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Evan Lyon

Paul Farmer

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Inequality, Infections, and Community-Based Health Care

Evan Lyon, M.D.* and Paul Farmer, M.D., Ph.D.†

Advocates for better health care for the world's poor are fond of the mantra that "infections know no boundaries." Part of this logic evokes the reality of our global community, connected by the easy and frequent movement of people across national borders. But this mantra is also meant as a warning, reminding those of us in wealthier nations that we just might not be safe from exposure to the poor, huddled, coughing masses. HIV, tuberculosis, and other infectious diseases on the African continent have been declared a U.S. national security priority.¹ When the global extent of the multi-drug resistant tuberculosis epidemic was being uncovered—in part by the community-based efforts of our small non-profit health care organization working in the slums of Lima, Peru²—news of exposure to drug-resistant tuberculosis on international flights made headlines.³ The emergence of SARS and the worldwide fear it evoked mobilized

* Resident in Internal Medicine, Brigham and Women's Hospital. Dr. Lyon is a recent graduate of Harvard Medical School and divides his clinical time equally between Boston and central Haiti.

† Presley Professor of Medical Anthropology, Harvard Medical School. Dr. Farmer, a physician and anthropologist, is the founding director of Partners In Health.

1. NAT'L INTELLIGENCE COUNCIL, NIE 99-17D, THE GLOBAL INFECTIOUS DISEASE THREAT AND ITS IMPLICATIONS FOR THE UNITED STATES (2000), <http://www.cia.gov/cia/reports/nie/report/nie99-17d.html>; Barton Gellman, *AIDS Is Declared Threat to Security*, WASH. POST, Apr. 30, 2000, at A1.

2. Carole Mitnick et al., *Community-Based Therapy for Multidrug-Resistant Tuberculosis in Lima, Peru*, 348 NEW ENG. J. MED. 119, 120 (2003).

3. Thomas A. Kenyon et al., *Transmission of Multidrug-Resistant Mycobacterium Tuberculosis During a Long Airplane Flight*, 334 NEW ENG. J. MED. 933, 933 (1996) ("The transmission of *Mycobacterium tuberculosis* that we describe aboard a commercial aircraft involved a highly infectious passenger, a long flight [Honolulu-Chicago-Baltimore-Chicago-Honolulu], and close proximity of contacts to the index patient."); see also M.A. Miller et al., *Tuberculosis Risk After Exposure on Airplanes*, 77 TUBERCULE & LUNG DISEASE 414, 415 (1996) ("The index case [a Russian refugee] in this study flew from Moscow, Russia to Frankfurt, Germany in March 1993. There he boarded a flight originating in Bombay, India destined for New York City. In New York, he changed aircraft and flew to Cleveland, Ohio.").

unprecedented resources in a very short period of time.⁴

While it may seem that our increasingly connected world is getting smaller, the boundary of inequality that separates the world's rich and poor remains very much intact. In fact, the gap between the haves and the have-nots is widening.⁵ And if we admit that there are material differences between the living conditions of the vast majority of the world's poor in the global South and those living in the developed world, then inequalities—not just economic, but also gender, racial, ethnic, and religious—emerge as important determinants of health.

The relationship between poverty, other forms of inequality, and poor health remains whether making comparisons between countries or within a nation. For example, our poorest patients in Boston, Massachusetts do not suffer from malaria or typhoid (as our patients in rural Haiti do), but they are at increased risk for diabetes, cardiovascular disease, obesity, and disability from mental illness or addiction. Certainly, infectious diseases are not equitably distributed. Sub-Saharan Africa holds ten percent of the world's population, but is home to two-thirds of people living with HIV.⁶ In the United States, more than half of new HIV infections are in the black community, which represents only thirteen percent of the population.

4. Writing about SARS, Jerome Singh claims that there are fast and well-funded responses to epidemics threatening affluent countries. Jerome Singh, *SARS, A Challenge from the South*, 423 NATURE 585, 585 (2003); see also Paul Farmer, *SARS and Inequality*, 276 THE NATION 6, 24 (2003).

