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Editorial

This issue of *EJAIB* focuses on medical ethics with several papers examining the basis of health care access policies. Currently there are debates and bills being discussed in USA and other countries regarding the building of national health care systems. The Paper by Boyd and Nejati examines the US situation, and the paper by Selvanayagam and Xavier examines the Indian situation. As two of the world's largest democracies they are in need of better safety nets for medical care.

Miyasaka examines the history of exclusion of leprosy sufferers in Japan, and calls upon the government and legal-medical system to address some unanswered questions. Saniotis examines the surge in use of caesarian sections in Australia. He questions the justifications for this, and also points out the rates are significantly higher in patients with private medical insurance. The definition of disease is examined in the paper by Chakraborti and Chakraborty, while Verma examines evolution in humankind.

Siti Nor reports from a workshop held in Malaysia in June 2009 that was organized by several government departments in cooperation with UNESCO on the establishment of a National Bioethics Committee there. At the COMEST session the Malaysian Minister of Science, technology and Innovation announced that such a committee will be established by the end of the year. In July at a UNESCO workshop in Bangladesh, the Bangladesh Bioethics Association was founded, and the Minister of Education also expressed his support to establish a National Bioethics Committee there.

The next issue of *EJAIB* will focus on the Ethics of Energy Technologies in Asia and the Pacific (EETAP) Project of UNESCO Bangkok, with a growing number of papers open for consultation and peer review on the website.

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Health Care in a Democracy

- Ann Boyd and Mariam Nejadi

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Democracy is a form of government in which the people hold power through a free electoral process. Hereditary and arbitrary class privileges are not honoured as automatic access to office but require the majority of the electorate's endorsement. The composers of the U.S. Constitution and Bill of Rights shared a commitment to the principle of natural freedom and equality. The Constitution adopted in 1788 provided for an elected government and protected civil rights and liberties. The United States Declaration of Independence reflects the rights and liberties of men [sic] and was adopted by the Second Continental Congress on July 4, 1776. The second section of the Declaration of Independence states: "We hold these truths to be self-evident, that all men are created equal, that they are endowed by their creator with certain unalienable rights, that among these are life, liberty and the pursuit of happiness." To the extent that laws promote and protect human beings free pursuit of happiness, they are good. When laws exclude members of the community, such as women's right to vote, in opposition to the wording of the Declaration of Independence, either the law is unjust or the purpose of law is inconsistent with the underlying principles. Defending one's rights and liberties is accordingly guaranteed (Dunn, 1994). Laws crafted by human beings for their benefit regulate community only so far as they apply to all the people, a significant omission in practical application between 1776 and today. One must wonder why it was not more self-evident that all human beings are in need of the same freedoms.

One civil war and two world wars later, the United Nations considered the proposed Declaration of Human Rights and approved the Declaration with a forty-eight - nation affirmation and eight nations abstaining. The Declaration set forth a common universal standard of human rights for all people. Wording in Article 3 of the Universal Declaration of Human Rights is very close to the Declaration of Independence, "Everyone has the right to life, liberty and security of person. What rights are extended to all persons is articulated in Article 25 of the United Nations Declaration of Human Rights: "Everyone has the right to a standard of living adequate for the health and wellbeing of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection" (UNDHR, 1948). Eleanor Roosevelt, wife of President Franklin D. Roosevelt was an active proponent and sponsor of the UNDHR. It may be historically significant that the U.N. delegate, Eleanor Roosevelt, was supportive of a universal application of human rights and moreover that

the U.S. did not ratify the Declaration until civil rights section was separated from economic rights in 1966. Verbal affirmation of human rights finds consistent opposition when economic factors emerge, as appears in the conflict regarding universal health care and in particular the State's Children Health Insurance Program (SCHIP).

Students' written papers and oral discussion frequently refer to rights in order to legitimate their moral claims. Few know the history of the UNDHR, but most assume that things are now as they have always been. It is interesting that the majority of students favor human rights to the extent that allows individuals to do what seems right and best to him or her. Rather than embrace human rights as an example of a universal normative principle, most students apply "rights" in ways that support liberty from interference so that an individual can do what he/she desires. One student was appalled that the United States Congress and President failed to extend SCHIP. She wrote: "The United States is one of the wealthiest nations in the world. It is a nation that conducts costly clinical trials in different parts of the world, bears the burden of paying the medical bills of individuals on respirators for decades, and can wage wars that cost Americans over USD808 billion, yet it cannot (or will not) provide [all] its children with medical care. The president vetoed SCHIP, stating that it was a step toward federalizing healthcare, which would ruin choice and competition of privatized healthcare, as well as increasing government spending" (Nejadi).

Being a federally funded-state managed program, SCHIP provides medical insurance to children 18 years and younger living within families with more income that the qualifying amount recognized by Medicaid and without enough income to pay for private medical insurance. All employers do not provide health insurance and some employees opt-out. SCHIP provided medical insurance through state sponsorship to 6.6 million children in 2007. Legislation to continue SCHIP met stiff opposition in the administrative branch of our democracy. The student asserted: "Failing to provide children with health insurance is a failure by the American government to provide social justice for its children" (Nejadi).

The challenge presented by the student's essay raises questions appropriate for democratic public discourse on health care. Whose responsibility is it to oversee, monitor, and provide social justice? What is social justice? Is social justice the correct ethical lens to evaluate health care in a democracy? How is consensus achieved regarding medical care for any or all citizens in a capitalistic competitive culture? Is the ideal of social justice compatible with the competitive-commodity based health care system in the U.S.? How is SCHIP related to health care reform in the US? These comments-questions on the bottom of the student's essay prompted her to request an opportunity to examine U.S. health care from a perspective of social justice and human rights. This paper reflects our ongoing search for answers.

SCHIP and the status of US healthcare

Healthcare in the U.S. is a competitive and commodity based system in which economic constraints risk some

persons having no access to health care except through the hospital emergency room. Every citizen is a member of the nation (which we will hereafter call the "commons" to emphasize the importance of community in contrast to individualistic moral values). It is vital to the overall health of the commons that individuals receive treatment when they are sick. Individuals will not require the exact same amount of care so a flat voucher worth x dollars per person per year is unrealistic. Recent practice has shown that failure to insure all citizens leads to wasteful spending through emergency room based care (the most expensive option). An estimated 47 million citizens lack health insurance in the U.S., consequently, the uninsured forego preventative care, and frequently allow conditions to deteriorate until they resort to emergency treatment (estimated to cost \$30 billion each year). Balancing the drain of uninsured treatment costs and escalating cost of care, premiums increased 87% from 2000 through 2006 (Capretta, 2008). The average cost of insurance for a family of four is \$12,680/year. To offset the cost, employers reduce wages, and to retain coverage employers bid among insurance companies for the best deal. The cumulative cost for U.S. health care is \$2.1 trillion annually. Moreover, only 30% of this money is used to improve health, while the remainder funds administrative, diagnostic and unnecessary treatment (Anft, 2008).

Employer-based insurance covers 55% of U.S. citizens. National systemic coverage for the poor (about 1 in 6) is available through Medicaid. The poverty level for a family of four in 2008 was \$21,200. All citizens 65 years of age or older qualify for Medicare with a graded fee for coverage based on income. Federal employees, including elected officials and military and civilian employees are covered by federal insurance programs. Those who are classified as uninsured comprise about 15% of U.S. citizens. When Nejati presented some of her preliminary research findings to a class of undergraduates, the majority of students were opposed to any form of universal health care on the basis that it would compromise quality of care and limit individual choice.

An outside observer might question why the Medicaid, Medicare, and Federal insurance programs are not universal health care systems, even if they do not currently enroll all citizens. The short answer is that such programs have limited scope. If they were merged and expanded it would create a universal healthcare system. The resistance to moving in that direction is based on the potential lack of choice currently available through private competitive based insurance. A 2007 poll revealed that 41% of those surveyed were opposed to any government controlled health plan, while 47% favored such a plan (Jacobs, 2008). If during the interview the respondent was told that universal coverage could mean a reduction in some form of treatment, 64% of those who initially supported universal coverage became opponents. The perception of a superior standard of care in the US in comparison with government sponsored programs is frequently made as illustrated in the following published article. "Outcomes for diseases such as cancer and

hypertension depend much more on access to quality health care than infant mortality and life expectancy, so are a better measure of quality. Five-year survival of all types of cancer is higher in the United States than in Europe...in Europe, the incidence of hypertension is 60 percent higher and the slope of hypertension related to advancing age is steeper compared with the United States; this might be explained by the higher United States spending on prescription drugs" (Sade, 2008 p 486).

