era "of limited [fiscal] resources." Although difficult to treat, MDRTB is not incurable. Farmer emphasized that MDRTB is not curable by the Directly Observed Therapy Short Course (DOTS) now so often employed, but only in conjunction with long-course therapy. By Farmer's account, poor treatment programs, lack of access to appropriate programs, and failure of public health givers to ensure availability of reliable treatment are the keys to explaining the increasing prevalence and virulence of MDRTB.

Representing a range of pertinent disciplinary and institutional affiliations and national origins, the four commentators composed a panel particularly well constituted to engage the afternoon's subject matter. First in series and later during a lively exchange with the audience and paper presenters, each panelist offered his or her field-tested perspectives on the pitfalls, opportunities, and obligations that epidemiologists, development specialists, and social scientists encounter in addressing questions of infectious diseases and social inequality.

Epidemiologist and international health organization administrator Dr. David Brandling-Bennett cogently defended traditional epidemiology's core mission and methods, while simultaneously acknowledging the need to eradicate a troubling professional blind spot concerning misuse of epidemiological associations between poverty and epidemic disease. Anthropologist Dr. Veena Das, tying the papers' contents to reflections upon her own research in India, addressed the interdisciplinary gap between basic and applied natural science disciplines regarding infectious diseases, and she pursued several issues pertinent to cost-effectiveness.

Economic demographer and international development specialist Dr. Ruth Levine offered some privileged glimpses into the self-questioning processes of international financial institutions, and noted that more effective interventions were possible if all parties to these issues eschew a direct chain of causation in favor of acknowledging the many different ways to conceive cause and effect. She also speculated on how an international lending institution, such as the Inter-American Development Bank, could incorporate findings such as those of Drs. Briggs and Farmer into its operations. Dr. Naomar Monteiro de Almeida-Filho, a critical epidemiologist and educator in Brazil, discussed how these issues relate to a range of Brazilian health issues, and suggested a "health-dominated" approach as an alternative to the prevalent "disease-dominated" one. He also offered his interpretation of two disciplinary "shock

therapies” he discerned in the work of Drs. Briggs and Farmer: the “shock of humbleness,” regarding any given discipline’s actual impact, and the “shock of openness,” concerning recognition of the true extent of globalization—beyond economic opening to exchange on all levels, including that of meaning.

The final open discussion on these topics incorporated the views of the audience, largely composed of epidemiologists, many from the Pan American Health Organization (PAHO), and other national and international health and policy practitioners.

### **Commentators:**

#### **David Brandling-Bennett, MD**

Dr. David Brandling-Bennett, former Centers for Disease Control (CDC) epidemiologist and present Deputy Director of the Pan American Health Organization, has worked on health issues in Central America, Thailand, Kenya, and the United States. Dr. Brandling-Bennett noted that these papers afforded him a chance to think about these issues from a markedly different perspective than his customary one. Although he found that the papers convincingly demonstrated shortcomings in the ways epidemiologists perceive links between disease and poverty, he was troubled to discern a possible imputing to epidemiologists of evil intentions, rather than merely errors of oversight and omission.

All of us, stated Brandling-Bennett, consider close associations of poverty with ill health to be amply demonstrated. Epidemiologists, principally conscious of an urgent need to find effective interventions to reduce disease prevalence, often identify these poverty/ill health “associations” as causal linkages or contributing factors. Identified thus, these “associations” allow epidemiologists to devise possibly useful interventions, such as particular sanitation regimes.

Unfortunately, as the Briggs and Farmer papers demonstrate, in their urgent quest to find effective interventions for infectious disease, epidemiologists often fail to realize that their discussion of or emphasis upon such associations or linkages may be utilized by governments or other parties in ways that prove pejorative, even stigmatizing to the individuals or populations so described. Epidemiologists must take more care to prevent such misuse.

Still, scholars should not interpret epidemiologists’ sometime historical failure to protect against such misuse as indicating any measure of evil intent or intention to “lay blame”. Specifically, Brandling-Bennett noted that Dr. Briggs appears to impute to leading cholera epidemiologists some deliberate intention to stigmatize as poor or unsanitary certain cholera-afflicted Latin American populations, assigning responsibility to the victims. In fact, Dr. Brandling-Bennett emphasized, these responsible epidemiologists try to do nothing more than to identify immediate factors contributing to cholera transmission, particularly those susceptible to intervention.

Given the broad linkup of health and poverty, and accepting the concept that poverty contributes to ill health, PAHO and many others are starting seriously to assess whether



intervening in and improving peoples' health will help them to overcome poverty. Brandling-Bennett related this to Dr. Farmer's conclusions regarding tuberculosis treatment: you can treat peoples' tuberculosis and thus to some degree do something about their poverty, but it is much more difficult—though not impossible—to do something directly about people's poverty and in that way improve their health.

Epidemiologists, Brandling-Bennett continued, strongly agree with the presenters that social and cultural factors contribute to disease problems; the cholera epidemic is the most striking evidence of this in the recent history of the Americas. Without doubt, the 1980s' economic difficulties and resulting economic policies, including perceived efforts in Peru and elsewhere to increase the private sector's economic role, with downsizing and decreased investment in the public sector, directly contributed to increasing the susceptibility of populations in general. PAHO, Brandling-Bennett asserted, is now particularly emphasizing an effort to identify and reduce inequities within populations in order to improve their health. Such inequities include access to health services, which Dr. Farmer has identified as a major issue in tuberculosis.