5. The World Bank estimates that over one billion people live on less than one U.S. dollar per day; 2.7 billion—representing over fifty percent of the world's population at the last calculation in 2001—live on less than two U.S. dollars per day. For more information, see The World Bank Group, *Global Poverty Monitoring*, <http://www.worldbank.org/research/povmonitor/> (last visited Nov. 5, 2004). A World Bank summary paper found that “there was a net decrease in overall incidence of consumption poverty over 1987-98. But it was not enough to reduce the total number of poor by various definitions.” SHAOHUA CHEN & MARTIN RAVALLION, DEV. RESEARCH GROUP, WORLD BANK, *HOW DID THE WORLD'S POOREST FARE IN THE 1990s?* 1 (2000), <http://www.worldbank.org/research/povmonitor/pdfs/methodology.pdf>. The authors “point to two main proximate causes of the disappointing rate of poverty reduction: too little economic growth in the poorest countries and persistent inequalities that inhibited the poor from participating in the growth that did occur.” *Id.* For in-depth analysis of the relationship between poverty, international financial structures, inequality, and health, see JIM Y. KIM ET AL., *DYING FOR GROWTH: GLOBAL INEQUALITY AND THE HEALTH OF THE POOR* (2000); and MEREDITH FORT ET AL., *SICKNESS AND WEALTH: THE CORPORATE ASSAULT ON GLOBAL HEALTH* (2004).

6. Joint United Nations Programme on HIV/AIDS [UNAIDS], *Sub-Saharan Africa*, at <http://www.unaids.org/EN/Geographical+Area/By+Region/sub-saharan+africa.asp> (last visited Nov. 5, 2004).

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Gender inequality is also embodied in differential rates of disease: Among young people ages fifteen to forty-nine in sub-Saharan Africa, women are 1.2 times more likely than men to be infected with HIV.⁷ Moreover, the prevalence of HIV in adults in seven southern African countries is now over twenty percent.⁸ African-American and Hispanic women represent less than one-fourth of all women in the United States, but they account for seventy-eight percent of AIDS cases among women.⁹ While tuberculosis has become less prevalent in the United States, it still disproportionately affects the marginalized. One recent study showed that non-Hispanic blacks suffer from tuberculosis at rates eight times greater than non-Hispanic whites.¹⁰

Indeed, the relationship between poverty and disease is perhaps clearest when we consider an airborne infectious disease such as tuberculosis. Conditions of urban poverty—overcrowding, poor housing, and poor nutrition—continue to encourage the spread of tuberculosis worldwide. While treatment of tuberculosis is highly effective, it was the improvement of living conditions—not treatment—that first changed the trajectory of tuberculosis in the developed world. The state-of-the-art system of sanatoria that existed in the United States and early, expensive antibiotics like streptomycin were primarily available to the wealthy.¹¹ In the 1940s, prior to the advent of effective tuberculosis antibiotics, the rate of active tuberculosis in the United States plummeted—due mainly to the post-World War II economic boom and the migration of people from tenements in cities to single-family homes in the suburbs.¹² Tuberculosis then made a striking reappearance in the urban United States in the 1990s, fueled by HIV and structurally associated with overcrowding in prisons, increased rates of homelessness, and the deterioration of public

7. *Id.*

8. *Id.*

9. Ctrs. for Disease Control & Prevention, HIV/AIDS Among U.S. Women: Minority and Young Women at Continuing Risk (May 2002), <http://www.cdc.gov/hiv/pubs/facts/women.pdf>.

10. For information on tuberculosis and race in the United States, see *Racial Disparities in Tuberculosis—Selected Southeastern States, 1991-2002*, 53 MORBIDITY & MORTALITY WEEKLY REP. 556, 556 (2004).

11. For a comprehensive history of tuberculosis in the United States, see FRANK HERBERT, *THE WHITE PLAGUE* (1983). For other works of historical interest, see THOMAS M. DANIEL, *CAPTAIN OF DEATH: THE STORY OF TUBERCULOSIS* (1997); and RANDALL M. PACKARD, *WHITE PLAGUE, BLACK LABOR: TUBERCULOSIS AND THE POLITICAL ECONOMY OF HEALTH AND DISEASE IN SOUTH AFRICA* (1989).

12. See HERBERT, *supra* note 11.

health infrastructure.¹³ This outbreak shows us that public health safeguards—disease surveillance, active case finding, and universally accessible and organized medical treatment—cannot be safely removed without addressing the inequalities that continue to put many at risk.

As physicians who frequently travel between an academic tertiary care hospital in Boston and clinics in the deeply impoverished Central Plateau of rural Haiti, among other places, we can attest that these boundaries of inequality persist. Inequality puts the poor at greater risk for sickness and disease while also leaving poor communities with fewer resources to respond to new and ongoing health challenges. Long after tuberculosis in the United States had been relegated to prisons, homeless shelters, and immigrant populations infected in their home countries, it remains the leading infectious killer of adults in Haiti, less than two hours by plane from Miami. Risk of becoming sick with active tuberculosis is sixty times greater in Haiti than in the United States or Canada.¹⁴ While AIDS has recently overtaken tuberculosis as the leading infectious killer of adults worldwide, the less-visible tuberculosis epidemic is still raging in poor communities around the world, now compounded by the deadly synergy of co-infection with HIV.

