WHOSE HEALTH?:

A CRITIQUE OF WHO'S DEFINITION OF HEALTH

WHOSE HEALTH?:

A CRITICAL ANALYSIS

OF THE

WORLD HEALTH ORGANIZATION

DEFINITION OF HEALTH

By

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Abstract

This thesis offers a critical analysis of the World Health Organization (WHO) definition of health. Feminist epistemology is used to reveal how health and disease are dualistically constructed. Beyond serving as designations for different physiological statuses, these terms are of metaphorical significance, such that individuals affiliated with 'health' are socio-economically, politically and effectively morally preferred over those associated with 'disease'. Popular and immunological conceptions of 'disease' provide justifications for maintaining the oppression of the latter identity. Given WHO's history of prioritizing disease control over primary health care and the consequent implementation of both objectives within a disease-oriented framework, WHO's definition of health is in danger of supporting the health/disease dualism, which in turn jeopardizes the organization's mandate to treat its members formally and substantively equally, and to provide 'health for all'.

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For Grace

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Introduction

"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

World Health Organization, Basic Documents. 1999.

In this thesis, I argue that the World Health Organization (WHO) definition of health discriminates against those most vulnerable to illness, (infectious) disease, and overall poor health status. My accusations of discriminatory practices arise from WHO's inability to honor the values established in compliance with the principles of the organization's constitution: formal equality, substantive equality, and health. WHO's ongoing effort to either control or eradicate infectious diseases sets scientific and economic precedence over the installment of its primary health care initiatives.

Consequently, policy-making for the latter is conceptually confined to the former, perpetuating the harms that are implicit in the context of disease.

The immorality of WHO's definition of health is disclosed through an examination of the metaphors that contribute to the construction of 'disease'. Disease metaphors are used to discriminate against groups of people both macroscopically and microscopically. At the macroscopic level, popular conceptions pit 'health' against 'disease', where the latter is linked to social deviance, ungodliness, poverty. Ascribed onto a 'diseased' individual are metaphors that devalue and denigrate that individual's personhood. At the microscopic level, Immunology utilizes popular conceptions (such

as war) metaphorically as a means to elucidate complex cellular and molecular functions and to concretize an elusive immune identity. Microorganisms, the causative agents of disease, are identified within an antagonistic paradigm; they are largely represented insofar as they challenge an individual's bodily integrity. This paradigm insufficiently and/or inaccurately characterizes microbial existence so that immunologists and epidemiologists are constrained to advance drug therapies and public health policies which restrict and ultimately problematize human behavior. WHO unwittingly adopts metaphors from macroscopic and microscopic levels in its implementation of disease eradication programs which are then appropriated into primary health care initiatives.

Historically, WHO has struggled to balance garnering political and economic support from donor member states and catalyzing the political will to make fundamental changes to health infrastructures worldwide. In light of this disunity the definition of health has come to represent a division between the organization's focus on primary health care initiatives and disease control programs, where the former correlates with the first part of the definition and the latter the second part. Due to the popularity of self-limited disease eradication programs, firmly grounded on an immunological basis (upon which predictions, results, and economic forecasts are quantifiably measurable), WHO is resigned to represent primary health goals in a disease framework with the expectation that primary health can properly compete for WHO funding. Unfortunately, in the effort to be more accountable to its funders, WHO adopts a scientific methodology that reinforces the very metaphors which have rendered poor and disease-ridden areas incapable of exacting health decisions. Without making a significant, qualitative shift in WHO's focus, the organization will continue to embrace policies that rely on denigrative

metaphors of disease, becoming further removed from meeting the acute and long-term health needs of the world's poorest populations. I urge WHO to redefine 'health', taking into consideration the issues that are raised in this thesis.

The thesis is divided into three sections. The goals of each section are quite diverse, however, they contribute to a substantial critique of the WHO definition of health. By summarizing the major objectives of each chapter, I hope to exhibit the significance of these components to the task at hand.

In the first section, I provide a brief history of WHO and a detailed examination of the organization's constitution. In this section, my overall aim is to show that WHO is dedicated to adhering to the principles laid out in its constitution. In Chapter One, I provide a brief history of WHO. A historical examination of the organization is important because it advances several reasons for WHO's present state of affairs. Dedication to the constitution has been hindered by limited funding, political (dis)interest and scientific protocols, leading up to the emergence of two competing foci: disease control and primary health. The favoring of disease control programs proves to be detrimental for the organization's promotion of the values which have arisen in attempts to yield policies that reflect the constitutional principles.

In Chapter Two, I identify the three values that WHO constantly promotes: formal equality, substantive equality, and health. Briefly, WHO values formal equality in that it believes that all persons ought to be free of any health barriers that prevent them from achieving their goals. Formal equality is premised on the idea that individuals are self-determining, autonomous decision-makers. Thus, WHO is clearing the path for the actualization of the individual's plans. Mass vaccination programs best exemplify

WHO's commitment to formal equality, where vaccines safe-guard the individual from contracting a disease which would otherwise prevent her/him from pursuing other (non)health related objectives.

WHO's valuing of substantive equality on the other hand reveals that the organization recognizes that individual capacity varies with the context. Treating individuals equally entails providing the necessary means to empower differently abled individuals to achieve their goals. A good example of WHO's promotion of substantive equality is found in Halfden Mahler's vision of Health for All by the year 2000 (HFA2000). HFA2000 supports that idea that individuals are the best judges of their health needs; therefore, WHO is obligated to aid in the establishment of health goals that are realistic for those circumstances.

Health is the third value which will be discussed in this thesis. Health is instrumentally valuable; that is, good health is a major determinant of an individual's ability to generate an income. The pursuit of health has also led to international alliances between member states of WHO, advancing the idea that health goals can contribute to peaceful relations between and within nations. At the same time, the attainment of health is worthwhile in and of itself.

The identification of WHO's values is useful for a number of reasons. First, it verifies WHO's engagement with the constitution. Justification for the introduction of new health policies can be traced back to WHO's striving to commit to the principles. In other words, WHO policies are defensible insofar as they are linked to one or more of the three values. Second, the relationship between these values is far from straightforward. For instance, at times the recognition that individuals are formally equal precludes the

realization that they are substantively unequal. Disease control measures may lead to the glossing over of different health circumstances between individuals. At other times, one could argue that substantive equality is a necessary condition for formal equality. Without honoring the specific health needs of different nations, long term solutions to disease control are not feasible. The multiple ways in which these values coincide or contradict one another is symptomatic of the tensions that originate from within the constitution itself. Third, these values can be used as measures against which WHO's actions are evaluated. In the failure to promote formal equality, substantive equality and health one can ask: What are the possible reasons behind WHO's inability to realize their values? Perhaps the values are diametrically opposed. Or, perhaps the policies that ought to reflect WHO's values actually prevent the advancement of them. The identification of formal equality, substantive equality and health and WHO's failure to uphold these values offer strong incentives for pursuing the answers to the questions and for knowing when adequate answers are found.

In the second section, I introduce a feminist methodology for the critical assessment of disease. Feminist discourse on oppression is very insightful, introducing novel means to identify unequal treatment of individuals and groups. In Chapter Three, I use Val Plumwood's logical structure of dualisms in order to deconstruct metaphors of 'disease'. First, what is a dualism? Plumwood argues that many words are constructed in opposition to other terms. Dualism is "a process by which contrasting concepts are formed by domination and subordination and constructed as oppositional and exclusive." That is, one concept is preferred over the other, to the point that the latter is considered

¹ Val Plumwood, <u>Feminism and the Mastery of Nature</u>, (London: Routledge, 1997), p. 31.

merely derivative. Furthermore, in the application of a dualistic conceptual construction, that to which the subordinate concept refers is likely to be subordinated in reality. I wish to deconstruct the metaphors surrounding disease to determine whether they form part of a system of conceptual dualisms.

Disease can be evaluated at macro- and micro-levels. In Chapter Four, disease is analyzed at the macro-level. Popular metaphors that oppress persons who live in 'diseased' areas tend to suggest that health and disease are dualistically constructed. In Chapter Five, at the micro-level, Plumwood's discussion on dualisms elucidates how oppressive metaphors are incorporated even into the scientific language of disease.

In the final section, I consider the ethical implications of 'disease' on WHO's definition of health and the policies that have been built upon the definition. Concluding that the definition requires serious redirection in Chapter Six, I tentatively offer suggestions for a remedial project to foreground the needs of persons especially vulnerable to poor health status in the final chapter.

Chapter One: Introduction to the World Health Organization

In the 1995 World Health Report, the World Health Organization (WHO) announced that 'poverty' was the world's deadliest disease. Over 1.3 billion people or greater than one-fifth of humanity live in extreme poverty. Not only are social gaps widening between the rich and the poor, the gaps are also widening between the poor and the poorest both within and between nations. Furthermore, infectious diseases, often found to be closely linked to poverty conditions, are on the rise. Plague, Tuberculosis (TB), cholera have returned in full force, challenging the successes of previous immunization and vaccine programs which had held promise of control if not eradication of these diseases.

At present, WHO is experiencing an identity crisis. Within the 52 years since the organization came into existence, the nature of illnesses, health and the world order have changed tremendously. Change within the WHO has come painfully slowly, however. Perhaps the successes made earlier in WHO's policies have prevented the organization from engaging in primary health care policies, far removed from their disease eradication and control programs. Infectious diseases, which were one of the main priorities when WHO was first established, ought to have been well under control by now. A brief history of the organization will be followed by a discussion of WHO's constitution, a document which for the most part has not been adequately revised since its inception.

WHO, World Health Report 1995; Bridging the Gaps, Fostering Development, (Geneva: WHO, 1995), p.

The purpose of this study is not to wholeheartedly condemn the work of the WHO.

Rather, I wish to critically assess the most fundamental tenet of the organization - WHO's definition of 'health'. This investigation will shed light upon the shortcomings of the WHO with respect to the ongoing programs to eradicate or control infectious diseases. I will argue that the organization's definition of health is flawed, such that the policies which rely on this definition cannot achieve the principle of 'health for all', fundamental to WHO and founded upon the human right to health.

1.1 A Brief History of WHO

In the mid-1940's the world was in a shamble. In the aftermath of the Second World War, countries around the world were facing health, economic and political crises. To solve these problems, nations came together to form a world governing body - the United Nations (U.N.). The U.N. recognized the need for an international body to govern the world's health needs. Thus, WHO was developed in response and designated as a 'specialized agency of the U.N.

In 1948, the first year that WHO was in operation, the world was bombarded with numerous microbial epidemics. For example, Yaws - a disease caused by a spirochete - had afflicted 50 million people worldwide.³ Other infectious diseases that required control included Malaria (a mosquito-vector borne parasite that breeds in human red blood cells),⁴ Tuberculosis⁵ (TB), and Syphilis.⁶ WHO's focus to eliminate these

² Ibid., p. V.

³ WHO, Four decades of Achievement, (Geneva: WHO, 1988), p.16.

⁴ WHO, World Health Report 1996: Fighting disease, Fostering development, (Geneva: WHO, 1996), pp. 47-48.

infectious diseases led to its search for partners that shared its interests. Those collaborations tended to be made with organizations or groups that could offer a particular type of scientific expertise. For example, WHO's adoption of Albert Sabine's polio vaccine in the 1950's proved to be of vital importance in the next two decades. Indeed, the move to establish scientific standards was seen to be among WHO's greatest long lasting achievements. In short, the biomedical model of health - a model that is premised upon the notion that health is and should be limited to physical conditions and biologically-based solutions - took economic precedence over other less technologically dependent forms of health care, especially in the early years of the WHO. This top-down approach to eradicate specific diseases came under increasing criticism in light of WHO's inability to eradicate malaria.

In 1963, WHO's Malaria Eradication Programme was deemed a complete failure. Researchers had hoped that the parasite could be wiped out in two ways: by vaccinating those living in malarial locations, and by implementing a DDT spraying program which would destroy the disease vector - mosquitoes. Initially the programs were highly successful. For instance, in India the annual incidence of malaria fell from one million/12 million exposed persons in the early 1950's to 18 cases in 1963. This initial optimism did not prepare WHO for the worst scenario: both the parasite and the mosquito

⁵ Tuberculosis is a disease that primarily attacks the lungs. It is caused by *Mycobacterium tuberculosis*, an airborne bacteria. In the past scientists had believed that TB was 100% curable, thanks to antibiotic therapy. However, multiply drug resistant strains of the bacteria exist. In the cases where someone contracts MDRS-TB, the disease is fatal. See WHO, <u>World Health</u>, 46, No. 4, p. 6.

⁶ Syphilis is a sexually transmitted disease, caused by a spirochete (*Treponema pallidum*). Penicillin is often used to treat syphilis. If left untreated, this disease will cause severe neurological damage. See Thomas D. Brock and Michael T. Madigan's <u>Biology of Microorganisms</u>, (6th ed.), (Englewood Cliffs: Prentice Hall, 1991), pp. 529-530.

had conferred resistance to the anti-malarial drugs and DDT, respectively. In 1963, with the withdrawal of USAID's support – WHO's biggest donor for the malaria eradication program - WHO had lost any financial capacity to maintain the program. Failure of the malaria eradication program was expected for two reasons. First, an effective link between the scientists and policy-making politicians was extremely tenuous. Therefore, funding was inappropriately allocated to suit the political needs of the latter. Second, politicians in the governing bodies of the specialized agencies preferred to support popular projects; they did not consider the scientific unfeasibility of eradicating such a fastidious parasite.

Yet, between 1958-1968, WHO continued to develop strong collaborations with scientists and bio-technological industries. In this decade, WHO began to aggressively promote the smallpox eradication program, emphasizing the desire to rely upon strictly scientific methodology to combat this epidemic. Still recovering from the failure of the Malaria Eradication Programme, WHO was determined to prove that the world had the scientific tools necessary for the success of the smallpox initiative.

The emergence of many African states during this decade was another major factor in the organization's prioritizing of specific disease control over other programs.

Their membership resulted in a sudden increase in statistics of infectious diseases endemic to Africa. These statistics were previously unavailable due to a lack of surveillance prior to the nations' designations as member states of the WHO. According

⁷ WHO boasts that its success in the standardization of 200 substances is based upon the high standing which the organization has received in the scientific community. See WHO, <u>World Health Report</u>, 1996, pp. 83-84.

⁸ "Strictly scientific methodology" means that WHO's eradication strategy was restricted to methods which utilized the available scientific research regarding the immune system and epidemiological data.

to a health assessment of Sub-Saharan nation states, WHO researchers found that the countries which needed the most health services were also the ones with the least financial resources for development. The researchers believed that the lack of qualified personnel – who knew nothing about planning - was the greatest obstacle to health improvement in Africa. The diversity of and reliance upon traditional medical practices on this continent were ignored or subordinated in comparison to the biomedical standards established by the international community. In fact, one of the "crowning achievements" of the 1958-68 decade was WHO's international classification of diseases. This classification system enabled medical practitioners around the world to code a full range of illnesses and diseases in any given country. The statistics of nation states could be compared over time and with other members.

The 1968-78 decade placed WHO at the peak of its success. Two major events demonstrated WHO's authority in health. First, in 1979, the announcement that smallpox had been successfully eradicated re-established WHO as a scientific authority on disease control. Smallpox eradication was relatively straightforward compared to the malaria program. In terms of epidemiology, the malarial parasite *Plasmodia spp.* had a very complex life cycle and could remain in the host for years after the primary infection, where it would replicate and cause organ failures. The smallpox virus, on the other hand, was self-limiting. Unlike malaria, no carrier state existed and sub-clinical infections were extremely rare.¹¹ Furthermore, in clinical terms, even laypersons could easily diagnose the disease, because the lesions, which marked the skin during an infection, were very

⁹ WHO, "Health in Africa South of the Sahara", WHO Chronicle, Vol. 22, p. 399.

¹⁰ Ibid.

¹¹ WHO, WHO Chronicle, Vol. 22, p. 523.

distinct. Thus the number of unreported cases of smallpox remained low given that documentation of its epidemiology was well established.

WHO's roles in the Smallpox Eradication Programme included: (1) catalyzing collaboration between scientists, governments, health workers and ordinary citizens; (2) smoothing out any technical difficulties in the eradication program; (3) breaking down political rivalries.¹² All three functions confirmed the viewpoint that health collaborations were best founded upon the dissemination of objective, scientific expertise. WHO was seen as a "neutral umbrella" under which nations coming from vast socioeconomic status could jointly eradicate infectious diseases. Epidemiological studies of smallpox also had shown research capacities could be strengthened if new analytical tools were applied in the detection, treatment and prevention of diseases. The construction of these tools depended upon sustained relationships between nations. WHO saw a need for all member states - regardless of level of development - to produce health care policy that would enable researchers to compile and systematize data regarding health and disease. Therefore, the second major event which verified WHO's authority came in the form of Dr. Halfden Mahler's introduction of the "Health for all by the year 2000" campaign. This campaign marked WHO's redirection in health from a sole focus on infectious diseases to the universalization of health which wholly raised the world's standard of living.

Between 1978 and 1988 WHO attempted to clearly articulate and practically implement the "Health For All" campaign. Mahler believed this campaign would make people realize their duty to improve their own environments. That is, community

¹² WHO, Four decades of Achievement, (Geneva: WHO, 1988), p. 16.

members, and not only medical staff, would be urged to participate in raising their quality of life. Health was not only a matter of acute care, it moved into the realm of preventative medicine. In 1977, Mahler introduced a blueprint for the "Health For All" campaign in the WHO Chronicle. The campaign did not translate to mean formally equal coverage of health care for all of the world's citizens. Instead, Mahler was making a bold move in his appeal to member states to adopt primary health care initiatives. Disease control became only one of numerous health measures, which would wholly improve health status, based upon the social expectations and economic capacity of respective member states. 13 Thus, WHO slowly began moving away from the safety of objective technical expertise into the treacherous political grounds from which WHO could compel its member states to radically change their health care systems. Health projects carried out by WHO exploded as funding was allocated to propagate a wide range of research, including: potable drinking water strategies, studies of food and housing hygiene. further research in vector control, etc. Mahler envisioned a health care system that would produce socially relevant health research, pertinent and culturally sensitive to the recipients of the information and technology. Health Systems Managers had to extend beyond determining the allocation of scientific expertise. They also had to find innovative means to critically assess and prioritize funding toward economically sustainable long term health programs which depended less on drug and technological regiments.14

In the following decade, 1988-1998, the 'Health For All' campaign was criticized from all sides. Under the supervision of Hiroshi Nakajima (the fourth Director-General

¹³ Mahler, WHO Chronicle, Vol. 31, p. 499.

of WHO, following Mahler's term), who understood "Health for All" as a diversification of (biomedical) health interests, the focus of the organization had gone awry. An overdiversification of research projects dangerously spread thin WHO's continuously diminishing resources, meanwhile building a knowledge base which tended to benefit the wealthy rather than the poorer nations. 15,16 Others complained that Nakajima's approach reflected a lack of strategic planning. Mahler's "Health For All" began to fail. Donor members who were dissatisfied with the lack of transparency of resource allocation withdrew support from the general programs, instead investing in special programs. which were more accountable for the use of money. "Health For All" came to mean a lack of prioritizing of scarce resources. far removed from Mahler's intention to move WHO policies toward primary health care. As research projects diversified, WHO employees became less confident in the organization's ability to address issues of "poverty, education and environmental degradation."¹⁷ At the same time, collaboration with other specialized agencies was extremely tenuous given the agencies' inability to adapt their dissimilar philosophies for the purposes of achieving specific goals.

Finally, infectious diseases (both newly emerging and re-emerging diseases), of top priority in the early years of WHO and once thought of having been manageable by the scientific community, are returning in full-scale force. The eradication of smallpox had created an atmosphere of complacency, in which time a wide range of

¹⁴ Mahler, WHO Chronicle, Vol. 31, p. 495.

¹⁵ Fiona Godlee, "WHO at Country Level - a little impact no strategy," BMJ, Vol. 209, p. 1639.

¹⁶ In 1982, the World Health Assembly (WHA) voted to freeze WHO's budget which at the time was valued at \$310 million (US). Due to inflation WHO is increasingly unable to maintain its many programs. Detractors of WHO have also stated that the money is often wasted on bureaucratic inefficiency and petty corruption. See Godlee's "WHO in Crisis" <u>BMJ</u>, Vol. 309.

¹⁷ Fiona Godlee, "WHO in retreat: is it losing its influence," BMJ, Vol. 309.

microorganisms had conferred resistance to many antibiotics and vaccines. Today, the world has been declared to be in a state of emergency with regard to TB infection. Many new strains are now multiply resistant to all available drugs, taking the world back into a time before antibiotics were available; thus humans are at the mercy of these microorganisms.¹⁸

WHO is in a state of crisis. Special programs compete with general campaigns for the dwindling funds allocated to the organization. WHO has had to keep pace with political displacement from a position of objective, technical advisory to front-line advocacy for primary health care initiatives. What are WHO's objectives? By determining which philosophical bases are implicit to the constitution (and subsequently WHO's functions), we will be able to decide if WHO in its present form has the capacity to improve the quality of life of its global citizens.

1.2 WHO: Roles and Expectations within the United Nations

The UN (United Nations) represents a part of the UN system, known as the UN family. ¹⁹ The UN system is composed of six principal organs²⁰, fourteen special agencies and twenty-eight other organs. The smaller and specialized organs report to the UN, which itself sits at the center to maintain international peace and security, to promote development and international cooperation, and to coordinate the whole system. The WHO is a specialized agency that deals directly with one of the six main organs of the

¹⁸ Phyllida Brown, " A disease that is alive and kicking," World Health, 46, No. 4, p. 4.

¹⁹ Joachim W. Müller, The Reform of the UN, (Oceania Pub. Inc., 1992), p. 3.

²⁰ The six principal organs are: General Assembly, International court of Justice, Trusteeship Council, Security Council, Secretariat, Economic and Social Council.

UN system - the Economic and Social Council (ECOSOC).²¹ A specialized agency is one that has been distinguished from others on the basis of function. Designated as a 'specialized agency' under the UN family, WHO has worked in close collaboration with other specialized agencies.²²

In general, WHO acts as an autonomous agency within the UN system. However, it is obligated to adhere to laws made specifically for the specialized agencies within the UN system. First, as a direct member of ECOSOC, WHO must adhere to Article 55 of the UN Charter of Rights. Article 55 states:

With a view to the creation of conditions of stability and well-being which are necessary for peace and friendly relations among nations based on respect for the principle of equal rights and self-determination of peoples. the UN shall promote: a) higher standards of living, full employment and conditions of economic and social progress and development; b) solutions of international economic, social health, and related problems; and international cultural and educational cooperation; c) universal respect for, and observance of human rights and fundamental freedoms for all without distinction as to race, sex, language or religion.²³

Article 55 plays a central role in the UN Charter, most commonly invoked by members as a means to achieve their particular goals. The promotion of the world's economic and social progress is a key role of the UN.²⁴

The goals set up by Article 55 are to be achieved through the specific functions of the fourteen specialized agencies, as established in Article 57. The UN's approach to

²¹ Muller, p. 3.

²²For example, UNICEF (United Nations Children's Fund) has had a long-standing relationship with the WHO. The latter served as a directing authority in the Yaws campaign through which the former conducted a Yaws control program. They also established joint programs in the study and control of TB, malaria, maternal and child health programs.

²³ Leland M. Goodrich, Hanbro Edward, and Anne Patricia Simms, <u>Charter of the United Nations:</u> Comments and

Documents, (New York: Columbia Univ. Press, 1969), p. 371.

²⁴ This task has become increasingly difficult as member states, which fall under the category of "less developed country", have proportionately increased with membership into the UN.

economic and social reform is premised upon the idea that the goals are to be achieved "through autonomous specialized organizations created by intergovernmental agreement and brought into relationship with the UN by agreement freely entered on both sides."²⁵ In other words, WHO and other specialized organs act as autonomous bodies, creating and adhering to their respective constitutions. This independence is governed by the knowledge that ECOSOC, a liaison between the GA and the specialized organizations, will set research priorities that reflect the human rights mandate in Article 55.

Article 57 also lays out the UN's specific expectations of each specialized organ. WHO is expected to achieve the "highest attainment by all peoples of the highest possible level of health". ²⁶ WHO's major functions include: (1) promoting cooperation among intergovernmental agencies, governments and other groups; (2) providing technological aid to governments and specialized groups; (3) drafting conventions and other forms of international agreements; (4) promoting and conducting research; (5) promoting better teaching standards and training in medical and related programs; (6) developing international standards for food, biological and pharmaceutical products. ²⁷ These functions have been implemented into WHO's own constitution.

1.3 Practical Criticisms Against WHO

From the time that the principles of the constitution have been laid out, WHO has been the target of many criticisms. These criticisms are directly and indirectly associated with the principles and with the definition of health itself. First, perhaps one of the most

²⁵ Goodrich et al., p. 387.

²⁶ *Ibid.*, p. 388.

²⁷*Ibid.*, pp. 388-389.

common attacks mounted against WHO is that the organization lacks any sort of health strategy. Health decisions seem to be quite eclectic, reflecting donor preferences rather than focusing on developing universally applicable health infrastructures. Donor agencies prefer to allocate funds toward self-limited and well-conceptualized special programs, therefore, less resources are distributed to the maintenance of long-term regional activities. The six regional offices²⁸ reported unnecessary overlapping of programs, lack of the member states' political wills to effect change in health policy, and detachment from those that WHO ought to be targeting: the citizens of the Regions.

WHO repeatedly responds to these allegations by congratulating itself for maintaining "decentralized control" of the Regions.²⁹ Because each region differs in socio-economic development, epidemiological characteristic, culture and history, those who coordinate regional activities are the best judges in determining which policies actually suit the needs in those areas. Although in theoretical terms decentralization gives regional staff more autonomy, field staff and regional coordinators are confronted with the practical implications of their independence. First, in most of the member states, the Ministries of Health often carry the least political status (ranked in relation to other ministerial offices). Low prioritization of health systems development directly affects the WHO liaison officers, who are incapacitated from promoting changes in health care policy.³⁰ Furthermore, WHO insiders find that health postings in member states are often granted to persons who are on friendly terms with the popular government. Selection of

²⁸ State memberships vary from region to region. This range does not affect a country's vote in a WHA congressional meeting, according to WHO. Every member state is given an equally weighted vote; that is, the state's influence is not measured in terms of economic contributions to WHO.

²⁹ WHO, World Health Report 1996: Fighting Disease, Fostering Development, (Geneva: WHO, 1996), p. 91.

the health officer is not a meritocratic process. That these appointments are directly linked to the government in power reflects the high turnover rates of the health officer position. In politically unstable countries, where governments abruptly change, health officers do not remain in their post long enough to study the needs of the communities and to understand their own role as a WHO representative. Ultimately, the communities suffer the most; an ongoing chain of inexperienced and untrained personnel promises the failure of sustaining much needed long term health infrastructural developments.

Second, regional independence comes at the cost of receiving adequate funding. WHO ineptly oversees the diverse research projects implemented at the regional level. This lack of control leads to opaqueness in terms of financial accountability; thus WHO cannot compete with other more centralized agencies which adequately account for their spending. 'Decentralization' masks the bureaucracy that obstructs WHO's work at the local, country and regional level. WHO enters into a vicious circle where decreased funding leads to greater immobilization of field staff. In turn, the field workers become further alienated from the communities that they were to represent; subsequently, funding is cut further to reduce spending on futile projects.

The problems that surface at the level of practical implementation of health policy are indicative of flaws fundamental to policy-making derived from specific constitutional principles, including WHO's definition of health itself. In the next chapter, I will analyze WHO's principles and determine the values that WHO attempts to promote in its health policies. Chapter Two will be followed by an evaluation of the organization's efforts to actualize the values implicit to its constitution.

³⁰ Godlee, <u>BMJ</u>, Vol. 309, p. 1636.

Chapter Two: Values of WHO

According to WHO, health is a fundamental right as expressed in Principle 2 (P2). This fundamental right is founded upon at least three values: health, formal equality, and substantive equality. Presumably more values exist; however, I have limited this discussion to the three mentioned above because they are consistently referred to in the drafting of health policies, which implies that they are integral to the WHO constitution.