As a region, the Americas is one of the most inequitable in the world, by various measures, including those of Inter-American Development Bank and World Bank economists. The total investment in health in the Americas is around 7 percent of Gross Domestic Product, fairly high, but fares poorly in health indices relative to other regions. PAHO feels that is due in large part to inequitable resource distribution, specifically of income and education, as well as in limited access to and poor quality of health services, particularly for those of lower socioeconomic status.

However, it is essential to recognize that correcting inequities, particularly those of socioeconomic status and even ones of health service quality and access, are relatively long-term undertakings. When dealing with an issue such as cholera, one has to find more immediate solutions.

Dr. Brandling-Bennett noted that, as Dr. Briggs indicated, the association of poverty and cholera is long known. Dr. Eugene Gangarosa, whom Dr. Briggs mentions, is attributed as saying that the best prevention for cholera is having two quarters to rub together. In saying that, emphasized Dr. Brandling-Bennett, Dr. Gangarosa certainly would not have meant to stigmatize poor people, but to indicate that their limited resources made them more susceptible than others to cholera, and that something must be done about both the susceptibility and the limited resources.

Dr. Brandling-Bennett then offered the PAHO view of the Americas' modern cholera epidemic. Cholera actually had disappeared from the Americas during the late nineteenth century because the countries of the Americas perceived it as a serious, primarily urban, problem. They decided the best intervention was to build municipal water systems and widely distribute reasonable quality water, as all were at risk, regardless of socioeconomic status. Cholera's disappearance was not accidental. Nor was its eventual return. Indeed, many had expected cholera to return to the Americas in the 1970s, when it entered Africa. In preparation, Brazil had even set aside cholera wards and cholera cots.

Although it did not return at that time, noted Dr. Brandling-Bennett, certainly the deterioration of infrastructure in the 1980s, particularly in Peru, allowed the later entry and rapid spread of cholera. In 1991, within three months, Peru was experiencing a massive cholera epidemic. No one can reasonably argue that this return was related to the “bad behavior” or “cultural practices” of poor people. In Peru, generally covered with cholera organisms, the well-off could use their resources to avoid infection or quickly get treatment. Without recourse, the rest of the population became infected at extraordinarily high levels; fortunately, there were not commensurate death rates, thanks to the health services’ surprisingly good work.

With the Peru beachhead, cholera was fairly readily disseminated to a relatively susceptible region. There was an immediate need to identify the factors related to transmission. PAHO was not satisfied only to identify and treat cholera where it already existed (using the usual diarrheal disease approach, emphasizing distribution of oral rehydration salts), but also deliberately worked to prevent or at least contain cholera’s continued transmission throughout the Americas. PAHO was challenged on this more comprehensive approach at its 1991 executive committee meeting, at which time Dr. Brandling-Bennett explained that PAHO felt this effort was critical, though undoubtedly destined to be only partially successful.

Reiterating his earlier point, Dr. Brandling-Bennett emphasized that while epidemiologists may quite often be guilty of allowing their findings to be used to stigmatize people, usually their actual intent is to find effective, immediate interventions to protect people from epidemic disease. As Dr. Briggs indicated, epidemiologists can become aware of and guard against possible misuse of the information they provide about contributory disease risk factors, thus reducing the likelihood that governments particularly will turn such work to stigmatize populations, or to hold those populations uniquely responsible for their epidemic disease problems and therefore deny measures to combat the underlying causes.

Dr. Brandling-Bennett questioned the meaning of Dr. Briggs’s mention of “critical epidemiologists or epidemiologists of social inequality in Latin America”; did that imply a prevalence of uncritical epidemiologists? Dr. Brandling-Bennett also noted that he might not accept Briggs’s critical stance toward the 1993 World Bank Report “Investing in Health,” for its recommending selective targeting of health services delivery rather than “broad-based. . . health infrastructures.” Practitioners trying to find effective interventions cannot fall into the trap of just trying to do good and accepting bad—that is, inefficiency and ineffectiveness—as a standard in the absence of measurable results.

Dr. Brandling-Bennett then specifically addressed Dr. Farmer’s presentation and papers, noting first that those who categorize “emerging disease,” who are usually at least somewhat politically motivated, did not initially include tuberculosis as an emerging disease. He concurred with Dr. Farmer that tuberculosis, which infects one-third of the world’s population, hardly is “emerging,” or even re-emerging, though one might argue that it has, in a sense, reemerged in New York, and perhaps in the United States, since of late the numbers have increased there instead of continuing to go down.

Dr. Brandling-Bennett noted that Dr. Farmer has also highlighted the significant fact that tuberculosis, like many if not all diseases, must be looked at as a local disease. We tend to study national statistics, which obscure what is going on in local situations. PAHO is encouraging efforts to have countries develop and utilize statistics for more local administrative areas, starting with state and municipal levels, with the idea that they will identify inequities. Over time, this finer screen should detect where these tremendous differences are, as Dr. Farmer highlighted with Harlem, which had no local decrease in tuberculosis incidence. If people had been looking at those Harlem statistics earlier, they would have seen a problem in the area, well before United States statistics generally began to rise.

Dr. Brandling-Bennett considered absolutely correct Dr. Farmer's commentary in his article, "Social Scientists and the New Tuberculosis," regarding the problems created by using the terms "noncompliance," or nonadherence. He concurred that measures are needed to improve the quality of care, not the quality of patients, indicating a problem integral to the practitioners.