Recognizing the troubled healthcare system and the rising costs of care, universal coverage or some alternative reform is high on the political agenda. The 2008 election of President Obama signaled a movement in support of several healthcare related issues. Within the first weeks in office, he signed the \$32.8 billion SCHIP bill providing coverage to 11 million children. In signing the bill, President Obama said, "this is a down-payment on my commitment to health care for all citizens" (AARP Global Network, Feb. 5, 2009).

Proponents of reforms argue on the basis of better economic efficiency: "There will come a time when the inequities, inefficiencies, and costs of the current methods of financing health care will be so intolerable that the public will not only accept but demand comprehensive reform. At that time, the political feasibility of the voucher system will be compelling. It is more congruent with American values than are the alternatives of employer or individual mandates with explicit subsidies or a single-payer plan. By providing publicly funded basic care for all, with free choice of a plan and freedom to buy additional services, the voucher system reconciles the distinctively American tension between equality and individual freedom more directly and efficiently than do any of the alternatives" (Emmanuel, 1258, 2005). This proposal may be a useful bridge from our unjust and inadequate system toward universal coverage. A national organization of physicians argue that single-payer plan would be more efficient and affordable but the administrative branch has shown little interest in the proposal, claiming it is too disruptive a step given other economic concerns.

Opponents assert that health care reform will mean loss of freedom, choice, and an implicit lower standard of care. The more inflammatory pendents warn of a Leviathan model in a non-benevolent state: "*The Leviathan model of the state explains many features of public health insurance: its uncontrolled growth, its tendency toward monopoly, its capacity to buy trust and loyalty from the common people, its surveillance ability, its controlling nature, and even the persistence of its inefficiencies and waiting lines*" (Lemieux, 2008, p 416).

It is clear that extrapolating to extreme poles in a debate about health care is more effective at increasing the volume in the debate than inspiring deliberative dialogue. Alarms, warnings, and labels, such as "socialized medicine" are effective polemics and retardants to democratic debate. In class, students will use inflammatory language such as "socialized medicine" to oppose universal health care. The media fuel the flames by reporting on how inferior "socialized medicine" is in contrast to the U.S. standard, such as

long waiting periods for medical intervention, rejection of treatment on the basis of age, etc. The news media report frightening stories of long waiting periods for elective surgeries and denial of intervention in universal health care countries. Such warnings are not juxtaposed with similar triage of our organ transplant system. Regretfully affluent consumers are easily manipulated to pay attention to rights in a defensive posture rather than to consider the needs of the community and the rights of the less privileged. What is surprisingly strange is that the opposition to universal health care fails to admit that health is as necessary to individual flourishing as is education or fire and police support.

Health care reform is not a new political topic in the US. President Nixon made a bold proposal for broader health insurance coverage through an employer mandate that was defeated in Congress. In the subsequent administrations, President Carter and President Clinton proposed plans which were also defeated in Congress. The issue in each attempted reform has been disagreement over how a universal plan, employer mandated, or voucher based system would be financed (Morgan and Lee, 2005). This particular issue again highlights the separation of civil rights from economic rights.

Medical bankruptcy is rare in industrialized nations with universal health care whereas 40% of bankruptcies in the US are due to medical debt (Gottlieb, 2000). It is difficult to explain how wasteful the current system is. Emergency based care by law cannot deny treatment to a person without insurance. A 2005 report calculated that \$43 billion was spent on care for uninsured and \$29 billion of that was shifted into higher premiums for private health insurance, raising the price of premiums. Competitive marketing among private insurance companies increases the cost of private coverage over Medicare by 31% (\$420 billion a year) (Menzel and Light, 2006).

The underinsured and uninsured population of the US is between 46 and 48 million, about 16% of the population. The Institute of Medicine reports, "Uninsured children and adults suffer worse health and die sooner than those with insurance" (2004). In addition to not covering nearly one in every six citizens, health care per capita is a higher percentage of gross domestic product than any other developed country (Anderson, 2005). Health care expenditures rise at an average of 10% per year. A single-payer system of national health insurance has been proposed to be the most cost-effective way of achieving the goals of care (DeGrazia, 2008). Proponents of single-payer system of insurance argue that cost of care is reduced by eliminating overhead in the competitive for profit system currently in place. A single-payer system would have standard fees for services, annual negotiations between hospitals, physicians, and drug prices and the one payer insures that the whole population realizes the savings and benefits of efficient delivery and long-term health promotion. Using a universal information technology system would allow efficient retrieval of patient's records. The Medicare system in place for persons over 65 years of age has lower administrative and overall costs per patient than any other system tried thus far (DeGrazia, 2008).

Opponents claim that a single-payer system is socialistic, but if the system is publicly funded it is not any more socialistic than universal education. Objections to single-payer plan like universal coverage in general include, fear of loss of individual choice about physicians and treatment options, rationing of care, and longer waits for services, diminished quality, and general limitations on individual freedom. Ironically, the lack of care and its accompanying costs have similar affects. If costs are not contained, other risks emerge e.g. compromising other items in the federal budget. Further opposition comes from the libertarian position of negative rights: in a system of free market exchange of goods, each individual is free to pursue and purchase what suits his/her goals. The Lockean conception of rights is negative: the right of an individual to not have interference by government or other agents in his pursuit of happiness.

Sade claims that the right to liberty is a meta-normative principle: without guidance to right or good choices are particular, individual, to choose between alternatives within those available without constraint. Sade further asserts that welfare rights obstruct the freedom of individuals to choose and the power of government should be limited to protective functions. Health care reforms in the past have only complicated the system by entitlement programs and therefore the reform necessary to liberate health care from the mistaken community interest back to individual interest is to return to an entirely free market system in which every person purchases his/her health care and restructures Medicare and Medicaid to allow clients to buy insurance like everyone else or to rely on the charitable voluntary gift of benevolent members of the community (Sade 2008).

The argument will doubtless find favor with many free market proponents, but it does not provide the kind of community ethos necessary to protect the innocent and vulnerable. Children are not consumers or competitive bidders in the economic health care system. Children are the wards of parents, whose choices or lack thereof, impose limitations on many aspects of human flourishing. For a society to deny to its most vulnerable members the right (even entitlement) to adequate health care places money over humanity. Even prisoners get health care while incarcerated. Negative rights will not spawn community solidarity. Standing with those who suffer evokes compassion. Health care does not seem to be any less basic than adequate clothing, shelter, and food, in a just society. While a vision of justice has yet to gain consensus in the U.S. positing the ideal reminds us to work to a more perfect union where every member has a fair and equal chance at the human potential free societies promise.

Healthcare is considered a primary human right in treaties passed by the United Nations and ascribed as such in many countries; sadly the US is not among them. Few rational people would disagree that adequate health is a prerequisite for living a good life. Basic health like education, food, clothing, and shelter are preludes to the pursuit of other forms of happiness. Any distribution scheme seeking to assure equal access to the basics of life, including education and healthcare, require funding priorities. Budgets reflect the values of a person and a nation. Failure to provide a

community based system of health care equivalent to the education system is a failure to protect the basic rights of citizens. Competitive, for-profit care systems are appealing to self-interest so long as one has the position within a society to enjoy the benefits of health insurance. Community based systems of care require a broader sense of who deserves what in the social order; it requires that healthcare be equated with other basic survival needs of human persons such as education. Universal health care like universal education does not dictate that every person pursue every possible benefit, rather provides the basic elements necessary to contribute to the society in which one resides.

Human Rights, civic and economic

The Declaration of Human Rights crafted in 1948 embraces an ideal of human commonality. Human rights speak across national and cultural boundaries, and are interpreted and protected within the context of economic and political cultural diversity. Contemporary debates about universalism and relativism, individual and communitarian norms press ethics boundaries in search for common ground. Without some philosophical common conception of the good for human beings, we invite an infinite plurality of culturally conditioned norms to thrive. The problem with extreme relativism is the failure to find common ground on which to build an ethical discourse. At the opposite extreme of absolutist universalism, the dictation of one norm over other considerations likewise rejects open dialogue. The appeal of human rights as a universal claim to the dignity of individuals regardless of economic, social, educational, and geographical circumstances carves out a commons for humanity. Accepting human rights as universal does not exclude relative interpretations of how and where specific rights are granted to individuals and herein lies our trouble.

Fundamental human rights claim the goal of sustaining life, by ensuring economic, social, political and personal freedoms. Respect for freedom of conscience respects plurality of values, social customs, cultural norms, and individual free moral agency. Government is that aspect of a social construction that holds the power and responsibility to establish laws that insure mutual respect of human dignity. Inherent in the establishment of political systems is the tension between the good of the individual and the good of the community. Respecting the dignity of each person, the polis must protect freedom and create conditions that promote each person developing his/her full potential (Hollenbach, 1979).