In this chapter I wish to accomplish three goals. First I wish to identify the values pertinent to WHO policies. Second I hope to show how they are derived from the principles of the WHO constitution. Values are implicit to the constitution until WHO attempts to interpret the principles through its health policies. The rationales behind these policies provide evidence for the existence of WHO's commitment to follow particular values, which in turn act as correctives - at least in part - for policies that have gone awry. Third, I want to suggest that there is something fundamentally flawed in WHO's definition of health, responsible for the tensions that exist between WHO's promotion of these values.

Values should not be identified strictly on theoretical grounds. The theory does not precede the practice; instead, theory and practice are reciprocally related. By

¹ The nine principles of the WHO constitution are provided in Appendix 1.

following WHO's history of implementing international programs, one begins to understand the organization's attempt to identify and realize the values imbedded in the constitution. WHO's values emerge through a process of elucidation of the principle(s) in question.

2.1 Health

WHO identifies health to be a value. At first, this statement appears to be glaringly obvious considering that the organization was formed for the sole purpose of meeting the world's health needs. However, a deconstruction of the statement discloses the daunting task that WHO has set to accomplish, given the scope of its project: to provide adequate levels of health *for all*. At the same time, health, through the multiple ways in which it is valuable, is elucidative in the analysis of (in)effective WHO policies. When policies either hinder or fail to promote health, researchers can return to the types of values that health has come to represent in order to analyze how the policies relate to them.

Why is health valuable? Inarguably, health is a fundamental good in and of itself. P4, without any qualification, states that the attainment of health is a value to all peoples. To achieve a state of health is to fulfil a basic good. Yet, the value of health can also be expressed in terms of its supportive roles in the attainment of other goals. In turn, the instrumental values of health may illuminate our conception of the rather elusive idea that health is fundamentally good.

Health is instrumental to the achievement of several ends. WHO recognizes that health is instrumentally valuable for the attainment of peace (P3) and the alleviation of poverty. Health catalyzes international cooperation and peaceful relations because nations are drawn together to accomplish a common goal. For example, in the eradication of smallpox, Donald Henderson, who was in charge of the campaign, states that the program's success was in large part due to the American - U.S.S.R. collaboration. Despite the Cold War tensions between the superpowers, scientists from both sides cast aside their social differences in order to create a research group capable of implementing mass vaccinations.² This collaboration alone was a necessary but insufficient component in the eradication of smallpox. Regional directors of WHO as well as the countries which the directors represented all had to dedicate their energies onto the project. What had begun as a mass vaccination strategy evolved into a country- based system of surveillance and notification of new incidences of the disease. The creation of the surveillance system has been attributed to the designation of a mobile surveillance team at the national and/or provincial level.³ In the history of WHO, the smallpox eradication campaign is probably one of the most famous examples of researchers sidelining their national allegiance in order to achieve a common goal.

Health initiatives can be used to break down political barriers between conflicting nations. In response to P3, in "The WHO Definition of Health", Daniel Callahan criticizes WHO for suggesting that peace necessarily follows from the attainment of

² D. A. Henderson, "Smallpox eradication – a cold war victory," World Health Forum, Vol. 19, p. 116.

health.⁴ Countries that are in a state of affluence and physical health are not necessarily in a state of peace. Indeed, the pursuits of health and peace can very well be mutually exclusive tasks. However two points must be made here. First, Callahan assumes that health alone is sufficient for the creation of peace between and within nations. WHO's statement that "health is fundamental to the attainment of peace" is not equal to the statement that "health is the *only* condition for the attainment of peace." To make such a claim is to oversimplify the relationship between health and peace. In fact, recalling Article 55 of the U.N. Charter, health is only one of many conditions that contribute to the making of friendly relations among nations. Because WHO is among thirteen other "specialized agencies", it cannot be given sole responsibility in the resolution of political conflicts. Rather, WHO should be perceived as promoting peace through its health policies, just as the other agencies are expected to do so from their respective focal points.

Second, health is instrumental in reducing states of poverty worldwide. In the BBC Reith Lectures 2000, the present Director-General of WHO, Gro Harlem Brundtland discusses at length the relationship between poverty and health. The two are engaged in a positive feedback loop where poverty causes degradation in health, and poor health hinders a person from engaging in economically productive activities. Brundtland's mission is to fight against poverty.

³ D.A. Henderson, "Epidemiology in the Global Eradication of Smallpox", <u>International Journal of Epidemiology</u>, 1, No. 1, (1972), p. 26.

⁴ This essay is published in <u>Contemporary Issues in Bioethics</u>, Tom L. Beauchamps and LeRoy Walters (eds.), 3rd ed., (Belmont, CA: Wadsworth Publishing Co., 1989), pp. 80-85.

⁵ Gro Harlem Brundtland, BBC Reith Lectures 2000, WHO/DG/SP/140.

Health is placed in two key positions relative to poverty: it is both a determinant and outcome of poverty reduction. First, health is a determinant of poverty, where the former is inversely proportionate to the latter. In the phrase "health...is fundamental to the attainment of ...security", P3 suggests that good health cultivates economic growth, where 'security' is interpreted in economic terms. To designate health as a variable is to subsume it under the goals of alleviating poverty. The declaration to fight poverty is indicative of WHO's subsuming of health to be a part of the bigger picture: to improve the general quality of life. With good health status an individual has the capacity to resist or alleviate poverty conditions. Conversely, poor health often correlates with progressing levels of poverty.

WHO policies advance an economic interpretation of 'security'. Brundtland suggests a methodology to break the poor health-poverty cycle. Rather than attempting to raise health levels by generating greater movement of monies in the country, community or region, Brundtland wishes to improve health status for the purposes of reducing states of poverty. Studies have shown that the former solution - infusing the country with economic assistance and income promoting activities - does not necessarily increase an individual's health status. In fact, growing evidence "links uneven distribution of wealth in communities, regions and countries with high rates of ill-health". These conclusions merely emphasize what WHO already knows: health care is not highly prioritized in many countries. Unless governments see direct and immediate benefits from their health

⁶ See G. Davey Smith, "Income inequality and mortality - why are they related?", BMJ, Vol. 312.

investments, they are unwilling to allocate funds toward an area which is perceived as draining already dwindling resources.

Brundtland appeals to the "enlightened self-interest" argument in her attempts to eradicate poverty conditions. Instead of persuading people to fight against poverty on moral grounds (i.e. normative exclamations of what humans are obligated to do for fellow humans), she contends that one ought to convince governments that increased health will lead to increased national prosperity.⁷

Second, not only does health serve as a means to reduce poverty, it is also an outcome of an individual's improved socio-economic status. P5 warns how unequal development in different countries (scientific or economic?) may thwart the promotion of health. According to Brundtland, "poverty deprives people of a number of choices they must have available in order to live a satisfying life". Generally, the poorest nations are often the ones afflicted with serious endemic conditions. For example, at the country

⁷ Forecasts on the direct and indirect costs of diseases can be assessed. Direct costs are calculated in terms of the amount of money allocated to the health care system. Indirect costs are measured in terms of employment and productivity deficits in the agricultural, industrial and service sectors. Health care costs and production loss are both measures of the economic impact of a disease. The former represents direct costs, whereas the latter represents indirect costs of disease. The Kenyan government projects that by 2010 the demand for HIV/AIDS-related hospital stays will be two times greater than the number of beds available. Only half of the HIV positive persons will have access to in-patient hospital care in Kenya. In terms of indirect costs, the agricultural sector will suffer the highest percent losses in production. Kenyan economists predict that by the year 2010, the agriculture sector is projected to lose approximately KSh 2.2 billion in primary production, approximately 1.7% of the total value of production (and up from 0.3% in 1990).

If the Kenyan government acts now to stop any further spread of HIV, then perhaps the realization of these problems can be avoided. Economic prosperity is understood in terms of the amount of money saved from having not to allocate it toward the AIDS epidemic, and from the maintenance of the present level of production. Whether this strategy will provoke the economic interests of governmental leaders to invest in preventative health measures is yet to be determined. For more information on how HIV/AIDS affects the Kenyan economy, please see Ch. 4 and 5, of AIDS in Kenya: Socio-economic Impact and Policy Implications, Steven Forsythe et al. (eds.), (Arlington, Virginia: Family Health International, 1996).

8 Brundtland, BBC Reith Lecture Series 2000.

level, the countries in Africa make up 29 of the 47 least developed nations in the world. At the same time, sub-Saharan Africa alone carries 75% of the world's AIDS burden. Almost none of those living in this region have access to the cocktail therapies, which specifically target the virus as well as sustain immunological functions.

How are the poor barred from or not given the economic means to improve their health? To find answers to these problems, Brundtland states that we must first "look through the eyes - and spirit - of poor people". This rather cryptic statement may allude to the judgment that seeing through the eyes of the wealthy would prevent one from truly fighting against the cycle of poverty and ill health. In the appeal to take the poverty-stricken gaze, Brundtland incites WHO to consider two other values: formal equality and substantive equality.

2.2 Formal and Substantive Equality

Through its health policies, WHO expresses the need to treat individuals equally.

This vague sense of equality is articulated as "a fundamental right of every human being..." to enjoy the highest attainable standard of health. Specific principles in the WHO constitution clarify the notion of equality in the promotion of formal or substantive

⁹ WHO, The 1995 World Health Report (Geneva: WHO, 1995), p. 71. At present, billions of dollars have gone into chemotherapeutic research, but only individuals living in the affluent and often "Northern" nations benefit from drugs which run at an annual cost of \$US 10 000 per person. In African countries, where the capita expenditure on health range between \$3.50-\$290 US per person, HIV-positive individuals have access to only the most basic treatments for opportunistic infections.

¹⁰ See Deepa Narayan's Voices of the Poor, (Oxford: Oxford University Press, 2000).

¹¹ See P2 of the WHO constitution.

equality. As we will see later, some principles ambiguously express both types of equality.

Equality can be understood both formally and substantively. Formal equality presupposes that individuals, abstracted from their particular circumstances, are fundamentally equal. Individuals who are free of any constraints have the equal capacity to pursue their goals. The best pragmatic expression of formal equality is given as the effort to remove any barriers that would otherwise prevent one from pursuing her/his active interests. Equality is measured in terms of equal opportunity; no persons are treated with more value than another. On the basis of formal equality, all persons have the negative right to pursue their own interests. Treating individuals formally equally, however, does not entail recognizing them in their differences.

A theory of substantive equality involves the idea that specific contexts prescribe an individual's capacity to act and the extent to which s/he wills those acts. Individuals are not depicted as atomistic, autonomous decision-makers; instead, they are identified in relation to others and their material environments. An individual's actions lead to social circumstances, which may include shifts in the individual's social standing within the community. Pragmatic expression of substantive equality is given as the initiative to provide the means for an individual's realization of her/his goals. Those committed to treating individuals substantively equally would actively challenge the status quo, which may systematically bar individuals from engaging in particular activities. Often,

¹² Marilyn Friedman; "The Social Self and the Partiality Debates" in <u>Feminist Ethics</u>, Claudia Card (ed.), (University of Kansas Press, 1991), p. 163.

treatment of individuals on a substantively equal basis is contingent upon the awareness that some individuals are subordinated in relation to others.

The following example will clarify the difference between formal and substantive equality. A person in a wheelchair can be seen as both formally and substantively equal to a person who walks. Like the walking person, the one in the wheelchair has a formally equal right of access to a two-story building. Here, the latter is treated the same as the former so far as both are permitted to enter the building. However, this sameness is without substance. The person in the wheelchair must also be recognized in contrast to the person who walks. To promote substantive equality, equal treatment entails that measures must be taken (such as the installation of wheelchair ramps) so as to enable the woman to actually enter the building. Notwithstanding the right to enter, the special needs of the person in the wheelchair must be met before she can enter. Formal equality respects individuals in their sameness; whereas, substantive equality respects individuals in their sameness; whereas, substantive equality respects individuals

2.2.1 WHO and Formal Equality

WHO upholds the idea that formal equality is valuable. The best examples of WHO's commitment to achieve formal equality is found in P2 and P7 of the constitution. P2 goes beyond the identification of health as a value. It also enables all persons to claim

¹³ Christine Koggel presents the wheelchair access example in <u>Perspectives in Equality</u>, (Lanham, Maryland: Rowman and Littlefield Publishers, 1998); p. 168.

¹⁴ Critics of substantive equality argue that the recognition of difference propagates further discrimination of already disadvantaged groups. Koggel is aware of this "dilemma of difference" and offers a

ownership to a state of "complete physical, mental and social well-being". 15 Insofar as P2 regards the highest attainable level of health of "every human being", the principle attempts to achieve a respect for human life outside of social, economic and political factors, which would otherwise prevent one from recognizing the aspect of existence common to us all: our humanity. Imbedded in P2 is the metaphysical claim that human identity can and must be recognized without resorting to any accidental causes such as social status, productivity, ethnicity. The inability to perceive basic humanity may lead to the removal of a right to health which necessarily depends upon it. However, without further discussion, this interpretation of P2 is merely speculative. Part (c) of Article 55 in the U.N. Charter more clearly states what P2 has alluded to. The U.N. has a mandate to promote universal respect for human rights outside of influences from race, sex, language and religion. The close resemblance between 55.c of the U.N.Charter and P2 of the WHO constitution is not a matter of coincidence. Rather, WHO is committed in its role to create conditions of well-being in compliance with the U.N. Charter. Underlying both the U.N. Charter statement and the WHO constitutional principle is the belief that human rights are not contingent upon social factors.

WHO policies on infectious diseases reflect the tendency of a formal equality approach to abstract from particular situations and to regard populations in their sameness. For example, in the Smallpox Eradication Programme, mass immunizations are premised on the idea that human physiology is constant regardless of geographical

location. In human anatomy texts, cell, tissue, and system functions are generalized; they are distinguished on the basis of normality or abnormality, health or disease. Vaccines are designed with the assumption that all humans will confer equal resistance to Smallpox. Indeed, failures in early vaccine trials often were attributed to the production of sub-standard batches of the vaccine and physiological limitations of the vaccine. 16

P7 of the WHO constitution further endorses the idea that individuals are formally equal. P7 stipulates "the extension to all peoples of the benefits of medical knowledge, psychological and related knowledge" so as to promote the fullest attainment of health. WHO is obligated to reduce the barriers to these benefits, making them readily accessible to health-seeking individuals. Once again, WHO policies on infectious diseases concretize the commitment to formal equality implicit to P7.

Control of the AIDS epidemic largely depends upon the world's compliance with 'safe sex' practices.¹⁷ In the Global Programme on AIDS, WHO prioritizes programs on condom promotion and reducing instances of stigmatization and denial.¹⁸ Underlying WHO's approach is the assumption that individuals, given the access to relevant information and prophylactics, can readily incorporate and make use of these protocols. WHO counts on the idea that individuals are waiting to pursue their goals; thus, WHO is expected to reduce any barriers which hinder persons from maintaining HIV-seronegative

¹⁵ WHO, Basic Documents, 1999, p. 1

¹⁶ See D. A. Henderson, <u>World Health Forum</u>, Vol. 19, p. 115; Of course, abstraction from the context itself insufficiently registers the formally equal treatment of individuals. A major condition for treating individuals on a formally equal basis is to perceive individuals as autonomous and in active pursuit of their goals.

¹⁷ Fiona Godlee, "WHO's special programmes: undermining from above", BMJ, Vol. 309, p. 1637.

status. Workshops on AIDS stigma ought to dismantle obstacles that couples face in negotiating safe sex practices. Likewise, a constant supply of condoms to an area ought to lead to lower transmission rates.

WHO has found, however, that equal treatment requires recognizing individuals not merely in their sameness but in their differences as well. In the case of the AIDS epidemic, initially researchers were baffled by the evidence that regardless of the amount of AIDS education offered or the consistent access to condoms, HIV infection rates continued to rise. They have started to ask different types of questions, such as: Why are condoms not being used? Why do AIDS stigmas persist? WHO is becoming increasingly aware of the need to examine specific contexts and how they may constrain individuals to make health decisions that deviate from the ideal.

2.2.2 WHO and Substantive Equality

The WHO constitution stipulates the recognition of substantive equality. A researcher with a substantive viewpoint studies the conditions for enjoying the rights promised in formal equality. Sometimes a substantive equality analysis incorporates an awareness of subordination. WHO is now very much aware that socio-economic class, ethnicity, and political diversity tend to place some nations at a disadvantage for access to health care.

The discussion of substantive equality is very important in the analysis of WHO's constitution for numerous reasons. First, let us return to Section 55 of the U.N. Charter.

¹⁸ WHO, The World Health Report, 1996, p. 66.

On the principle of equal rights, the UN - through the work of the specialized agencies - is to create solutions for "international economic, social, health and related problems" as well as to instigate international cultural and educational cooperation. In this context, 'equal right' is based upon a substantive rather than a formal sense of equality. When context-specific economic, social and physical features are factored into the provision of health, WHO must be willing to accommodate for a wide range of needs in a given area.

P3 and P9 of the WHO constitution promote substantive equality. P3 and P9 are principled upon a substantive conception of equality. Although I have identified P3 as an expression of formal equality, it also serves as a foundation for WHO's 'Health for All' initiative. Health of all peoples expresses the formally equal right to health. At the same time however, exactly what this right entails necessarily differs from one situation to another.

The Health For All by the Year 2000 (HFA2000) campaign provides a strong example of WHO's commitment to recognize substantive equality. In "Blueprint for Health For All," Halfden Mahler writes:

[I]t is both unrealistic and undesirable to seek worldwide uniformity in such matters [as health access]. Yet social justice demands that all citizens of the world reach an acceptable level of health that permits them to lead socially and economically productive lives. Each society must determine what is essential in keeping with its social expectations and economic capacity.¹⁹

Formal equality is implemented in the policy that all humans receive basic health care.

On the other hand, the call for substantive equality requires that policy makers acknowledge the different levels of need in different regions, nations, and municipalities.

On the basis of substantive equality, Mahler advocates distributive justice. Not only does he want to change the amount of medical funding to increase it in developing countries, he also wishes to radically change the type and direction of funding that is entailed by HFA2000. Health is not a commodity present for those who can afford it. Instead, Mahler's vision is to redirect health plans to cater to the poorest communities in the world. Only then would the disparities between the elite and the most impoverished be decreased. HFA2000 is a campaign that attempts to raise the level of health of those living in extreme poverty; it is an appeal to change the direction of funding from medical technology to the affordable field of primary health care. Hopefully, HFA2000 will prioritize the needs of the poor, and the wealthier nations will understand and contribute to the increase in the quality of life of every global citizen.²⁰

On the presumption that individuals ought to be treated substantively equally, WHO must move beyond simply acknowledging that contexts and relationships restrict individual actions. The organization needs to provide the means for alleviating disparities in health access between and within nations. P9 requires WHO to persuade national governments to act in accordance with the different health needs of individuals who fall within their jurisdiction. This appeal to governments suggests that WHO is promoting a horizontal approach to gauge health requirements around the world.

HFA2000 concretizes WHO's efforts to actively deliver services for individuals who can identify but cannot meet their own health needs. HFA2000 relies on P9 in its

¹⁹ Halfden Mahler, "Blueprint of Health for All", WHO Chronicle, 31, No. 12, p. 491.

²⁰ Mahler, WHO Chronicle, 31, No. 12, pp. 492-495.

appeal to national governments to take up the responsibility to care for its citizens, and to determine what "health and social measures are 'adequate' in the fulfillment of health goals. By inciting national governmental bodies to act on their countries' behalf, WHO is offering a forum for individuals to voice their specific'health needs. Mahler's HFA2000 lays out the pivotal role that governments have in the redirection of health care systems toward catering to the people's requests. Insofar as WHO's role is to act as health politicians to generate the political will in order to make the transition from a biomedical model of health to primary-care strategies, state governments and regional committees have duties to fulfill as well. Governments must be willing to forego making other economic commitments; that is, they must develop the political will to focus on health policy-making, and to ensure that health and social measures, which are pertinent to the peoples, are provided on a bottom-up basis.²¹

Unfortunately, WHO faces international resistance to embrace HFA2000. Indeed, policy makers have a daunting task to gauge the effectiveness of revising and creating health care systems.²² In order to convince governments of the merits of HFA2000, policy-makers have used scientific approaches to quantify the benefits of standardizing health management systems. WHO utilizes DALY (Disability Adjusted Life Years) as an analytical tool in the assessment of the quality of life of individuals. DALY measures the

²¹ Mahler, WHO Chronicle, Vol. 31, p. 495.

²² Goran Sterky, Kim Forss, Bo Stenson, <u>Tomorrow's global health organization: ideas and options</u>. (Stockholm: Nordstadts Trycheri AB, 1996) p. 79.

burden of disease on an individual; it is expressed in terms of the years of life lost to premature death and the years lived with a disability.²³

WHO justifies measuring the burden of disability and disease within a primary health care framework. First, DALY quantifies and adapts incongruent country-specific health summaries from which outputs for intervention, program evaluation and planning are measured. Second, WHO can use DALY statistics in its setting up of health research and service priorities. Third, WHO can identify disadvantaged groups and develop health interventions accordingly.²⁴ DALY measures not only the effects that infectious diseases have on one's life; it is also used to evaluate one's life in relation to non-infectious conditions (e.g., cancer) and injuries. DALY summarily quantifies any activity or condition which affects the human life span. These statistics have been used to evaluate situations spanning from domestic violence and road traffic accidents to infectious diseases.²⁵

DALY measurements are premised on the scientific characteristics of quantification, generalization, prediction and simplification. This method assumes that qualitative analyses of health are quantifiable. From quantified and organized data, human actions and situations are generalized. In "Quantifying the Burden of Disease," C. Murray grounds DALY assessments upon Rawls' "original position", a thought experiment where a group of individuals, ignorant of one another's social position, age, sex and other identifying characteristics, must choose the values and institutions which

²³ One DALY = one lost year of a healthy life. See WHO, World Health Report, 1999, p. 15.

ought to run the society.²⁶ In other words, a formal sense of equality undergirds the application of DALY as a health analytical tool. The individual is abstracted to the point that only age and sex are used to differentiate his/her health status from others. Murray explains that to use attributes such as race, ethnicity or political beliefs as distinctive characteristics would lead to the development of discriminating health practices.

Furthermore, in practical terms, treating like health outcomes as like allows one to compare the burden of disease across the board, regardless of community or region.

Otherwise, researchers could not make sense of individual-specific health outcomes.

Reliable health policies are predicated upon the generalization of the environment upon and the abstraction of individual experiences. In subsequent chapters I will show that the 'scientification' of primary health care detracts from Mahler's vision of advancing substantive equality.

2.3 Toward a Critique of WHO's Definition of Health

WHO advances health, formal equality and substantive equality as values that ground (and are elucidated by) its health policies. These values are implicit in the constitution; only through the actualization of the principles are the values themselves realized. Tensions exist between the promotion of formal and substantive equality. Without the latter, the former offers an empty promise to treat individuals equally. Unfortunately in order to convince governments of the latter, WHO adopts scientific

²⁴ C.J.L Murray, "Quantifying the burden of disease: the basis for disability-adjusted life years," <u>Bulletin of</u> the WHO, 72, No. 3, p 429.

methodologies such that focus falls back onto the former. Somehow, WHO must strike a balance in its engagements with formal and substantive equality; otherwise, it cannot achieve the ultimate task of articulating health as a value and effectuating the subsequent goods—the alleviation of poverty and the advancement of peace—that are linked to health.

These tensions are reflected in WHO's inclinations to favor disease control strategies over primary health care. Does the prioritizing of disease programs exacerbate the tension, so that the constitutional values are rendered unattainable? Perhaps deconstruction of WHO's definition of health will explain why and how the organization is overwhelmed by these problems. The most interesting challenge to WHO's health emerges from a critical analysis of disease. The next three chapters are devoted to examining the metaphors which inform our understanding of disease. Based upon the conclusions that I draw from this investigation, I will return to the WHO constitution and offer some tentative recommendations for revision.

²⁵ See The World Health Report, 1990, p. 18.

²⁶Murray, p. 430.

understand how these metaphors can be used to discriminate against vulnerable persons. Finally, I discuss how metaphors either define or are constructed upon disease discourse. Susan Sontag's evaluations of the metaphors surrounding TB and AIDS are useful for initiating a detailed feminist analysis of disease at the macro- and micro-level in Chapters Four and Five, respectively.

3.1 A Feminist Understanding of Context

Why is context so important? First, feminists believe that concrete situations should be the starting points of any ethical analysis.³ They believe that moral agents cannot be abstracted from their socio-political economic and historical situations.⁴ Only when individuals are measured in relation to other individuals and/or to the cultural, political, historical structures themselves can a feminist determine whether social justice is attained or obstructed. An individual's context often reveals how s/he is constrained to act or prevented from fulfilling a desired goal. Feminists argue that in the process of abstracting from the particulars, moral concerns often imbedded in the contextual details are lost. Second, a contextual analysis favors subjective over objective viewpoints. That is, an individual's interpretation of a situation is central to a feminist analysis of ethics. A subjective interpretation of the context foregrounds issues and ideas, otherwise ignored in an 'objective' analysis of the situation.⁵

² Ibid. p. 54.

³Carol Robb, "The Framework for Feminist Ethics" The Journal of Religious Ethics, 9, No. 1, p. 50.

⁴Robb, pp. 30-31. Also see Sherwin, No Longer Patient, 1992, p. 53.

⁵ Sandra Harding argues that the merging several subjective viewpoints leads to the development of a 'strong objectivity', one which better represents a collective understanding of the situation. Strong objectivity is presented as an alternative to traditional conceptions of objectivity, which tend to negate the

Many traditional ethicists oppose the feminist focus on the subjective viewpoint. One major concern is that the subjective viewpoint is too specific. The agent tends to become so caught up with her/his position and the particular details of the concrete context that s/he is distracted from finding the real basis of the problem. Feminists counter-argue that the subjective viewpoint enables one to evaluate the situation from a different perspective, meanwhile acknowledging that no perspective takes absolute precedence over others. Feminists are suspicious of any perspective that flaunts an 'objective' world view because this position imposes a moral authority that impedes rather than encourages philosophical revision. Declarations of objective decision-making prevent the declarer from searching for possible biases and privileges that are imbedded into a viewpoint, rendering the position to be as subjective as someone who has an overtly subjective viewpoint. As we shall see, such biases are imbedded in the key concepts embraced by the WHO, contributing to rather than alleviating oppressive contexts.

3.2 Oppression

Regardless of the diversity amongst feminist philosophers, all agree that women are oppressed. From very diverse positions, feminists offer to define and challenge oppression. Marilyn Frye offers one of the first significant definitions of oppression, comparing oppression to a birdcage. Like a bird confined to a cage, a woman is trapped by many different social aspects of her life. Social depictions, economic status, historical affiliations – all systemically imprison the woman, so that she cannot escape her

circumstances.⁷ Frye's birdcage metaphor has inspired further analysis of this key concept. Often, feminists present phenomenological accounts of oppression. However, Val Plumwood looks beyond the specific experiences of women's oppression to suggest that states of domination and subordination exist in a broad range of contexts, and offers a conceptual explanation for the construction and maintenance of oppressive systems.

Plumwood argues that oppression follows a logic of domination. Oppression is supported by the conceptual construction of two roles: the colonized and the colonizer. These roles are hyper-separated, thus creating a logical dualism, which goes beyond a simple difference, dichotomy, or non-identity. The "other" is systematically and pervasively represented as inferior to the dominant pole. Unlike in other hierarchies which are open to shifting, once this dynamic of domination is established, reconfiguration and open dialogue between these radically exclusive sets are not easily conducted.

Plumwood identifies five key characteristics of dualisms: 9 radical exclusion, backgrounding, homogenization, incorporation, instrumentalism. One indicator of dualism is radical exclusion. Members from either the dominant or subordinate group are seen as not sharing any significant common properties. Because of this deliberate maximized polarization, the two spheres cannot form a bridge of contact. Another characteristic of dualism is backgrounding. The dominant group sets aside its recognition and needs of the subordinated group in order to foreground its own directives. In effect,

⁶ Sherwin, p. 63.

⁷ See Marilyn Frye, <u>The Politics of Reality: Essays in Feminist Theory</u>; (Trumansburg: The Crossing Press, 1983); Ch. 1.

⁸ Val Plumwood, Feminism and the Mastery of Nature; (New York: Routledge, 1993); p.47.