Dr. Brandling-Bennett argued that, rather than just a short-course therapy, DOTS has evolved from a Directly Observed Therapy, Short course, to a Directly Observed Therapy with a Strategy. The "s" has come to stand for "strategy" rather than "short course." That strategy is supposed to include political commitment, case detection with sputum microscopy, Directly Observed Short Course Treatment, regular drug supply, and a monitoring system that will detect failures. Multidrug-resistant Tuberculosis does present a real challenge. Dr. Brandling-Bennett considered it encouraging that Dr. Farmer perceives the global tuberculosis program as having now recognized the problem and having begun to take some necessary measures.

As indicated in the comments on Dr. Briggs's paper, it is essential that these programs have a focus. The advantage of the global program on tuberculosis is that it has a target, namely the intersection at which the lines of decreasing susceptible infections and increasing resistant infections cross. Epidemiologists fear that becoming bogged down in big programs against MDRTB will prevent ever reaching that point, said Dr. Brandling-Bennett. One can question that argument, but one cannot ignore cases of MDRTB, and, overall, resources are indeed available. That said, the involvement of people like Dr. Farmer, who want to make these focused efforts, should be encouraged. It is nonetheless also important to continue the effort of those who are pressuring countries without effective programs—like India, Mexico, or Brazil—to undertake a basic DOTS approach rather than look initially at just the issues of multidrug resistance. In these locations, unless an effective basic strategy is mounted, we may fail to advance toward the point that MDRTB will be the major problem that has to be addressed.

### **Dr. Veena Das**

Dr. Veena Das, Professor of Anthropology at the New School for Social Research, author of *Critical Events* and co-editor of *Social Suffering*, chose to discuss the topic in a global framework. She observed first that the movement of ideas seems somewhat limited not only between social sciences and natural sciences, but even between public health and basic research. For example, micro- and molecular biologists' work on cholera sometimes does not accord with the public health conception that cholera is a known disease, that is, that we know how it spreads

and how to manage it. A new cholera strain, 0139, arose in Bengal in 1991-92. Between 1990 and 1991 cholera cases admitted to Calcutta's infectious diseases hospital were up 10.15 percent from the year before, and between 1992 and 1993 cases admitted went up 90.8 percent. For a time there was great uncertainty concerning what exactly was happening to cholera; nobody knew whether 0139 might cause another world pandemic, or whether it would be contained. For reasons not at all clear, it did disappear. (Some new research indicates that what looks like a classical 01 strain that has appeared is actually a clone.)

Similarly, public health practitioners talk about the development of effective vaccines. Yet pretrial results do not affirm the existence of effective vaccines. When the prevalent vaccines were laboratory tested, they showed only 35 percent effectiveness. The new recombinant vaccines seem to be more effective but have a problem of residual diarrhea. In an interesting development in 1996, Williams, working on some strains from Peru, showed that horizontal gene transfer was possible under laboratory conditions. This may be cause for serious concern. It may indicate that the entire strategy of developing vaccines could lead to environmental disaster, given the possibility of spread by horizontal gene transfer.

This relates to another significant point, noted Dr. Das. The idea that we know the nature of a disease is expressed in time frames that may be inappropriate for considering the evolution of the microbe. Regarding the Latin American cholera pandemic, one hundred years ago it would have been unlikely that anyone could have predicted that El Tor would probably remain dormant for a very long time, and then reemerge as a pandemic a century later, as it actually did. But for some reason, this outsized time frame is not featured in the international scientific journals. Locations such as South America tend to be seen as exotic places where cholera might happen any time, even while in other places the risk remains very low. It may be time seriously to question the tendency to such presumptions.

Dr. Das commended Dr. Briggs's discussion of the language of social stigma and the phenomenon of stigmatization of groups that lack the resources to follow recommended health practices. Stigmatization is not purely a matter of intention, but it is not sufficient merely to assert that when people write in such language they do not intend to stigmatize such groups. By now, she emphasized, practitioners should have enough experience in this. The language of stigmatization came into being a hundred years ago, when Hopkin first tested his vaccine in India. The idea that there were "dirty" places and the associated discourses created entire administrative histories by which choleric and noncholeric districts and their respective characteristics were distinguished. So, even if there is no intent to stigmatize anyone, Dr. Briggs's point about the manner in which these cultural responses are bred highlights how this language of stigmatization may develop and circulate in different contexts and how it may affect the way such groups are treated. She noted that Dr. Briggs had offered interesting and very important examples of precisely such processes.

Dr. Das then noted that, in his work on AIDS, Dr. Farmer has introduced an exciting and important concept, that of the geography of blame. The social sciences, she noted, often are not comfortable with generalizations. In relation to the culture and political economy of infectious diseases, this is an extremely important insight into the manner in which such processes as state

formation, political demography, or self-styled political epidemiology have looked at the problem of numbers as one that is equivalent to a certain kind of political demography.

Dr. Das then offered some annotated suggestions for several possible themes for the postcommentary discussion. First, cost-effectiveness; if resources are limited, how best to use them? Within a disease-specific approach, cost-effectiveness is typically discussed thus: for a given cost of giving Hepatitis-B vaccine to the whole population, calculate the benefits in terms of preventing both Hepatitis-B cases and, for instance, later liver cancer. Never undertaken is a comparison within particular local contexts characterized by a certain cluster or burden of disease; would investing the same resources in other diseases or populations provide a different outcome? Important to consider, noted Dr. Das, is the issue of writing about this in terms of disease-specific criteria rather than as a cluster of diseases, and at global rather than local and municipal organizational levels. Often, a particular line of reasoning is presented specifically because a disease-specific approach lends itself more easily to a disease-specific argument.