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Consider the story of one of our patients in Haiti. Joseph Pierre¹⁵ comes from the mountains above Maïssade, four hours on foot from our clinic in the regional capital of Hinche. When we first met Joseph, he had been sick for more than a year with a cough and night-time fever. He had wasted away to just seventy-five pounds, which hung loosely on his 5'8" frame. Our first suspicion was that he suffered from tuberculosis and the advanced stages of HIV disease, but a rapid blood test revealed that he was

13. Karen Brudney & Jay Dobkin, *Resurgent Tuberculosis in New York City: Human Immunodeficiency Virus, Homelessness and the Decline of Tuberculosis Control Programs*, 144 AM. REV. RESPIRATORY DISEASE 745, 747-49 (1991).

14. Tuberculosis incidence in Haiti in 2004 is 296 per 100,000. This is compared to an incidence in the United States of 4.2 and in Canada of 5.8. Haiti's neighbors also harbor less tuberculosis. The Dominican Republic, which shares the island of Hispaniola with Haiti, has a tuberculosis incidence of 87.8 per 100,000, while Cuba, Haiti's neighbor to the west, has an incidence of 9.8—nearer to the rates seen in the developed world. For additional statistics and more information about the global tuberculosis epidemic, see WORLD HEALTH ORG., *GLOBAL TUBERCULOSIS CONTROL—SURVEILLANCE, PLANNING, FINANCING* (2004), at http://www.who.int/tb/publications/global_report/2004/en/.

15. A fictitious name is used here to protect patient confidentiality.

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HIV-negative. A chest x-ray confirmed the presence of tuberculosis, and we started Joseph on anti-tuberculosis antibiotics the same day. He stopped coughing within a week and gained almost ten pounds in his first month of treatment. By the time this Essay is published, he will almost certainly be cured and back to work as a subsistence farmer.

Haiti is, notoriously, the poorest nation in the Western hemisphere. And its population, not surprisingly, suffers some of the worst public health problems in the world.¹⁶ Why, then, is the story of one young man with treatable tuberculosis important? Joseph Pierre's story reminds us that even in settings of universal poverty, gradients of inequality exert their effect on health. Joseph Pierre is poor even by Haiti's standards: He has no family; he lives in a small village far from medical care; he had to rely on the kindness of his neighbors—many of whom are themselves hungry—when he could not tend his own crops. After he became ill, stigma and fear forced him to live in a small shelter on the edge of his community, and he became further isolated.

Joseph came to care through the intervention of a community health worker trained by Zanmi Lasante (ZL), the non-governmental branch of a public-private partnership that is expanding access to HIV, tuberculosis, and basic health care services across Haiti's Central Plateau. Joseph's community health worker was trained to recognize the signs and symptoms of tuberculosis, and he was able to refer this patient to our clinic. Joseph will continue tuberculosis treatment for six months with the help of an *accompagnateur*, a neighbor who will deliver directly observed therapy

16. Life expectancy at birth in Haiti is the lowest in the Western hemisphere at fifty years and falling. WORLD HEALTH ORG., THE WORLD HEALTH REPORT 2004, at 114 (2004), http://www.who.int/whr/2004/en/report04_en.pdf. Less than half the population has access to an improved water source. U.N. DEV. PROGRAMME, UNDP HUMAN DEVELOPMENT REPORT 2004 149 (2004), <http://hdr.undp.org/reports/global/2004>. One-quarter of childbirths are attended by a health professional. *Id.* at 159. Half the population is undernourished. *Id.* at 163. Many areas—including parts of the Central Department, where we work—are suffering from famine-like conditions. Maternal mortality is high, at 680 per 100,000 live births. *Id.* at 171. Per capita GDP has “grown” at a rate of -3.0 percent between 1990 and 2002. *Id.* at 187. HIV prevalence is estimated to be as high as 6.1 percent, the highest in the Western Hemisphere. In Haiti, AIDS kills an estimated 24,000 people annually, has orphaned 200,000 children cumulatively through 2002, and has also aggravated an already severe tuberculosis epidemic. *See, e.g.*, UNAIDS, EPIDEMIOLOGICAL FACT SHEETS ON HIV/AIDS AND SEXUALLY TRANSMITTED INFECTIONS: HAITI 2 (2004), <http://www.unaids.org/en/geographical+area/by+country/haiti.asp>; UNAIDS, EPIDEMIOLOGICAL FACT SHEETS ON HIV/AIDS AND SEXUALLY TRANSMITTED INFECTIONS: HAITI 2 (2002), http://www.who.int/emc-hiv/fact_sheets/pdfs/haiti_en.pdf.