⁹ Ibid., pp. 48-54.

the colonizer denies its dependence upon the colonized group, meanwhile relying on the colonized for the establishment of its own identity. Third, an important aspect of dualism is the homogenization of the subordinated group. Differences in individuals who occupy the periphery are negated or minimized so as to legitimate the stereotypes that mark the inferior group's identity. Fourth, the identity of the inferiorized other is incorporated into that of the dominant group. In other words, without the master identity, the inferior group cannot be defined, because the emergence of any qualities of the inferior group depends upon the existing characteristics of the dominant group. The inferior group is defined in negative relation to the dominant set and recognized insofar as it is assimilated into the dominant identity. Fifth, dualisms depend upon the instrumental value of the inferior group. The inferior group is seen as a means through which the dominant group fulfils its own interests. 10 The dominant side uses the inferior as a resource, as something to be manipulated and applied when and if the need arises. The features of a dualismradical exclusion, backgrounding, homogeneity, incorporation, and instrumentalism - are useful tools of analysis in the study of the relationship between any terms collectively introduced in opposite relation to each another.

Let us look at an example to clarify the discussion. Plumwood argues that the historical subordination of women closely follows the logic of oppression. The dichotomization of women and men is not a matter of the identification of simple differences. Rather, the two are hyper-separated and characterized such that women are depicted as inferior to men. The inferiorising of women is marked by the features of a dualism. First, women and men are radically excluded. In 'Western' cultures, desirable

¹⁰ Plumwood, pp. 48-53.

masculine characteristics (such as active, intellectual, competitive...) are contrasted with complementary undesirable feminine characteristics (passive, intuitive, nurturing...).¹¹ Every deprecating female feature corresponds to a meritorious male feature. The endless ascription of these qualities onto women confirms that women are necessarily and unchangeably different from men. Second, women's needs are backgrounded in the prioritization of men's needs. For example, traditionally, women are the primary caregivers for children. Dubbed 'women's labor' very little attention has been given to ensuring that women who care for either their own or other children are reasonably remunerated for their work.¹² From the master perspective, time should not be wasted worrying about work that women are naturally endowed to perform. At the same time, men rely on women's care-giving in order to pursue their own interests. Third, women are homogenized. In keeping with the care-giving example, all women are generalized to be effective and enthusiastic nurturers. From the dominant viewpoint, other aspects of women's individuality are obliterated, and their identities are based upon this care-giving stereotype. Fourth, women are incorporated into the men's domain. As a care-giver, the woman is co-opted to cultivate the dominant other. Her care-giving qualities reflect nothing more than support for the man's public interests. Fifth, the woman's work is instrumental for the man's pursuit of his own goals. In other words, instrumentalism is an outcome of her incorporation into the man's clearly articulated space.

11 Plumwood, p. 50.

¹² Private communication with Genevieve Jones, former Community Outreach Coordinator at Grant McEwan College. In most Canadian provinces, a day-care worker receives minimum wage. To work in a daycare, an individual must receive between 1-3 years. of college training. Ms. Jones has stated that regardless of this education, care-givers are grossly underpaid for their work (esp. in private homes where the care-giver is offered room and board and a monthly stipend, insufficient for living outside of that home).

According to Plumwood, in an oppressive context, new dichotomies easily adopt an hierarchical relationship, thereby reinforcing the context. New dualisms do not replace the old ones; instead, they all accumulate to produce a solid structure of oppression. These pairings vertically interconnect in a polarized manner, such that one half of a dualism is associated with the same half of other dualized pairs. Identification with the subordinated (or dominating) half of a dualism evokes other dualisms, which have either aided in the establishment or formed in consequence of that subordinated position.¹³ Plumwood provides a non-exhaustive list of set pairs, each of which contribute into an interlocking system of oppression. These are: culture/nature, male/female, master/slave, reason/emotion, freedom/necessity, human/nature, civilized/primitive, self/other.¹⁴ Each pair not only exemplifies the logical structure of oppression, it also reinstates and promotes the acceptance of an oppressive dynamic between the dominant self and subordinated other.

Oppressive actions harm both the subordinated and dominant groups. The subordinated group directly suffers from its identification with the inferiorized half of the dualized pair. Because identity is prescribed onto the inferiorized individual, all of her/his actions are defined through that position. The more that dualisms construct the individual's identity the more s/he becomes estranged from the aspects of her/himself that could empower her. The oppressed person's lack of protest serves as a justification for the oppressor's application of dualisms in the construction of the inferior other.

However, the oppressor her/himself is also harmed by the structures of oppression. Although it is incorrect to say that the subordinated oppress the dominating

¹³ Plumwood, pp. 42-43.

group, nevertheless the dualistic construction of oppression itself constrains individuals from both poles to act from a particular identity. Systemic oppression inevitably confines the oppressor's identity to the point that s/he is compelled to appropriate the oppressed in order to sustain her/his own position and identity, much to the detriment of members from both groups.¹⁵

I argue that only through understanding how an individual's occupancy of the oppressor position of one dualism maintains her/his oppressed status in another dualism can one begin to make suggestions for a new identity, one which does not reproduce or reinstate oppressive relationships. On this point, I extend Plumwood's project by suggesting how a 'double-occupancy' advances and maintains oppressive constructions. I will return to this discussion in a later chapter. For now, I would like to explore further the moral implications of groups and individuals entrapped in oppressive relationships.

In the following section, I will investigate the types of harms endured by the oppressed. My main focus is to present a conceptualization of symbolic harm, which is crucial for the subsequent discussions on WHO's efforts to accommodate 'health for all' within the framework of infectious diseases.

3.3 Symbolic Harm

An oppressed individual is materially and symbolically harmed. The material consequences are readily measurable in contrast to symbolic harms. Indeed, many

¹⁴ Ibid., p. 43

¹⁵ Plumwood warrants this claim. Recall that the oppressor relies upon the oppressed in order to construct and sustain his own identity. See Plumwood, 1997, pp. 51-53. One could counter-argue that the foregrounding the oppressor's experience of harm only reinforces the backgrounding and instrumentalizing of the oppressed.

feminist writers limit the articulation of oppression to citing the negative socio-economic effects affiliated with the oppressed state. For example, feminists argue that in the workforce, a woman's oppressed status is defined by: the attainment of lower incomes for the same work as men, exclusion from managerial positions, lower status for engaging in "women's labor" (i.e. providing child-care, which may or may not generate an income), etc. The presentation of empirical evidence for oppression-related outcomes, however, is bereft of a more conceptual analysis of oppression. Plumwood has offered a logical explanation for the maintenance of oppressive relationships. The next task consists of examining how one's status of personhood is fundamentally affected by an oppressed identity. This investigation may be insightful for feminists who struggle to broaden their understanding of oppression beyond the reporting of material outcomes.

Like material harms, symbolic harms are consequences of oppression, however the type of analysis that a symbolic harm entails contrasts from the descriptive presentation of material harms. A symbolic harm is defined as a deontological affront to an individual's personhood. The term 'deontological' is not to be understood in general moral terms where moral duties exist regardless of the consequences. Instead, a specifically Kantian notion rivets one's attention to the moral duties that arise in someone insofar as s/he is a (rational) member of the kingdom of ends. Thus, a 'deontological affront' is something that threatens an individual's membership, such that her/his role as an active, autonomous subject becomes questionable.

How is personhood compromised or obliterated? In "Symbolic Harm and Reproductive Practices" Elisabeth Boetzkes answers this question. Boetzkes defines symbolic harm in three ways, two of which will be discussed here. One form of symbolic

harm occurs through a *devaluing of personhood*. In this case, the oppressed individual is recognized as a person, however her/his interests count as less than the oppressor's desires. The oppressed individual's personhood is devalued insofar as other aspects of her/his identity are disproportionately minimized and replaced with an exaggerated attribute, one which reduces and essentializes.¹⁶

Another form of symbolic harm is the *denial of personhood*. A person who fails to be recognized as a person is harmed. Characteristics that qualify an individual as a decision-maker are replaced with attributes that mark her/him as objects available on demand for the oppressor. In effect, the individual is no longer respected as a subject in her/his own right, and is dissociated from self-determining individuals.¹⁷

The two expressions of symbolic harm interrelate in a complex manner. The devaluation of personhood and denial of personhood can be differentiated on the basis of a quantitative analysis. They can be described as occupying two poles on a continuum of symbolic harm, such that the denial is the most extreme outcome of the devaluing of personhood. Certainly, it can be argued that extreme stereotyping can result in the complete objectification of an individual. However, a quantitative analysis diverts attention away from the moral implications that arise from a qualitative analysis of these symbolic harms. Qualitatively, the devaluing and denial of personhood are remarkably different, such that the former reduces the moral worth of a person as a person, whereas the latter wholly excludes the individual from the kingdom of ends.

¹⁶ Elisabeth Boetzkes, "Symbolic Harm and Reproductive Practices" accepted for publication in <u>Current Legal Issues 3: Law and Medicine</u>, (Oxford University Press), p. 9. Note: the page number indicates those that match the pre-publication page numbers. This draft was used by the author in a graduate Feminist Bioethics course at McMaster University, Spring 2000.

¹⁷ Boetzkes, p. 8.

Boetzkes discusses symbolic harm within the context of Contract Pregnancy (CP), ¹⁸ clarifying the classification of symbolic harms and the moral implications of these categorizations. CP leads to the devaluing and/or denial of a woman's personhood. First, a woman's personhood is devalued in cases where her identity is *reduced* to that of a 'breeder' or 'incubator'. Condoning CP presupposes accepting the woman's role to be an instrument for the asking couple. The practice degrades the woman's status as a self-determining individual, because her actions and behavior are often constrained by the regulations imposed upon her by the contracting couple. This devaluation evokes the mind/body dualism, in which the gestating woman represents a consenting 'bodily' means to fulfil the couple's intentions.¹⁹

Second, in the case of CP, a woman whose identity is *restricted* to a 'human incubator' is denied personhood. The woman represents nothing more than an instrument or means to achieve the ends of others. It is in this incomplete identification of womanhood that the woman is defined. Her rationales for wanting to be a contracting mother - such as supporting her other children, renovating a house, purchasing a house, etc.²⁰ - are not meaningful for those who see the woman as a non-person. In the

¹⁸ Contract Pregnancy (CP) is a reproductive practice in which a woman is commissioned to gestate for an asking inferitle couple, with the agreement that she will surrender the baby to the couple upon conception. Often, the gestating woman receives a nominal fee for her 'work'. In some cases money is not exchanged, and it is argued that CP is moral on altruistic grounds. In "Symbolic Harm" Boetzkes adheres to the first type of CP, where the contracting couple pays the gestating woman. Her understanding of CP is very much aligned with Christine Overall's explanation of Surrogate Motherhood in "The Case Against Legalization of Contract Motherhood", Human Reproduction: Principles, Practice, Policies (Oxford: Oxford University Press, 1990), Ch. 7. For an in-depth look at non-commercial cases of CP please see Uma Narayan's "The "Gift" of a Child: Commercial Surrogacy, Gift Surrogacy, and Motherhood" in Expecting Trouble: surrogacy, fetal abuse, and new reproductive technologies, P. Boling (ed.), (Boulder: Westview Press, 1995). An excellent source of legal and ethical discussions on CP, please see Reproduction, Ethics and the Law, Joan C. Callahan (ed.), (Bloomington: Indiana University Press, 1995), Part One.

²⁰ See Lori B. Andrews, "Surrogate Motherhood: The Challenge for Feminists" in <u>Surrogate Motherhood</u>: <u>Politics and Privacy</u>, <u>Larry Gostin</u> (ed.), (Bloomington: Indiana University Press, 1995), p. 235. Andrews

mind/body dualism, the woman is simply a means for the fulfilment of the couple's intentions.

Many critics are skeptical of symbolic harms. Yet, dualisms (and their construction) establish grounds for the identification of symbolic harms. Wherever Plumwood maps the logic of a systemically inferiorized identity, Boetzkes explores the moral implications of such a logic for the oppressed person. These dualisms take on metaphorical roles in the construction and maintenance of oppression through which means the oppressed are harmed.

One of the ways in which dualisms tend to oppress is as metaphors. Dualized metaphors depend upon an oppressed framework to reinstate the oppressed person's inferiority. In the next section, I suggest that 'health' and 'disease' are dualistically constructed, where knowledge of disease arises from the stigmastizing of infectious diseases and persons affiliated with those conditions.

3.4 Metaphors of Health and Disease

Prior to a feminist critique, it is taken for granted that health and disease are necessarily opposites. In the abstract discussion of 'health' and 'disease' these attitudes are prevalent. From an individual assessment, diseases are something which harm and possibly debilitate the body, and physically prevent one from fulfilling his/her other goals. Outside of any social context, diseases can be understood in terms of incorporation and instrumentalism. First, disease, in negative relation to health, is incorporated into the identity of health. Health is the primary objective. Characteristics

of disease are informative insofar as they indicate how one is obstructed from achieving health or why health is absent; thus, the definition of disease is created in contrast to the goals of health. Second, disease is instrumental to the understanding of health. 'Disease' is utilized as an identification of a lack of health such that the proper course of treatment leads to the state of health. Even in abstraction, the relationship between health and disease is characterized by aspects of a dualism. But the scope of the dualism is only revealed by examining its application in a specific context. In a social context, the terms 'health' and 'disease' do not merely designate states of physical well-being, they also present social categories of human identity, where one category (health) is preferred over another (disease).

Infectious diseases more than any other conditions create a popular conception of unhealthy conditions. Physiologically, infectious diseases are often easily identifiable. Indeed, the most infamous diseases such as TB, Syphilis, AIDS all physically distort the body. In many countries, for example, the local term for AIDS literally translates to "wasting" because body weight is drastically reduced in the infected individual. Epidemiologically, for many individuals the risk of infection elicits fear and the adoption of cautionary measures. Knowledge of the threat of infectious diseases has one alter his/her behaviour, whether they be sexual, dietary, or social changes. Geographically, the uneven distribution of infectious diseases as well as their sporadic, unpredictable spread creates large pockets of unhealth, worldwide. For example, from the statistic that 30% of the Ugandan population is HIV+ arises the idea that Uganda is in a state of unhealth of

epidemic proportions. Physiological, epidemiological, and geographical features of infectious diseases characterize the popular conception of diseases in general.

Below I wish to discuss the metaphors surrounding Tuberculosis and AIDS. Both have significantly influenced our understanding of diseases, and they continue to change the shape and perception of our world.

3.4.1 Tuberculosis

The association between TB and humans has been traced back as far as ancient Egyptian times.²¹ TB, initially thought to be a physiological condition, has propagated a public understanding of disease that evokes passion and repression, wealth and poverty, creative poise and artistic malaise. It also evokes fear of the unknown and resignation. Ultimately TB has become another means to characterize the self, the self in relation to others, and society as a whole.

According to Sontag, the romanticizing and metaphorizing of TB signifies the first major promoting of the self as an image. The diagnosis of TB gave a person an identity; it evoked a mark of distinction, and it provided a rationale for a psychological sense of malaise.²² In Victorian times, TB came to signify refinement, artistry, and wealth. Often, people would look onto the TB+ person with envy, because her/his invalidism presupposed a life of leisure; while others earned their keep, s/he had the time to be ill.²³ Deeper still, a person with TB signified a melancholic character - sensitive and creative. The link between creativity and TB did not condemn the artist; rather it

²¹William H. McNeill, <u>Plagues and People</u>, 3rd ed., (New York: Doubleday, 1998), p. 187.

²² Sontag, 1989, p. 30.

²³ Ibid., pp. 35-36.

elevated him above others (both figuratively and literally) to live in wide open spaces on mountain tops where he could create and recover.²⁴

TB incidence reached its peak in the 17th century in European populations. In this time period, people were thought to be 'consumed' by this unpredictable disease.²⁵ The term 'consumption' evokes the imagination. For the wealthy, TB-infected individuals are consumed by passion, too much ardor. The repression of those passions precedes and catalyzes fevers, which release built-up desires.²⁶ But TB was and is disease of the poor as well as the wealthy. For the poor, consumption is a sign of the individual's inability to fight off poverty. They are consumed by deprivation, malnutrition and poor hygiene.²⁷

Furthermore, TB has come to signify menace and medical futility. In the age of antibiotics and vaccines, TB continues to mutate and to confer resistance to these drugs. Its persistence elicits images of the disease's awesome capacity to cause death in humans. TB threatens human existence, depicting nature to be an adversary of humans. Like a fire, it consumes and destroys everyone in its path.

Emergent TB metaphors are incorporated into the popular conception of disease.

Other infectious diseases such as AIDS contribute to and combine with TB metaphors in the popular construction of diseases in general.

3.4.2 AIDS

AIDS is a relatively new disease in human history. From the first diagnosis of AIDS in the early 1980's, the disease has swept into almost every human consciousness.

²⁴ Ibid., p. 32.

²⁵McNeill, 1998, sp. 287.

²⁶Sontag, pp. 18-20.

Many metaphors arise from the AIDS epidemic. First, the AIDS label associates an individual with deviant behavior. Because the disease initially appeared to be limited to the gay population, AIDS was soon seen as a 'gay disease'. Until AIDS, people engaging in same-sex relationships were marginalized from the mainstream. AIDS brought homosexual relationships into public view where these sexual interactions were condemned as being deviant, unnatural and immoral. Substance-users too were brought into the public imagination to be condemned in their HIV-sero-positive status.

Second, the association between AIDS and social deviance has led to another metaphorical understanding of AIDS: punishment. In the early days of the epidemic, medical professionals encouraged the use of fear as a means to halt the spread of the disease. Conservative religious leaders used (and continue to use) the 'punishment from God' argument to prevent the public from participating in activities which tended to put them at risk for infection. In the process, 'risk groups' came to signify not only a risk for HIV transmission, but also a risk of acting immorally. As a result, today persons associated with these groups are condemned.

Both AIDS and TB have provoked intuitively denigrating conceptions of disease in the public conscience.

3.4.3 Metaphorical Use of 'Disease'

The public perceives disease as depicting negative states of being: deviance, poverty, menace, punishment and ultimately death. These metaphors are not confined to describing physiological conditions. In fact, diseases themselves have been used

²⁷Ibid, p. 13.

4.1 Context

The question arises: (How) Are individuals affected by disease metaphors?

Metaphors of 'disease' and 'health' have been used in many different contexts. In order to determine whether or not the dichotomy of health and disease follows the logical structures of oppression, the context in which these terms are adopted must be described. If the health/disease dichotomy causes symbolic harm, and if that harm reinforces existing dualisms and further entrenches the oppressed individual's state of subordination, then the dichotomy is itself dualistic.

4.1.1 Setting up the specific context: "Third World" Africa

One way to contextualize the discussion of health/disease is to follow the route of spread of actual infectious diseases. Geographically, the world's poorest countries tend to experience the most serious bouts of infectious diseases. It is important to determine how 'disease' is understood within this context for two reasons. First, because of the dualistic metaphors already associated with poor countries, if the disease/health dichotomy is in fact oppressive, then the severity of its oppressive power is most clearly shown within this setting. Second, if disease and health can be dualistically constituted into this context, then WHO must consider the possibility that its definition of health may oppress the very groups that the organization is mandated to protect.

Let us return to the discussion of TB and AIDS. Higher rates of infection for both diseases are found in poor rather than wealthy areas. First, despite the romantic stereotypes surrounding consumption, TB often infects persons living in poverty conditions. People in closed and confined quarters are vulnerable to this air-borne

disease. Poverty prevents these individuals from renovating their housing or moving into a larger space. However, TB is only one of several diseases which seem to target the poor. Second, AIDS is another epidemic which strikes poorer populations. Indeed, of all persons who are HIV+, over three-quarters of them live in sub-Saharan Africa. The poorest countries in the world are overrun with infectious diseases.

Yet diseases alone do not ascribe an identity onto persons living in these countries. These citizens have long endured numerous stereotypes which alienate them from the healthy other. The disease/health dichotomy is defined within the context of the following dualisms already affiliated with persons dwelling in the poorest countries: Third/First World, colonized/colonizer, developing/developed, witchcraft/science, primitive/technologized, rural/urban. The left side of the dualisms are features assigned to the person coming from the poor country. These dualisms signify a history of oppression of the world's poorest by the wealthiest nations.

In order to understand the extent to which health and disease may oppress in a particular context, one must look at the historical establishment of dualistic metaphors which presently set up the oppressive context. I will look at Sub-Saharan Africa as a case in point to which all of the First/Third World dualisms apply.

Not all contexts have been created equal. Over the years, Sub-Saharan Africa has accumulated numerous dualisms that together form an imposing structure of oppression. Powerful metaphors of oppression applied against "Third World countries" are epitomized by the continent of Africa. Every term corresponds with an oppressive counter-term. The words which are often applied to Sub-Saharan Africa - colonized,

Third World, developing, witchcraft, primitive, rural - reflect a history of oppression between that region and those attempting to master it.

The dualistic metaphor of colonized/colonizer, emerges from actual practices of colonization of all African countries. As early as 1492, European travelers explored African soil. By the early 1900's, Europe alone had control over approximately 85 percent of the world's community, in which time nearly all of Africa was colonized. According to Uma Narayan, the secret behind Europe's colonial power was in presenting the colonization to be in the interests of the colonized.

The term 'colonization' has served as a crucial metaphor from which new terms derive oppressive meaning. As the basis for the adoption of new dualisms, 'colonization' is a strong metaphor because the oppressor is equated to 'colonizer', a term that connotes power, control, and ownership, while the oppressed is described as 'colonized', a term that connotes weakness and lack of control. Colonization evokes the image of an authority figure who comes in to make decisions for the helpless other. Because of the powerful image that 'colonization' arouses, new dichotomized metaphors easily fit into and justify the assignment of the oppressor and oppressed identity. That is, colonization metaphors appropriate expert/layperson dichotomies such that colonizer and colonized correlate with expert and layperson, respectively. Like the colonizer the expert is in a powerfully privileged position; this power derives from having access to knowledge, which eludes the layperson who must rely on the expert for the attainment of that knowledge. The expert in its correlation with 'colonizer' is granted the authority to disseminate knowledge

¹Uma Narayan, "Colonialism and Its Others: Considerations on rights and core discourses" in <u>Hypatia</u>, 10, No. 2, p. 133.

²Ibid.

from the oppressor perspective. Reciprocally, the colonizer is endowed with another expression of his position: expertise.

Today, in the public consciousness, Africa symbolizes a land of famine, tribal wars, poverty, primitivism, hopelessness, a land in constant need of colonization. And the popular 'Western' culture feeds into this depiction. On the 17th of January 2000 issue of Newsweek the words "10 million orphans" are written below the face of an African child. In a May issue of The Economist, a photograph of an African man holding an automatic rifle is cut into the map of Africa. The caption reads, "The hopeless continent". Finally, in a recurring 20-minute commercial for a non-governmental organization, a popular Canadian actress spends time in an African village. In the commercial, this actress visits a mud-thatched house, where the owner silently yet proudly displays how food is stored, where family members sleep, etc. The actress does not directly talk to the woman. Instead, she directs her attention onto the camera and quietly states her shock with these abhorrent living conditions: the small size of the hut, the holes visible through the ceiling, the dirt floor. At the end of the commercial, the actress is seen playing with a group of African children, who have made a ball by winding string and thread together. But the ball is not good enough, it symbolizes the African lack of consumerism, the lack of buying power. The actress brings out a shiny, red, plastic ball as the children's eyes light up.

All of these examples contribute to dualistic metaphors, which make up the oppressive context in which 'disease' and 'health' are understood. The *Newsweek* magazine attempts to evoke pity; the image of the child triggers ideas of helplessness. innocence, desperation. It promotes the view that the Western gaze is that of the adult, a

position of power from which changes can be made. 'Africa' is subordinated in relation to Western culture. Africa is relegated to the oppressed half of the adult/child, strong/weak dualisms. *The Economist* cover page reminds the reader of other dualisms which shape our view of African life. The man in the photo, carrying the gun and a look of contentment on his face evokes the dualisms of civilized/savage, international/tribal, hopeful/hopeless, peace/war. In this case, the 'Western' reader dissociates from all of the terms which reinstate the oppressed standpoint, and chooses to associate with the positive metaphors of civilized, peace, international, etc. The "values" of the Africans are made to be unlike the values that peace-loving developed countries embrace. This image of savagery evokes the Westerner's exasperation and frustration with the entire continent of Africa for no one can imagine forcing these 'savages' to change their tribal practices. By reminding Westerners of the many characteristics that distinguish themselves and the Africans, a greater chasm is created between the oppressor and oppressed standpoints.

Third, the television commercial establishes yet more dualistic metaphors of Africa - primitive/technologized, developing/developed, producer/consumer, backward/forward, colonized/colonizer. It is up to the White person to show the Africans what they do not have according to the commercial. 'Western life' is the model against which the house and ball - all African life - are measured. Furthermore, the commercial assumes that without the aid of 'developed' countries, Africans will continue to live a primitive, ignorant life. Here, as Narayan has suggested, colonization takes on the guise of helping and promoting the welfare of the subordinated other.

Popular depictions of Africa are authoritative. Media images promote and legitimate the use of dualistic metaphors that oppress Africa. Furthermore, by

Westerners are radically excluded. So many dualized metaphors are placed to distinguish the African from the Westerner that the two positions have become polarized. We will later find that these and other features of oppression perpetuate the spread of diseases.

What are the moral implications of these metaphors? Anyone associated with Africa is vulnerable to a devaluing or denial of personhood. In other words, they are symbolically harmed. First, Africans experience a devaluing of personhood. Metaphors of savagery and primitiveness promote the 'Westerners' disapproval of 'African' behavior. Although human, Africans are depicted as having chosen to behave less morally than their Western counterparts. From a Western perspective, Africans have diminished their right to be treated equally. Second, these metaphors lead to the denial of personhood. According to bell hooks, stereotypes take the place of what is real. Stereotypes prevent one from hearing about lives not depicted within the oppressor context. By adopting these images of Africa, 'Westerners' deny that African individuals have their own stories to tell. That is, individual identities are melded into an unsubstantiated common unity; subjective viewpoints are objectified in the eyes of and to make sense for the dominant group.

Up to this point, I have laid out a context into which the language of 'health' and 'disease' will be introduced. Understanding of the context is crucial for understanding the meanings that people will place onto 'health' and 'disease'; the context determines the uptake. In the Third/First World context where group identities are molded and divided based upon affiliation with one half of the dualized metaphors, 'health' and 'disease' take

³Masolo, "Some Misleading Abstractions About Identity" in <u>Post-colonial African Philosophy: a Critical Reader</u>, Emmanuel Chukwudi Eze (ed.), (Cambridge, Mass.: Blackwell Publishers, 1997) p. 291.

on dualized identities; they become words that reaffirm other dualistic metaphors already in place, substantiating the oppressor/oppressed identities. Disease legitimates oppression insofar as it reinforces and is defined through an oppressive context.

4.2 Third World Africa: Disease metaphors oppress

In the "Third World", disease easily conforms to and is defined through the accepted dualisms. Disease is perceived through its affiliation with other terms of the oppressed. 'Disease' is justified by and justifies the use of other dualized metaphors. First, it is understood within the context of the oppressed/oppressor relationship and within the language which has set up the hierarchy. Within an oppressive context, oppressed persons are vulnerable to adopting a new identity, one made up of half of the dualistic metaphors cemented into the context. Because of the metaphorical divisions that distinguish the 'Third' and 'First' world, 'disease' not only represents poor physical status, it also comes to be known as a state of poverty, war, primitivism, backwardness in short, 'disease' is associated with *the* "African" identity. Thus the definition of disease is politicized, defined through our perception of the dualized metaphors that describe Africanness.

Second, dualized metaphors themselves not only clarify but also validate the meanings of the very metaphors that enabled its dualized integration into the context in the first place. Disease itself describes conditions that are devalued, unwanted, repulsive. Thus these negative metaphors contribute to our knowledge of the African identity. New metaphors of disease increase the denigrative and devaluing vocabulary of the oppressed

⁴bell hooks, "Representations of Whiteness in the Black Imagination", Black looks: race and

African identity. For example, writers can say "the practice of witchcraft diseases the Africans from adopting the rules of science" or "Africans are plagued by tribal wars." As a result, 'health' takes on the identity of and adds another facet of control onto the oppressor, and disease becomes another identity of the oppressed.