Apropos of this issue, Dr. Das cited her own work in regard to poverty and food security. In certain districts in India, of two hundred children interviewed, only two had eaten two meals per day. Many had never even seen bread. In those districts, immunization programs are successful; children are not dying of childhood diseases. Yet malnutrition is at an appalling high of about 70 percent. Although agreeing with Dr. Brandling-Bennett that since we cannot actually address poverty, it is sometimes important to focus on curing tuberculosis, Dr. Das suggested revisiting the circumstances of similarly stark problems. For example, when people are lacking food for eight months of the year, we may question the value of investing resources in, say, efficient global immunization programs, such as a polio eradication.

This is one set of questions, suggested Dr. Das, that should be subjected to more detailed analysis by destabilizing the received models. Not only can we not invest resources in what we cannot measure; the proposed manner of measurement is itself highly problematic. In India, the very measurement of the growing burden of disease is based on primary health center reportings from only one state. Given the diversity of diseases implicated in reporting, we may ask if it really makes sense to have global measures and programs for resource investment.

Dr. Das closed with two other questions. First, how is it that something so problematic at the level of basic science may become so unproblematic at the level of public health? For instance, during the 1980s, trials of BCG effectiveness demonstrated a range between 20 and 80 percent. No one has determined exactly why it showed such variation. There is some consensus that such a vaccine would prevent something like TB with meningitis, but not normal tuberculosis. Given such conditions, why does public health continue with a certain consensus (e.g., about giving BCG vaccine at birth), and assume that such immunization programs are taking care of TB control? Second, just as Dr. Farmer raised questions about cases of multidrug resistance, one might also ask which kinds of public health practices and programs continue even given reasonable consensus at the basic research level indicating no basis for so continuing. In the context of larger questions on this subject, we need to ask both where are resources being invested, and where are they not.

## **Dr. Ruth E. Levine**

Dr. Ruth E. Levine, economic demographer and Advisor to the Executive Vice-President, Inter-American Development Bank (IDB), has worked in both Africa and Latin America. She offered as disclaimer at the outset of her remarks the statement that she was speaking as a private citizen, not as a representative of the IDB.

Dr. Levine noted that the day's papers and presentations reminded her of many discussions at the IDB. Early in her career, explained Dr. Levine, she realized the tremendous extent of discourse within international financial institutions about right and wrong, and about the institution's proper role, discourse not always perceived by those on the outside. The IDB staff spends considerable time pondering whether they have correctly identified the key problems, whether they are tackling the genuine causes of those problems, and even whether they have sometimes brought about new problems.

Rather than discussing TB or cholera, Dr. Levine chose to share reflections on two themes suggested by the papers and presentations. The first concerns levels of explanation and how we decide upon what causes what. To her, one of the central messages of the papers is that complex phenomena can be explained in many ways depending on the optic one is using. For example, at a child's death by infectious disease, a doctor may see the pathogens, while perhaps the mother sees a doctor's failure. In the same instance, epidemiologists may look at the temporal associations to see if they are biologically plausible, and establish some causal framework. A Ministry of Health official may see a failure on the part of the mother, or of the community, and a lack of hygiene in the environment. A microeconomist might observe some sort of rational decision-making process, determining where certain investments were made in the child, and other investments were made in other household activities or products. A sociologist might see the results of various social forces.

We can spend a good deal of time trying to assess who is right and who is wrong, who is biased, who has supporting data, continued Dr. Levine. But it could be much more productive simply to accept that there are multiple explanations. With a complex phenomenon, she noted, explanation is largely a function of where one sits. One's experience, knowledge, political persuasion, what one represents, and whether one perceives one's self to be powerful or powerless all play into what cause one construes. If we accept that there is no single, direct chain of causation, but rather many different ways to conceive cause and effect and explain a phenomenon, there are many different opportunities, levels, and types of intervention that can have a positive outcome.

Dr. Levine's second theme concerned how the subject matter of the conference, including the issue of levels of explanation, is manifested or applied in the daily actions and decisions of a bank or development institution like the IDB. As background to her commentary on this theme, she briefly discussed the IDB's history, structure, and function.

The IDB was established in 1959 as the first regional development bank. Major impetus for its creation came from the Latin American governments, who considered global institutions insufficiently responsive to the needs of Latin American and Caribbean governments. Present members include all the countries of Latin America, most of the Caribbean nations, the United States, Canada, and most of Western Europe. Cuba and a few other Caribbean countries are not members.

The IDB is a development institution. More than that, it is a developing institution, learning, or at least changing its ideas with each generation of projects, hopefully in response to existing regional conditions. Since the early 1960s the IDB has been intimately involved in the region's economic and social changes, witnessing and variously participating in the 1980s period of hardship, hyperinflation, negative growth, and other problems that have been referred to in this conference. In recent years, the IDB has participated with the IMF and the World Bank in promoting reforms, including efforts toward greater fiscal discipline, toward somewhat more market-based economies, and, to some extent, toward the building of democratic institutions.

Many Latin American nations have recently demonstrated considerable economic rebounding. Still, high and often increasing levels of poverty, inequality, and income and welfare gaps persist in the region today. Across the board, the absolute number of people in poverty has about doubled in the past decade. High-growth Chile, where the measurable numbers have gone down, is the exception. This bad news has escaped no one's attention. The IDB has a general mandate to address poverty, inequity, and the region's resource gap. Currently it operates under a specific mandate to allocate 40 percent of the dollar value of its program to programs that enhance social equity, particularly targeted at poor communities. In total, the IDB lends between 7 and 8 billion dollars per year; 40 percent of that goes to social sectors, broadly defined to include health, education, housing, social investment funds, and environmental protection programs.