The multifaceted nature of human beings requires that rights are intrinsically interrelated, the rights to life, bodily integrity, food, clothing, shelter and to some degree, health care. Rights that defend the dignity of the person, including the right to work, economic rights that insure a fair wage, the right to expression, assembly and social interaction, contribute to conditions that support the truly human person within diverse social and cultural circumstances (Hollenbach, 1979). Where does access to health care fit in this functional scheme?

Justice

Justice according to Plato is a social system of distributing a fair share of resources according to need. Treating persons equally according to need recognizes human dignity. Sitting in a sidewalk café watching people pass by should show the observer the diversity among persons. Equal treatment does not require an equal share of attributes. Being a member of the same species should awaken us to the natural common ground among us. The ideal of justice, as inclusive, mutual, interdependent embraced in the human rights movement rests on the cardinal axiom that all human beings are born free and equal, in dignity and rights, and are endowed with reason and conscience (Kunz, J.L. 1949; Annas, G.J. 1998). Broad and encompassing claims to freedoms and rights gloss over specific rights to things related to human flourishing.

Human beings live in communities, families, societies, large and small. Our nature is both reasoning and relational. If we view rights in a freedom from interference (negative rights) manner, we risk losing sight of the larger group which provides the context for choice. It is possible to do harm by neglect.

Human beings do not flourish in isolation but in community. It is the communal, relational nature that suggests that there is within the nature of the person an intuitive and natural claim to human rights. *"All persons share a common human nature and can discover by reason an order in nature, and resolve by reason and the human will to act in order to pursue the purpose of being human"* (Maritain, 1943). Protecting the conditions that strengthen the nature of the person allows each member to achieve his/her potential. To the extent that human rights are intrinsically interrelated: the right to life, bodily integrity, food, clothing, shelter, and to some degree health care pertain to the holistic wellness of the human being. The right to work for a fair wage, the right to expression, assembly and social interaction contribute to conditions that promote social interactions and community solidarity (Hollenbach, 1979).

Rights language promotes human dignity. Only a society of clones could be conceived as having absolutely equal abilities, talents, and desires. Rather than expect that every member of the commons contribute and extract the same amount in health care, the view of a true democracy ought to focus on the wellbeing of the entire populace. Karen Lebacqz observes, "Relative justice involves the calculation of competing interests, the specification of rights and duties, and the balancing of life forces" (Lebacqz, 1986). An egalitarian system of justice fails to recognize the different endowments of health and wealth. A person should not be restricted to a "life-time" allotment of medical treatment just as no person ought to be forced to take the allotted amount. Limited resources force choices, and the values of equity and freedom provide principles with which to approach a just allocation (Lovin, 1995). Limitations also create an opportunity inviting us to look more closely at what we value and why spurring ethical dialogue.

Children ought to have a special place in the dignity principle recognizing our duty to protect and care for the vulnerable. Breaking the stranglehold of injustice requires a deeper understanding of who suffers from lack of equal access to prompt and preventive health care in the current system. Hearing the cry of the oppressed is a challenge to the privileged. It requires recognizing that we are more likely to have privilege as a lottery of birth than a consequence of our merits. The reciprocal is also true: those who suffer chronic ill health are not sick by choice or lack of merit but by chance. Particular diseases may have genetic or environmental causation but what child controls his or her genes or living environment?

Responding to the needs of the poor in a preferential manner gives dignity to those who suffer and demonstrates compassion by the caregiver. A moral agent has a duty to create strategies that liberate and empower full participation in the society. Justice begins by taking injustice seriously and making a commitment to mutual responsibility in which the entire human community experiences a restoration of the fundamental relational nature of persons (Lebacqz, 1987). Justice is as important as autonomy except for those concerned about the particular choices and benefits to themselves. Those at the margins of a society may know from experience how unequal ethical principles are applied in modern policy matters.

The ideal of the common good is difficult for liberals and communitarians alike. The pluralism of contemporary society makes a single vision of the good society difficult, but jettisoning the project altogether is more threatening. The common good may be a pluralistic ensemble, but to support and promote the dignity of every human person requires recognition of the relational nature of human beings. The interrelationships and interdependence of persons in society cannot be justified by an individualistic understanding of human rights. Dignity of a human person is an ontological claim. What persons of limited abilities contribute to community is the opportunity for us to learn to care for our neighbor. We may learn compassion best in the laboratory of human suffering.

Duty of Democratic Government

The duty of government is to craft fair policies that allow individual freedom of choice within a system of choices, not assure all potential choices are viable. The failure to see the negative consequences of neglected care for millions of citizens on the public health of all citizens limits the ability of individuals to embrace a community based system of care (Iltis and Cherry, 2008). The example of SCHIP highlights the inequality of the competitive private based insurance system. The current system is unjust because children are vulnerable and lack the autonomy necessary to acquire health care insurance independent of their guardian(s). Shifting to universal coverage could and should eliminate some forms of injustice in the current system. A step in that direction is to fund SCHIP so that all children are given access to insurance while the nation decides what to do with a commodity based competitive health care system.

Autonomy or dignity in Kantian terms requires that vulnerable individuals be protected by other rational

and free persons. Because children cannot make important decisions on their own, society has a duty to provide services that protect their quality of life. Health insurance and access to care for children are no less important than legislative intervention to prevent child neglect and abuse. Failing to provide general access to health care, except in cases of emergency, children are at risk of developing more serious conditions with higher treatment costs. Saving a few dollars today by delaying or denying preventative care is a debt laid on future generations of citizens.

The ideals of social justice prohibit discriminatory allocation and access, rather require that inequalities be corrected (Daniels, 2002). If the majority opinion is self serving the universal health care ideal is far from the current practice in this democracy. A positive benefit of the current economic distress could be a shared experience some formerly privileged citizens may share will those neglected for too long. When by choice or force we are in need, our vision is clearer about why access to healthcare should or could be understood as a human right. To reform health care for all citizens the competitive commodity driven for profit system will have to change (Taylor, 2008). Democratic systems change by majority consensus or dramatic need. Future generations will pay a premium price if justice delayed is justice denied.

In the 2008 election, health care was one of many social reforms that voters named as a factor in their selection of a candidate. Few constituents could claim more moral legitimacy than children. In cases of neglect, social services have the authority to transfer a child into foster care. It is ironic that education is not only universally available but that legal enforcement of attendance is practiced with penalties for truancy. Food is made available in schools for children who need it. How voters can deny health care while supporting education as a universal standard for the open future for every child is a mystery. Health care is one strand in the social web of factors that affect the lives and development of children. Citizens of a democracy, even a representative one (republic) should understand that the community has a duty to transmit the "inalienable rights" for all citizens from generation to generation.

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Punishing Paternalism: An Ethical Analysis of Japan's Leprosy Control Policy

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Abstract

Leprosy (Hansen's disease) has been associated with a deep stigma that dates back to ancient history. Japan's leprosy control policy exemplifies the ethical questions this disease evokes in the context of human rights in modern medicine. This paper explores the history of Japanese leprosy control policy which started during its rapid modernization in the late 19th century and continued until 1996. I argue that the responsibility of the medical profession for development of the overall control policy which resulted a mass human rights violation. Japanese leprosy control policy can be interpreted as four powers given to the medical profession: 1) forced isolation, 2) sterilization, 3) forced labor, and 4) arbitrary punishment. Japanese leprologists considered forced isolation necessary, even after sulfone drugs became widely available and the international medical community suggested that forced isolation should be abolished. Male patients who wished to marry had to undergo vasectomy, and pregnant female patients were forced to have abortions. Patients with milder symptoms were assigned heavy labor, which may have exacerbated their condition. Leprosarium directors were empowered to arrest and punish disobedient patients without court order. Records show that 22 of 92 persons imprisoned in Jukambo, a special leprosarium facility for the most severe punishments, died in confinement. In the landmark Kumamoto judgment in 2001, the court ruled that forced isolation was not justifiable after it became medically unnecessary, since at least the 1960s. However, the other three troubling aspects of the control program were left unquestioned, even though those would be much more difficult to justify. Furthermore, the lawsuit was filed against the country, and no individual responsible for the establishment and continuation of the policy was prosecuted.

1. Introduction

Leprosy, or Hansen's disease, has been associated with a deep stigma that dates back to ancient history. In many parts of the world, patients were ostracized by their communities and families based on religious or popular beliefs that often described leprosy as a result of sins or wrongdoings. It was described as a divine punishment for immorality in the Old Testament, and hundreds of leprosy patients were considered to be killed because of rumors that some of them poisoned wells and fountains in medieval Europe.¹⁾ In Japan, there was a Buddhism-rooted belief that explained leprosy as an outcome of wrongdoings in the patient's previous lives. Japanese folklore tells of leprosy

patients cast away in valleys or on mountains.²⁾ However, the leprosy control policy in modernized Japan exemplifies a situation that has evoked serious ethical questions in the scientific period of modern medicine and public health. In the second section of this paper, I will explore the history of Japanese leprosy control policy from a *paternalism* point of view in which four powers were given to the medical profession. The third section briefly sketches how the control policy ended.