What is the significance in stating that the determinations of health and disease follow and reinforce the structure of oppression? First, the discussion of oppression is not strictly a matter of academic interest. People's lives are shaped by their social circumstances. Groups of people can be greatly discriminated against on the basis of being 'diseased'. As a metaphor, disease evokes images of moral and social disvalue. Coupled to other dualistic metaphors as well as to geographical locations which express its power and pervasiveness, the effects on those so labeled are catastrophic.

Disease metaphors are forceful. They clarify the conception that tribalism and witchcraft hinder development. They emphasize the severity with which tribalism and witchcraft stagger development. Finally, 'disease' evokes the imagination, denigrating Africans further, because it establishes new metaphors to describe the dualisms already in place. Rather than being a term which can dispel the myth of the African identity, 'disease' perpetuates the association of African with the dualized metaphors that have constructed the African stereotypes.

Our so-called "knowledge" of Africa offers a case in point about the oppressive power of 'disease'. Africa is bombarded with oppressive metaphors. These metaphors distinguish Africans from all that is good.⁵ At the same time, epidemiologically, infectious diseases like AIDS and TB are amongst the greatest cases of death on that

continent. In a context where the oppressed are well-defined by multiply subordinating metaphors, 'disease' is easily integrated into that identity. The face of AIDS is African. At this point, disease no longer only defines a state of being, it defines a social identity, an actual person or groups of people. The African takes on the role of 'patient', which in turn designates the Westerner as 'doctor'.

In a context where colonization has long established roles for those who provides aid and those who requires it, the patient/doctor dualism offers a medical impetus for recolonizing the subordinated other. In effect, a person from Africa is rendered powerless to make decisions for themselves because metaphors of 'primitive' 'backward' developing' describe the African as not knowing what is best for him/herself. In terms of medical intervention, the African has very little political power to challenge the types and amount of medical aid that 'Westerners' bring into the continent. Why? For every metaphor that subordinates the African an 'opposite' metaphor reinforces the oppressor's position of power.

The metaphor of colonization has enabled other metaphors to serve as justifications for intervention. Africans need to be colonized on the basis of being unscientific, uneducated, immoral, poor. Any medical solution that Africans present is understood within the dualistic metaphors that oppress them. For example, recently, South African president, Thabo Mbeki, announced that he was willing to investigate the possibility that HIV does not cause AIDS. He has garnered the support of Peter Duesberg and David Resnick, two U.S.-based AIDS researchers who believe that HIV is

⁵ Good is defined in terms of aesthetics, development, culture, morals.

harmless and does not cause AIDS.⁶ Mbeki states "As Africans we have to deal with this uniquely African catastrophe" and to simply accept Western conventional wisdom in AIDS is "absurd and illogical." U.S. government officials and AIDS researchers are outraged with the preposterousness of ever questioning the link between AIDS and HIV. Mbeki has been labeled as "contrarian", and "proud", and that his flirtation with "weird science" could cause great human suffering as a result of "challenging the fundamentals of AIDS science." Upon hearing this, one is faced with a dilemma between siding with Mbeki who has stood up to "scientific authority" to challenge Western medicine, and siding with the researchers who have repeatedly shown that HIV is the cause of AIDS and that time spent debating the legitimacy of this foregone conclusion takes away from researching ways to prevent the further spread of the disease. In the next chapter I will show that in fact there is a way out of the dilemma. For now, I wish to show that this example illustrates how persons who are associated with the oppressed are discredited on the basis of that standpoint. Mbeki is depicted as being unable to discern good from bad science, as not caring about the lives of 25% of the South African population who are HIV+, and as dogmatically challenging the U.S. for the sake of national pride. On the basis of Mbeki's glaring ignorance of AIDS pathology, U.S. officials discount his appeal to think of other ways to stop this disease.

In the context of a dualistic relationship between Africa/Non-Africa, Mbeki's statements are not authoritative. Although he attempts to defy the fundamentals of AIDS science and those who claim ownership of that knowledge, his identification with the

⁶ Please see Peter Duesberg's "Non-HIV Hypothesis Must be Studied More Carefully", <u>BMJ</u>, Vol. 312; "Is HIV the cause of AIDS?," <u>Lancet</u>, Vol. 346; "HIV is not the cause of AIDS," <u>Science</u>, Vol. 241.

⁷ See Tom Masland and Patricia King's "Flirting With Strange Ideas," <u>Newsweek</u>, 17 April 2000, p. 36;

oppressed group causes his statements to misfire. Mbeki's detractors rely on stereotypes of African primitiveness in order to downplay his concerns that of all the money that has gone into AIDS research, very little has been distributed to Africa, a continent which houses over 75% of the world's HIV+ persons. In negating Mbeki's position, the "West" makes a number of reinforcements. First, it substantiates the stereotype of the primitive, reactionary, backward Africa. Second, it validates the use of dualized metaphors to denigrate and devalue Mbeki's identity. Third, the West confirms its residence in a position of power in relation to Africans. Oppressive dualisms are used as effective tools to silence the subordinated other. According to "Westerners", Mbeki and other Africans have been shown not to have anything valuable to contribute in terms of finding a solution for the AIDS epidemic. Thus, without Western intervention, Africans can only passively suffer from their diseases; Africans are thus objectified to the point that they are indistinguishable from the diseases that they may or may not carry.

4.3 Third World Africa: Disease metaphors cause symbolic harm

The uptake of health/disease occurs within a construction of established dualistic metaphors. Disease as metaphor causes symbolic harm in a "Third-World" context. In the context which already has been associated with actual diseases, the term 'disease' represents more than just a designation of physical dysfunction, it connotes a state of undesirability.

John Jeter, "Mbeki v. AIDS Experts," <u>The Washington Post</u>, 16 May 2000, Section A1.

8 Interestingly, health/disease is historically closely affiliated with the colonization of Africa. It was through many colonizing expeditions that soldiers first encountered tropical diseases, and were subsequently killed off by diseases like Yellow Fever, Malaria, and Amoebic Dysentery. The 'conquest of Africa' also came to mean a conquest of tropical disease, forming an association between Africa and the

Africa's association with disease presents a means to devalue or deny the personhood of individuals who comes from that region. First, the 'disease' label causes harm in that it devalues personhood. For example, a person from Africa who may or may not have AIDS might be stereotyped by the very metaphors that surround the disease itself. She may be judged as being promiscuous, drug-addicted, deviant, lesbian, etc. AIDS metaphors (and disease metaphors in general) create a stereotype of the infected person, who then must struggle to break out of the inappropriate characterization. Second, she is denied personhood insofar as the term 'disease' defines who she is. Other characteristics of her existence become meaningless in relation to that designation, unless these characteristics aid in the "diseasification" of that individual. Recall that the HIV+ person who lives in Sub-Saharan Africa is simply the "face of AIDS". No other aspects of that person's identity are presented. In the Newsweek magazine, Westerners do not know where the "AIDS" orphan is from, how many siblings she has, her favorite hobbies, etc. We are only reminded that AIDS equals Africa. The girl does not exist as a person. because AIDS identity dissociates her from the world of morally distinct subjects. She has become an undesirable object that exemplifies meanings of 'unhealth'.

Hopefully, I have shown that not only does 'disease' cause symbolic harm, but that in the context of oppression, it itself becomes an oppressive term. Words are defined and carry political weight within a particular context. Disease and health are not simple dichotomies, they are dualisms, in which the latter has oppressive power on the former. In the context of Western/African (which exemplifies First/Third World) relations, where regions and communities interact following the logic of oppression, 'disease' can be used

to devalue and deny personhood of the oppressed. Based on a feminist analysis of disease (and the metaphors that give it meaning) health and disease follow and reinstate the logical structure of oppression. From an external viewpoint (i.e. outside of WHO practices) these conclusions significantly affect WHO's definition of health.

4.4 WHO's oppressive definition of health

WHO gives two definitions of health. (1) Health is...not merely the absence of disease...(2) Health is a state of complete physical, mental and social well-being. What is the significance of the first definition in view of our discussion on metaphor? If we accept that 'health' and 'disease' can be dualistically understood, and metaphorically used to create greater oppression, then WHO's definition of health is problematic. Numerous interpretations can be made from "the absence of disease". First, perhaps WHO intends for health to be defined as the absence of both non-communicable and infectious diseases.

The definition of health and principles of the WHO constitution are defined in light of the policies that WHO has developed. Policies are thus to be seen as pragmatic expressions of the principles. The first definition - health "is...not merely the absence of disease" - suggests that at one time health was understood strictly in relation to disease. The 'merely' hints at the chronological order in which the WHO definition of health developed into its present meaning. The history of WHO shows that disease control was the main focus of the organization at its inception in 1948. However over the decades

WHO has come to appreciate that other health concerns like nutritional factors, access to clean water, etc. also contribute to the improvement of one's health.

'Merely' may also notify the reader -policymakers, ethicists, physicians - that disease eradication nonetheless is the prime directive of WHO. It can be interpreted as "You can't think solely about disease control and eradication, you must remember to look at social issues". Citations of WHO's emphasis on eradication programs and its 'scientification' of primary health objectives reveal that WHO tends to interpret the definition such that primary health care is a secondary concern of the organization.⁹ Proof of this interpretation comes from WHO literature, where disease eradication and control are of top priority in WHO's programs. 10 Disease control and eradication programs take strong economic precedence over WHO's public health programs, because primary donors of WHO find that self-limiting disease programs are more accountable and open about their use of funding. 11 The emphasis on disease eradication in WHO's definition of health poses a problem for definition (2). That is, (2), which is identified with emphasizing the primary health care aspect of WHO's work, comes secondary to WHO's focus on infectious diseases. The first interpretation of WHO's definition of health is of significant concern when it is compounded to and understood through a metaphorical interpretation of health and disease.

⁹Please read Ch. 2 of this thesis for a more in-depth explanation of WHO's prioritization of disease eradication programs.

¹⁰The "Stop TB", "Global Malaria Strategy", and IARC institution are few of the numerous programs/institutions created by WHO. IARC (International Agency for Cancer Research) conducts epidemiological and laboratory research in order to develop scientific strategies to prevent cancer. Educational programs, training manual and publication of IARC is aimed at training country field workers. WHO, World Health Report, 1996, p.76.

¹¹Godlee, BMJ, Vol. 309, p. 1425.

Health as the 'absence' of disease can be interpreted metaphorically as well. In the preceding sections I have shown that disease not only designates a condition, it also represents persons or groups of persons. Geographically, countries and regions can be divided on the basis of those which house infectious diseases and those which do not. Although diseases do not acknowledge political borders, many of the most serious infectious diseases - TB, AIDS, malaria - are often associated with the poorest nations. Health/disease therefore becomes identified with metaphors surrounding First/Third World countries. In *The Coming Plague*, Laurie Garrett talks about the economic impact that AIDS could have on Africa. Described as "Thirdworldization", Garrett attempts to show that the AIDS epidemic will lead to the destruction of many fledgling economic systems in Africa. "Thirdworldization" has been used to describe the economic impact of AIDS in 'developed' nations of North America and Western Europe as well. Garrett uses the "Third World" as a metaphor for poverty conditions, further making a link between disease and "developing" countries. 'Disease' is compounded and contributes to the identity of 'developing' countries.

A metaphorical reading of WHO's definition of health implies that health at least means the restriction of human behavior and at most the eradication of diseased individuals. First, because disease evokes ideas of 'helplessness', 'savagery', 'primitiveness', these terms are the very ones which create images of Third World areas, places like Africa also come to be associated with 'disease'. As such, Africa becomes a location of medical intervention, and a place where the people cannot protect themselves. Although they still count as persons, their disease status brands them incapable of acting

as an authority on health. Their best contribution to the eradication of diseases is to cooperate and adhere to the guidelines established by the scientific experts.

At *most*, the eradication of disease may mean the eradication of human lives.¹² A diseased person may be completely denied personhood such that their health status is discounted and perceived to distract experts from preventing the further spread of diseases. Certainly WHO would think this to be a gross misinterpretation of the definition. However, in the next chapter I will show how WHO does in fact favor policies that benefit the wealthier nations, meanwhile failing to support the needs of the poorer nations.

What are the possible consequences of compounding the two interpretations of health/disease? A very ironic scenario emerges. In previous chapters I have shown that WHO has been criticized for focusing too heavily upon disease eradication programs at the cost of strengthening much needed primary health care systems, worldwide. The first interpretation of the definition - the one that WHO perhaps intends to invoke - expresses a bias toward disease programs. The second interpretation - a metaphorical interpretation of the definition of health in relation to disease – may be understood in terms of discriminating against already oppressed groups of people. History has shown that WHO policymakers approach Africa (and other 'Third World' regions) as a land of disease before they address it as a region in which primary programs are to be established. As a 'disease', Africa must be controlled; therefore, WHO sends their experts to stop further spread of epidemics. This intervention in turn reinforces Africa's state of helplessness, so that once WHO turns to look at the primary health care policies most appropriate for this

region, Africans have very little political power to direct what these policies ought to be.

Less money is channeled into primary health care, an area that relies on field assessments. In ('Third World') regions where diseases are rampant, field workers have little authority. Their Third World position prevents them from communicating the policies that best fit the needs of the citizens. Because disease metaphors lead to the devaluing and denial of personhood, in metaphorical terms these individuals are impoverished so far as they are deprived of authority and bargaining power.

Disease programs are readily funded compared to primary health care programs. As more money goes into disease eradication, these programs are deemed successful in comparison to primary health care initiatives worldwide. Thus, primary health care workers are pressured to measure their legitimacy in a language that is respected: science (and specifically, Immunology). Unfortunately, because the language of disease is ridden with metaphors like 'poverty', 'helplessness', 'Third World', primary health care policymakers, in adopting the scientific standards, perpetuate the problematization of different regions and areas, thereby objectifying and preventing persons living in those areas from expressing their own health needs. As a result, greater poverty is created metaphorically, and subsequently, literally.

WHO can make a number of responses to this proposed scenario. First, it may state that the scenario is not realistic. It may support this claim by explaining that the constitution is laid out to protect the rights of individuals and nations. The constitution, it insists, clearly communicates WHO's values and methodology. First, the principles insure that the definition recognizes health and equality as valuable. Second, the

¹²In 1976, prevention of further spread of Ebola in the former Zaire required the quarantine of persons in

principles express a governmental responsibility to achieve health. All persons should benefit and contribute to the shaping of health benefits.

Yet, WHO's historical activities determine the meanings of the definition of health and the constitutional principles. The principles are meaningful only so far as they represent different aspects of the definition. Furthermore, the metaphors surrounding disease and health not only affect the interpretation of the definition itself, they also bias our interpretation of every single principle which follows from the definition. If health and disease are metaphorically understood, then the principles take on vastly different meanings. For example, in P5 of the constitution, two meanings can be derived from WHO's warning that "unequal development in different countries in the promotion of health and control of disease, especially communicable disease, is a common danger." First, P5 may be interpreted as appealing to governments to work internationally so that all persons receive equal access to health. A second interpretation of P5, however, which takes into consideration the metaphors surrounding health and disease, may be translated as a warning against granting too many liberties to diseased individuals. The oppressive metaphors of health and disease may lead one to interpret the principles as appealing only to healthy persons. All diseased persons and nations are excluded from any of the programs and policies which enhance one's health status. The second interpretation of P5 is certainly controversial and seemingly utterly inaccurate. However, in the next chapter, I will show how WHO policies support this view.

Another response that WHO may make regarding the proposed scenario is that the organization is not - nor should it be - responsible for all the different interpretations of

the definition of health. How can the organization possibly anticipate the multitude of meanings that are derived from their definition of health? Unfortunately for WHO, in its unwillingness to look at the oppressive nature of 'disease', it cannot fulfil its obligation to realize values of equality and health. First, the oppressive dualism of health/disease undermines WHO's recognition of formal equality. Recall that formal equality demands treating individuals equally in their sameness. WHO ought to reduce any barriers to one's access to health on the grounds that all persons are to be treated the same. Yet, 'disease' problematizes any solutions that emerge from 'developing' countries'; subsequently, options are narrowed as these nations become more dependent upon external intervention. For example, traditional medical practitioners face a lot of discrimination with regard to the treatments they develop. The diseased identity can be used as proof of the traditional medical practitioner's ineffectiveness; it also propagates the stereotype that "Third World nations" cannot find solutions to their own problems. As a result, wealthy nations intervene at the cost of a person's access to and faith in traditional medications.

Second, disease metaphors threaten WHO's implementation of substantive equality. In keeping with the demand to treat all persons substantively equally, WHO ought to make active provisions for persons who may be discriminated against because of their disease status. Governments and organizations know how to provide the means for their clients only if they realize the diverse needs of their clients in the first place. Thus WHO must compel governments and organizations to investigate the different ways in which social, religious, ethical and other engagements prevent one from participating in programs that would improve his/her health status.

However, if an individual's identity is masked with metaphors which denigrate and devalue him/her, then WHO is in great danger of setting up health policies and directing governments and organizations to cater to an identity which does not properly represent the daily problems that the individual faces. In other words, public health care policies that rely on oppressed representations of the vulnerable other only exacerbate the oppressive metaphors already in place, meanwhile acquiring new dualisms. By equating disease to the "Third World" (which is already defined through other dualistic metaphors) the particularities of each region, country and individual are homogenized and understood through popular stereotypes; their needs are homogenized as well. Moreover, the accumulation of these metaphors creates a stronger sense of Us vs. Them, where individuals are radically excluded and segregated according to the stereotype they represent. Subsequently, the oppressed groups' needs are backgrounded and made more invisible from the perusal of health care workers. The oppressed other becomes instrumental to the oppressor's identification and avoidance of problems which have been linked to the subordinated group. 13 WHO can only access these needs by going through the demands of the oppressor group whose identity is foregrounded and where stereotypes of the oppressed are entrenched in the conscience of the dominant group.

Third, dualistic metaphors of health and disease obliterate WHO's emphasis on fundamental and instrumental values of health. Once the needs of the oppressed are backgrounded and recognized only through the needs of the dominant group, the chances are that support for persons qua persons is overtaken by the role they play to sustain the oppressor group. As a result, health is a fundamental value for those who have intrinsic

¹³For example, in a recent outbreak of E. coli in Walkerton, ON, many people were heard saying "I can

worth as humans: members of the dominating group. WHO must ask itself, "How is the intrinsic worth of oppressed persons defined?" followed by "Do the programs we make on a 'developing' country's behalf truly reinforce the idea that health is inalienably valuable?" If in any way the answers to these questions depend upon a dualistic metaphorical understanding of "developing nation' then, because meaning is mediated through the gaze of the oppressor, the value of health for itself in this region is easily confused with the instrumental value that this group has in relation to the oppressor(s).

The instrumental value of health takes on a second meaning within an oppressive context. Not only is health in *general* instrumental for other social concerns such as alleviating poverty, the *particular* health of the oppressed is instrumental for the achievement of health for members of the oppressive group. Yet, this second understanding of the instrumental value of health precludes the goals of the first interpretation. If WHO instrumentalizes the oppressed group to achieve the directives of the oppressor group, then the former is situated such that it can only receive (and cannot contribute to) orders from the dominant group. Individuals from the oppressed group have less political power to take control of their own problems. As the subordinated group is silenced, resentments toward the dominant group may grow because the former is made to passively wait for external health and other socio-political issues interventions established by the latter group.

Why should WHO be responsible for addressing possibly symbolically harmful interpretations of 'disease'? If WHO really is serious about alleviating poverty, then it must look at all of the possible ways in which the implementation of health and equality

are stunted, and the ways in which the values themselves recreate the system of oppression. WHO has defined poverty in economic terms.¹⁴ However, it can also mean the privation of one's ability to represent and make decisions for him/herself. In this sense, poverty is a disempowerment on the basis of misrepresentation. WHO policies that are derived from stereotypes rather than from the needs voiced by the oppressed group will more than likely *feed into* the cycle of poverty and poor health status. As Brundtland stated, those who are not healthy are not in the position to work out of their impoverished conditions.

One final response that WHO can make with regard to the created scenario is to state that the organization itself does not rely on a dualistic understanding of health and disease. Instead, it uses objective scientific standards to come up with health strategies applicable to everyone. In the next chapter, I will show that in fact the policies developed from immunological standards are ultimately based upon dualisms themselves.

Immunology employs a metaphor of the self/non-self. This dichotomy adopts the same oppressive qualities that characterize the logic of oppression. Furthermore, the field of Immunology illustrates how scientific protocols also fail to eradicate diseases. Perhaps by basing the understanding of disease on an oppressive construction, we can see the limits to our understanding of microorganisms, so that better solutions to our infectious disease crises can be discovered.

In this chapter, I have used the feminist understanding of oppression to make an external criticism of WHO's definition of health. By studying WHO's health through the logical structure we are presented with a different kind of ethical analysis, where harms

¹⁴ See WHO, World Health Report, 1999, p. 19.

are contextualized and the identification of groups that oppress and groups that are oppressed come to the fore. Feminist tools of analysis can also be used to understand Immunology from a different perspective as well. The next chapter will therefore be a critical examination of WHO's definition of health from an internal perspective. That is, WHO can be judged by the very methodology - Immunology - which it uses to develop health policies and programs. With the help of feminist ethical theory, I will critique WHO's definition of health from an immunological point of view.

Chapter Five: A Micro-Analysis of Disease

In the previous chapter, I provided a feminist critique of WHO's definition of health. The purpose of that chapter was twofold. First, I wished to analyze WHO's health external to the organization's implementation of programs and projects. From an external point of view, I tried to determine how WHO's definition would fare given the dualistic metaphors that inform one's uptake of 'disease'. The metaphorical interpretations of disease revealed how and why WHO tends to develop oppressive health policies. The second purpose of the previous chapter was to establish feminist epistemology so that it would be instrumental in an internal criticism of WHO's 'health'. By 'internal' I mean to critique the very tools that WHO adopts and uses to effect health care policies. Let us now focus on completing the second objective.

In this chapter, I will evaluate WHO's use of Immunology and determine if its adherence to this discipline is detrimental to its mandate to provide 'health for all'. WHO in its international capacity attempts to set health policies that reflect its commitment to provide health for all, on the basis of substantive and formal equality. Yet it continues to employ top-down strategies to eradicate or control diseases in 'developing' (and 'developed') countries. In this respect, WHO relies upon its hierarchical relationship with developing countries (where WHO, as the dominating group exercises ultimate control over health policy) in order to justify its patriarchal and unquestioned

commitment to scientific methodology. Whether this commitment results in attainment of the goals as set by the WHO constitution is yet to be determined.

A critical look at Immunology is instructive for two reasons. First, unlike many other areas of science it is a field that is constantly and at times drastically evolving. New diseases and conditions challenge 'fundamental truths' upon which discoveries have been made. Re-emerging infectious diseases (such as TB) compel researchers to refine or even replace earlier assumptions about microbial/ human interactions. Because of this flexibility. Immunology, through example, challenges the establishment of facts and the methods through which a fact is produced. In short, Immunology tests scientific paradigms from within the system itself. There are many instances where theoretical knowledge of microorganisms has reached its limit. New discoveries force researchers to revise or replace beliefs concerning human/microbial interactions. Second, a critical analysis of Immunology reveals that the discipline employs metaphors in two ways. It is a science that is fundamentally grounded upon the metaphor of the 'self'. Furthermore, in an effort to concretize the immunological self, scientists utilize metaphors of war. In every textbook, immunologists express self and non-self interactions in terms of 'defense', 'attack', 'fight'. A critique of Immunology is pertinent for our evaluation of WHO's definition of health.

WHO draws upon Immunology - both its fundamental tenets and methodology - in order to organize and implement primary health care and disease eradication programs. The organization appropriates the biases and shortcomings inherent in Immunology. By developing both primary health care and disease eradication strategies within an immunological framework, WHO limits its understanding in both areas. Uncritical

adherence to immunological directives places WHO in a vulnerable position to produce health strategies that amplify rather than resolve the world's disease problems.

This chapter is divided into four parts. In the first section, I will provide a brief introduction of Immunology. Because of the specialization of this field, historical background of this discipline contextualizes the subsequent feminist analyses on WHO's activities and the critique of Immunology itself. In the second section, I will give a comparative analysis of Smallpox (SP), Tuberculosis (TB), and Acquired Immunodeficiency Syndrome (AIDS). The purpose of this comparison is to show the strengths and limits of Immunology, and WHO's historical reliance upon this discipline. I will draw upon primary literature from Immunology textbooks and scientific journal articles in order to establish the tentative conclusion that growing social pressures to conform to restrictive control measures correlate to increasingly inefficient scientific means of disease prevention. In the third section, I will attempt to delve deeper into Immunology to see why we seem to be reaching a crisis in disease intervention. Alfred I. Tauber offers a comprehensive explanation of the metaphors of the 'self' which drive our understanding of Immunology. I rely upon Tauber's discussion in my hypothesis that metaphors of the 'self' and war create a very restrictive framework through which microbial life is apprehended. This limited perspective in turn affects the way humans understand and react to 'disease'. Fourth, I will examine WHO in light of this critical analysis of Immunology. To what extent does WHO adopt immunological standards? How does this dependence affect WHO's work in both primary health care and disease eradication? These questions are answered in the final section of this chapter. Let us begin with a brief introduction of Immunology.

5.1 Immunology: An Introduction

Immunology is the study of how the immune system responds upon antigenic or foreign challenge. Immunity is the state of being resistant to poisons, foreign particles and pathogens. The immune system is composed of many organs, tissues, and cells that help to maintain homeostasis of the body. Immunology is not limited to explaining how the body fights off infectious diseases. Rather, it covers a broad range of topics, all of which contribute to our understanding of how the body struggles to sustain structural and functional integrity. Immunologists study how the immune system develops the ability to recognize its own cells and to identify non-self particles.

Today, Immunology is considered to be an experimental science. The perception of Immunology as an experimental discipline has developed from and enables researchers to set up controlled studies in this field.²

5.1.1 The history of Immunology

The evolution of Immunology into its present form has been impassioned and political. The concept of immunity may date as far back as 500 B.C.E. Records show that the Chinese and Turks were the first to attempt eliciting an immune response by applying dried crusts of smallpox pustules to individuals who had not had prior contact with the disease. They found that upon introduction of these particles, individuals did not

¹Tortora and Grabowski, 1993, p. G31.

² Gerard J. Tortora and Sandra Reynolds Grabowski, <u>Principles of Anatomy and Physiology</u> (7th ed.), (New York: Harper Collins College Publishers, 1993), p. 698. See also Abul K. Abbas, Andrew A. Lichtman and Jordan S. Pober, <u>Cellular and Molecular Immunology</u> (2nd ed.), (Philadelphia: W. B. Saunders Co., 1994) p.4.

develop a full-fledged version of smallpox upon subsequent contact with others who were already infected.³ Much later, excursions to Turkey first led to England's introduction of smallpox inoculations.

Soon after, Edward Jenner, an English physician, established a more 'scientific' approach to immunization. Jenner noticed that milkmaids who had recovered from cowpox would be immune to smallpox. Perhaps, he thought, cowpox infections protected one from the more serious smallpox. He tested this hypothesis by presenting cowpox pustule fluid to an eight year old boy, and followed this procedure by intentionally infecting the boy with smallpox. Indeed, the boy was immune to the disease. Jenner's practice popularized the concept of vaccination. Today, vaccines are widely used as a means to protect individuals against serious infections.⁴

Although the concept of immunity has been around for a long time it was not until much later that the field of Immunology was accepted as a scientific discipline in its own right. A number of scientific events in different areas of biology converged, leading to the creation of a new discipline: Immunology. According to Alfred Tauber and Leon Chernyak, studies in microbiology, pathology and embryology principally contributed to the formation of Immunology. Robert Koch and Louis Pasteur independently studied anthrax, determining that bacteria was present in the blood of all animals afflicted with this disease. In order to show that it was the bacteria which caused disease and not *vice versa*, Koch ran further experiments on the bacteria. First, he took blood from an infected animal and inoculated a second. Sure enough, the second animal too expressed

³ See Abbas et al., 1994, p. 4, Tortora and Grabowski, 1993, p. 2, and William McNeill's <u>Plagues and Peoples</u>, 1998, pp. 258-262.