The many limits to the capacities of an organization like the IDB have significant implications for how research like that of Briggs and Farmer can affect what the bank finances. The IDB primarily works with governments, though now increasingly with nongovernmental organizations (NGOs). NGOs have been shown to be more responsive than governments to local-level concerns, and often more rapid to detect changes and rectify local-level problems. Over the years the IDB has altered its perception of what types of health interventions it should have a role in. Previously, the IDB was largely focused on hospital and health facility construction. Now the emphasis is increasingly on improving organization and financing, particularly of health services, often in partnership with in-country NGOs. Regarding epidemic and other disease control, IDB's primary role is to help create a context in which the health services can be more responsive. As earlier speakers pointed out, this is a very slow process. At present, institutions like the IDB give relatively little attention to programs for control of specific diseases.

That "where one sits" affects what decisions one makes, and what one perceives as the explanation for particular problems, is variously demonstrated in work done at the IDB. It is seen in how the IDB designs its projects. Those who focus specifically on the health sector are often isolated from those who deal with macroeconomic issues and with other types of local or

regional reforms. This is a bureaucratic problem, one associated with the isolation of different disciplines. In some ways, it mirrors the problems that occur within the governments with which the IDB works, for example between Ministries of Health and other ministries.

The question of cause also arises in terms of how health interventions or projects are evaluated. Interestingly, a team that is developing a certain health project will usually initially defend or promote that project's design, asserting that they are actually addressing the cause of a certain problem, the cause of ill-health in a given setting. But when it comes time to evaluate a not-so-successful project, the tendency is to say there were other causes beyond those that could be addressed. Dr. Levine reflected that the IDB needs to develop more consistency between the design and evaluation aspects of its work.

She then noted that one key message of Briggs's and Farmer's work, as well as of some other research now influencing the IDB, is the importance of consulting very widely in the design of a program. In the typical program design routine, the main sources of information about needs are the colleagues with whom IDB staff work, primarily at the central Ministries of Health. Clearly these individuals, at any given moment, have a particular perception of what are the central problems and their causes. It is easy for IDB staff to be immoderately influenced by that perception; it would be well worth while to make an additional effort to take into consideration other views and concerns, particularly at the community level. Among the various ways to do that, the most effective is to facilitate increasing involvement by nongovernmental organizations.

Dr. Levine closed by encouraging Drs. Briggs and Farmer to continue their endeavors to disseminate their research. In support of these efforts, she invited them each to visit the IDB and share their work with program health specialists. Endorsing the utility of an ongoing dialogue among all categories of individuals concerned with the conference themes, she emphasized her view that the closer such dialogue approaches actual project staff, the more effective it will be.

### **Dr. Naomar Monteiro de Almeida-Filho**

Dr. Naomar Monteiro de Almeida-Filho, physician and Dean of the Instituto de Saude Coletiva at Brazil's Universidade Federal da Bahia, noted that his institution's name would translate as the "Institute of Collective Health"; in Brazil, the name refers to an approach intended as an alternative to "public health," its motto being "equal health for all." Dr. Almeida-Filho observed that he was the only panelist at the table from Latin America, and noted that most of what is today called "public health" or "collective health" historically has been called "tropical medicine." Indeed, the field has been pursued, perhaps haunted, throughout its history by this exoticism.

Pertinent to the issue of health and diversity or inequality, Dr. Almeida-Filho offered a brief reflection on some Brazilian issues, sketching a profile that counters the easy illusion of homogeneity. He noted that HIV, cholera, and tuberculosis are serious problems; yet in Brazil, dengue fever and malaria must be recognized as being more pressing. More critical still are, for instance, traffic accidents. One year's traffic accidents have killed more people in Brazil than the AIDS epidemic has in fifteen years. Also significant are environmental health problems,



occupational health problems, and rapid modernization. An “epidemic” of cardiovascular disease is causing higher rates of morbidity and mortality than HIV, cholera, and tuberculosis. Stress-related disorders, including mental illnesses, are the major reason for use of health care services, and the second leading health budget expenditure.

Dr. Almeida-Filho commented that Dr. Farmer correctly points out the contradiction between public health messages, such as “AIDS is for everyone,” and the hidden reality, not acknowledged in the general discourse, that certain groups are at differential, heightened risk. This points up a disjunction; on one hand, an attempt to depict the risk as a common, widespread phenomenon, on the other, a reaffirmation of the inequality or inequity of risk. This disjunction can have serious consequences.

First, such a disjunction may prevent a health-centered approach, an approach not dominated by the concept of disease. Commenting on the conference’s theme, Dr. Almeida-Filho stated that an infectious-disease focus is just an excuse to deal with a larger issue; positively defined, the real issue is health. Infectious disease, in this case, stands as a proxy for the condition of poor health. As illustrative as are contributions such as the ones presented here, they are still disease-dominated approaches. In his opinion, the approach to be pursued would go beyond them to embrace the issue of health. A second consequence of this disjunction concerns the issues of stigmatization and social exclusion. Even more interesting, Dr. Almeida-Filho stated, is the issue of the invisibility of a problem—how semantic maneuvers may be used to present something else—emerging, or reemerging, or new, or old. The phenomenon is thus constructed in terms of a discourse; this is most important to consider in any analysis that would tend to integrate (disease and health-dominated) approaches.

Dr. Almeida-Filho also noted that in both presenters’ work we encounter attempts to overcome two oppositions, or contradictions. One is between North and South, and the other between epidemiology and social sciences. Predicting that practitioners will find it impossible to deal with these in isolation, he advocated efforts to overcome both at once.