(DOT) and accompany Joseph through his illness. In 1988, when ZL began systematic treatment of tuberculosis in central Haiti, cure rates were unacceptably low. In response, ZL developed a community-based DOT system, and deaths from tuberculosis nearly disappeared.¹⁷ This experience, and the human infrastructure constructed in response to the tuberculosis epidemic in rural Haiti, has become the backbone of our expansion of HIV treatment and prevention services.¹⁸

Many in public health circles point to a lack of infrastructure as one reason to limit investment in and expansion of treatment, in favor of disease prevention efforts. We have written in other settings that construction of a system of community health workers and *accompagnateurs* may be the answer to this missing infrastructure.¹⁹ Our experience with tuberculosis treatment in rural Haiti shows that this method is clinically successful, and preliminary results from our AIDS treatment efforts—DOT with antiretroviral medicines—suggest the same. Furthermore, in rural Haiti—as in most communities with high burdens of disease, poverty, and unemployment—a rich surplus of human resources remain untapped.²⁰ In Haiti, we have many more applicants to become community health workers than we have jobs available. In our experience, only basic literacy is needed to provide effective DOT, and literacy training is part of our comprehensive approach to community-based health care.²¹ Full

17. An early study by ZL suggested treatment relying only on monthly clinic visits—even when consultation and treatment were provided free of charge—led to an unacceptable level of treatment failures. When a comprehensive approach to tuberculosis control was initiated, including DOT, modest financial and nutritional support, and active case-finding through contact screening, tuberculosis rates and deaths from tuberculosis fell. Patients now at greatest risk for developing tuberculosis are those that live outside our catchment area, which is covered by community health workers and *accompagnateurs*. Paul Farmer et al., *Tuberculosis, Poverty and “Compliance”: Lessons from Rural Haiti*, 6 SEMINARS IN RESPIRATORY INFECTIONS 254, 255-56 (1991).

18. Paul Farmer et al., *Community-Based Approaches to HIV Treatment in Resource-Poor Settings*, 358 THE LANCET 404, 404 (2001); see also Joia S. Mukherjee et al., *Tackling HIV in Resource Poor Countries*, 237 BRIT. MED. J. 1104 (2003).

19. Heidi L. Behforouz et al., *From Directly Observed Therapy to Accompagnateurs: Enhancing AIDS Treatment Outcomes in Haiti and in Boston*, 38 CLINICAL INFECTIOUS DISEASES S429, S430-31 (2004).

20. Precise employment statistics are not available for rural Haiti, but wage-earning employment is rare. The majority of the population practices subsistence farming. While the stipends we provide to community health workers and *accompagnateurs* do not replace the need for continued subsistence agriculture, they are one of the few available sources of income. With a modest budget, we have become the largest employer in the region.

21. ZL operates both primary and secondary schools that serve over a thousand students

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community participation also assures that priorities are set by the local population rather than from the boardrooms of Geneva or Washington, D.C.

ZL's community-based structure was recently tested by the coup d'état which removed Haiti's popularly elected president, Jean-Bertrand Aristide, on February 29, 2004.²² During the months leading up to the coup, much of the nation's already-fragile public health system was further disrupted. The medical staff at the University of Haiti's General Hospital in Port-au-Prince—the only national referral hospital—was on strike, protesting the lack of security. Their doors were closed for weeks during the coup and its aftermath. Many private and public clinics also closed during the months of February, March, and April 2004. But despite working in the Central Plateau—an area of concentrated rebel activity near Haiti's border with the Dominican Republic—and despite ZL's collaboration with the Aristide administration (which was unprecedentedly supportive of nationwide efforts to expand HIV treatment and prevention), all six of ZL's clinics remained open during the unrest. From our staff of over one thousand employees, only six—the entire non-Haitian staff, including the authors—were displaced temporarily by the coup. ZL provides directly observed therapy to over 1100 AIDS patients and 1500 patients with active tuberculosis. Almost none of these patients missed a single dose of their medications, which is important not only for the health of individual patients but also in the prevention of drug resistance.²³ This unwelcome test of ZL's community-based health care system in central Haiti shows that a decentralized, community-based infrastructure can survive even the most disruptive social and political upheaval.