2. Leprosy Control Policy In Japan

Japan's leprosy control policy started during its rapid modernization in the late 19th century when the country opened its ports and started introducing Western socio-legal systems and medicine. Leprosy patients of the day gathered and formed colonies around shrines, temples, and hot springs. Some Westerners observed them leading miserable lives on the streets as outcasts or beggars,³⁾ and some missionaries established private leprosaria. In 1889, the French Catholic missionary Germain Léger Testevuide opened the first private leprosarium, Koyama Fukusei Hospital in Shizuoka Prefecture. The establishment of private leprosaria by several other foreign missionaries followed. Their activities were welcomed by patients, but stimulated a rivalry from Japanese leaders who wished to make Japan "a first-class nation" with a modernized public health system.⁴⁾

From an ethical point of view, Japanese leprosy control policy can be interpreted as four powers given to the medical profession which resulted a mass human rights violation: 1) forced isolation, 2) sterilization, 3) forced labor, and 4) arbitrary punishment.

1) Forced isolation

The first International Leprosy Conference was held in Berlin in 1897, in which two Japanese physicians participated. The conference acknowledged leprosy as a contagion caused by *Mycobacterium leprae*, as described by a Norwegian physician, Armauer Hansen, in 1873. There were differing views among the attendees regarding the containment of leprosy by isolation,⁵⁾ but the conference eventually concluded that patient isolation was necessary as part of the disease control strategy. This conclusion inspired Japanese leaders and physicians to support patient isolation⁶⁾ In 1900, the Japanese Ministry of Home Affairs conducted a national survey and reported 30,359 leprosy patients.⁴⁾ In 1907, the Leprosy Prevention Law (LPL) was enacted, under which physicians were required to report all leprosy patients they found, and political officers were empowered to order these patients admitted to leprosaria. In 1909, five public leprosaria opened in Aomori, Tokyo, Osaka, Kagawa, and Kumamoto. Additional leprosaria were added later to total 13 national leprosaria that covered most of the country.

During the 20th century, international and Japanese health care professionals gradually diverged in their views of forced isolation of leprosy patients. The International Leprosy Association (ILA) increasingly emphasized voluntary and limited isolation. After sulfone drugs were found effective in the 1940s and their use increased in the 1950s and 1960s, the ILA

and other international medical organizations recommended that enforced isolation be avoided as much as possible.⁶⁾ In Japan, on the other hand, leprologists continued to believe that patient isolation was effective and necessary. Furthermore, they repeatedly requested expansion of the capacity of leprosaria and more intensive isolation. There was only minor argument among Japanese leprologists that forced isolation may not be necessary. In 1931, leprologist Noboru Ogasawara of Kyoto University insisted that the disease was not incurable, not heritable, and not highly contagious,⁷⁾ but his claim was ignored and attacked by other leprologists. In 1935, the government adopted a program to eradicate leprosy within 20 years, and local governments launched a nationwide campaign in 1938 named Muraiken Undo (literally, "campaign to clean up leprosy in every prefecture") through which they encouraged local residents to identify leprosy patients in their neighborhood and inform officials in order to send them to leprosaria.

After WWII, Japanese society was drastically democratized under US occupation; however, the policy of forced isolation of leprosy patients survived. The new Constitution proclaimed fundamental human rights for all nationals, including freedom of political activity. In 1951, the National Leprosaria Patients' Association was established. Although this association demanded the abolition of forced isolation, leprologists were successful in maintaining it. In the same year, three leprosarium directors, Kensuke Mitsuda, Yoshinobu Hayashi, and Matsuki Miyazaki, recommended that the Diet maintain and reinforce the isolation policy. The LPL was revised in 1953 in accordance with the leprologists' opinions: it upheld compulsory isolation, prohibition of leave without permission, and punishment of disobedient patients. As the law defined no discharge codes, patients had to be isolated for life. Meanwhile, the nationwide campaign Muraiken Undo had resulted in almost complete isolation of patients. The number of those hospitalized in leprosaria reached 11,057 in 1955, which was estimated to be 91% of all leprosy patients in the country.⁸⁾ Therefore, in the 1950s, almost all leprosy patients in Japan had been isolated in leprosaria and were destined to live out their lives there, even after they were treated with sulfone drugs and proven not to have bacilli.

2) Sterilization

The notion that leprosy patients should be prevented from having children had been accepted, not only by Japanese leprologists, but also by foreign missionaries involved in the care of leprosy patients. However, they adopted very different approaches. Hanna Riddell, an English missionary who opened a private leprosarium, Kaishun Hospital in Kumamoto, insisted on sex *segregation*, the idea of hospitalizing female and male patients separately. However, Kensuke Mitsuda, a leading leprologist, argued against her approach, pointing out that sex segregation was unrealistic. He wrote, "It will be natural for desperate persons to live only for the pleasure of the moment. But the only pleasures they can obtain in leprosaria are gambling or adultery. ... Here, a moral anarchy has emerged that resulted in more than a dozen babies that should not

have been born." ⁹⁾ Mitsuda concluded that sex segregation was impracticable in national leprosaria, and that *sterilization* of patients was more realistic and would contribute to patient welfare by permitting them to marry. Furthermore, he believed that sterilization would contribute to a peaceful atmosphere in leprosaria, because physicians could allow patients to marry without letting them have children.

In 1915, Mitsuda began to vasectomize male patients who wished to cohabit with female patients. In the book he published in 1950, Mitsuda wrote that the first vasectomy was performed on a voluntary patient, ¹⁰⁾ but many patients later claimed that sterilization was conducted against their wishes and that it severely impaired their dignity. Furthermore, pregnant female patients were often forced to have abortions. Former patient Shige Tamashiro regretfully described an enforced abortion, or rather, the infanticide. She clearly remembers the infant waving its hands and legs on a surgical plate, before a nurse covered the nose and the mouth of the infant with a piece of gauze to terminate its breathing, saying to Tamashiro, "It is a cute girl, and looks very much like you." ¹¹⁾

During Japanese colonization of the Korean peninsula, officials of Shorokuto Kousei-en, a Japanese-run leprosarium on Sorokdo Island near the southwestern tip of the peninsula, performed patient sterilization as a *punishment*. A former Korean patient testified in a lawsuit against the Japanese government in 2004 that he was vasectomized when he refused to worship at a Japanese Shinto shrine in the leprosarium. He was placed in the confinement room, and forced to undergo sterilization without being given any explanation. Vasectomies and abortions had been conducted on leprosy patients without legal basis, but both were legalized by the Eugenic Law (*Yusei Hogo Hou*) enacted in 1948.

3) Forced labor

Former patients have claimed that living conditions in national leprosaria were far from appropriate. They were assigned many types of labour, because doctors in leprosaria "encouraged patients towards mutual aid." ¹²⁾ Patients with milder conditions were assigned to nurse invalid patients, bury dead patients, wash bandages and gauze for reuse, collect night soil, and repair buildings and roads. For example, During WWII, patients of Kuryu Rakusen-en, a national leprosarium in Gumma located on a hillside at an altitude of 1200 meters, were ordered to walk down to markets about 10 kilometers (6.3 miles) away to buy charcoal and firewood in order to save gasoline. They had to walk on mountain trails back to the leprosarium carrying heavy loads of charcoal and firewood. ¹³⁾ It is presumed that heavy labour exacerbated their condition, because the disease renders victims insensitive to wounds and pain. Former patient Yuji Kodama of Kuryu Rakusen-en related that when he and other patients were gathering firewood in a steep valley, he noticed that bunches of firewood passed from one patient to another were stained with blood.