Describing the first opposition, Dr. Almeida-Filho noted that an imaginary equator divides the world into North and South. Some of us cross that “line” several times a year. Although invisible, it still divides people in some way. The spirit of both presenters’ papers appears to challenge the force of that line. Dr. Briggs’s paper, especially, overtly addresses the imperative to overcome the second opposition. Epidemiology, noted Dr. Almeida-Filho, is self-defined as measurement, quantification; in other words, as structured meaning codified in standardized, uniformly accepted terms. Epidemiology means a fixed semantics of research. Addressing an anthropologist or sociologist, an epidemiologist usually poses the question, “Can you give us some measurable sociocultural variables? Because if they are not measurable, they are not useful.”

On the other hand, we may view sociocultural approaches to disease as being based on a contextual semantics of research, of meanings structured by the research process. The richness, elaboration, and sophistication of such approaches have tended to give the social sciences a “compensatory superiority complex.” Social scientists ask epidemiologists, “Why are your epidemiological theories so naive, so simplistic? Don’t you understand that reality is not in the

laboratory or the data set, that diarrhea is real, out in the world, and it is killing people?” Interestingly, noted Dr. Almeida-Filho, this is the same type of argument that many basic scientists have used to displace epidemiological research.

According to Dr. Almeida-Filho, the two paper presenters correctly observed that these oppositions present complex problems requiring similarly complex approaches; no magic bullets, no privileged discourses will resolve them. He does discern in the papers prescriptions for two “shock therapies” to address these problems. One is a “shock of humbleness,” the other, a “shock of openness.”

An oft-used expression of Dr. Farmer is “immodest claims of causality.” Dr. Almeida-Filho noted that he would underline the adjective “immodest.” Claims of causality represent the type of rational instrument epidemiology and biomedical sciences use when intervening with reality. Given his training in psychiatry, Dr. Almeida-Filho is inclined to perceive immodesty, pride, or arrogance as signs of insecurity. The symptom of epistemological or disciplinary insecurity is definitely immodesty. Thus, he might rephrase the conference’s subtitle, “From Hemispheric Insecurity to Global Cooperation,” in order to better reflect the papers’ focus on disciplinary divides and insecurities, to “From Epistemological Insecurity to Transdisciplinary Cooperation.” More disciplinary humility may be a key to transdisciplinary cooperation.

In keeping with what other commentators have noted, the second shock of openness is the inevitable discovery of the fallacy that globalization means exclusively economic exchange. It is not possible to open borders only for economic purposes; along with exchange of goods, globalization means the exchange of people, ideas, culture, science, and technology. Today we can even say that, along with money, “meaning” itself is revolving faster and faster around the world. This is not only the opening of barriers or boundaries; it is also flexibility, overcoming of rigidity, and readiness for change, for new things, for the unexpected. The incidence of this is so strong in the contemporary imagination that perhaps the single most frequently used term in this discourse is “emerging,” with a precise meaning of new and unexpected.

Dr. Briggs’s key remark about a “unidimensional flow of epistemology” addresses the assumption of a single North to South flow of ways to perceive reality, wherein Western science offers the only privileged approach to social and natural reality. But, observed Dr. Almeida-Filho, there is no outflow without inflow, as metaphors from the hydrological cycle reflect so well; the water stream depends upon rainfall, which is water recycled. Water flows and returns. Similarly, the supposedly “unidimensional flow of epistemologies” actually has a counterpart in well-embedded responses, that is, in viruses, in the cybernetic, epistemological, and, not least, microbiological senses of that term.

It is important to note, continued Dr. Almeida-Filho, that Dr. Briggs’s use of “unidimensional” is not naive. Implicit in the discourse about equality and inequality is the reference to one single dimension, one single approach to reality. Equality is also a mathematical relation of equal values on the same dimensional scale. In light of this, another valuable approach would be to consider no hierarchy to be implicit. That is why the term is so handily adopted by both epidemiological and econometric approaches, and by epidemiological-econometric approaches, wherein the idea of risk is turned into a kind of economic input.

Finally, in a third possible approach, we could talk about diversity, or heterogeneity, in terms of equity and inequity, guided by qualities, by values, by differences that ought not to tend to be sources of exclusion or stigmatization, or valued such that being different would necessarily mean being less than something else.

Dr. Briggs's and Dr. Farmer's papers, noted Dr. Almeida-Filho, call for a kind of methodological and theoretical integration to tackle the issues of dimensionality and qualitative differences. The prescription they both indicate is an integration between qualitative and quantitative methods. At the level of explanatory models, at the level of research instruments, strategies, and techniques, but especially at the level of interpretive approaches, it would be possible to profit from a real integration between the two transdisciplinary fields.

Dr. Almeida-Filho concluded with a few general recommendations. First, he advocated support of South-to-South networking, both directly and articulated or integrated with North-to-South relationships. Academics, government professionals, and those in similar positions should strongly support such networking, focused on technical or scientific exchange. Carefully pursued, networking south of the equator would provide excellent, cost-effective, and easily integrated resources for furthering any effort to overcome the problems under discussion.

He also recommended a strong impetus toward transdisciplinary cooperation, which would help overcome the hierarchies we tend to construct between thinkers and doers, theory and practice, science and knowledge, biological and social. In all such hierarchies, one element tends to attain status as "the best." The danger is that if someone, some group, or some approach is held up as the best, others are perceived as less, even perhaps, as "the worst." Dr. Almeida-Filho also recommended efforts to overcome or blur some of the divisions among the sciences of health disease care, thus making any effort both cheaper and intellectually richer.