⁴ McNeill, pp. 257-258.

symptoms of the disease. Second, Koch successfully grew the bacteria *in vitro* (i.e. outside of the host) and used this bacteria to infect animals.⁵ Koch's work on anthrax established an experimental basis to the field of microbiology.⁶ He also showed the microbial link between humans/animals and disease. Thus, disease pathology was brought into and emerged from the science of microbiology.⁷

It was not until Elie Metchnikoff founded the concept of 'phagocytosis' in the field of embryology that Immunology fully developed into its modern orientation. In his extensive studies of amoeboid cells in invertebrate embryology, Metchnikoff recognized that cells living on the surface of starfish protected their host by devouring potentially harmful microbes also found on the host's surface. From there, his interests turned to the area of pathology where he introduced the idea that immunity arose from active defenses of the host. According to Metchnikoff, the "phagocyte" was the protective effector cell.8

Metchnikoff's phagocytosis theory was highly criticized by a group of scientists which held the "opposing" view that bacteria were killed passively. Paul Erlich, who championed the idea of the antibody, argued that the (host) body released soluble bactericidal substances that would destroy the microorganism. According to Tauber, Metchnikoff and Erlich were spurred on by different agendae. Whereas Metchnikoff wished to demonstrate how the host continually strove toward an internal harmony,

⁵ Thomas D. Brock and Michael T. Madigan, <u>Biology of Microorganisms</u> (6th ed.), (Engelwood Cliffs: Prentice Hall, 1991), pp. 18-19.

⁶ Alfred I. Tauber and Leon Chernyak, <u>Metchnikoff and the Origins of Immunology</u>, (New York: Oxford University Press, 1991), p. 3.

⁷ Ibid.

⁸ Darwin's "Origin of the Species" prompted Metchnikoff's interest to empirically show the evolutionary unity of animals. His studies in invertebrate development led to his 'discovery' of phagocytosis. For a more detailed account, please read Tauber and Chernyak, 1991, Ch. 2-3.

Erlich wanted to standardize and quantify his antibody-antigen reaction. By the early 1900's researchers on both sides of the debate realized that in fact their work was complementary. The body used humoral and cellular defenses to protect itself from antigenic challenge. Nonetheless in the early twentieth century, focus on the quantification and comprehensive study of the immunochemical aspects of Immunology overtook Metchnikoff's concerns about immunity as a process of self-definition.

Today, Metchnikoff is recognized as the 'founder' of immune research and of the notion that the host actively responds to pathogens. ¹² At present, immunologists have returned to the problems of host identity that Metchnikoff had pursued. Researchers find that as the scope of Immunology increases, theories must be revised to accommodate a number of phenomena such as auto-immunity ¹³ and issues surrounding transplantation. ¹⁴ Immunology should not only investigate the specific question of *how* the host defends itself against pathogens, it must also answer the more fundamental question of *why* the host reacts in a particular way. Solutions to the latter concern may present answers for

⁹ See Tauber, 1997, pp. 28-29.

¹⁰Antibodies (Abs) are the main effectors of a humoral response. Abs are protein molecules that are either expressed on the surface of B-cells or found in the blood serum. They directly attach to and destroy antigens (any particle recognized as "foreign"). See Brock and Madigan, 1991, pp. 428-431; Kuby, 1994, pp. 10-11.

T-cells are the main effectors of a cellular response. There are two main types of T-cells: $T_{(H)}$ -cells and $T_{(C)}$ -cells. $T_{(H)}$ -cells or T-helper cells aid in the activation of both humoral and cellular immunoresponses. They rarely kill infected cells themselves. Whereas, $T_{(C)}$ -cells differentiate into cytotoxic T lymphocytes which destroy 'self' cells that harbor antigens. See Kuby, 1994, pp.11-13; Abbas et al., 1994, Ch. 13. 12 Tauber and Chernyak, 1991, p.39.

¹³ Auto-immunity is a state in which the body actively attacks its own cells. It occurs when lymphocytes cannot recognize self-antigens, therefore they attack these particles. Normally, the immune system has set up a mechanism such that self-reactive cells are selected out of the cell-development repertoire. For more information on auto-immunity, please see Abbas et al., 1993, pp. 282-93.

¹⁴ Transplantation is the process in which cells, tissues, or organs are taken from one individual and placed into another individual. Many problems ensue regarding the receptive individual's inability to accept the graft; that is, the host recognizes its graft as non-self and immunological defensive cells 'reject' the transplant. For more information, please see Abbas et al., pp. 339-355.

problems faced by those attempting to answer the first question. In essence, Immunology is the study of organismic identity and integrity.

5.2 Context: WHO and Smallpox, TB, AIDS

At this point, I would like to shift our focus. The best way to look at the strengths and failures of Immunology is to see how this discipline has been applied to solve health problems. Because Immunology covers such a broad range of topics, I would not do it justice to provide a general overview of its work. Instead, I wish to look at aspects of the science which are pertinent to the World Health Organization. One of WHO's main objectives is to eradicate infectious diseases. The organization has relied on the field of Immunology to come up with measures to control if not eradicate harmful microorganisms.

In this section, I will compare three major epidemics that have greatly influenced our understanding of the immune system: Smallpox (SP), Tuberculosis (TB), and AIDS.¹⁵ Some of the immunological successes as well as the problems that persist with regard to these epidemics will be highlighted. The purpose of these summaries is two-fold. First, I want to show that because Immunology is such a young science, perhaps it provides a limited perspective of human-microbial interactions. Second, I want to show that Immunology is ill-equipped to deal with the socio-political problems that arise in the effort to stop more physiologically complex diseases like TB and AIDS. Ultimately, this discipline provides socially coercive solutions to the world's pandemics.

¹⁵ For a more in-depth summary of each disease please check Appendices 3-5 at the end of this thesis.

I compare SP, TB, and AIDS by looking at their respective pathology and epidemiology, control measures, and socio-economic impacts. First, immunologists study the pathogenesis of the disease. What is the microbial cause of this disease? Researchers answer this question by investigating how the microorganism inflicts damage on the host. By looking at a pathogen's ability to enter, colonize and grow, and, in many cases, destroy the host cell, immunologists hope to come up with a strategy to stop the progression of disease. Epidemiology, a field borne out of Immunology, is concerned with the study of the disease at a (host) population level. Studies pertaining to the occurrence and distribution of diseases aid researchers to find ways of controlling the disease. Epidemiologists look at rates of mortality and morbidity in order to determine the incidence and prevalence of disease.

Second, control measures are strategies that depend upon the pathology and epidemiology of diseases.¹⁹ Some disease control measures are installed after an individual has been infected with the microorganism. For instance, in TB control programs, antibiotics target and destroy the pathogen so that no further spread within and between humans of the disease occurs. Other control measures, such as vaccines, are used prior to microbial host interactions.

The rationale behind the use of vaccines is that the body, when challenged by an antigen, or a foreign particle, will elicit an active immunologic response. Specific

¹⁶ Brock and Madigan, 1991, pp. 400-411.

¹⁷ Ibid., p. 496.

¹⁸ For further explanations of these terms, see Ch. 3 of this thesis; also see Brock and Madigan, pp. 496-497

¹⁹ Although the definition of 'Epidemiology' includes the study of the control of disease, I have deliberately divided them into two sections to emphasize the measures that have been implemented in SP, TB, and AIDS control programs.

sufficiently prevent further spread of the disease.²⁶ The SP-specific surveillance system is successful because in light of the easy diagnosis of the disease, lay persons are qualified to report outbreaks. Societies around the world could adopt the SP surveillance measures without drastically changing their health systems since SP surveillance work independently of health systems.

The control of TB on the other hand requires drastic changes in health structures. WHO utilizes the DOTS (Directly Observed Treatment Short Course) program to stop further spread of TB. DOTS is premised on the idea that the spread of TB will decrease if all active cases are inactivated. Persons with active TB must comply with the full course of TB treatment, because only remission of TB ensures prevention of new infections. Thus the purpose of DOTS is to improve the detection and surveillance of these patients.²⁷

The DOTS program is designed to control a persistent disease. In many of the poorer countries (and in the poor regions of affluent countries) failures of TB programs are mostly attributed to poor patient compliance to the drugs.²⁸ Unlike SP, an easily recognizable condition, TB carriers may not know that they have an active form of the disease. Only health personnel who have been appropriately trained to run tests like sputum smears and radiographical analyses can make an accurate diagnosis of TB, thereby necessitating education of countries which lack this knowledge. Coupled to this

²⁶ See D. A. Henderson, "Epidemiology in the Global Eradication of Smallpox" <u>International Journal of Epidemiology</u>, 1, No. 1., pp. 27-28.

²⁷ See Mario Raviglione et al., "Assessment of worldwide tuberculosis control", <u>The Lancet</u>, Vol. 350, p. 624. Ann Fanning, "Tuberculosis: Introduction", <u>CMAJ</u>, 160, No. 6, p. 837; Richard Moore et al., "Cost-effectiveness of Directly Observed Versus Self-administered Therapy for Tuberculosis.", <u>American Journal of Respiratory Critical Care Medicine</u>, Vol. 154, p. 1013.

²⁸ World Health, 46, No. 4, p. 11.

problem is the realization that health care systems in many of the poorest areas cannot sustain the surveillance of non-compliant individuals.²⁹ The tight surveillance of patients is only possible if the health care system is consistent, reliable and organized. If the health care system in question does not meet these requirements, then it must be restructured to accommodate a highly specific disease eradication initiative.

The underlying assumption of the DOTS program is that the drugs are the answers to control TB. DOTS is a complex means of obliging the patients to adhere to their prescriptions. However, when TB and AIDS are compounded, the efficacy of the DOTS program comes into question.

The AIDS epidemic tests the scope of our understanding of the immune system and of the extent to which science can be used to stop the spread of disease. Anti-viral drugs and medications against opportunistic infections are prescribed to control HIV spread within the infected individual. Because of HIV's ability to break down effectors of the immune system, the body becomes vulnerable to the toxic effects of the drugs as well as to the intended target.

Individuals co-infected with HIV and *M. tuberculosis* cannot take certain TB antibiotics due to the lethal effects of the drug on that immunocompromised individual. The amount of medication that an HIV+ individual takes can be so taxing on her/his strength that TB and other disease-related prescriptions may need to be terminated. Because the immune system may not have successfully dealt with the infection, the remaining microbes have the opportunity to confer resistance to the drugs. Researchers

²⁹ See John D. H. Porter and Keith P. W. J. McAdam, "The Re-emergence of Tuberculosis" <u>Annual Review of Public Health</u>, Vol. 15, pp. 309, 315-317; A Pio et al.; "National tuberculosis programme

must decide between reducing anti-viral therapy, and halting medication that fight off opportunistic infections, where in either case, the microorganisms can confer resistance to the drugs.

Unlike SP and TB, no specific surveillance system has been universally applied for the control of AIDS. Instead compliance to consistent condom use appears to be the gist of AIDS control.³⁰ WHO prevention strategies include promotion of condom use and sexual negotiation between couples. Condom campaigns have not been as successful as epidemiologists would have liked. Researchers have found that sexual negotiations are hindered by power asymmetries between couples and nations.³¹ Meanwhile millions of dollars continue to be pumped into the development of an effective vaccine. Do future medical costs take priority over the health of presently infected individuals? I do not have the space to answer this question. However, I would like to suggest that in the present lack of effective chemical prophylaxis for AIDS, perhaps some money can be invested in producing anti-viral drugs for distribution to HIV+ persons living in areas where previous access has been denied.

AIDS, more than SP or TB, seems to reflect the attitude that control measures are prioritized over treatment of those already infected. Individual control measures like zidovudine (AZT) have been on the market for years, but the costs of these drugs have not been reduced, limiting access to only the wealthiest nations. The unavailability of AIDS treatments in countries with the highest rates of people living with HIV suggests

review: experience over the period 1990-95, <u>Bulletin of the World Health Organization</u>, 75, No. 6, pp. 576-578.

³⁰ See Fiona Godlee, "WHO at country level - little impact, no strategy", <u>BMJ</u>, Vol. 309, p. 1637.

that greater emphasis is placed on preventing non-infected persons from infection rather than on sustaining the health of those who are infected.³² In TB, because the control measures involve the prescription of antibiotics, the DOTS program appears to be equally concerned with treating the infected and preventing further spread. The SP program is aimed at preventing the spread of the disease *because* post-infection drugs are not available. In this case, one could argue that prevention is the only means to protect humans from SP to justify research aimed at improving the efficacy of presently available vaccines. Perhaps in the same way, AIDS researchers are attempting to persuade the public that a vaccine would save the world from billions of dollars that would otherwise go into treating increasing numbers of HIV+ persons.³³ Yet, this argument distracts one from noticing that millions of HIV+ people are limited to the most basic drugs for opportunistic infections.

WHO is lobbying to reduce the costs of AZT. Yet, advocacy for cost reductions does not explain why the drugs are so expensive in the first place, or why the scientific community is in the position to dictate social compliance to sexual measures. With less reliance on a scientific (and chemical) means to control AIDS coupled with the politics of smart sex negotiation, people are becoming aware of the social effects of disease eradication and control programs.

³¹ See <u>AIDS in Kenya</u>, 1996, Ch. 3; Christine Overall's "AIDS and Women: The (Hetero)Sexual Politics of HIV infection" <u>Perspectives on AIDS</u>, Christine Overall and W. R. Zims (eds.), (Ontario: Oxford University Press, 1991).

³² Many issues emerge from this criticism. From an economic perspective, some argue that distribution to these nations would not be a worthy investment, considering the amount of money gone into anti-viral research and the lack of returns from these poor countries. Others argue that due to the scarcity of resources, priorities of needs must be set. Ironically, the communities with the most money and least rates of infection seem to be dictating what those priorities ought to be.

Aspects of Vaccination," <u>International Archives of Allergy and Immunology</u>, Vol. 108, p. 307.

In all three epidemics, social and cultural practices are criticized in their failure to adhere to disease control programs. Within the paradigm of disease control, different regions are constructed in a particular way. WHO researchers are in the position to dismiss information not pertinent to their goals. First, in the SP eradication program, many cultural practices were perceived as obstructing international efforts to solve the problem. According to Isao Arita, one of the leading scientists in the WHO Smallpox Eradication Program, ³⁴ local attempts to control the disease were depicted as inefficient or hazardous. In India the use of the rotary lancet was rejected on the basis of being too painful and traumatic for the patient. ³⁵ In another WHO publication. A. W. Downie *et al.* report that in many developing regions, local police officers who were "ignorant of health matters" were partly responsible for poor reporting of smallpox incidence in their jurisdiction. ³⁶ Downie *et al.* cite the presence of minority groups and movements of nomads, refugees and migrant workers as contributing to the spread of the disease. ³⁷

Even in cases where nations successfully implement a surveillance system, social judgments are made. In his discussion of disease surveillance and notification, Donald Henderson states how "even illiterate villagers" could diagnose SP.³⁸ Henderson gives examples of three 'developing' regions which have successfully complied with WHO's surveillance system, parenthetically noting that in his discussion of India, excellent surveillance in one state is the exception and not the standard for this region.³⁹

³⁴ See Laurie Garrett, <u>The Coming Plague</u>, 1995, pp. 42-47.

³⁵ Arita, WHO Chronicle, Vol. 34, p. 176.

³⁶ Downie et al., "The Eradication of Smallpox," WHO Chronicle, 22, No. 12, p. 527.

³⁷ thid n 526

³⁸ Henderson, International Journal of Epidemiology, 1, No. 1 p.26-27.

³⁹ Ibid.

rates of TB are reported. Raviglione et al. are suspicious of these rates, because information-gathering in these countries is generally poor.

In all three examples, nations (and specifically, poor nations) are critiqued within a disease control framework. DOTS not only identifies poor health care systems, it also emphasizes these nations' ineptitude in using a 'simple' policy to ward off a major epidemic. This reputation enables WHO experts to administer a paternalistic approach where these countries are lauded in their compliance to these measures.

Finally, the AIDS epidemic illustrates mounting public concern over the solutions that scientists have presented. After billions of dollars have gone into the search for a means to control HIV, no grandiose schemes are forthcoming. Therefore, societies are encouraged to rely on social behavioral measures to prevent further spread of the disease. Failure to comply with condom programs gives scientists grounds to lay cultural blame for the spread of HIV. Something about the culture hinders individuals from engaging in life-saving prophylactic practices.

In the absence of a biomedical strategy to control AIDS, the public is given an incentive to question the rationale behind AIDS research and education. Proven effective in suppressing depletion of immunological cells, anti-viral drugs have been in the market for many years; however, they are available to only the wealthiest nations.⁴³ Individuals like Mbeki question the lack of access of the world's poorest populations (with the highest prevalence of AIDS) to these anti-viral drugs. So far, scientists and policy-makers have not taken Mbeki's challenges seriously.

⁴³ Barton Gellman, "African President Escalates AIDS Feud," <u>Washington Post</u>, 19 April 2000, A1, A20, Col. 1.

Such simple dismissals inform the reader of the perspective of the researcher. It suggests that WHO establishes the scientific standards upon which local methods are measured. It further suggests WHO is in a position to reject or accept the proposed solution, often to the detriment of a culture's reputation. Also within a disease control framework, different cultures are represented in terms of aiding or hindering eradication. I do not deny that these behaviors may propagate further spread of the diseases, nor am I renouncing WHO's demonstration of excellent skills to organize mass campaigns; however, I believe that it is easy to lose sight of the idea that these "facts" are constructed within a framework of disease control. Within a disease paradigm, practices and behaviors – such as burial rites, care for the infirmed, movement of (nomadic) groups, sexual behaviors – are condemned for epidemiological reasons.⁴⁴

In race discourse, post-colonial writers discuss how the dominant group rationalizes the objectification and subsequent judgement of the inferior other. In "Eating The Other" bell hooks discusses at length how cultural, ethnic and racial differences of the subordinated are commodified for the 'consumption' by the dominant set. WHO, with its economic clout and scientific expertise, is susceptible to 'consuming' regional cultural practices, passing its approval of the practice on the basis of the culture's compatibility with the organization's prescribed norms. As long as the practice is evaluated in its instrumental worth for/against eradication and epidemiological measures, its meaning is subject to denigration and obliteration for the sake of the people's physical safety. The practice is rated by those in power: WHO experts on SP, TB, AIDS.

⁴⁴ Downie et al., WHO Chronicle, 22, No. 2, p. 526.

⁴⁵ bell hooks, Black looks; race and representation, (Toronto: Between the Lines, 1992).

David Theo Goldberg takes 'consumption' a step further. Goldberg argues that science is a mode of racist expression that establishes one of many types of normative patterns. 46 In a scientific paradigm, the researcher takes on the role of objective observer; s/he is disengaged from the activity, participating insofar as s/he organizes the collected data.

Classification is fundamental to objectification within a scientific paradigm.⁴⁷ It enables a distant ordering of data; that which is under investigation is objectified and explained within an organizational framework. Thus, the classification of cultural practices in terms of disease pathology places the scientist in a veil of ignorance. S/he does not see how her/his personal values are applied in the collection of objective data.

In comparing SP, TB, AIDS, I want to argue that as scientific control measures become more doubtful, the coerciveness of those measures becomes more pronounced. The successful eradication of smallpox serves as a justification for problematizing human activities such as care-giving and burial practices. Researchers can argue that without analyzing all variables, the smallpox program would not have succeeded. In the case of TB, near control of this disease in the past compels researchers to be optimistic about the DOTS program so long as everyone cooperates. Nonetheless, there is a niggling fear that perhaps TB and AIDS are slipping from our scientific understanding. The AIDS epidemic more than any other elicits public criticism of scientific measures. In the same way that AIDS advocacy groups have petitioned for changes to early access to experimental therapies, people like South African President Mbeki now are speaking out

⁴⁷ Ibid., p. 49.

⁴⁶ Other modes of racialized discourse are: aversive, academic, legalistic, bureaucratic, economic, cultural, linguistic, religious, mythical or ideological. See Goldberg, <u>Racist Culture</u>, p. 47.

against scientific experts who implement socially controversial policies without offering to contribute the drugs that they have developed in the interim.

The more limited chemical strategies become in the fight against complex diseases, the more apparent is the coerciveness of social measures. As microbes confer resistance to available drugs and new vaccines, scientists must spend more money to quickly develop treatments that are more expensive and immunologically specific. In the meantime, in order to avoid further microbial mutations, the scientific community urges strict compliance to presently available treatments. Within the framework of disease eradication, the key to preventing the spread of a disease is in *responsible* human adherence to these treatments. If the disease continues to spread, then cultural practices are problematized.

Yet one must question whether something about the immunological solutions themselves lead to crises in disease controls. Perhaps disease control programs unnecessarily condemn cultural practices. And perhaps strict social measures are a means to over-compensate for a scientific lack of understanding non/epidemic diseases. These speculations must be further investigated.

5.3 Immunology and Conceptions of the Self

Does our current knowledge of Immunology somehow limit our understanding of infectious diseases? In this section, I will show that Immunology depends on metaphors of the self and war. These metaphors generate an oppressive actualization of the immune 'self'. The self is contrasted from the 'other' in the same way that the oppressor and the oppressed are dualized – through homogenization, backgrounding, radical exclusion, and

instrumentalism. Thus, built into Immunology are strategies to problematize and discriminate against vulnerable groups.

5.3.1 Three conceptions of the Self

In this section, I will briefly summarize Tauber's exegesis of 'self' metaphors in Immunology. In doing so, I want to show that the quest to define the immune self develops from Immunology's history of understanding how the body protects itself from disease. These metaphors reflect a very combative ontology of self, one in which the other is vilified and conquered.

In *The Immune Self* Alfred Tauber explores how 'self' metaphors are used in Immunology. Tauber's overall aim is to show how Immunology is the latest effort to define 'selfhood' in the history of philosophy. In other words, Tauber investigates the philosophical significance of Immunology.

My interest in Tauber's work stems from his discussion of metaphorical representations of the immune self within the paradigm of science. A closer analysis of the effects that metaphors of immunity have on human populations shows how ultimately 'self' metaphors perpetuate discrimination against certain groups of people. Therefore, unlike Tauber, I am unenthusiastic about the influence that Immunology has had in reshaping our metaphysical notions of selfhood.

Immune identity can be defined in its movement between two metaphorical extremes: the elusive and punctual selves. The elusive self is an intangible space, with no clearly defined coordinates or borders. This 'self' is the one that immunologists first ascribed onto the immune system fifty years ago. It is a vague sense of knowing that the

body can identify aspects of ownership and foreignness. However, the elusive self needs much more clarification. The 'punctual' self is at the opposite end of the continuum.

The punctual self is definable. It is concrete, having the ability to make clear delineations between itself and the outside world.⁴⁸

Three metaphors of the self are placed on different points of the elusive-punctual continuum: ontological, cognitive and embodied selves. First, the ontological self is the most elusive. This self is implicitly understood in the immune system's structuring of its own identity. The ontological needs more clarification, beyond the use that scientists intuitively make in their comprehension of immunological activities.⁴⁹ Concretization of immune identity occurs in the construction of the cognitive and embodied selves.

Cognitive metaphors are first introduced in the 1960's as a means to explain the immune system's development of antibodies. Although Jerne is initially wary of making too strong a comparison between the nervous and immune systems, he finds that the former best formulates the functional integrity of the latter. Immune systems "recognize molecular shapes, remember the history of encounters of the individual organism, define boundaries of a molecular 'self', and make inferences about molecular species likely to be encountered..."51 Like the CNS (Central Nervous System) the immune system ignores whatever does not come into its awareness or surveillance. The

⁴⁸ Tauber, The Immune Self, 1997, p.134-35.

⁴⁹ Ibid., p. 146.

⁵⁰ Ibid., p. 165.

⁵¹ A cognitive explanation of immunological activities is tentatively introduced by Jerne, and then strongly asserted by the "Paris School", a group of immunologists (Antonio Coutinho, John Stewart, Francisco Varela, et al.) who for the past twenty years have been trying to show that the cognitive metaphor makes the most sense in explaining the functional integrity of the immune system. For more details, see Tauber's The Immune Self, Ch. 5; "Immunology gropes for its theory."

nervous and immune systems have numerous activities in common, presenting a dual surveillance system of the body.

The cognitive metaphor of the immune self not only illustrates how the immune system functions, it provides a rationale for *why* the system behaves in a particular manner. In other words, the cognitive self is teleological; it establishes goals for the body, and specifically for the immune system, to pursue. Rather than viewing the immune system as the sum of separately operative parts, immunologists see this system as orchestrating its activities, bringing cohesion to the multiplications tasks that immune effectors fulfil. Self-recognition, some assert, comes prior to immuno-responses.

The cognitive metaphor of the self reorients Immunology toward Mechnikoff's project of understanding the self-defining functions of the immune system. The focus of the immune system is to reflect the self and then to reflect the world in relation to it.⁵²

Thus, the 'non-self' is defined in order to contribute to an ongoing process of searching for a self-identity. Reaction to 'foreign' particles becomes a corollary of the development of the immunologic identity. The cognitive metaphor constructs a context in which 'foreignness' emerges from the immune system's inability to identify the new particle.

According to Tauber, foreign particles are not intrinsically foreign but become so when they are contrasted from the effectors that comprise the immune system. These antigens are 'abnormal' in relation to the host's constituents. Thus, foreignness is determined in the context of a cognitive sense of self.⁵³

The embodied self presents a means to concretize immune identity even further.

The embodied self is the most punctuated; it presents the most vivid and lucid

⁵² Tauber, 1991, p. 167.

explanation of the immune self. The main purpose of embodying the immune self is to clarify extremely technical operations of the immune system; that is, embodiment offers conceptual images borrowed from every day experiences. The body itself establishes physical boundaries of 'us' v. 'them' (i.e. the environment), providing an immediate example of immune identity. This literal separation of self v. other greatly affects how we perceive immunologic structure and function.⁵⁴

War metaphors are commonly used to construct a punctual representation of the immune self. Self and non-self are engaged in a constant battle: the former to defend and the latter to dismantle bodily integrity. Microbes are depicted as *attacking* the immune system, and the host's effector molecules react by setting up a complex system of host defense. Immune effectors continuously survey the body, in search of 'foreign' particles. T-cells and B-cells follow distinct measures to attack the particle, in order to maintain the integrity of the host. T-cells are labeled as 'helpers' or 'killers', garnering a cell-mediated attack of the foreign particle. B-cells release antibodies, which attach to and eliminate the antigen from the body. Both B and T-cells destroy any particle capable of causing host injury. Immune effectors set up both physical and chemical barriers to protect the body against microbes. 56

Salyers and Whitt liken host defenses to a military strategy.⁵⁷ First, immunological effectors defend a city based on attackers who have already entered the city. Second, the military metaphor is used to develop strategies to fortify the host in the

⁵³ Ibid., p. 179.

⁵⁴ Tauber, 1991, p. 183.

⁵⁵ See Abbas et al., 1994; Salyers and Whitt, 1994; Brock and Madigan, 1991, Ch. 12; Kuby, 1994.

⁵⁶ Abbas et al, p. 4.

⁵⁷ Salvers and Whitt, 1994, Ch. 1.

first place. Metaphors that are deeply imbedded in our world-views best provoke an intuitive understanding of Immunology. It comes as no surprise that these war metaphors arose during two world wars.

Today, embodied metaphors extend beyond the boundaries of physiological explanation, so that the public equates the immune system with individual identity in its entirety. Diseases, like AIDS which destroy the immune system, are interpreted as dismantling individual identity.⁵⁸ The immune system loses the war against HIV and begins to resemble a 'besieged fortress' such that the body is attacked, cellular soldiers of the system are depleted, and the host is irreparably damaged.⁵⁹ The AIDS epidemic adopts metaphors of self/other found in non-scientific circles as a means to explain the technical functions of the immune system and the complex life of HIV.

AIDS more than any other infectious disease tests our present knowledge of the Immunology and of the metaphors we have used to construct this discipline. How does HIV avoid T-cell destruction? What molecular and genetic factors allow HIV to evade host defenses? Researchers hypothesize that HIV impairs specific and natural immune defenses. However, they can merely speculate as to how HIV induces the depletion of T-cells. In AIDS and other immuno-compromising conditions, the self faces an identity crisis. Instead of recognizing the foreign, the immune system progressively betrays and exposes itself to antigenic challenge. The boundaries between the self and non-self are inexplicably distorted such that the elusive nature of immune identity re-emerges from within a popular and concretizing conception of embodiment.