4) Arbitrary punishment

Leprologist Mitsuda wrote that some patients in leprosaria committed assault and battery, theft, adultery, and incited riots, but "there was no way to control disorderliness." ¹⁴⁾ He also pointed out that if a leprosy patient who was not institutionalized committed a crime and was arrested, he or she would be sent to a leprosarium instead of a prison because prisons would not accept leprosy patients. In 1916, the government accepted their request for police power by revising the LPL so that leprosarium directors were empowered to arrest and punish disobedient patients. Accordingly, confinement facilities were built in all national leprosaria. The director could imprison patients for up to one month and reduce their meals to twice a day without a court order. However, leprologists of the day regarded confinement as nothing but a mild "house arrest" which "seldom had any effect on the brutal ones who could repeat their crimes." ¹⁵⁾ Directors of national leprosaria decided to build a special facility in which they could give more severe punishments. The special facility was constructed in Kuryu Rakusen-en in 1938 and officially named Tokubetsu Byoshitsu ("special sickroom"), but was called Jukambo ("maximum confinement facility") by patients. In fact, it was a place of deadly confinement composed of eight cells. A post-WWII investigation of Jukambo unveiled one of the darkest aspects of Japanese leprosy control policy. Records showed that 22 of 92 persons imprisoned died during their imprisonment or within a few months after their release. The dates of their deaths in Jukambo were concentrated between November and March, when the air temperature of the region dropped to -16°C (-3.2°F) or below. Jukambo cells had no heating apparatus, and the building was on a low foundation, probably to prevent patients from escaping through the floor. Furthermore, patients were usually imprisoned much longer than the ordained period. The average length of confinement was more than 130 days. The longest imprisonment was over 500 days.

In 1947, media coverage made Jukambo a scandal and officials of the Ministry of Health and Welfare (MHW) commented at the Diet that they would abolish it. However, the power given to leprosarium directors to arrest and punish patients remained in effect, and a "leper's prison" was established in Kikuchi Keifu-en, a national leprosarium in Kumamoto, in 1953.

3. End of The Policy

The Japanese leprosy control policy remained unchanged for a long time. It survived the 1950s when post-WWII reform democratized Japanese socio-legal systems, the 1960s when sulfone drugs became widely available and studies showed that leprosy was rarely contagious, ¹⁶⁾ and the 1970s and 1980s when Japanese scholars introduced bioethics and its concepts (i.e., patients' rights and informed consent). Its crucial last moments came as late as the 1990s, when all residents in leprosaria had become "former patients" who were bacteriologically negative and had spent most of their lives there.

1) Patients' rights movement

It should be noted that patients' activities to abolish the control policy started early. Since the 1920s, patients' associations were organized in each leprosarium to improve living conditions. Their activities were suppressed during wartime, and they were terrorized by arbitrary punishment, especially confinement in Jukambo. However, the suppressed energy burst out once the Constitution of Japan guaranteed fundamental human rights, including freedom of assembly and speech, and the Jukambo was abolished. As mentioned above, the National Leprosaria Patients' Association was established in 1951, and demanded abolition of the above-mentioned questionable powers. Some patients went on hunger strikes at their leprosaria, and a few hundred went on a sit-down strike in front of the MHW and Diet Building. However, their movement came up against public ignorance. There had seldom been media coverage about the patients' movement, and Japanese media generally approved of the isolation policies until around the 1980s.

2) Abolishment of LPL

Admittedly, at least in the 1980s, patients' unions and medical professionals began to cooperate to change the situation. Fujio Otani, a medical official of MHW, is regarded as a key player in the partnership between medical professionals and former patients who were now old and afraid of being discharged from leprosaria by force. Furthermore, due to sterilization, they had no children who could support them when they went back into society. The powers given to medical professionals over patients were now applied mildly. Former patients were almost free to leave their leprosaria and were released from heavy labor (which had gradually been assigned to the leprosarium staff).¹⁷⁾ Otani expressed his opinion that the LPL should be repealed and replaced by a new law to guarantee their livelihood and welfare at the 1994 meeting of the Japanese Leprosy Association and at the 1995 Government-organized LPL Review Committee. In accordance with the Committee's report, the Diet passed the Act to Abolish the Leprosy Prevention Law in 1996.

3) Lawsuit against the country

On May 11, 2001, the Kumamoto District Court declared that the isolation policy had violated the fundamental human rights guaranteed in the Constitution of Japan. The court associated the isolation policy with an "absolute isolation" and "extinction" of leprosy patients. It held the MHW responsible for failing to seek an early reversal of the LPL, and the Diet responsible for inaction in repealing it, ordering compensation and an apology from the government.¹⁸⁾ The point at issue in the Kumamoto judgment was the forced isolation of leprosy patients, which the court ruled to be unjustifiable after it became medically unnecessary, since at least the 1960s. However, the other three questionable aspects of the leprosy control policy that I have considered here were left unexamined, even though those would be even more difficult to justify. Furthermore, the lawsuit was filed against the country, and no individual responsible

for the establishment and continuation of the policy was prosecuted.

Conclusion

The history of Japanese leprosy control policy described here suggests that the responsibility of medical professionals for development of the overall control policy was significant. Most aspects of the control policy were proposed by leading leprologists, and the policy can be considered as their strong paternalism being realized as extreme powers to accomplish 1) forced isolation, 2) sterilization, 3) forced labor, and 4) arbitrary punishment. On the other hand, the history also shows that there was a patients' rights movement in its own right - a half century before academic bioethics introduced Western concept of patients' rights to the country. However, the movement found the society less supportive in pre-bioethics Japan in which overwhelming power was given to the physician. The patient's only choices were to obey or to offer a hopeless resistance at the risk of punishment.

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¹⁴ Mitsuda, op. cit., 204.

¹⁵ Mitsuda, op. cit., 204-205.

¹⁶ Sato, H. and Narita, M. Politics of Leprosy Segregation in Japan: The Emergence, Transformation and Abolition of the Patient Segregation Policy. *Social Science & Medicine*. 2003;56:2529-2539.

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Caesarian Sections in Australia: Medical and Ethical Issues

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Abstract

Caesarian Sections in Australia have risen exponentially in the last fifteen years. Reasons for the rise of caesarian sections are both broad and complex and highlight the increasing medicalization and intervention of the western bio-medical model. This article gives an overview of caesarian sections in Australia and discusses some of the main medical and ethical issues regarding this practice.

Keywords: Caesarian section, intervention, medicalisation, ethics

Introduction

Until recently, caesarian section (CS) has been complementary to vaginal birth deliveries among Australian women. However, during the last 10-15 years there has been an exponential rise in CS among Australian women. Consequently, the steep rise in CS has brought up various medical, social and ethical issues which have not been adequately addressed. This paper gives an overview of CS in Australia and purports some of the medical and ethical issues which are located in this practice.

Prevalence in CS among Australian Women

CS has increased in Australia as a preferred form of giving birth, from a base of 19.4% in 1994 to 28.5% in 2003.¹ Australia's rates of CS are high when compared with other countries. For example, CS rates in the United Kingdom during 2003-2004 were 22.7%,² 22.7%

in New Zealand,³ and 9.2% in the Netherlands.⁴ In relation to CS "in 2003, 57.9% were without labour while 41.9% were with labour."⁵ In addition, CS deliveries from Aboriginal and Torres Strait mothers were less frequent at 23.3% compared to 28.8% for non-indigenous mothers.⁵ From 1983-2003 emergency CS have increased in Australia by 70%.⁶

In Western Australia there were more than 430,000 CS deliveries for the period between 1984-2003.⁶ Statistics reveal that planned or elective CS have risen among females in Western Australia from 6% to 13% over a twenty year period, while there has been a 70% increase in emergency CS for the same period.⁶ In New South Wales 20% of 131,101 women had a CS for the period 1998-2002.⁷ Research has also found that Australian women with private medical cover are three times as likely to have elective CS than women who are not insured.⁶ This trend is further illustrated with women having CS at 37.4% in Australian private hospitals while women in Australian public hospitals having CS at 25.7%.⁵

Medical Risks of Caesarian Section

The popularity of CS among Australian women should not downplay its inherent risks. A 2005 study of 136,000 "second pregnancies" in New South Wales that had CS performed during their first delivery were found to be at greater risk of uterine rupture, hysterectomy and infection. Moreover, babies that were born prematurely needed intensive care.⁸ In addition, women who had CS in their first delivery had increasing complications if the second birth was also delivered by CS.⁷ Despite medical improvement, CS delivery has increasing health complications for the mother and child.⁶

According to Fenwick *et al*, CS "poses greater physical and emotional risk to both mother and baby."⁹
¹⁰ ¹¹ ¹² ¹³ ¹⁴ A study conducted in the United States

³ New Zealand Health Information Service (2004) *Report on Maternity: Maternal and Newborn Information*, 12 November 2005, at <http://www.nzhis.govt.nz/publications/maternityreport.html>

⁴ G. Bernard. "Summary of Vital Statistics 1995," *Pediatrics* 98, no. 6 (1996): 115-120.

⁵ "Caesarian Sections and Births on the Rise in Australia." *News-Medical.Net* 15 December 2005. 17 October 2007, at <http://www.news-medical.net/?id=15000>

⁶ "Dramatic Rise in Caesarian Section in Australia," *ScienceDaily.com* 21 May 2007. 17 October 2007, at <http://www.sciencedaily.com/release/2007/05/070516091842.htm>

⁷ Effects of Caesarian Sections on Future Pregnancies. 17 October, at http://www.pregnancy-info.net/csections_future.html

⁸ J. Robotham. "Tough New Rules for Caesarian: Growth Spurt Caesarians in NSW." *Sydney Morning Herald*. 7 April 2007.