Finally, if the aim is to reduce inequity in health, we should sincerely pursue this aim in actuality, not merely in articles or position papers. An effort toward reducing inequity, using all available resources, would have impressively concrete consequences, in terms of raising ethical standards. Thus, we could have the perfect health care policy; cheap, intellectually rich, and ethical. We would have a chance to reaffirm the belief that the theory of a common human kind is the motivating force for both science and policy.

## **Discussion**

Dr. Briggs invited the audience to join with the presenters and panelists in considering different perspectives on ways to reduce health inequities.

One audience member inquired about cost-effectiveness and the extent to which a unilateral approach to health care priorities actually increases or decreases health equity. Dr. Das replied that part of her own research attempts to deconstruct what "cost-effectiveness" actually signifies to the health-care community. Pharmaceutical companies often put pressure on international authorities to assure them of world markets, a largely hidden "lateral model" of decision-making. She reemphasized that global programming priorities tend to ignore problematic local conditions; for instance, developing a vaccine for Hepatitis B, but not for

Hepatitis C, did not necessarily reflect local needs in some districts in India. Therefore, she called for a new model of planning and prioritizing, combining the global and the local. Regarding cost-effectiveness, Dr. Levine offered her personal observations that research allocation decisions are now too often based on arbitrary criteria, such as a Health Ministry official's private opinions or the previous year's spending patterns. In her view, some use of a cost-effectiveness criterion at least somewhat regularizes such decisions, while hopefully not becoming too mechanistic. Dr. Farmer suggested the banking system might consider social justice as a possible alternative or complementary approach to cost-effectiveness, mitigating the crudeness of some present-day cost-effectiveness analyses and their consequent adverse net effects upon the poor. Dr. Brandling-Bennett suggested that if the health community could compile and utilize data showing enormous resource-allocation inequities, it could likely embarrass politicians into more effectively and equitably dealing with the issue.

Dr. Briggs also replied to the same audience member's question regarding whether community-level measurement of health-threatening conditions might better demonstrate underlying threats than could collecting and analyzing data on individuals. Dr. Briggs responded that, in the interest of producing robust data sets with strong theoretical and methodological underpinnings, he would advocate collecting wider and more detailed information at all levels. Collecting at only the community level would increase the already evident tendency of researchers to desocialize and decontextualize the relation of an individual's health to that of the community. Many social scientists, he explained, now try to embed observable individual and ethnological or ethnographic data into data on larger populations. Blending quantitative and qualitative methods, these researchers are trying to comprehend how representative are those individual data. Still developing as an exciting research area is the study of the role of extrapersonal event processes in individual lives—assessing how large-scale economic and political forces, such as racism or a coup d'état, are embodied as individual experiences.

Another audience member, himself a PAHO epidemiologist, suggested that the epidemiological perspective was dominating the afternoon's proceedings. He proposed that to make progress in addressing health care inequities, it might be necessary to forget for a while about those who are sick but not socially vulnerable, noting that this would require consciously setting aside basic epidemiological training. In place of focusing on particular diseases, he suggested looking at the health inequities affecting the poorest 20 percent of the population.

In reply, Dr. Briggs suggested that further discussion, perhaps in a PAHO conference, might be useful in expanding the range of perspectives heard on these issues. Noting that he is an admirer of epidemiological research, Dr. Briggs suggested that epidemiologists might be underestimating their own power in terms of the potential links between poverty and health interventions. He also called for researchers to find not a common, but a complementary language in which to share data among disciplines, a language for critical engagement for pointing out the false research assumptions embedded in each others' disciplines. Specifically, he asked Dr. Brandling-Bennett how he, Dr. Briggs, might find the right language for engaging epidemiologists with respect to these issues.

Dr. Brandling-Bennett reiterated his concern that epidemiologists may inadvertently be allowing misuse of words they use to describe risk factors or to discuss poverty-disease

associations. He felt the key might be not in changing epidemiologists' language, but in engaging them in dialogue to modify their awareness of what is happening after they produce this language, to influence them to insist that the authorities not misuse their findings.

Reflecting on this exchange, Dr. Almeida-Filho was skeptical of the possibility of dialogue and intercommunication among scientific professionals, as such individuals are agents of some particular scientific practice, and their reflections are contained within their particular interpretive paradigms. He does believe in the possibility of transdisciplinarity in terms of complementary training, as exposure to a second professional culture. He also posited that inequity is the core definition for epidemiology, since all epidemiological indicators are perforce indicators of inequality; the day inequality disappears, the epidemiological discipline will also disappear. Language is not the key; the dialogue should focus rather on what are the basic objects in each disciplinary field.

Venezuelan physician Dr. Clara Mantini-Briggs noted that people in powerful circumstances must redefine how they speak. Specifically, she registered her objection to the racism and discrimination evident when those in power speak about emergent epidemic diseases in Latin America. Another audience member added that the media often underscores discriminatory stereotypes. In terms of the "sociology of knowledge," Dr. Charles Briggs noted that epidemiologists sometimes deliberately employ scare tactics, using certain terms in order to move new resources into the funding stream. As an example, he cited "Ebola with wings," the considerable new resources that have been generated by irrational fear of the Ebola virus.

Responding to a question concerning HIV and the notion that North American and Latin American standards of efficacy might be different, Dr. Farmer noted the major risk factors for HIV today are poverty and inequality. Often, anthropologists and epidemiologists, looking at situations of constraint, conflate structural violence with cultural difference. Thereby, they misdiagnose inequality and poverty as some kind of cultural difference, mainly because they have approached a group seeking cultural difference. Starting from this mistaken basis, then, they ignore other factors, such as class, and thus have difficulty in engaging in fruitful discussions about disease in the Third World.