⁵⁸ Tauber, p. 186-187.

⁵⁹ Ibid., p. 187.

⁶⁰ Abbas et al., 1994, pp. 423-425.

The embodied metaphor is a punctual expression of the elusive and cognitive selves. It presents the immune system in its immediacy to other non-physiological notions of the self. The embodied self politicizes our understanding of host/antigen responses. Although the cognitive self governs the direction of embodiment, the embodied self reciprocally influences our knowledge of the elusive cognitive self.

Tauber claims that the study of Immunology has evolved beyond the reductionistic focus on host/microbial interactions. In his efforts to downplay the contribution that antibody/antigen makes on the construction of the self, Tauber fails to see how the embodiments of host/microbe have catalyzed a transformation of immune identity. Built into the ongoing search and revision of immunological identity are the concrete images of the self. That is, war metaphors impel researchers to transform immunological identity in a particularized way, one that expands beyond the simple dichotomy and at the same time validates this host/microbe distinction. These metaphors create a self-other dynamic that is fundamentally antagonistic. Host integrity is not a given, but a constant struggle against destructive foreign forces. War metaphors have significantly contributed to the present conception of the immune self.

5.3.2 A feminist analysis of the Immune Self

The transformation of the immunological self strikingly corresponds to Val Plumwood's logical structure of oppression. Immune identity is dualistically contrived in its depictions of self and non-self. The positions are related in their dissimilarity, where the meaning of the self takes priority over the problematized non-self. Plumwood argues that in a Western framework reason characterizes the master's domain. In the dualism of

man/nature, 'man' has the rational capacity to depict the other – nature – as the inferiorized other.⁶¹ In like manner, the *cognitive* self depicts the immune system as rationally setting up strategies to defend the body against pathogens. Microbes are thus viewed as 'behaving' in an inferior manner such that they can be conquered and controlled.

The self/non-self dualism has the following features of oppression:
backgrounding, radical exclusion, instrumentalism, homogenization. First, the non/self is backgrounded in relation to the self. Immunology is at a point of shifting the framework of the self. promoting an identity that does not rest solely upon host/microbe interactions. Immunity is a matter of self-establishment, without having to promote images of the other.⁶² As a result, microbial identities are progressively inessential for the constitution of the self. Microbial life is devalued insofar as the cognitive self denies how the former significantly contributes to immunological identity.

Second, the self/non-self are radically excluded on the basis of the inferiorization of the other. Self and non-self are polarized, with no continuity between two positions. The embodied self applies war metaphors casting the non/self as simplistic and powerless to the cognitive defenses of the immune system. For example, viruses are presented as 'primitive' in their inability to reproduce on their own. Production of viral particles requires the invasion and utilization of the host's cell.⁶³ The immune system can make many measures to prevent the virus from attaching, penetrating, replicating or assembling

⁶¹ Plumwood, Feminism and the Mastery of Nature, 1997, pp. 46-47.

⁶² Tauber, 1997, p. 195.

⁶³ Brock and Madigan, 1991, p. 189.

in the host cell. The sophistication of the immune system has many strategies to interrupt the life cycle of a microorganism that heavily relies on the complex features of the host.

Third, in the self/non-self dualism the non-self is instrumental to the goals of the self. In the cognitive metaphor of immune identity, the non-self is a kind of constraint that the self uses in performing self-referential functions.⁶⁴ Self-discovery, to some degree is contingent upon interaction with the non-self. For example, immunological interest in retro-viruses (such as HIV) comes from the researcher's interests in finding aspects of the self which make it vulnerable to viral infection and understanding how in some cases viruses irreversibly alter self-identity.⁶⁵ Our knowledge of viruses has been built upon the host/microbe dualism. The definition of the virus depends on the existence of the host, without which viral life is meaningless.⁶⁶ Viruses are described as subverting different host immunological mechanisms in order to prolong their own survival; they neutralize antibodies, mutate to present unidentifiable antigens, and evade host defenses. Viral life is instrumental to a revision of the host self.

Fourth, the non-self is homogenized to enrich the immune self.⁶⁷ The specificity and unique features of a wide range of microorganisms are forcibly molded into the war metaphor as a means to concretize the cognitive notion of self. The definition of the non-self is governed by and defined as a result of self-reflective processes.

Immunology is constructed on a dualistic metaphor of the self/non-self, characterized by backgrounding, radical exclusion, instrumentalism and homogenization. The dualistic construction of the non-self suggests that a cognitive metaphor of

⁶⁴ Tauber, 1997. p. 195

⁶⁵ Ibid., p. 186.

⁶⁶ Kuby, 1994, pp. 485-486.

immunologic identity propagates a conceptualization of the non-self (microorganism) which is over-simplistic, distorted and detrimental to our strategies to control disease.

The concretization of the elusive and cognitive selves through popular metaphors of war leaves much to the imagination to answer "What is the immunologic self?" In the first part of this chapter, a comparison of SP, TB, and AIDS reveals that Immunology is failing in its war against infectious diseases. Upon analyzing the metaphors that Immunology employs, I would like to suggest that this discipline rests on a self/non-self relationship which fundamentally amplifies the spread of disease. Because microorganisms are defined in dualistic relation to humans, I am skeptical that Immunology has adequately analyzed all the features of these microorganisms that may contribute to manifestation of disease. The cognitive self is so fixated on self-revision that the construction of the other is made secondary to it. Microbes are distorted to service the definition of immune identity; otherwise, they are neglected independently of their instrumental roles. In the process of identification, perhaps the self too is misconstrued. Tauber acknowledges that the concretization of the self is a risky task. Metaphors can only represent the immune system in a finite number of ways. Because it is difficult to gauge when the metaphor distracts from or clarifies the scientific enquiry of immunity, Immunology is still an immature science.⁶⁸

Disease control measures that rely on this narrow and caricatured version of microbial life may dwell on a misrepresentation of these microorganisms. Empirical analyses of SP, TB and AIDS show that the latter two epidemics have had immunologists question their knowledge of microbial physiology and the rationale behind the

⁶⁷ Tauber, 1997, p. 196.

developments of (in)effective treatments. The empirical data support my claim that the current understanding of Immunology reduces the conceptualization of microbial life to its effects on human self-identity. I use a feminist analysis to shift the gaze away from the self, or at least to show that over-emphasis of the self limits and dictates the construction of the microbial other.

Prioritization of the self exposes something more *insidious* – immune identity is a dualism of the self/non-self. The dichotomizing of human v. microbe is structured upon the dualistic othering of the non-self. The narcissism in Immunology leads to the foregrounding of the self and backgrounding of the non-self until the latter proves to be meaningful for the former. What develops is a one-on-one 'us' v. 'them' pattern of studying the immune system and microorganisms, respectively. Because microorganisms are increasingly defined as instrumental to the self for the sake of the self, this hierarchical and linear relationship precludes the complex interactions between microorganisms themselves.

Although microbial existences are vastly diverse, they are homogenized on the basis of one common thread which runs through them all: their hierarchical relation to the immune self. Within this dualized framework, representations of microorganisms are constructed in pathological and epidemiological relation to the host. Consequently, researchers can assimilate microbial life in the latter's pathogenic tendencies to: evade immune cells, attack the human body, compromise host defenses. By fixing the 'immune self' to be the key point in microbial comparisons, researchers may confuse learning about the functions of the immune system with describing microbial life cycles.

⁶⁸ Tauber, 1997, p. 199.

The self/non-self dualism may partly account for the limited use of vaccines and antibiotics. Both are designed to specifically target and debilitate (or destroy) one particular causative agent of disease. However, TB/HIV co-infections show that infection by one microorganism compromises the human's ability to withstand the toxic effects from drugs intended to destroy the other agent. In the attempts to solve these problems, researchers continue to look for newer and more specific medications, meanwhile, health care workers must place patients under strict prescriptive regiments and surveillance in order to avoid microbial resistance. Yet, these measures do not explain why the drugs are not compatible.

5.4 Implications for a Dualistic Conception of Immunology

In the previous sections, I have analyzed Immunology using Plumwood's logic of oppression. This internal critique clarifies the prescription of coercive social measures in disease control programs and reveals the ascription of popular dualistic metaphors in the construction of the immune self. First, great gaps exist in our present knowledge of Immunology. The human/microbe dualism advances a narrow, homogeneous understanding of microorganisms that limits medical research options for the development of bio-chemical and non-medical treatments. Instead of developing methods to target different microbial infections in tandem, researchers are confined to finding increasingly physiologically specific treatments on a one-to-one basis for each disease.

A human/microbe dualism at the micro-level sustains the First World/Third World dualism at the macro-level. At the micro-level, all humans (the oppressors) are

pitted against microorganisms (the oppressed). Insofar as the immune self is foregrounded, knowledge of microorganisms becomes more elusive. The backgrounding of microbial life explains at least in part the maintenance of dualisms at the macro-level, where some humans (the wealthy oppressors) are pitted against other humans (the poor oppressed). Rather than risking the ridicule of questioning the science itself, researchers blame the oppressed for spreading diseases. Considering how the oppressed have been so symbolically harmed that their challenges do not have political authority, researchers are not pressured to question a methodology which rarely caters to the needs of those most infected by infectious diseases. Oppressive constructions harm both the oppressed and oppressor. The human role as oppressor at the micro-level validates the oppression of some humans at the macro-level.

Second, an internal critique of Immunology shows that theoretical developments in this field rely on macro-level popular dualisms. War metaphors enter into the scientific realm as a means to punctuate the immune self. Metaphors of war not only differentiate human from microbes, they also evoke the dualism of international/tribal, war/peace, First World/Third World. In effect, the use of dualistic metaphors at the micro-level validates dualistic applications at the macro-level. At the same time, the immune self/microbe dualism itself offers another explanation for dualisms that are already in place. Employment of metaphors in Immunology expresses a subjectivity denied by those who cling to the belief that science is objective. This particular subjectivity reestabishes discrimination against the world's most vulnerable groups.

These insights are crucial for seeing how WHO policy-makers inadvertently support dualistic metaphors of disease.

5.5 WHO and Immunology

How does the discussion of Immunology relate to the critical analysis of WHO's health? Since its inception, WHO has focussed on the eradication of diseases. However, by implementing Immunology to achieve this goal, WHO is impelled to set up policies that challenge the rights of billions of people to be treated formally and substantively equally and to live healthily. First, all persons are not treated formally equally. Disease eradication/control programs that rely on vaccination generally have been successful. Mass-production of the vaccine drastically reduces the cost per person; furthermore, often after one or two doses of the vaccine, the immunized individual may be protected for up to several years. In disease programs where vaccines are either unreliable (TB) or unavailable (AIDS), health workers control the disease by prescribing long-term antibiotics to already infected persons. Depending upon the physical state of the patient – s/he may be ill from other diseases, malnourished, very young/old – the dosage and types of available medications vary. The empirical data show that many of the poorest countries do not have access to expensive and effective treatments for the most persistent infectious diseases. Moreover, by the time the prices have been reduced enough for the poorest countries, the microorganism may already have begun conferring resistance to the drugs. Overall, the poorest countries with the highest infection rates (TB, AIDS) have the least access to the most effective treatments. Consequently, the health of these people continues to be compromised by these diseases.

Although WHO advocates for the reduction of drug prices, advocacy alone does not address more deeply imbedded issues. Why are the drugs so expensive? Why in

some cases do drugs have such a short duration of efficacy? Some would argue that reducing the cost of drugs in the long-term helps to break the poverty-disease cycle. People who have access to medications can recover and go on to become economically productive.⁶⁹ Unfortunately, this response does not lend insight as to why the person is living in poverty conditions in the first place, nor does it change the order of access to the drugs so that the countries which need it the most will receive it first or at the same time as those countries where disease prevalence is much lower.

We have seen that in terms of formal equality WHO is failing to dismantle economic barriers so that all persons have an equal opportunity to access the most appropriate medications for their conditions. However, before WHO conjures ways to provide the means for drug access, it must critically analyze its methodologies for disease control. The organization itself may be relying on strategies that perpetuate the very problems it is supposed to solve.

All persons can be rendered substantively unequal. In my analysis of Immunology, I have shown that the formation of this discipline is fundamentally linked to a dualistic metaphor of the self/non-self. WHO uncritically relies on Immunology in order to formulate its disease control strategies. Yet, experience shows that as medications become scarce, WHO implements more drastic social control methods, indicating that the success of the disease programs rests on the people's willingness to comply with the presented strategy. If the treatment program fails, the onus of blame falls on the country that could or would not adhere to the set measures. In failure, these countries also pose a threat to non-infected areas. In epidemiological terms, infected

⁶⁹ Brundtland, Reith 2000 Lectures.

individuals themselves become vectors of disease; therefore, their actions must be controlled as a means to prevent further spread. Because these nations are defined and problematized within the parameters of the disease, they themselves become objects of disease control. Within a disease control framework, immunologists are in the position to deny these countries the means to make their own health decisions; that is, 'diseased' countries are treated substantively unequally.

Immunology is not only used in disease programs, it is also applied to WHO's primary health care initiatives. Tentative primary health care programs must compete with disease eradication programs. Yet primary health continues to come secondary to disease programs for a number of reasons. First, focus on primary health has historically been an unpopular concept due to its politicization of health solutions; therefore, WHO has difficulties convincing itself and others to promote primary health over disease eradication programs. Second, primary health covers a wide range of topics. It is often difficult to know what the scope of primary health care ought to be. Thus, WHO tends to present a 'mixed bag' of health care initiatives that do not seem to logically cohere. The properties of primary health care, donors are wary of 'investing' money into an area that will not provide clear returns. Third, in order to solve the second problem, WHO must devise a way to quantify data sets from primary health care studies.

⁷⁰ Tollison and Wagner, 1993, p. 15.

⁷¹ M. Makinen et al., "Inequalities in health care use and expenditures: empirical data from eight developing countries and countries in transformation," <u>Bulletin of the World Health Organization</u>, 78, No. 1, p. 55.

Presently, WHO uses DALYs to measure non-infectious conditions. Page 22 applying DALYs to primary health care, researchers validate the disease eradication programs. Implicit to the use of DALYs in a primary health program is the idea that primary health ought to be defined in relation to disease control. WHO presents disease programs as having a firm basis in science, therefore scientific measures can be used to generalize, hypothesize and design experiments for disease conditions.

The application of DALYs as a means to quantify primary health care programs contributes to the distortion of the programs' scope and direction. That is, disease control programs infiltrate WHO's primary health strategies.⁷³ For example, immunization is included as a component of Child Health.⁷⁴ Consequently, immunization programs overtake other crucial aspects of primary health, namely the installation of adequate health care infrastructures.

In taking steps to quantify primary health, WHO inadvertently appropriates the problems of Immunology into its strategies. Built into Immunology are dualisms that obfuscate microbial life which in turn promotes disease control measures that problematize human behavior and cultural practices. In its association with the spread of disease, the cultural practice is condemned, and cannot be used to set up health infrastructural systems. A country overridden with infectious disease(s) appears incapable of structuring its own health care systems.

⁷² WHO has also used the lot quality (LQ) technique to monitor health assessment programs. LQs confine health assessment to disease protocols. Thus, human behaviors are problematized. For more information please see Susan E. Robertson et al. "The lot quality technique: a global review of applications in the assessment of health services and disease surveillance" World Health Statistics Quarterly, Vol. 50, pp. 199-209.

⁷³ Jean-Marc Olivé et al., "Disease Eradication as a Public Health Strategy: is measles next?" <u>World Health Statistics Quarterly</u>, Vol. 50, p. 185.

According to Halfden Mahler, primary health care must be developed "by the people for the people."⁷⁵ Only those living in a particular region will know what kind of health infrastructure will be applicable to their life style, what nutritional requirements can be met in that location, and what additional research must be done to improve health status. However, countries burdened with disease do not have the liberty to initiate their health policies in light of their inadequate measures to control diseases. Health policymakers are justified to make decisions for these countries both in disease eradication control and primary health care. The more that a country's primary health care policies are shaped by top-down disease eradication measures, the greater are the possibilities that long-term health programs will not meet the needs of the people living in that country.

On the basis of disease control, WHO cannot avoid discriminating against different regions. Those countries that take the brunt of these criticisms – the poorest nations - must rely on WHO and other international organizations to bring epidemic diseases under control. At the same time, these nations cannot negotiate decisions made on their behalf because their ideas are associated with the root or persistence of the problem: the spread of disease. The poorest nations are condemned in their difference; consequently, primary health decisions do not reflect the unique needs of these peoples.

Given these problems, WHO presently is not in a position to promote health, nor can the organization advance the idea that access to health services is a right for all the world's citizens. The micro-level analysis of disease offers explanations for sustained discrimination against the most poorest and diseased regions in the world at the macro-

 ⁷⁴ World Health Report, 1995, pp. 4-10.
 75 Mahler, WHO Chronicle, 31, No. 12, p. 495.

level. In light of the historical, political, and scientific analyses of disease, WHO's definition of health, which presently reflects these issues, must be revised.

Chapter Six: A Negative Conclusion

Should WHO's definition of health be revised? A brief summary of the chapters will aid in constructing a response to this question. In Chapter One, I provided a brief history of WHO, where the tension between the organization's disease control programs and primary health care policies was first introduced. In my efforts to understand why this tension exists, I needed to investigate how and why WHO advocated both programs. Thus, in Chapter Two, I analyzed the WHO constitution in order to identify the values that it promotes. I found that WHO attempts to advance formal equality, substantive equality, and health. These values were implicit in the constitution and actualized only through WHO's development of specific policies. In Chapter Three, I introduced the tools for analyzing WHO's definition of health. Feminist examinations of oppression and symbolic harm were crucial for the deconstruction of disease at the macro-level (in Chapter Four) and micro-level (in Chapter Five). Upon the disclosure of dualistic metaphors of disease at both levels, I discovered that in prioritizing disease control over primary health care WHO unwittingly undermined its efforts to promote formal and substantive equality, and subsequently health.

WHO applies immunological ideas to develop both primary health care and disease policies. DALYs are just as useful in quantifying the effects that poor nutrition has on life years as in the calculation of the number of years lost to an infectious disease. Dualistic metaphors are brought into both analyses, because DALYs (and DOTS) are

premised upon a science which makes use of these metaphors at the most fundamental level. Coupled to the fact that WHO and its donors historically have prioritized disease programs over primary health initiatives, the former has set immunological standards for the latter, leading to the breaches in WHO's mandate to promote formal equality, substantive equality, and health.

In its present capacity, WHO cannot uphold the advocacy of its three values. First, WHO does not treat the world's citizens formally equally. Theoretically, disease control and eradication programs exemplify WHO's commitment to formal equality. Equal access to vaccines and antibiotics (and any other medical knowledge which would enable them to pursue their own health goals) (P7) is premised on the notion that all persons are equal regardless of race, religion, political belief, economic and social condition (P2).

However, the practical implementation of formal equality is hindered by an oppressive social context. Despite the objectives set by P7, not everyone is given access to basic drugs in the treatment of infectious diseases. A macro-level analysis of dualistic disease metaphors reveals that the identities of some individuals – most often the world's poorest citizens – are built upon oppressive constructions of disease. These identities are woven into other dualisms that compose the individual's identity. Collectively, they symbolically harm the individual; if dualistic metaphors wholly replace other aspects of the individual's existence, then she is denied personhood. Disease metaphors are used to objectify the individual and forfeit her right to make her own decisions and set new goals. WHO policies demonstrate the violation of human dignity through its paternalistic

disease interventions and provision of drug access to only wealthy nations; the first signifies their lack of autonomy and the second indicates the rejection of their intrinsic worth.

Problems in WHO's commitment to formal equality are linked to the organization's failure to defend the individual's right to be treated substantively equally. Theoretically, WHO's primary health care initiative – Health For All – is an excellent example of the organization's recognition that all persons are substantively equal. HFA concretizes substantive equality implicit in (P3) and presents an active role that governments play in promoting the health of their peoples (P9).

Unfortunately, oppressive disease metaphors deem diseased individuals substantively unequal to the un-diseased. Disease metaphors depict the diseased as primitive, helpless, unscientific – all of which serve as justifications for medical colonization. These dualized metaphors symbolically harm the diseased individual such that he experiences a devaluing of personhood. Although he can retain his personhood in some contexts he does not have the authority to effect changes; the disease identity is a mark of his failure to promote health. In regions where infectious diseases are prevalent, individuals are denied the recognition of diverse health needs because they have been homogenized in their common identifications with disease.

Governmental bodies which represent areas with high infection rates are not encouraged to contribute in the shaping of global health strategies, notwithstanding P9's stipulation of governmental involvement. Despite Mbeki's numerous attempts to compel health researchers to focus on alleviating poverty rather than relying on drugs to solve S.

Africa's AIDS epidemic, the S. African president is judged in light of his affiliation with the oppressed status; consequently, international researchers provide (illegitimate) reasons to dismiss Mbeki's views. On the grounds of substantive equality, WHO is obligated to provide the means for persons (like Mbeki) whose positions are compromised in their oppressed identity, so that they can offer alternatives to the experts' solutions. Yet, history shows that WHO enthusiastically adopts top-down disease control measures which discriminate against rather than protect the world's poorest communities.

WHO's faith in immunological protocols prevents the organization from questioning the possibility that these methodologies may contribute to the oppression of socially, politically, economically and physically vulnerable persons. Immunology employs the same metaphors that are ascribed onto the oppressed. Thus, diseased persons are harmed on two fronts. First, their actions are constrained within a scientific context which holds very dualistic, narrow and misguided constructions of microbial life. The problematizing of cultural practices is a consequence of a grossly inadequate knowledge of microorganisms and their complex relationships with human beings. Second, dualistic metaphors at the micro-level can be used to entrench the oppressed person's position at the macro-level. The human/microbe dualism posits another depiction of the subordinated as being less than human. Indeed, the diseased individual not only experiences a change in physiological capacity and appearance, she also undergoes a transformation of identity - from other viewpoints she represents the disease itself.

Due to WHO's history, policy-makers may be non-plussed by my suggestion and remain committed to the eradication of diseases, a focus which instills dualistic metaphors of self and other, the oppressor and the oppressed. A definition of health must therefore dismantle the dualistic construction of disease and health.

In the second attempt I try to incorporate lessons learned from the my first effort.

WHO's health may be amended to read:

(2) Health is a state of complete physical, mental and social well-being and the *understanding* of disease.

The definition "health is...the understanding of disease" changes the dynamic between the two terms. This expression advocates for a changed perception of diseases and of the microbial agents which cause those conditions. In this definition war metaphors may prove to be grossly inadequate descriptions of complex human-microbial relationships. However, the definition re-establishes the dichotomizing of primary health with disease programs.

Both definitions sustain strong components of primary health and disease control. Because of WHO's long history of presenting its employees as experts in disease, policy-makers may be complacent to act upon a revision of the definition of health which nonetheless retains the notion of disease. Perhaps a more radical reinterpretation of health needs to be advanced.

At this point I do not wish to continue proposing different revisions of WHO's health. Indeed that a Canadian graduate student should single-handedly formulate a new definition for WHO goes against the organization's efforts to advance substantive

equality. Therefore, I would like to make a more modest suggestion to WHO. Revisions to WHO's definition of health (which I strongly urge) must be the result of a collaborative effort, one that begins to undo the harms established by the implementation of the present definition.

Chapter Seven: Toward A Positive Definition Of Health

In the previous section I urged WHO to revise the current definition of health. Yet this request is much easier to make than to fulfil. Perhaps one method through which WHO can accomplish this goal is to involve the perspectives of individuals who have been most discriminated against in the history of global disease interventions. Their active participation – in a space where they are not condemned in their beliefs – may catalyze the deconstruction of dualistic metaphors, which have been used to alienate them. The search for a more just definition of health itself can be a means to treat persons both formally and substantively equally and to confirm WHO's commitment to value the health of all citizens.

In the following sections, I present a sampling of interviews that I conducted while in Ghana and Kenya. In presenting these interviews here, I hope to demonstrate a diversity of perspectives that greatly influence our understanding of health and challenge denigrating representations of these peoples.

7.1 Ghana

In Ghana, I participated in a community initiative to integrate differently abled persons (DAPs) into their communities. The Community Based Rehabilitation Program (CBRP) was run in affiliation with the Catholic Diocese of Wa and funded through the international non-governmental organization, Christophel Blinden Mission. Briefly, The

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CBRP worked with twenty-four rural communities in order to come up with

economically sustainable means to support differently abled persons. Eight in total, each

field worker (FW) was responsible for three communities. These FW would examine the

needs of the differently abled and the communities themselves. They would report back

to the Coordinator, Mr. Christopher Baborooh, who would then try to accommodate field

requests. During my stay I tried to conduct as many interviews both within the CBRP

and with other community members living in the Wa region.² My aim was to learn

about life in this area. Here is a sampling of those interviews.

7.1.1 Interview One: Felicity Gyilku

Date: 15.04.97

Parish: Lawra, U.W.R., GHANA

Format: Standard O/A Interview

Interviewer: Ayumi Goto

Interviewee: Felicity Gyilku (FG), FW for Laura Parish³

1. a) Education – I finished Korle-Bu, completed secondary school. We just had short

training in office, not necessarily going to an institution.

b) Previous Employment – I was with Ministry of Agriculture. I was mainly with

women's groups.

AG: What did you normally do?

¹ For a more detailed description of the CBRP please see Appendix 6.

² Wa is the capital town of the Upper West Region (UWR), Ghana.

³ Felicity Gyilku is the only female FW working for the CBRP program.

FG: Normally, we teach them home management and income generation activities and so on. We were with home extension so we teach them the above. We also encourage them to farming.

AG: How long did you work with the Ministry of Agriculture?

FG: Six years. Let me see... I was employed six years.

AG: Was the program successful?

FG: Some of us were not trained so we were affected by the redeployment system. Immediately from school, I joined the Ministry of Agriculture. Apart from Agriculture, I was also attached to the Water Project. I was employed from '85 to '86. I joined Water up to the point that I was redeployed.

2. AG: How is your interaction with Volunteers?

FG: They're very, very friendly. The way I do, the way they help me, I use my pocket

money to buy them drinks to encourage them to work harder.

3. a) AG: What do you think is the role of the FW?

FG: My role as field worker is to assist the DP in the village to get to some level that they can also manage their own affairs, to be self-reliant because there is no...They didn't know what to do as DPs. So they think they only rely on other people.

Because of this program, they learn that they can also do something to help themselves without family members supporting them.

b) AG: What are some roadblocks to your work?

involved. Eremon, there are a lot of (blind) cases. Eremon alone, I referred four cases to Orthopaedic in Nandom Hospital. So far, two have went.

5. a) AG: What are the rewards of work?

FG: The work to me, it is interesting. Only the facilities are not there. And that's what's despaired me. If not, I enjoy working with the disabled. My interest is to assist them. The disabled are neglected in a way and some of them are really suffering, so if I have my own way, I have a need to assist them.

b) AG: Which areas of CBRP need improvement?

FG: One thing is that this my work, they say it is community-based. That means the community has to shoulder some of the responsibility and looking at the community, they are disabled in a way so if I'm hungry what do I give to a disabled? I think the family members will appreciate it much to support them. This our work would have been more interesting if things were going on. For example, those referred to hospital now they are all complaining that they have no assistance. But empty-handed, to tell them to go to hospital...So most of the time, you go to a client without giving any assistance. The next day you go again and next day you go again. And sometimes, when they see you, they feel like hiding because they don't see any help in you. The few people who've had help are going on all right. Like Abideen. The only improvement...if our in-service training could be confirmed so that we can also improve. We had this training once volunteer training area...and I learned it's supposed to be quarterly, but we've only had two.

6. AG: What are some rewards of the job?

FG: Well, the little we receive is, I'm satisfied with it. The little they gave me...but not very satisfied because it's better than none. Half a loaf is better than none...Just this afternoon, I was returning from Babile I met (a client's) his father. He told me he has sent his child to the hospital and placed in treatment and it's my desire that the child gets treated. I like it when people take my advice and there's improvement. When I advise you and you don't take it, it disturbs me. But when they listen to me, I feel very happy.

7. AG: What are some village attitudes toward DAPs?

FG: Some places, they actually help. Some places, the people are interested with our CBRP, to help DP. But some notorious people are still negative towards DPs. With this CRC group...but when they are called for DPs, they are reluctant because they don't have DP in their family.