⁹ J. Fenwick., J. Gamble., & Y. Hauk. "Reframing Birth: A Consequence of Caesarian Section," *Journal of Advanced Nursing* 56, issue 2 (2006):121-130.

¹⁰ E. L. Ryding., K. Wijma., & B. WijmaB. "Predisposing Psychological Factors for Posttraumatic Stress Reactions After Emergency Caesarean Section," *Acta Obstetrica et Gynecologica Scandinavica* 77 (1998): 351-352.

¹ Australian Institute of Health and Welfare. (2007) "Australia's Mothers and Babies 2003." *AIHW* (online)

6 October 2007, at <http://www.ranzcog.edu.au/womenshealth/index.shtml>

² Department of Health (2005) NHS Maternity Statistics, England: 2003-04 Bulletin 2005/10. *Department of Health*, 3 March 2006, at <http://www.dh.gov.uk/Home/ft/en>

cites that newborns delivered by CS are three times more likely to die than newborns delivered by vaginal birth.¹⁵ Death rates in the US for CS babies was 1.77% for every thousand births compared with 0.62% for every thousand births from vaginal delivery.¹⁵

Medical and Ethical Issues

Research also indicates that there are long term "disturbances to children's emotional, behavioural and cognitive development when their mother has suffered a postpartum mood disorder, which tends to occur more after CS."^{9 16 17 18 19} There are several reasons for the increase in CS. Firstly, CS offers women a sense of control and planning which is not given by vaginal delivery.⁹ This notion is greater management of CS accommodates within the western model of control over unknown circumstances. "Fewer unknowns" are interpreted by many women with increasing safety of CS.⁹ Women's onus on baby safety is reflected in research in which half of mothers who chose CS did so on the belief that it was safer for their baby than vaginal birth.²⁰

Increasing CS has also been linked to the invasive element of the western bio-medical model in dictating what is considered best for women. This issue involves loss of women's autonomy over their bodies. Dr Farrell (Australian Council for Obstetricians and Gynaecologists) stated on ABC radio that "it is important that women are given accurate information and that they have the right to choose."²⁰ Professor Sabaratnam Arulkumaran (President of the UK Royal College of Obstetricians and Gynaecologists) stated that women should be educated "rather than just agreeing to do a caesarian."²⁰ In New South Wales new rules are coming into force which will outline to women the benefits and risks of CS compared to

vaginal birth.⁸ The new policy change also stipulates that health practitioners need to advise women about the "implications for subsequent pregnancies" due to emerging evidence of the health risks of CS. The onus on educating women on CS is based on evidence that 20% to 50% of women having had CS were not satisfied by the amount of information provided to them nor by their decision to have CS.²¹ Turnbull *et al* ask whether women who have had CS in the first birth will opt for vaginal delivery in subsequent births if given appropriate information?²²

Western Australian Health Minister, Jim McGinty went so far as to treat CS with circumcisions in that both should be performed if medically required.¹⁵ McGinty claims that giving birth at present has too much medical intervention. McGinty's comments may hold some truth. Although uterine rupture is uncommon it is more likely to occur during subsequent vaginal delivery rather than repeat CS. For this reason women need more information.^{21 23 24 25} A survey practice sent to Australian and New Zealand obstetricians and gynecologists attempted to determine current rates for women with a prior CS. 96% of respondents agreed that vaginal birth after CS (VBAC) should be presented as an option to women, while 44% disagreed that VBAC was the safest option.²⁶ In addition, most obstetricians indicated that VBAC was safest for women, while they were less certain if it was safest for babies.²⁶ Turnbull's study reveals that 25% of women "insisted on" and were "keen to have" CS.^{21 22} Similarly, according to Mould *et al*, 10% of women in a London hospital felt that they had autonomy in their decision to have CS while 50% of women indicated that they would have CS in a further pregnancy.^{21 27}

Another reason for the dramatic increase in VBAC is the result of a targeted campaign.⁹ For example, Goer *et al* in a letter to the editor of *Birth* explains that the prestigious *New England Journal of Medicine (NEJM)* has "served as a platform for anti-VBAC, and indeed, anti-vaginal birth movement within the obstetrics

¹¹ E. K. Slaytor., E. A. Sullivan., & J. F. King. "Maternal Deaths in Australia 1997-1999." Maternal Deaths Series No. 1. *Australian Institute Health and Welfare Cat. No. PER-24*, (2004) Canberra, Australia.

¹² C. A. Armstrong., S. Harding., T. Matthews., & J. E. Dickinson. "Is Placenta Accreta Catching Up With Us?" *Australian and New Zealand Journal of Obstetrics and Gynaecology* 44:210-213.

¹³ H. Goer. "The Case Against Elective Caesarean Section," *Journal of Perinatal and Neonatal Nursing* 15, no. 3 (2001): 23-38.

¹⁴ N. Jukelevics. "Women in the Crossfire: Forced Repeat Cesareans," *Birth* 29 (2002):149-150.

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¹⁹ V. Koo., J. Lynch., & S. Cooper. "Risk of Postnatal Depression After Emergency Delivery," *Journal of Obstetric and Gynaecology Research* 29, no. 4 (2003): 246-250.

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²¹ C. M. de Costa. "Caesarian Section: A Matter Choice," *The Medical Journal of Australia* 170 (1999):572-573. <http://www.mja.com.au/public/issues/jun21/decosta/decosta.html>

²² D. Turnbull., C. S. Wilkinson., & A. Yaser. "Women's Role and Satisfaction in the Decision to Have a Caesarian Section," *The Medical Journal of Australia* 170 (1999): 580-583.

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²⁴ M. McMahan., E. Luther., W. Bowes., & A. Olshan. "Comparison of a Trial of Labor With an Elective Second Caesarian Section," *New England Journal Medicine* 335 (1996): 689-695.

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²⁶ J. Dodd., & C. A. Crowther. "Vaginal Birth after Caesarian Section: A Survey of Practice in Australia and New Zealand," *Journal of Obstetrics and Gynaecology* 43, no. 3 (2003):226-236.

²⁷ T. A. J. Mould., S. Chong., J. A. D. Spencer., & S. Gallivan. "Women's Involvement with the Decision Preceding Their Caesarian section and their Degree of Satisfaction," *British Journal of Obstetrics and Gynaecology* 103 (1996): 1074-1077.

profession by publishing several demonstrably biased articles and editorials in recent years.”²⁸ Moreover, Goer contends that 1998 Guidelines on VBAC by the American College of Obstetricians and Gynaecologists (ACOG) limited VBAC and supported repeat “CS as protection from malpractice suits.”⁹ The fact that CS has become an acceptable alternative of childbirth should be considered in relation to women’s objections in having vaginal births. For some women “fear of pain, sphincter damage, possible stress incontinence and “compromised sexual dysfunction” were other reasons for opting for CS.²¹

The role of medical practitioners was a significant indicator affecting women’s decision making in having CS. Fenwick *et al* state that vaginal birth was in some cases not a possibility while other women were told that VBAC had not been discussed with them.⁹ Another group of women noted that VBAC was not an option. As one woman said, “I knew my doctor would not let me have a normal because he believes in all CS. So I just never expected to have one.”⁹ Moreover, some medical practitioners have sometimes tended to discuss birthing issues in such a way that pressures women in complying with their recommendations.⁹ This is expressed by one woman whose doctor said, “Do you want a live baby or a dead mother, or a dead baby or a live mother, or do you want a dead baby and a dead mother.”⁹ Such language is tenuous as it acts to compromise women’s autonomy in deciding which type of delivery is most suitable for her. Apart from its unethical stance, such language is particularly distressing to pregnant women whose condition makes them especially vulnerable and dependent on others.