An audience member suggested that Dr. Briggs consider providing greater historical context to his observations on Venezuela. In particular, he suggested looking at the significance of Venezuela's late and rapid twentieth-century economic development for the outcomes Dr. Briggs encountered. Dr. Briggs concurred with the utility of the suggestion, mentioning specifically the parallels of the 1854-57 cholera epidemic and, for the twentieth-century, collaboration between Venezuelan institutions and the Rockefeller Foundation.

Another health practitioner in the audience suggested that a central problem may be that those in the health sector are not certain of their principal motivation—to prevent disease, to cure people, or to look at health education. He noted that some focus on inequality and insecurity is often considered key to global cooperation, since inequality is often held to lead to social unrest. Dr. Brandling-Bennett noted that we do run the risk of unintentionally stigmatizing nations when we tell Congress about their problems. Dr. Das concurred that presenting countries in the worst possible light on Capitol Hill sometimes has world consequences, regardless of intentions. Dr.

Almeida-Filho noted the significance of exploring who produces scientific and academic discourse, particularly regarding who is accorded the right to describe themselves as representing another culture or group. Apropos of this, he noted that the day's discussion topics have been well-developed in Latin American scholarly literature in the past fifteen or twenty years, but that few of these papers have reached the English-speaking community. To avoid treading the same paths again, it would be fruitful for practitioners in the North to find out what those in the South have already thought and written about these issues. To effect this, he added, strong, open discourse is needed that recognizes that people in the South are practitioners as well as subjects of this scientific research.

In closing, Dr. Farmer noted that PAHO, the World Health Organization, and other such institutions are in fact supplicants for funds, agencies constrained by their own structures. He asked those present if they could put into practice a commitment to those most likely to suffer—namely those in poverty—and return to front and center the original idea of public health as advocacy for the poor.

Dr. Briggs closed the proceedings by reemphasizing his call for more critical dialogue regarding and encompassing those experiencing the stigmatizations of poverty, racism, and sexism, and by welcoming the opportunities this conference had opened up for further critical discussions and dialogue at the IDB, PAHO, and at Dr. Almeida-Filho's institution in Bahia.

## About the Contributors

**Charles L. Briggs** received his Ph.D. in Anthropology from the University of Chicago in 1981. Having previously taught at Harvard University, New York University, the University of Pennsylvania, and Vassar College, he is now Professor of Ethnic Studies at the University of California, San Diego. He has been awarded fellowships by the Andrew W. Mellon Foundation, the National Endowment for the Humanities, the John Simon Guggenheim Memorial Foundation, and the Woodrow Wilson International Center for Scholars. His books include *The Wood Carvers of Córdoba, New Mexico: Social Dimensions of an Artistic "Revival,"* *Learning How to Ask: A Sociolinguistic Appraisal of the Role of the Interview in Social Science Research,* *Competence in Performance: The Creativity of Tradition in Mexicano Verbal Art,* *The Lost Gold Mine of Juan Mondragón: A Legend of New Mexico Performed by Melaquíás Romero* (with Julián Josué Vigil), and a number of edited volumes. He is currently finishing books on the politics of language in the making of modernity (with Richard Bauman), cholera, race, and social inequality in Venezuela, and infanticide and social injustice in the shadow of globalization. His articles have appeared in the *American Anthropologist*, *American Ethnologist*, *American Journal of Folklore*, *Cultural Anthropology*, *Language in Society*, *Pragmatics* (of which he is Co-Editor), *Semiotica*, *Social Identities*, and other journals. His wife and collaborator, Clara Mantini-Briggs, is a Venezuelan public health physician.

**Paul Farmer**, an infectious disease physician and anthropologist, has worked in health care the Americas for over a decade. Author of *AIDS and Accusation* (University of California Press, 1992), *The Uses of Haiti* (Common Courage Press, 1994), and *Infections and Inequalities* (University of California Press, 1998), he is also co-editor of *Women, Poverty, and AIDS* (Common Courage Press, 1996) and *Consumption of the Poor: Tuberculosis in the Late 20th century* (Common Courage Press, in preparation). Farmer has written extensively in these works and others on the structural roots of illness and disease in poor communities; he has also worked globally to promote effective medical care in settings of poverty. Farmer is co-director of the Program in Infectious Disease and Social Change at Harvard Medical School, and a member of the WHO Working Group on "DOTS Plus" for Multidrug-Resistant Tuberculosis (MDRTB). His clinical responsibilities include work as an attending physician in infectious disease at Boston's Brigham and Women's Hospital and as medical co-director of the Clinique Bon Sauveur in rural Haiti. In urban Peru, he is medical director of a community program treating patients with MDRTB. In 1993, Paul Farmer was awarded a John D. and Catherine T. MacArthur Foundation "genius award" in recognition of his work. Farmer donated the entire award to Partners In Health, a public charity he co-founded in 1987.

**Catherine A. Christen** received her Ph.D. in History from The Johns Hopkins University; her specialty is Latin American environmental history. Presently she is a Senior Program Officer for Analysis and Adaptive Management with the Biodiversity Support Program in Washington, D.C. She is also a Research Associate with the Smithsonian Institution Archives, studying the history of the Smithsonian Tropical Research Institute. Her publications include "Tropical Field Ecology and Conservation Initiatives on the Osa Peninsula, Costa Rica," in *Twentieth Century*

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