8. AG: What attitudes do villagers have towards HIV?

FG: I have had no interaction with HIV patients. I'm not afraid of HIV. If you pinpoint is someone is having it, they he (the HIV+ person) can take you to court. Even if you hear it, you can't say it. As for signs and symptoms, we all know it but you can't tell someone that has it. People are really afraid. These days, they don't joke with their condoms and I think things are a bit careful now.

9. a) AG: Is there anything you want to ask me?

FG: Well, the problem is, I think I have given some of my problems but I don't know how you'll help best to overcome them. Like I said, the community, itself, is handicapped. That means the community has to shoulder part of the responsibility.

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Whenever we talk to them (the community) about assisting...so I don't know how

best to solve the problem. The work's not interesting because the family is not

responding because of the money problem.

b) FG: I don't know whether you want to come back and work with us.

AG: I would like to come back as a doctor, as a paediatrician to Ghana and to Wa.

c) FG: Well, we also need your advice, advice sheets to each field worker. General

advice so far as work is concerned. We are not professional workers so we need

training in the field.

AG: I will make assessment sheets for each field worker.

7.1.2 Interview Two: Abideen Mohammed

Date: 15.04.97

Community: Lawra, U.W.R., GHANA

Parish: Lawra

FW: Felicity Gyilku

1. Client: Abideen Mohammed (AM)

Format: Client interview

Interviewer: Ayumi Goto (AG)

2. Disability: At birth, I was walking until the sickness got me. I received no polio

vaccine. At that time, vaccination was not available here. Suddenly, I could not

walk.

- 3. Treatment: I went to Isawam for the calipers. First time (I got the calipers) I was three years old. Then, 13. Now, I'm 19 years old. I did not receive any local treatment.
- 4. Educational Background: For primary, I went to English Islamic. Then I went to Lawra J.S.S. and Lawra S.S. There were no other children with walking disabilities. Other children helped, aided in walking. No other DPs were in school.
- 5. Occupation: I make crafts, local crafts. I learned it from my great-grandfather. I started working since J.S.S. Per month, I make about 20 000 to 25000 Cedis if materials are available. Normally I buy [materials] at the market.
- 6. Family Members: I've got three sisters, one older and the rest younger. The older sister is an apprentice hairdresser. She gives me financial assistance.
- 7. Future Plans: I have advertised for training (taking an apprentice). And I would provide the materials but still I have had no trainees. I have sold crafts to Accra. ⁴ I sent some supplies to a trade fair there.
- AG: What products do you make?
 AM: Purses, watch protectors, wallets, necklaces, juju holders, knives, leather wallets.
- 9. AG: Will you teach me how to make a, um...wallet?

 AM: Sure.

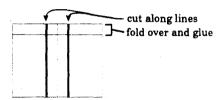
⁴Accra is the capital of Ghana.

Instructions to make a wallet:

1. Cut three rectangles and soak in water.



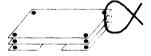
2. Of the three rectangular strips, draw and cut along the lines of the largest.



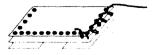
3. Stack the three leather pieces together.



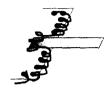
- 4. Design the top layer using dye, using a wood piece to make indented designs into the leather.
- 5. Allow the leather to dry.
- 6. Cut/poke 4 holes into and through all layers of leather in each corner. Tie through the holes with temporary ropes.



7. Along three of the sides, sew through the leather after puncturing along the seam (don't soak this 'thread leather' in water).



8. To make a fastener, make a slit into the top layer, slipping in a damp white leather flap, then sew in **while** sewing around with the thin layer.



7.1.3 Interview Three: Saaka Gyewama

Date: 07.04.97

Parish: St. Cecilia Parish

FW: Amatus Bamark

Community: Nakori, U.W.R., GHANA

Client: Saaka Gyewama⁵

1. Age: Mid to late 40's.

- 2. Family: her husband and brother care for her as tradition goes. Her son is also a client, having mental disabilities. The son is ~33 years old and has epilepsy.
- 3. Employment: She does petty trading in the market; her son is taken care of. Four children have died, only one has survived.
- 4. Disability: Difficulty walking; toes are curled and spread apart. Also has pain in right eye and complains of pain in eyes. She talks very slowly, drawling words.
- 5. Cause of disability: When she was about three years old, her mother was taking her to the market. She (the daughter) suddenly started wailing.

⁵ In this interview, the FW served as a translator for this woman. Here I have written his translation of her responses.

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6. Treatment:

a) Hospital – did not attend.

b) Traditional – they traced the cause traditionally and found that someone had tried

to kill her but they only succeeded in disablement.

7. Knowledge of CPRB: She has the thought that when one is unable to do a thing then

others should help to give that person help. That's what she understands.

Present situation: The only thing she can do is to sell little things at the market. She does

not know local crafts.

7.1.4 Interview Four: Lawrence Dakorah

Date: 14.02.97

Format: Spontaneous Interview

Interviewer: Ayumi Goto (AG)

Interviewee: Mr. Lawrence Dakorah (LD), Coordinator, North West Development

Agency (NWDA)

Purpose: To become introduced to the tenets and practices of NWDA.

AG: When was NWDA established?

LD: The idea for NWDA came into existence at the same time as the creation of the

Upper West Region, in 1983. But due to setbacks in logistics, nobody could start it up

until 1994 when the office was established.

AG: What is the philosophy of NWDA?

LD: To give the philosophy, I must give the background. The creation of the UWR was done at a time when the economy of the country had gone through serious regression, and the government couldn't put in necessary infrastructure to get desired results. There was a need for the private sector (for example NGOs) but operations of NGOs was not substantial. Therefore, overall there was no enhancement in regional development. We needed a local organization to co-ordinate NGOs (i.e. sons and daughters who were overseas were the only sources of searching out for financial aid to the region – yet we needed a strong local organization).

Therefore, the philosophy or aim of NWDA is:

- 1) to co-ordinate the development of NGOs
- 2) to be a local arm for channeling of developmental support

AG: What are the main focal points at present?

LD: Main focus is on:

- 1) Organizing NGO forums on a quarterly basis and establishing a meeting.
- Providing information on developmental work (e.g. library, literature use) to help other NGOs to plan.
- 3) Producing a newsletter to keep people informed.

AG: What specific areas are you considering right now?

LD: We are looking at supporting other NGOs. In terms of women's groups, we work with "Christian Mothers" to promote income generating activities such as bee-keeping. Right now, we are in the process of preparing a proposal on poverty alleviations. We want to increase the financial capacities of women and cater to their needs.

AG: How is NWDA funded?

LD: Local NGOs contributed, especially the Diocesan development office. We also receive substantial financial support from the Danish embassy. All of our computers and office wares came from the embassy funds.

AG: What are your future plans for NWDA?

LD: One, we would like to widen our ability to generate funds and provide more of a support service. Two, we are in the process of developing a network communication centre, offering secretarial services for a fee.

AG: What types of assistance are you in need of at present?

LD: There are many areas in need of funding. First, we need a lot of office equipment such as computers. For meetings, we need screens, a VCR and TV for showing presentations. In terms of transport, our geographical covering is wide. At present, we have only one motorcycle and to rent a car to go out into the field is very expensive. We would also like to stock up our library with books relevant to NGO activity: books on health, education, income generation. Finally, right now we can manage with who we have. We have a CUSO volunteer, just on leave from Ethiopia. We are looking for volunteers who can establish networks and who have skills in either administration and/or developmental planning.

AG: Thank you very much for this interview.

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7.2 Kenya

In Kenya the AIDS approximately 10-15% of the population is infected with HIV. The motivation for these interviews was to determine how persons at the local level attempted to deal with the physiological, religious, and social consequences of this disease. Here is a sampling of the interviews conducted.

7.2.1 Interview One: Margaret Ogola

Date: 04.06.1997

Format: Open-ended interview/visit

Interviewee: Dr. Margaret Ogola

Place: Dr. Ogola's home, Nairobi, KENYA

Q: What is you educational background?

A: I finished a Ph.D in Paediatrics. It seems different from N. America. Here, after studying M.D., you need to work for a few years to see which area you eventually want to specialize in. By the time I finished med school, I had four children (she says, laughing). My husband is a doctor and I'm usually the one to be the caregiver in the family. Because of my clinic, it takes up too much of my time. I'm thinking of resigning and just focus on the clinic (Cottolengo Centre). Because by the time the children come home from school at 5:00, I have a lineup of people waiting at the clinic.

Q: What's the main cause of paediatric AIDS here?

A: Mother to child transmission.

Q: What are the major indicator illnesses of AIDS in children?

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A: Most have respiratory problems like pneumonia (not necessarily PCP). Many of the

children don't last through all of the stages of AIDS but some do struggle until the bitter

end.

O: Is that because the children do not have a fully developed immune system?

A: Yes, in fact that's a possibility.

Q: What is the general life span of HIV+ children?

A: It really depends on the standard of living. Some came to the Cottolengo Centre as far

back as five years ago and they're still healthy.

Q: How or what medical treatment do you provide for the children?

A: Treatment is symptomatic. Medications like AZT are just to expensive and most

people cannot afford them.

Q: What are the laws concerning HIV+ children in schools?

A: What laws? (she laughs ironically) For most HIV+ children, as soon as the schools or

teachers find out that the parents or students, themselves, are HIV+, the kick them out.

One of the children (a brother of a child here at Cottolengo) has managed to keep his own

HIV+ status secret so he still attends public school. At Cottolengo, we teach up to

primary 3.

7.2.2 Interview Two: Christine Kowi and Tuntena Amwayi

Date: 06.06.97

Place: TAPWAK (The Association of People Living With AIDS in Kenya), Head Office:

off Muthaiti Road, Nairobi, KENYA

AG: What are the reactions of other (HIV-) children when they learn that their classmates are HIV+?

KA: Before educational awareness, the children didn't understand before being told that. They refused to greet them. After education, they feel they've done something wrong. It's more easier with children to get along with HIV+ people; they learn. Adults already have conceptions and beliefs that are difficult to change.

AG: Do you actually have HIV testing through TAPWAK?

KA: Yes, we provide pre- and post-testing, and we send the samples to KEMRI. In pretesting, we explain to the client the benefits of having the test such as: if someone is growing thin, and unable to fight off infections, the fear of not knowing their status makes them more ill, they suffer from psychological effects. In post-test counselling, if someone is positive, we allow the client to arrive to that conclusion by asking questions about HIV.

AG: Is there a difference in telling a wife versus a husband of HIV seropositivity?

KA: When the wife comes and is tested positive, when she tells the husband, he becomes violent. If the husband tells of status, the wife usually stays. We find that men tend to hide their results.

AG: How does counselling help those who are HIV+?

KA: Psychological support slows down the onset of AIDS from HIV infection.

AG: Is it difficult to provide HIV counselling in your experiences?

KA: It's difficult to talk about HIV and sex. Everybody wants money: if they're sick, they won't say. One condom costs KSh 3. Most clinics supply them for free but some are expired. We have to work together for training and counselling.

AG: Can you think of other organizations which deal with AIDS?

KA: Nyumbani House is an orphanage and they take in young children who don't have support. They have a problem to provide medicine.

7.3 Closing Remarks

Reflected in these interviews are a wide range of interests, needs and suggestions.

So much diversity can be found within a single region of Ghana or a single city in Kenya.

If WHO provides a proper forum for the sharing of such unique and often misrepresented voices, then it becomes closer to achieving health for all.

Constitution of the WHO

WHO defines health as 1:

- [1]...[A] state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.
- [P2] The enjoyment of the highest attainable standard of health is one of the **fundamental rights of every human²** being without distinction of race, religion, political belief, economic or social condition.
- [P3] The health of all peoples is fundamental to the attainment of peace and security and is dependent upon the fullest co-operation of individuals and States.³
- [P4] The achievement of any State in the promotion and protection of health is a value to all.
- [P5] Unequal development in different countries in the promotion of health and control of disease, especially communicable disease, is a common danger.

¹World Health Organization, <u>Basic Documents</u>, 42nd Ed., (Geneva: WHO, 1999), p. 1. Definition [1] is part of the original Constitution which was adopted during the International Hea;th Conference in New York in July 1946. Amendments adopted by the 26th and 29th WHAs (resolution 26.37 and 29.38) were enforced on 3 February 1977 and 20 January 1984 respectively and incorporated into present text. Note: Bold terms are my emphasis.

² I have bold-scripted key words.

³ 'States' refers to member states of WHO. These nations are regions have accepted the tenets of the constitution and their role in promoting the principles and definition.

- [P6] Healthy development of a child is of basic importance; the ability to live harmoniously in a **changing total environment** is essential to such development.
- [P7] The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health.
- [P8] **Informed opinion** and **active co-operation** on the part of the public are of the utmost importance in the improvement of the health of the people.
- [P9] Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.

List of Acronyms

AIDS – Acquired Immuno- Deficiency Syndrome	IARC – International Agency for Cancer Research
AZT – Zidovudine	J.S.S Junior Secondary School
BCG – Bacillus Calmette – Guerin	KEMRI – Kenya Medical Research Institute
CBRP – Community Based Rehabilitation Program	MDR-TB – Multiple Drug Resistant-TB
CP – Contract Pregnancy	NGO – Non-Governmental Organization
CRC – Community Rehabilitation	NWDA – North West Development Agency
Committee	PCP – Pneumocystic Pneumonia
CUSO - Canadian Service Overseas	PWA - Person With AIDS
DALY – Disability Adjusted Life Years	RNA – Ribose Nucleic Acid
DAP – Differently Abled Persons	SP – Smallpox
DNA – Deoxyribose Nucleic Acid	S.S Secondary School
DOTS – Directly Observed Treatment	TAPWAK – The Association of People Living With AIDS in Kenya
	TB – Tuberculosis
DP – Disabled Person	UN – United Nations
ECOSOC – Economic and Social Council	UNAIDS – United Nations AIDS Organization
GA – General Assembly	UNICEF – United Nations Children's Fund
HFA2000 – Health For All by the Year 2000	UWR – Upper West Region
HIV – Human Immuno-Deficiency	WHA – World Health Assembly
Virus	WHO - World Health Organization

Smallpox (SP): Introduction

Smallpox can be traced far back in human history. Historians speculate that SP was one of the numerous diseases that devastated entire populations in Biblical times (1000 - 500 B.C.E.), which devastated entire populations. Chinese, Roman, Turkish, and Amer-indian records indicate having had contact with SP.¹ The Chinese and the Turks were amongst the first to attempt controlling the disease by applying dried pustules of smallpox to uninfected individuals. However, it was not until the early 1700's that smallpox vaccinations became widely accepted by the European community. Lady Mary Wortley Montague, an aristocrat who had recently returned from Turkey, learned of the practice of smallpox inoculation from her Turkish hosts and introduced the prophylactic treatment to English society. Greek Physicians who were practicing in England at the time reported that in Greece, smallpox inoculation had long been established prior to knowledge of the Turkish practice.² Two and a half centuries later Russian researchers with the support of WHO announced their goal to eradicate the disease. By 1978, WHO exclaimed that smallpox had been wiped off this planet. Whether this achievement is a success or has set an impossible precedent for other disease eradication programs is yet to be decided.

Smallpox: Pathology and Epidemiology

Pathology. Smallpox is caused by a pox virus which depends on the host to complete protein synthesis.³ The clinical symptoms of smallpox are easily identifiable. In a typical course of infection the individual experiences a sudden onset of fever, chills, back and head-aches for three to four days. During an infection, clearly visible spots (and in a

¹ McNeill, <u>Plagues and People</u>, 1998, pp. 20-21, 130-32.

² Ibid n 259.

³ Those infected with smallpox exhibit DNA synthesis outside of the nucleus, whereas DNA synthesis occurs in intracellular organelles in healthy individuals; see Brock and Madigan, p. 226.

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severe infection, bulbous inflammations) appear on the face and skin. At around the fifth day, these 'pimples' have filled up with a serum, which then turns into a pus-like liquid. The pimples scab by the tenth day, leaving permanent pock-marks. Extreme cases of smallpox cause blindness and/or death. Once someone has contracted the disease, no effective treatments are available to counteract the infection.⁴ Even after the poxing has healed, telling scars remain on the body.⁵ If a person recovers from SP s/he rarely experiences a re-infection.

Epidemiology. Transmission of SP does not require a vector - an animate or inanimate object which passes the microorganism from one human to the next.⁶ Instead, it is spread from host to host, either through direct contact or inhalation of pox particles. A single drop of exhalant contains approximately 1000 virus particles, which is more than enough to transmit the disease to an uninfected person. The disease moves rapidly within a community; an infected person is in an infectious state for only four to five days, at which time the disease can be passed onto other individuals.⁷

Smallpox: Control Measures

As I have previously mentioned, different groups attempted to control the spread of SP long before the scientific rationale behind vaccinations were understood. However, the impetus for world eradication came about only after potent standardized vaccines

⁴ See Satty Gill Keswani, "Eradication of Smallpox by the World Health Organization", <u>JAMWA</u>, 32, No. 9, p. 335.

⁵ Laurie Garrett, <u>The Coming Plague</u>, 1994, p. 41.

⁶ For example, mosquitoes are vectors for malaria. Mosquitoes carry the parasite *Plasmodia spp.*, and inject it into the human host.

⁷ Although nutrition and general health do not seem to be major factors of transmission, overcrowding – such as slum area in urban centers – facilitates rapid spread of the virus. However, the disease also occurs in rural areas, via migratory workers who move between cities and villages. A. W. Downie et al., "The Eradication of Smallpox", <u>WHO Chronicle</u>, 22, No. 12, p.525.

were produced, national governments expressed the political will to fight the disease, and researchers were provided with appropriate funds for mass vaccination campaigns.

The fundamental objective of WHO's smallpox eradication program was not to vaccinate "x" numbers of people. Rather, it aimed to achieve nil incidence of smallpox.⁸ Control required three components. First, primary emphasis was placed on the *surveillance* of smallpox so that researchers could determine where mass vaccinations would lead to the most effective interruption of transmission. Second, mass vaccinations followed studies of areas endemic to smallpox. Third, modification strategies in the form of mobile surveillance teams were put into place to aid in the control of sporadic outbreaks.⁹

WHO researchers faced many practical problems in their attempts to implement the eradication program. First, researchers came up against road-blocks in the production and distribution of vaccinia vaccine. It was quite a challenge to produce a heat stable vaccine that would not lose its potency in tropical climates such as Africa. In the 1950's, scientists in the U.K. developed a method to freeze-dry the vaccinia. However, another problem arose concerning the potency of the vaccine. Merely 15% of all vaccinations functioned at the standards that had been established by WHO. To solve this problem, two special measures were installed. First, all leading manufacturers received a manual for the proper production of freeze-dried vaccine. Second, WHO offered testing services and consultations for the manufacturers. WHO governed the annual production and distribution of approximately 200 million doses of vaccinia from the inception of the eradication program in 1965.10

⁸ D. A. Henderson, <u>International Journal of Epidemiology</u>, 1, No. 1, pp. 25-27.

⁹ Ibid

¹⁰ Downie et al., WHO Chronicle, 22, No. 12, pp. 523-524.

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The distribution of the smallpox vaccine proved to be equally difficult. Donald Henderson, Isao Arita and leading members of the smallpox initiative had to think of a cost-effective strategy to administer the vaccine to millions of people. Prior to the campaign, rotary lancets were commonly used to inject the vaccinia. Unfortunately, because this procedure was painful and left unsightly lesions, people would refuse the vaccination. WHO introduced two new methods of administration: inoculation by jet injector and multiple punctures using the bifurcated needle. The first method required a lot of maintenance, making it economically unfeasible to be used at an international scale. The second method – the bifurcated needle – turned out to be the most cost effective and nearly maintenance-free method of choice. 12

Smallpox: Socio-economic outcomes

Beyond the obstacles that the vaccine presented were more significant issues concerning the cultural willingness to accept the vaccine and change social practice and behaviors in order to prevent further spread of smallpox. In many communities, a social stigma surrounded individuals who had smallpox; infected persons were kept hidden, hindering researchers' abilities to stop further spread. As well, many communities had learned to distrust health workers who had shown their incompetence with earlier failed attempts to stop other epidemics.¹³ Finally, epidemiologists believed that many traditional methods of caring for the sick and funeral customs could cause further spread

¹¹ Isao Arita, WHO Chronicle, Vol. 34, p. 176.

¹² The bifurcated needle is designed such that a drop of vaccinia vaccine is held between two prongs. The vaccine is administered by piercing the epidermis with the prongs, enabling the liquid to enter the perforated skin. See B. A. Rubin, "A note on the development of the bifurcated needle for smallpox eradication", <u>WHO Chronicle</u>, Vol. 34, pp. 180-181.

¹³ S. O. Foster, "Smallpox Eradication: lessons learned in Bangladesh", <u>WHO Chronicle</u>. 31, No. 6, pp. 245-46.

of smallpox.¹⁴ To counter these problems and at the same time to ascertain the surveillance of endemic areas, WHO hired and trained health personnel to act as educators and field epidemiologists. The success of the eradication program was contingent upon the field worker's ability to change local opinions and to emphasize the value of immunization.¹⁵ Therefore, WHO needed to provide adequate logistical support for these workers. WHO also had to continuously evaluate the accuracy of different disease notification systems.¹⁶ Henderson reflects that the success of smallpox eradication rested primarily on the surveillance program and the morbidity notification system.¹⁷

Amazingly, the SP eradication program initiated international cooperation. Perhaps much credit can be given to two major superpowers – the U.S.S.R. and the United States – which despite Cold War tensions worked in close collaboration to achieve this success. The U.S.S.R. was the first to declare a mass campaign against smallpox in 1958. At the onset of the eradication campaign, in 1967, the U.S.S.R. donated 25,000,000 doses of vaccine to WHO, and went on to donate >80% of all vaccines ever contributed to the organization. A leading American physician, Donald Henderson, and his research group at WHO ultimately devised the mass-vaccination and surveillance methodologies to eradicate the disease.

Between 1967-77 WHO, along with American and Russian immunologists, were responsible for millions of vaccinations. Altogether, \$300 million (U.S. dollars) was

¹⁴ Downie et al., WHO Chronicle, 22, No. 12, p. 526.

¹⁵ Henderson, World Health Forum, Vol. 19, p. 116.

¹⁶ In some cases, the health professionals who were in charge of the vaccinations believed that mass immunization itself promised eradication. In other instances, more conservative national authorities refused to report the numbers of those who were (un)vaccinated. See D. A. Henderson, <u>International Journal of Epidemiology</u>, pp. 27-28.

¹⁷ Ibid.

¹⁸ D. A. Henderson, World Health Forum, Vol. 19, p. 115.

spent on wiping out SP.¹⁹ This amount is very low considering the number of lives that could have been lost and the impact that those deaths would have had on national economies. The U.S. and U.S.S.R. were the greatest economic contributors to the SP eradication program. Indeed, the eradication of smallpox provides a strong example of what political will and adequate funding can do in face of a straightforward, self-limited²⁰ infectious disease.

¹⁹ In 1991 dollar figures, the smallpox eradication program cost \$759 million (USD). This estimation is derived form the latest U. S. CPI (Consumer Price Index) data. See Garrett, p. 626.

²⁰ By self-limited, I mean that smallpox rarely if ever causes major organ failures. It is limited to the epidermis.

then, the numbers of infections have been on the rise. In 1993, WHO declared TB to be a global emergency.

Today, TB and HIV make a deadly pair, co-infecting the individual. Multi-drug resistant strains of TB are becoming more common, especially among HIV+ patients.⁷ In 1993, WHO declared TB to be a global emergency. Roughly 1/3 of the world population carries TB; of this proportion ten percent go on to have an active infection. Every year, approximately 10 000 000 new infections occur.⁸ TB is indeed a world problem.

Tuberculosis: Pathology and Epidemiology

Pathology. Tuberculosis is caused by Mycobacterium tuberculosis, a rod-shaped bacterium which requires oxygen for survival. The bacteria reside in macrophages, an immunological cell which usually actively ingests and destroys bacteria or viruses. In the case of TB, however, the bacterium has the ability to survive and replicate inside some macrophages. The immune system activates non-infected macrophages that surround the infected cell, creating a granuloma. This type of bacterial destruction causes tissue injury in the host. "Tubercles" or hard-edged lesions form as a result of immunologic activity and are not caused by the bacterium itself. 11

Epidemiology. In the infected individual, TB can progress in two ways. First, the most common form - pulmonary TB - infects the lungs. The patient experiences severe weight

⁷ World Health Report, 1996, p.22.

⁸ Salvers and Whitt, Bacterial Pathogenesis, 1994, pp. 307-308.

⁹ The immune system elicits a cell-mediated response against the bacteria. In a cell mediated response, specific effector cells – T cells – attack in two ways. First, it releases a protein hormone (cytokine) INF-which activate the macrophage enough to kill the bacteria. Second, T-cells also attack the bacteria from the outside, by killing the infected macrophage. See Abbas et. al., 1994, pp. 326-27.

¹⁰ Granulomas are giant multi-nucleated cells that form in response to persistent microbes. Granuloma are associated with tissue fibrosis, a healing reaction which nonetheless leads to the interference normal tissue function. See Abbas et al., 1994, p. 271.

¹¹ Abbas et. al., p. 271; Salvers and Whitt, pp. 309-310.

loss, fever, coughing (bloody sputum) and loss of energy. If the disease spreads to other organs, then the patient experiences extra-pulmonary TB, which is almost always fatal.¹²

TB is passed through the air from host to host. Transmission occurs only when a person is in prolonged contact with a person who has an active case of TB. ¹³ Recall that only 10% of all carriers have an active case of TB. In the other 90%, the bacteria is controlled by effectors of the immune system. Activation of TB can occur for many reasons. The individual may be immunocompromised due to other infections that either over-exert or destroy the immune system. Immunocompromise may also be a result of stress, over-exhaustion, malnutrition. Of all TB cases in the world, 95% of sufferers come from 'developing' countries. ¹⁴ However, the disease is not restricted to those areas. Researchers have seen a dramatic rise in TB cases in wealthier nations. Keep in mind that often the impoverished people living in these wealthy nations carry the largest burden of TB.

Tuberculosis: Control Measures

The rationale behind TB control (as in smallpox) is to break the chain of transmission of the causative agent. WHO researchers find that, rather than relying on vaccines, the best way to control TB is to cure all infectious patients, thus preventing any further spread of the disease. In the past, BCG (Bacillus Calmette – Guerin) was commonly used in mass immunizations around the world. PCG is an attenuated 18

¹² Salyers and Whitt, p. 308.

¹³ Salvers and Whitt, 1994, p. 307.

¹⁴ WHO, World Health Report, 1996, p. 27.

¹⁵ K.L. Hitze "Tuberculosis control: Is Modern Knowledge Being Applied?" WHO Chronicle, Vol. 26, p. 383.

¹⁶ WHO, World Health, 46, No. 4, p. 23.

¹⁷ Ibid., p. 384.

¹⁸ In an attenuated vaccine, the bacteria are alive, but have lost their virulence. Regardless, attenuated cells elicit an immune response. Brock and Madigan, 1991, p. 464.

vaccine made of *M. bovis*, a bacterium genetically close to *Mycobacterium tuberculosis*. An immune system that has been introduced to *M. bovis* will identify and kill *Mycobacterium tuberculosis*. WHO and other researchers have had a lot of problems with BCG. First, BCG can only protect those previously uninfected by the bacteria; revaccination does not improve immunity of those who have had previous exposure to the disease. Second, individuals living in tropical climates have a certain degree of natural immunity against *Mycobacterium tuberculosis*. In these cases, BCG does not contribute to greater protection against TB. Third, BCG vaccination can also lead to a disease called BCGitis. This disease most commonly occurs in people who are immunocompromised (such as AIDS patients). Although BCG is the only vaccine available for TB and extremely economical, ¹⁹ because of the problems cited above, it has been replaced with other, more effective control measures.²⁰

The best way to interrupt TB transmission is to prevent infected individuals from spreading the bacteria. Many anti-TB antibiotics are available. Each antibiotic has a specific mechanism to shut down replication of new bacteria. For instance, it is hypothesized that isoniazid and rifampicin – the two most common antibiotics against TB – inhibit synthesis of the bacterial cell wall.²¹ Unfortunately, some strains of *M. tuberculosis* are resistant to these and other antibiotics, especially if the drugs are used singly. Thus a combination of drugs are prescribed, so that if the mycobacteria are

¹⁹ BCG costs about ten cents U.S. per dose. However, because the effectiveness is so questionable, a lot of money may be inappropriately allocated to a vaccine which in many cases does not increase one's immunity against TB. Salyers and Whitt, 1994, pp. 318-319.