Conclusion

This article has provided an overview of some of the medical and ethical issues surrounding CS. In summary, Australian women have opted for CS due to their belief that it is safer for the baby than vaginal birth; and secondly, CS is deemed as being a more convenient and manageable way of giving birth.⁹ The rise of CS in Australia highlights the power of the medical intervention, as well as, the possibility of medical practitioners to “undermine women’s confidence to give birth vaginally.”⁹ For theorists such as Cahill, CS has been conducted within the ambit of a patriarchal medical model and is enforced by “legal and medical intervention.”²⁹ While this paper has not discussed CS in relation to gender issues, Cahill’s study on maternity in the United Kingdom prompts us to ask to what extent do doctor-patient interactions sanction or violate women’s autonomy in birthing? Cahill argues that obstetricians have regularly used definitions such as “normal and abnormal” in order “to strengthen their power base.”²⁹ On this point Cahill avers:

The successful medicalization of reproduction and its prevention accounts for the majority of consultations

between women and doctors (Clarke 1981) whilst the development of a specific medical specialty for dealing with women’s reproductive functions (i.e. gynaecology) and its association with obstetrics serves to further reinforce the pathological nature of pregnancy and illustrates the controlling influence of medicine over women’s lives.²⁹

CS clearly represents the increasing medicalisation of women’s reproductive functions while raising concerns about misinformed decisions by women. Cahill rightfully asserts that the medicalised and interventionist ‘birth culture’ invariably undermines psychosocial aspects which women undergo in the transition for woman to mother.^{29 30} On this theme, Oakley suggests that CS, epidural anaesthesia and forceps are “closely associated with postnatal mood disturbance.”^{29 31} Thus, mood disturbances may be due to iatrogenic causes. If this is the case, a moratorium on CS is needed.

I would suggest that CS in Australia reflects changes in Australian society, and its transition to becoming a high-tech culture. Australian medical culture advocates high-tech medical facilities and techniques with provisioning the needs of the population. Technological medical innovations are generally viewed as being progressive and increasing medicine’s mastery over the human body. In this way, medical technology attempts to fulfill social expectations while society encourages technological medical innovation. What is often ignored is the psychosocial well being of people and the fact that our humanity is rooted in biology, not technology. The dominance of the western bio-medical model needs addressing in order to place CS where it belongs, as an ancillary to vaginal birth, not as a principal form of giving birth.

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²⁸ H. Goer. “VBAC and the New England Journal of Medicine,” *Birth* 29 (2002):150–151.

²⁹ H. A. Cahill. “Male Appropriation and Medicalization of Childbirth: An historical Analysis,” *Journal of Advanced Nursing* 33, no. 3 (2001):334-342.

³⁰ R. E. Davis-Floyd. “The Technological Model of Birth,” *Journal of American Folklore* 100 (1987): 479-495.

³¹ A. Oakley. *Women Confined: Towards a Sociology of Childbirth*. (Oxford: Martin Robertson, 1980).

The Setting up of a National Bioethics Committee – Social and Cultural Considerations

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Abstract

The rationale for the establishment of a National Bioethics Committee is discussed. Social and cultural dimensions of bioethics that led to the flourishing of bioethics as a system of thoughts and ideas in the Western world and the influence it has made in parts of the Eastern world is explored. It is held that bioethics is valuable as an educational tool to enhance critical and decision-making skills. The need for a National Bioethics Committee in Malaysia is practical for the purpose of assisting the government in drawing up of sound public policies pertaining to health care and scientific research practices and, to advance bioethics as an integrated study of life, science, and society.

Introduction

On 19 June 2009, a *Workshop for the Establishment of A National Bioethics Committee*, was organized by two Ministries in Malaysia, with the cooperation of UNESCO. At the end of the workshop, it was concluded that it was necessary to initially form a Steering Committee or a Task Force to study the feasibility of establishing a National Bioethics Committee before one can concretely be founded. The need for such a committee has already been expressed five years earlier (July-August 2005), when a concept paper for the setting up of National Consultative Council for Bioethics was prepared.

To begin the discussion on the relevance of instituting such a committee, a talk on the "Social and Cultural Dimensions of Bioethics" was presented. The UNESCO Declaration on Bioethics and Human Rights (2005) preamble was recalled;

Conscious of the unique capacity of human beings to reflect upon their own existence and on their environment; to perceive injustice; to avoid danger; to assume responsibility; to seek cooperation and to exhibit the moral sense that gives expression to ethical principles.

This statement presented a challenge for the Malaysian community to be directly involved by responding in a conscientious manner to various advancements in the biosciences such as stem cell research, genetic testing and human cloning, which gives new power to control the development process of all living things. In addition, the Universal Declaration on the Human Genome and Human Rights (1997), article 21 has relayed that. "States should take appropriate measures to encourage other forms of

research, training and information dissemination conducive to raising the awareness of society and all of its members of their responsibilities regarding the fundamental issues relating to the defense of human dignity which may be raised by research in biology, in genetics and in medicine, and its applications. They should also undertake to facilitate on this subject an open international discussion, ensuring the free expression of various socio-cultural, religious and philosophical opinions."

It must be noted that bioethics is not alien to the Malaysian people, whether from the academic circle or the lay public. Issues affecting social, cultural and ethical implications of the then 'new' revolutions in human reproductive technology had already caught the attention of the popular media as noted by Nor (1999). Local newspapers in 1992 expressed public concern over moral implications of "the development of 'sperm-banks' and behind the controversial project, claims that the sperm-banks were necessary 'to help husbands of childless women to produce and store active sperms' [and that] an elite group donors were chosen among those who 'had the brains and could produce good progeny'." The furor eventually died down due to apparent Islamic sensitivities of the subject. Chan (1998) later deliberated the ethical aspects of health care reform in the country and observed cautiously how Western bioethics has given primacy to the individual against the interests of the community. He noted, "What has happened to our Asian values and ethics, which put the priority of our collective welfare above that of individualist concerns."

Social and cultural impacts of science and technology have led to development of bioethics as a novel discipline in the history of knowledge that significantly influenced societies on a great scale. It became an ideology that gained practical importance especially in matters dealing with decision-making that involves the physician and his/her patient. The word "bioethics" was first coined in English by Van Rensselaer Potter in 1970 to address a new discipline dealing with contemporary ethical issues in medical care such as abortion, euthanasia and the doctor-patient relationship. Before the mid-1960s medical ethics had been discussed in the context of the Hippocratic tradition, the 'duty of the doctor towards his patient'. Today, chants such as patient competency, patient rights and the best interest of the patient have dominated bioethics literature in unfettered ways.

Institutional developments related to bioethics began with the birth of a bioethics centre in June 1969 which later became known as the Hastings Center in New York. Soon afterwards in 1971, the Centre of Bioethics was founded by Joseph and Rose Kennedy Institute at the Georgetown University in Washington DC. It is noted that the US Society for Health and Human Values was founded as an expression of public concerns over the impact of technological and industrial practice of medicine on the lay society. (McCullough, 1978) Literature that developed from this discipline of knowledge emerged in the publication of the first *Encyclopedia of Bioethics* in 1978. In 1983, Thomas L. Beauchamp and James F. Childress produced a textbook *Principles of Biomedical Ethics* that introduced a vision of normative ethics with a strong emphasis on

prima facie principles. According to the book, actual bioethical problems may be resolved by the systematic application of four principles to each case, namely, autonomy, beneficence, non-maleficence and justice. It is worth noting that critics have argued, for example, that these principles ignore psychological factors including a person's (or patient's) character, life story, cultural background, and gender.

Under the aegis of bioethics, the practice and procedures including research management in the realm of medicine have been 'standardized' internationally. For example, the use of informed consent forms is virtually a taken-for-granted procedure. It is the norm, so to speak, and anything or any practice that goes against it is dubbed a wrongdoing or unethical. During Hippocratic times, the preferred conception was that physicians should protect their patients from information of their disease and their treatment options on the basis that doctors know what is best for their patients. In modern times, informed consent gives patients the upper-hand in a medical transaction or contract and the term 'informed choice' has been coined as an eclectic addition to put both parties at par with each other so as to reduce the 'subordinate' character of the 'weak' and ill patient.

Western bioethics is known to have also on a large sociological scale influenced Eastern culture. The transfer of new medical technologies seemed to be accompanied by the importation of new values (Macer, 2003). For example, before 1990, Japanese physicians routinely protected dying patients by not informing them of their terminal diagnosis. This is because decisions about dying are considered a communal affair and not the sole province of individual patients. In fact, organ donation from deceased persons is not an easy affair for transplant specialists in Japan (Ohunki-Tierney, 1994).

It is remarkable that it was also at the *Fifth World Congress of Bioethics* in London (2000) that I had the great opportunity to witness a public apology delivered on behalf of all the wrongdoings committed during the Japanese Biological Warfare of World War II (Tsuchiya, 2000 and Nie, 2001). Such is the power of bioethics, an enterprise of thoughts, that seemed successful in digging out every moral event worth mulling over openly.

The influence of bioethics has also swept across the world as manifested in the development of new curricula of almost all schools of medicine in the Western world and some in non-Western parts of the globe, including parts of Thailand, Taiwan and Croatia (Boyd & Doering, 2001, Gosic & Segota, 2001, Tai, 2000).

I am therefore inclined to say that bioethics is the development of a disciplined culture of ideas that not only reflects upon concerns regarding current practices in science and medical research and practice but that it has gained popularity as a tool for organizing logical and rational thinking that has pervaded all over the world to displace conventional, emotional and subjective behaviour. The 'brain death' definition, for example, has given doctors the additional 'license' to act fast to inform next-of-kin of deceased persons of the

option to donate organs. It has become a routine and acceptable procedure in most hospitals and the period to mourn has been overtly cut short.