During the most dangerous moments of the coup, we saw a decrease in the number of ambulatory visits at our clinics as villagers stayed home out of fear, all too familiar from the intimidation and violence inflicted by the military and various militias throughout Haiti's dangerous history. The average number of patient visits at four of our expansion clinics dropped

and twenty-five adult literacy centers in partnership with the Haitian government's nationwide literacy efforts.

22. For more on the February 2004 coup and subsequent politics, see NOAM CHOMSKY ET AL., *GETTING HAITI RIGHT THIS TIME* (2004); Paul Farmer, *Who Removed Aristide?*, 26 LONDON REV. BOOKS 28, 28 (2004); Paul Farmer, *Political Violence and Public Health in Haiti*, 350 NEW ENG. J. MED. 1483 (2004); and Peter Hallward, *Option Zero in Haiti*, 27 NEW LEFT REV. 23 (2004).

23. See Sally Blower et al., *Predicting the Impact of Antiretrovirals in Resource-Poor Settings: Preventing HIV Infections Whilst Controlling Drug Resistance*, 3 CURRENT DRUG TARGETS—INFECTIOUS DISORDERS 345, 351 (2003).

from 189 per day in January 2004 to 113 per day in March 2004.²⁴ The number of patients seen by ZL has since exceeded pre-coup levels. The real repercussions of this widespread fear and decreased use of the public health system will never be known, but they almost certainly account for the most damaging health consequences of the coup. Nevertheless, the fact that a grassroots health care movement functioned under such extreme circumstances gives weight to our belief that community participation is essential in the struggle to provide equitable health care to the world's poor. This unique stability adds to the benefits already mentioned—namely, local priority setting, strengthening of underutilized community resources, expansion of literacy and educational opportunities, and broad-based active case-finding of the kind that brought Joseph Pierre to our attention and care.

CONCLUSION

Inequality will persist as long as there is poverty. And inequality will continue to drive the vulnerable toward increased sickness and early death—whether in the prisons and inner-cities of the developed countries or among the billions living in poverty worldwide. Public health decisions that ignore this reality are doomed to fail. In our opinion, building a community-based, stable public health structure is a first step toward better health, alleviating poverty, and closing the gap of inequality that keeps poor communities uniquely vulnerable to suffering and disease. One recent meta-analysis showed that direct costs related to a death from HIV disease, in various settings, often amount to more than fifty percent of a household's annual income—and are sometimes greater than one hundred percent—even before accounting for the extensive indirect costs of lost labor, decreased agricultural production, and general social and economic instability.²⁵ For most of our patients in central Haiti, a return to health means they are better able to provide for themselves and their families and to participate in social and political change in their troubled nation. This is a small step in a setting of grinding poverty, but it is a step in the right direction.

24. Averages were calculated from daily reports from ZL clinics in Boucan Carré, Thomonde, Lascahobas, and Belladère (on file with authors).

25. Steven Russell, *The Economic Burden of Illness for Households in Developing Countries: A Review of Studies Focusing on Malaria, Tuberculosis, and Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome*, 71 AM. J. TROPICAL MED. & HYGIENE 147, 148 (2004). For more on the economic and social burden of HIV, see *Myth Eight: Limited Resources*, in GLOBAL AIDS: MYTHS AND FACTS 135-51 (Alexander Irwin et al. eds., 2003).

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A “basic minimum package” to support a complex intervention—in our case, the provision of antiretrovirals under DOT—was identified with input from ZL’s *accompagneurs* and the larger community. This basic package is organized around four pillars: HIV prevention and care; tuberculosis diagnosis, treatment, and active contact screening; STD case-finding and treatment; and comprehensive women’s health services. Relating our experience in the town of Lascahobas, one of ZL’s five expansion sites in Haiti’s Central Department, we showed numerous health improvements, some even beyond the four pillars framework. These included a rise in tuberculosis diagnosis and treatment from nine to over two hundred patients within fourteen months; a ten-fold rise in the number of patient visits per day; increased access to prenatal care, including HIV testing to help prevent mother-to-child transmission; increased access to vaccines; improved staff morale; and greater community participation in health education activities.²⁶ Our experience has shown that the expansion of complex health interventions, such as providing comprehensive HIV prevention and care, not only enhances the life of each patient, but also increases public health and primary care capacity. Integrated, community-based care is essential if equity in health and health care is to become a reality for the world’s poor.

26. David A. Walton et al., *Integrated HIV Prevention and Care Strengthens Primary Health Care: Lessons from Rural Haiti*, 25 J. PUB. HEALTH POL’Y 137, 152 (2004).