²⁰ Research money continues to go toward vaccine development. However, because of the physiology of TB, immunologists and bacteriologists have yet to discover a long-acting, complex vaccine which matches the complexity of TB bacterial life. More research must be done on *M. tuberculosis* at the cellular and molecular level in order to design an effective vaccine. John D. H. Porter and Keith P. W. J. McAdam, "The Re-emergence of Tuberculosis" <u>Annual Review of Public Health</u>, Vol. 15, pp. 314-315.

²¹ Salyers and Whitt, 1994, pp. 310-312.

resistant to one antibiotic, they will more than likely be killed off by the other(s), since the likelihood of natural resistance to more than one drug is very low.²²

Bacterial resistance has come about for a number of reasons. First, because of the millions of bacterial particles that grow during an infection, researchers assume that some are naturally resistant to the drugs. Second, a major reason behind resistance is due to the patients' failure to complete a course of treatment. They tend to stop taking the medication once their health has improved. Unfortunately, the TB infections are inactivated only if the entire prescription is completed. The living bacteria genetically mutate to avoid antibiotic attack. Although effective drugs against TB have been available for the past fifty years, poor patient adherence to the drug regiment has led to MDR-TB (multiple drug resistant - TB).

A patient has MDR-TB if the bacteria s/he carries are resistant to at least two anti-TB drugs.²³ In a case of full-blown MDR-TB, the individual cannot be cured by the four main anti-TB drugs: rifampicin, iosoniazid, pyrazinamide, ethambutol. The first cases of MDR-TB were diagnosed in New York City, often in conjunction with HIV. Since then, MDR-TB has spread to countries around the world. In poorer countries, individuals cannot afford the alternative drugs to kill off MDR-TB. If control of TB does not come quickly, many more individuals will be infected with MDR-TB.

WHO wishes to achieve two goals with the DOTS program. First, DOTS should achieve higher cure rates. In the DOTS program, patients take their medication under the supervision of health care workers. Whereas conventional TB therapies²⁴ can drag out

²² Ibid.

²³ WHO, World Health, 46, No. 4, p. 19.

²⁴ In a conventional treatment of TB, patients are hospitalized for the first two months of a six month treatment program. Hospitalization ensures that patients comply with the drug regiment, and are isolated so that subsequent spread of TB does not occur. In the third month, the patient is released from the hospital, but continues to self-administer drugs for the next four months. See Katherine Floyd, David Wilkinson, Charles Gilks, "Comparison of cost effectiveness of directly observed treatment (DOT) and conventionally delivered treatment for Tuberculosis: experiences from rural South Africa" BMJ, Vol. 315, p. 1407.

(due to poor compliance, growing bacterial resistance, etc.), in most cases, 85-95% of patients on the DOTS program are 'cured'25 within six months.

The second goal of the DOTS program is to improve case detection and surveillance of non-compliant patients. Similar to the smallpox eradication program, the surveillance and reporting of TB-infected individuals is important for the prevention of further spread of the disease. However, the DOTS surveillance strategy is more complicated than the smallpox plan. Because *M. tuberculosis* is a slow growing bacterium and not readily visible, diagnosis of recurrence must be made through sputum smear-microscopy, radiographical analysis and clinical diagnosis. WHO uses the sputum microscopy method to diagnose TB. In cases where sputum smears have come out positive (i.e. active TB), the health care worker can (re)initiate drug therapy.

The DOTS program improves case-findings of TB+ individuals who would otherwise spread the disease. However, presently a large number of TB cases remain undiagnosed while in other cases, patients receive inadequate treatment.²⁶ DOTS case detection of TB+ patients depends upon patients to self-report their infection to health care clinics.²⁷ Until measures can be made to allow health care workers have access to non self-reporting TB+ individuals, the spread of TB cannot be adequately abated.

WHO's DOTS program is still in its infancy. Researchers have found that the success of a national DOTS strategy is closely linked to a country's health care system. Countries that have deteriorated health infrastructure are more likely to have problems installing and sustaining the DOTS program.²⁸ Undoubtedly, more focus must be placed

²⁵ 'Cure' does not mean that the patient has killed off all of the bacteria. Instead, it means that the bacteria is in a latent phase, and reactivation can occur.

²⁶ Mario C. Raviglione et. al., "Assessment of Worldwide Tuberculosis control," <u>Lancet</u>, Vol. 350, p. 628. ²⁷ Ibid., p. 624.

²⁸ Porter and McAdam, <u>Annual Review of Public Health</u>, Vol. 15, pp. 314-315.

on analyzing and improving health care systems worldwide prior to successful international implementation of DOTS.

Tuberculosis: Socio-economic Outcomes

A number of economic issues arise from the TB epidemic. TB is one of the most cost-effective diseases to control. WHO implements DOTS, a strategy which is cheaper than conventional therapies because the extra money spent to hire health personnel to ensure patient compliance is much more economical than the cost of treating relapse cases of TB (where patients did not complete their drug therapies).²⁹ In other words, recovery rates in the DOTS program are higher, so that less money is channeled toward re-treatment of 'failed' compliance cases. As little as \$13-30 (U.S.) covers the costs of the DOTS treatment per person.

However, in some of the least developed countries where health care expenditure per person amounts to less than \$20 U.S. per person, TB drug therapies are economically unfeasible. WHO is negotiating with pharmaceutical companies to bring down the cost of TB antibiotics.

Other economic issues arise for HIV and TB patients. The co-infection of HIV/TB gives rise to problems in drug reaction and drug resistance.³⁰ For instance, TB/HIV patients in poor countries are treated with thiacetazone, an antibiotic that is three times cheaper than alternative drugs.³¹ In HIV+ persons thiacetazone treatments are deadly: it causes their skin to peel away, eventually leading to death. Drug reactions prevent the patient from accessing the more affordable and less toxic antibiotics. In some

Richard D. Moore et al., "Cost effectiveness of Directly Observed Versus Self-administered Therapy for Tuberculosis", <u>American Journal of Respiratory and Critical Care Medicine</u>, Vol. 154, p. 1016.
 WHO, <u>World Health</u>, 46, No. 4, p. 8.

³¹ In wealthy nations, thiacetazone is not available, due to its toxic effects. However, because it is the most inexpensive anti-TB drugs, many poor countries use this drug.

cases, the antibiotics have such a toxic effect on a patient co-infected with TB and AIDS that s/he must stop the therapy.³² The bacteria confer resistance to the antibiotics; therefore, the patient must purchase even more expensive and less effective TB drugs.³³

At the root of the economic straits of the TB and HIV-infected person are serious social issues. According to Paul Nunn and Avata Kochi, sometimes when a person has HIV-seropositive status, family members may not foot medical bills for his/her TB infection, knowing that AIDS will kill the person eventually.³⁴ The social and health stigma attached to HIV+ persons hinders economic and social access to anti-TB drugs. And in many cases where families want to pay for the drugs, the medications are too expensive and far beyond their economic reaches.

Not all social problems are limited to these surrounding HIV/TB co-infections. The DOTS program itself is in need of further evaluation. The success of the DOTS program is premised on the stability of health care systems already in place. Yet, many health care systems are sorely inadequate. Poor infrastructures may exist for several reasons. First, in a country facing governmental reform (possibly form a centralized to a liberal economy), health care systems are in a state of flux.³⁵ Second, if a country is at war, then other social infrastructural programs may suffer.³⁶ In cases of war, the

³² Most MDR-TB cases occur in HIV+ persons. See Mario. C. Raviglione et al., "Global epidemiology of tuberculosis: Morbidity and mortality of a worldwide epidemic," <u>JAMA</u>, 273, No. 3, p. 224. Researchers have found that the viral load of an HIV+ person increases by 5-160x during a phase of active TB infection. To solve this problem, researchers propose prescribing TB antibiotics prophylactically, to prevent activation of latent TB in the first place. The data show that prophylactic use of TB antibiotics is more economical than treating active TB cases, especially when secondary costs (such as lack of income due to illness) are brought into the calculus. See David N. Rose, "Short - Course Prophylaxis against Tuberculosis in HIV-infected Persons", <u>Annals of Internal Medicine</u>, 129, No. 10, pp. 779-786, and Jensa C. Bell et al., "Tuberculosis preventive therapy for HIV-infected people in Sub-Saharan Africa is cost-effective" <u>AIDS</u>, 13, No. 12, pp. 1549-1556.

³³ Raviglione et. al., <u>JAMA</u>, 273, No. 3, p. 225.

³⁴ Ibid.

³⁵ WHO, World Health Report, 1995, p. 43.

³⁶ See John Grange and Alimuddin Zumla, "Tuberculosis – an epidemic of injustice," <u>Journal of the Royal College of Physicians of London</u>, 31, No. 6, p. 638.

economy may shift to sustain the country's defense system at the cost of funding health programs. Third, wars often lead to large mobilization of groups of people, creating statistical errors of those who fall under the jurisdiction of health coverage. Fourth, the country may be facing other, more pressing health issues so that all the funding is allocated to solve that specific problem.

Any of these problems can severely compromise the successful implementation of the DOTS program. First, in many sub-Saharan countries, a lot of the health care money is spent to deal with the AIDS epidemic. In Kenya, for example, the Ministry of Health forecasts spending 79% of their budget for HIV/AIDS treatment by 2020 (up from 17% in 1990).³⁷ Thus, WHO will have a lot of difficulty convincing Kenyan health policy makers to adopt DOTS in light of the country's AIDS crisis. Second, DOTS requires the TB+ patient to take the drugs in the presence of a health care worker. For mobile groups – whether mobilization is because of nomadism, war, etc., strict adherence to a six-month drug program is very difficult. In the least, to see DOTS succeed, WHO would have to introduce a buddy-system where a designated person ensures that the patient completes the prescription.

At issue is a country's prioritization of health. Implementation of DOTS may be low in a country's list of concerns. When one's life is in immediate danger (like in war), the DOTS program may seem frivolous, time-consuming, or distracting. DOTS is extremely expensive to install; furthermore, one cannot see immediate benefits from the program.

The success of DOTS also depends on the prioritization of global health by wealthy 'donor' nations. Ninety-five percent of TB occurs in 'developing' countries.

³⁷ This estimate is given with the assumption that the health care budget will rise at the same rate as inflation and population growth. See Charlotte Leighton, "The Direct and Indirect Cost of HIV/AIDS" in AIDS in Kenya, 1996, p. 70.

WHO counts on wealthier nations to sustain (therefore, support) programs in the poorer countries.³⁸ Donor budgets can change as much as recipient budgets. WHO staffers find that donor nations are interested in very specific, short-termed, and self-contained disease eradication programs. For example, the United States may prioritize supporting the AIDS program, at the cost of emphasizing DOTS and, more importantly, the development of health infrastructures upon which DOTS rests.³⁹

The TB epidemic has forced WHO to come up with a cost-effective strategy to prevent further spread of the disease. Crucial to the DOTS strategy is the smooth functioning of well-established health infrastructure in the DOTS-recipient countries. Ironically, the most stable health infrastructures are found in the wealthiest nations where only 5% of TB exist. In many of the poorest countries, primary health care programs can neither financially nor structurally support the DOTS program. WHO is in a dilemma with regards to the DOTS program. Should WHO advocate for Health For All, a strategy to place more global interest (and funding) toward primary health care or should it place precedence on fighting TB, an infectious disease which is out of control? In the 1995 World Health Report, WHO answers this question. WHO states:

[I]t is no longer sustainable or cost-effective to set up self-contained task forces for individual illnesses. Fragmented and duplicated health care services jeopardize the effective use of available health resources and the continuity and sustainability of services.⁴⁰

WHO itself recognizes that DOTS must be built on solid health infrastructure and not vice versa. A health care structure built around the DOTS program is only created to

³⁸ The U.S. is WHO's biggest contributor, supporting 25% of the WHO budget. See Tollison and Wagner, 1993, p. 11.

³⁹ Godlee, <u>BMJ</u>, Vol. 310, p. 179.

⁴⁰ WHO, World Health Report, 1995, p.43.

solve one particular problem: TB. DOTS, designed to compel TB+ patients to comply to their prescriptions, is a program which emphasizes physical restoration over personal liberties. Individuals who do not comply with the complete course of treatment are labeled 'defaulters'.⁴¹ Thus, a health care system based on DOTS would be predisposed to use a problem-based approach; solutions to overcome inappropriate behaviors would set the conditions for infrastructural revisions. Why? The DOTS program is premised upon the idea that TB antibiotics are effective so long as individuals use them responsibly. Drug resistant TB is therefore due to human rather than scientific failure.

DOTS has illuminated the issue of WHO's dilemma to fund primary health care versus disease eradication. It is also useful in identifying examples of poorly run health care systems from a TB control perspective. However, it is not designed to replace or even improve primary health infrastructure already in place. If non-TB health issues are forced to conform to a DOTS then those issues may become distorted, giving rise to long-standing infrastructural problems in primary health care.

⁴¹ A. Pio et al., "National tuberculosis programme review: experience over the period 1990-1995,s" <u>Bulletin of the World Health Organization</u>, 75, No. 6, pp. 569-581.

AIDS: Introduction

WHO has designated AIDS to be the most serious of newly emergent diseases.

AIDS was first recognized in the early 1980's amongst the gay populations in the United States. Because infection was at first restricted to the gay community, it was initially dubbed "GRID" (Gay-Related Immune Deficiency). Early into the HIV epidemic, AIDS became associated with a lot of social taboos - same sex relationships, recreational drug users - creating a large division between those who affiliated with these activities and those who did not. Meanwhile, high rates of heterosexual transmission were reported in developing countries. Some governments in these countries publicly denied having an AIDS problem because they feared that panic would set in on an unsolvable problem.²

Interestingly, strong political advocacy for AIDS research by the gay community in the United States has made AIDS research one of the most political and most funded for a single disease, much to the envy of researchers working on other medical diseases.³ AIDS activism has led to significant challenges in the area of research ethics; alterations in research design methods are a result of individuals demanding access to controversial therapies.

Scientifically, AIDS tests prior knowledge of viruses, bacteria, and immunity.

For instance, AIDS exacerbates the TB pandemic, calling into question the control measures that have been established for TB. At present, HIV infections are on the rise

¹Tamsin Wilton, Antibody Politic: AIDS and Society, (Cheltenham: New Clarion Press, 1992), p. 7.

²See AIDS in Kenya, 1996, Ch. 1.

worldwide. The pandemic has brought to the fore issues regarding sexual negotiation, religious fervor against condom use, world travel, and social stigmatizing of the ill. We have yet to see the full impact of this disease.

AIDS: Pathology and Epidemiology

Pathology. Almost all AIDS scientists believe that HIV (Human Immunodeficiency Virus) is the cause of AIDS.⁴ HIV is a retrovirus that binds to and replicates inside of human T-cells. It uses the host DNA (deoxyribonucleic acid) as a template for the production of new viral particles. The T-cell is eventually destroyed as the new viral particles leave the host.⁵ AIDS is not a single disease. Instead, it is a term that is applied to an HIV+ individual who has two or more opportunistic infections. In a nonimmunocompromised individual, bacteria and fungi and viruses challenge but are controlled by our immune system. In an immunocompromised individual, the body cannot keep these microorganisms in check. Prior to AIDS status however, a number of clinical symptoms mark HIV infection. Within two to six weeks after exposure to the virus, the infected individual experiences flu-like symptoms – fever, headaches, sore throat, rashes. This initial phase is followed by an asymptomatic phase where the individual feels completely well and may not even be aware of the infection. This period may last up to several years. In the meantime, the virus continues to replicate inside of the host's T-cells. T-cell counts steadily decline. As T-cells decrease – key cells in

³Garrett, The Coming Plague, 1994, Ch.11 "Hatari: Vinidogodogo: The origin of AIDS."

⁴Peter Duesberg and David Resnick are among a number of 'dissident' scientists who challenge the link between HIV and AIDS. They argue that AIDS is a poverty-related condition and that HIV is harmless.

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immunological responses – the individual becomes more immunocompromised. Next, the individual enters into a *symptomatic* period where s/he begins to contract symptoms for "indicator diseases". At this point the T-cell count has fallen quite dramatically. Finally, the individual is diagnosed with AIDS if s/he concurrently experiences two or more AIDS indicator illnesses and has a low T-cell count.⁶ The AIDS patient eventually dies from one or more of these opportunistic infections.

Epidemiology. HIV can be transmitted through numerous means. First, a mother has a 25-35% chance of passing the pathogen to her unborn child.⁷ HIV virus is also passed in blood, semen, vaginal fluids. Although blood has the highest concentration of HIV particles, the most common mode of transmission is through heterosexual contact in which there has been an exchange of fluids. Traces of HIV have been found in tears, sweat and saliva; no cases of HIV transmission through these fluids have been recorded.

AIDS: Control Measures

Presently, an effective vaccine against HIV is not available, and the drugs that directly fight the virus are expensive and often extremely toxic. For years, researchers have been trying to come up with a safe, effective vaccine against AIDS. Recall that the function of the vaccine is to elicit an immunologic response in the host. However, because HIV has a very high rate of mutation, by the time a person has been immunized, the virus has mutated enough so that the host's cells do not recognize it. Even within a

⁵Abbas et al., 1994, pp. 419-21.

⁶ Ibid., pp. 426-427.

⁷ Although epidemiologists do not understand when and how HIV is transmitted to the child, research shows that treating pregnant HIV+ women with AZT weeks prior to delivery reduces the risk of

single person, many mutant strains of HIV exist. Researchers are trying to find any features (either genotypic or phenotypic) that remain constant in HIV throughout its mutations.

New anti-viral drugs are continually developed. The purpose of anti-viral drugs is to somehow prevent the viruses from replicating. Antiviral drugs are extremely specific. A very common drug on the market, AZT (zidovudine), inhibits reverse transcription.⁸
Unfortunately these drugs face the same problem as TB antibiotics: the pathogen confers resistance to the drugs. To avoid multiple-drug resistance, the patient must subscribe to a cocktail therapy of drugs, which often cause adverse side effects.

AIDS is a physiologically complex condition. As the immune system breaks down, other conditions which have been held in check come to the fore. For example, leishmaniasis is a sandfly-borne disease that causes severe disfiguration and death if left untreated. In the past twelve years, the number of leishmaniasis cases have risen abruptly, due to the AIDS epidemic. Also recall that in TB/AIDS cases, AIDS immunocompromises the patient so much so that former medications for TB become lethal for the patient. AIDS qualitatively and quantitatively changes other diseases. It has shown that perhaps the limitations of our knowledge of the other diseases and of the treatments that we have developed for these conditions.

WHO HIV/AIDS control measures do not rely on drug prophylaxis. Because HIV/AIDS is predominantly spread by sexual contact, preventative measures include

transmission. See Peter Lurie and Sidney M. Wolfe, and Neal A. Halsey et al., "Letters to the Editor" <u>BMJ</u>, Vol. 316, pp. 626-627.

advocacy for condom use. Condoms are cheap, and if used properly, prevent the spread of the virus.⁹ WHO has worked in conjunction with UNICEF to promote condom use. It has also funded and jointly overseen studies of antiviral drugs and promising vaccines with the UNAIDS program.¹⁰

AIDS: Economic and Social Outcomes

AIDS not only tests our immunological limits, it also unveils economic and social issues worldwide. First, available treatments - especially antiviral medications - are extremely expensive. In the United States, HIV treatment costs an upwards of \$10,000 per person per year. Many Americans struggle to foot the cost of HIV therapy.

Anti-viral medications are beyond the reach of most HIV+ persons living in poorer areas. In most African countries, less that \$5.00/person is spent on health care expenditures, far below the World Bank's recommendation of ~\$12.00/person.\frac{12}{2} Today 1.2 billion people live on less that \$1.00 U.S. per day; 2.8 billion live on less that \$2.00 U.S. per day.\frac{13}{2} In other words, these individuals rely on governmental assistance in health coverage. If that support is unavailable, then the likelihood that ill persons will have (economic) access to expensive medical treatments is close to nil. There are many reasons why the government does not provide more funding to the ministries of health.

⁸ Reverse transcription is a crucial step in viral replication where the viral RNA binds to the host DNA strand.

⁹ HIV is attached to a carrier protein, which is too large to penetrate the condom latex.

¹⁰ World Health Report, 1996, p. 66.

¹¹ Tamsin Wilton, 1992, p. 83.

¹² Godlee, <u>BMJ</u>, Vol. 309., p. 1569.

¹³ Deepa Narayan, Voices of the Poor: Can Anyone Hear Us? (Oxford: Oxford University Press, 2000), p. 265.

Health may be of low priority in a country's expenditures, or the country may not have the money to spend toward health care in the first place.

A person may have the best access to the most current drugs if s/he enrolls in a clinical trial. AIDS advocacy has caused re-evaluation of the ethics of randomized controlled trials. Because of the outcry that AIDS trials unjustly block and individual's ability to obtain effective medication, researchers have had to restructure trial procedures.¹⁴

The ethical issues surrounding drug trials in poor countries are disanalogous to those found in wealthy nations. First, in many cases, the experimental drug is not available after the trials are completed. For example, controversy surrounds performing AZT trials on pregnant women in Africa. Some argue that such trials are unethical on the grounds that individuals from poorer nations are used simply as a means for the benefits of wealthier nations. Others believe that in a fatal disease such as AIDS, temporary access to drugs is better than no access. In the latter case, it is argued that people with AIDS in poor countries do not see themselves as experimental subjects, they regard them selves as having access to a treatment. This very attitude propagated the American demand for 'drug trial' revisions. However, the major difference is that in the developing

¹⁴ Some researchers propose a 'catastrophic' threshold in which HIV+ individuals who are in advanced stages of their illness would have prioritized access to the experimental drug. In the United States, the 'catastrophic threshold' respects personal self-determination and fulfils the researcher's obligation to be beneficent. In the catastrophic threshold design, the phrase 'earlier access to' the medication assumes that after the drug trials are complete, and the experimental drug is deemed beneficial, all infected persons will have access to the new drug. See D. Salisbury and M. Schaechter, "AIDS Trials, Civil Liberties and the Social Control of Therapy", Health Care Ethics in Canada, Francois Baylis et al. (eds.), (Toronto: Harcourt Bryce and Co. 1995).

¹⁵ Justin Burden, "Letter to the Editor", BMJ, Vol. 316, p. 626.

¹⁶ Peter Busse, "Strident, but essential: the voices of people with AIDS", <u>BMJ</u>, Vol. 314, p. 888.

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country, HIV+ individuals may never reap the benefits of the medication after the trials are completed. UNAIDS is working toward bringing down the costs of expensive anti-viral medications. At this point, unless HIV+ individuals from poor countries are participating in 'Western' drug trials, they will not have access to either the experimental therapy or to nearly all of the expensive drugs, which are already on the market.¹⁷

Another problem arises from rationalizing the allocation of monies toward AIDS prevention. What does 'prevention' entail? From an immunological perspective, 'prevention' includes the development and dispersal of vaccines and antibiotics. Yet, AIDS epidemiologists have shown that in the absence of any vaccine or inexpensive drugs, the best 'prevention' consists in educating people to change their behavior so as to reduce vulnerability to HIV infection.

The condom campaign has not been as successful as AIDS researchers would have liked. In order to promote condoms, health educators must discuss sexual practices – a topic that is taboo in many cultures. Women and men must equally participate in advocating condom use when wishing to engage in sexual intercourse. That one can

¹⁷ The cost of anti-viral treatments for AIDS raises a number of issues concerning distributive justice and the researcher's obligation to fulfil duties of beneficence and non-maleficence. In this discussion, I do not want to exhaust the issue of drug trials in poorer countries. Many other articles discuss issues concerning the *informed consent* of persons coming form 'non-Western' countries. That is, does the notion of informed consent vary from one country to another? If so, how? For more discussion on this topic, please read: M. Barry, "Ethical Considerations of Human Investigation in Developing Countries: The AIDS Dilemma" and Lisa Newton's "Ethical Imperialism and Informed Consent" in Health Care Ethics in Canada, 1995. Also see Nicholas A. Christakis, "The Ethical Design of an AIDS Vaccine Trial in Africa", Applied Ethics: A Multicultural Approach; Larry May, Shari-Collins Chobanian, Kai Wong (eds.), (New Jersey: Prentice Hall, 1998), pp. 517-29.

¹⁸ For an example of sexual taboos, please see Lila Abu-Lughod's "A community of Secrets: The Separate World of Bedouin Women", Applied Ethics: A Multicultural Approach, (2nd ed.), 1998, p. 373-81. However, it must be emphasized that sexual taboos are not limited to foreign settings. In Ontario, sex education is banned in public schools because some fear that it will promote promiscuity. Personal communication with Denise Mousseau, Outreach Worker – Hamilton AIDS Network.

negotiate sexual practices assumes that both 'partners' have the equal capacity to speak and to be heard. This issue arises whether gender inequalities hinder sexual negotiation. Research has shown that women are socially, economically, historically constrained; therefore, the topic of sexual negotiation is difficult for women to broach.¹⁹

AIDS education has failed for a number of reasons. First, in the beginning AIDS educators in Europe and North America assumed that pedagogical strategies to promote 'safe sex' in their home countries would be just as effective in other countries. Second, because of this assumption and because of the high costs of developing drugs, the latter took economic precedence over the former. Today, AIDS educators realize their naivete in believing that dissemination of HIV/AIDS knowledge is so straightforward. However, the search for a 'magic bullet' has picked up considerable momentum, so that funds continue to be directed toward strictly scientific preventative strategies.

WHO offers lip-service for the promotion of safe sex behavior. Yet, AIDS prevention has centered on the purchasing of and advocacy for condom use,²⁰ and prioritizing of a biomedical solution to the AIDS epidemic. Dr. Michael Mersen, the program director of the Global Programme on AIDS has stated the "WHO's technical base was too narrowly medical for it to deal effectively with AIDS prevention and control." Management of the program has been removed from WHO's sole control.²¹

¹⁹ For more information on barriers that women face with regards to smart sex negotiation please see Christine Overall's "AIDS and Women: The (Hetero)Sexual Politics of HIV infection" <u>Perspectives on AIDS: Ethical and Social Issues</u>, Christine Overall and W. R. Zim (eds.), (Ontario: Oxford University Press, 1991). See also <u>AIDS in Kenya</u>, 1996, Ch. 3: "HIV and AIDS Within the Family: Women's responses and needs."

²⁰ World Health Report, 1996, pp. 32-33.

²¹ Godlee, <u>BMJ</u>, Vol. 309, p. 1494.

The AIDS epidemic brings forward issues of socio-economic inequality and sexual practices. Researchers who raise questions about these subjects place the *individual* in a defensive position; because aspects of the individual's history, beliefs, identity are scrutinized and possibly condemned by the external other. The power differential between the donor and recipient promotes the construction of a patriarchal notion of cure. The former uses its medical knowledge and treatments as justifications for directing how information and aid ought to be disseminated.

Community Based Rehabilitation Program (CBRP)

(Established Oct. 1995)

I) Introduction

A. Local Partners with International NGO

- 1) Local Diocese of Wa
 - a) head Bishop Bemile signature of approval
- 2) International Christopher Blinden Mission (CBM)
 - a) role fund salaries
 - b) assess work of social development at local level

B. Aims of CBRP

- 1) to involve communities to participate in the rehabilitation process of people with disabilities
- 2) <u>target</u> people of various abilities
- 3) <u>definition of disabilities</u> persons who are one or more of the following: blind, deaf, crippled, mentally challenged or erratic, those with leprosy, multiple disability persons, those with facial deformities.
- 4) age groups in consideration: 0-5, 6-15, 16-36, 37+
- 5) action to prevent as well as care for persons with disabilities
 - a) prevention through hygiene, education, immunization
- 6) <u>action plan/goal</u> to supplement GO (governmental organizations)

C. Level of Administration and Administrative Organization

- 1. This CBR works at the Parish level (whereas the government works through districts).
- 2) Eight Pilot Parishes under co-ordination by Chris Babooroh*

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