It is safe to say that in Malaysia, the first instance of bioethics encounter occurred as early as 1987 when the first 'test-tube' baby was born. This is attributed to a renowned Malaysian gynecologist, Hamid Arshat who reflected warily that "until March 1989, no formal code of ethics has been drawn to safeguard the legal, religious, and social norms regarding this human reproductive technology" (Arshat, 1989). It is elsewhere also emphasized that guidelines on the use of assisted reproduction should be explicitly made in accordance with the distinctive cultural and religious values of the Malaysian people (*Malaysian Laws and Policies on Human Reproduction, 1988*). There was, therefore, awareness that the peculiarities of the technology called upon careful and deep deliberation, ethically, socially and culturally. Similar concerns had earlier been raised by practitioners that the practice of ART may create ethical, legal and religious problems in the country, where jurisdiction in matters of the personal status of Muslims is governed by the religious *Shariah* and civil authorities (McCoy, 1989).

It is interesting though that others saw the coming of IVF to the country as 'timely technical solution' to 'marital problems' directly affected by childlessness – the staging of a *Public Forum on Infertility and the Pathway to Parenthood* in 1993 seemed to portray this (Nor, 1999).

Over in the Western world, the new reproductive technology made impact of a different nature; the recognition of third parties, the surrogate, into family institutions. An unrelated woman may be paid for gestational services, sisters and even grandmothers could bear babies for their siblings and daughters, respectively. While some discussed that anonymity be given to donors (of gametes), others contemplated if they should be recorded on birth certificates of such children.

Some in the audience at the workshop questioned the need for the formation of an over-arching National level Bioethics committee. Accordingly, there were already in place various Institutional Ethics Review Committees in medical schools, medical research centres and universities throughout the country besides the availability of various internal guidelines that supposedly offer rules of conduct for the implementation of various scientific research activities such as the "Guidelines on the Release of GMOs" or the "Guidelines on the Disposing of Chemical Waste." The role of existing accreditation bodies that audit institutions to monitor and/or combat non-conforming practices was also pointed out. In addition, there are also acts to govern medical malpractice such as the Private Healthcare Facilities and Services Act 1998 which has been effective in deterring unethical behaviour. Some members of the audience anticipated that the task of the NBC would overlap the numerous mechanisms already in place for maintaining professional integrity among scientists and researchers and some believed that the task ahead for the NBC would be immensely larger than it envisaged.

So what then would essentially be the job scope and specifications of a National Bioethics Committee? A National Bioethics Committee would, of course, primarily provide consultation service that assists with identifying and resolving ethical, cultural or social issues in the planning and conduct of research in the realm of bioscience and medical innovation. The responsibilities and the scope of duties that the NBC would be tasked with would include:

1. Advising scientists and program organizers on ethical, social and cultural (ESC) matters in biotechnological research and medical innovation.
2. Educating researchers on ethical concerns and on their proper resolution.
3. Providing consultation to researchers and university-based ethical review committees to resolve differences over ethical concerns.
4. Developing outreach programs that foster better understanding of the ESC challenges in research to the scientific community and the public.
5. Promoting public forums, surveys and other mechanisms to help identify public concerns over biotechnological research agendas and to provide information on the goals and conduct of such research and,
6. Assuming the role as mediator between scientists and the public so as to maintain scientific integrity and foster public trust.

To begin effectively, the first task would be to compile a directory of researchers or experts with interest in bioethics to establish lines of communication. This would aid the Committee in maintaining a pool of experts hence providing qualified persons to serve as ethicists, for example, on bio-safety monitoring boards. It is most important for the NBC to work closely with policy makers of relevant Ministries with the ultimate aim of assisting the nation in developing common ethical standards in an organized manner. The NBC is expected to disseminate information to the widest possible audience within the nation by regularly developing materials (publication) that provide essential coverage of ethical, social and cultural concerns of the biosciences. Last, but not least, and consistent with the goals of the 1974 UNESCO *Recommendations of the Status of Scientific Researchers* which specifically states the importance of the "development of educational techniques for awakening and stimulating ethical personal qualities and habits of mind", the NBC should advance training programs and assist the development of university courses on bioethics so as to create a bioethics competent group of citizens of the future.

It is expected that there will be two major functions of the NBC and this would include; first, the drawing up of sound public policies pertaining to health care and research practices giving unwavering consideration to demonstrate respect for every ethnic group or community's value system and worldview because these may profoundly affect their livelihood, and;

second, to advance bioethics as an integrated study of life, science, and society. The latter is expressed in the 1997 Universal Declaration on the Human Genome and Human Rights;

States should take appropriate measures to promote the principles set out in the Declaration, through education and relevant means, *inter alia* through the conduct of research and training in interdisciplinary fields and through the promotion of education in bioethics, at all levels, in particular for those responsible for science policies.

Bioethics is appreciated as a tool for the development of critical thinking capacity. This aspect must never be dismissed as has openly been done by opponents who are against assimilating bioethics within normal school or university curriculum. Bioethical deliberations consider the medical, scientific, societal, and political factors that represent troubling dilemmas for both individuals and societies. In the same week that the Workshop was organized, a paper by Nor (2009) titled "Institutionalizing Ethics – How may COMEST help Malaysia" was presented at a UNESCO-ISTIC satellite conference held in correspondence with the *Sixth Ordinary Session of the World Commission on the Ethics of Scientific Knowledge and Technology (COMEST,) Kuala Lumpur 15-19 June 2009*. It was disclosed that the course *Professional Ethics and Morals* which incorporates issues on bioethics including, human cloning, GM foods and the human genome project, has indeed been taught to students of Biology, Chemistry, Physics, Geology and Mathematics since 2001. It is held that the valuable outcome of the course that was conducted using the problem-based learning method is that it encouraged the students to be bold decision-makers. Students had the opportunity to engage in discussions of risk, benefits, strengths and drawbacks of technologies which they never have been given the time to consider in the usual undergraduate curriculum. Through such discussions, students are able to hone their analytical and critical thinking skills.

Conclusion

The Steering Committee must understand that no one in the academic (or professional) world would accept any compulsory compliance with rigid rules. The not too distant task for the Steering Committee to execute is to first understand that there are two ways to view and apply bioethics- *Descriptive and Prescriptive*. *Descriptive bioethics* is the way people view life, their moral interactions and responsibilities with living organisms in their life. *Prescriptive bioethics* is to tell others what is ethically good or bad, or what principles are most important in making such decisions including who has rights and who has duties (Macer, 1998).

I believe the Steering Committee should steer clear from the dogmatic adoption of prescriptive bioethics as has been done by undiscerning members of the scientific and medical fraternity and first embark upon a series of local research on descriptive bioethics so as to assess, define and map the cultural loci of the plural mixture of the Malaysian community. Bioethics covers several aspects of human life as reflected by the encroachment of new technologies that gives (and begs) new meanings to "when life begins", "when it ends", "what constitutes the family unit", and the current

fashionable question, "how can we live right and sustainably". Some writers say that, "Bioethics is not about thinking that we can always find *one correct solution* to ethical problems." I beg to differ and believe that there is actually only one answer to each of those questions and each answer is unique and intrinsic to each culture and that has to be respected.

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Are Human Rights and Health Care Universal?: Reflections on Health Care in India?

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Introduction

Human rights and the right to health care have explicit intrinsic connections and have emerged as powerful concepts with regard to human dignity and fullness of life. A rights-based approach to health uses International Human Rights treaties and proposes norms to hold governments accountable for their obligations. It recognizes the fact that the right to health is a fundamental right of every human being and it implies the enjoyment of the highest attainable standard of health that governments have the bounden responsibility for the health of the citizens which can be fulfilled only through the provision of adequate health care and social concern. The same should get integrated into research, advocacy strategies and research tools, including monitoring; community education and mobilization; litigation and policy formulation. The right to the highest attainable standard is encapsulated in Article 12 of the International Covenant on Economic, Social and Cultural Rights.

The enjoyment of the highest standard, in any given milieu is one of the fundamental human rights without distinction of race, religion, political belief or social condition. Article 25 of the Universal Declaration of Human Rights is concerned with the right to health. According to this article, everyone has the right to a standard of living with reasonable health of oneself, including food, clothing, housing, medical care as necessary to ensure fullness of life. The preamble of the World Health Organization states that the enjoyment of the highest standard of health is a fundamental right of every human being. Aristotelian philosophy is based on the principle that it is society's obligation to maintain and improve people's health. Therefore, public health should focus on the individual's capacity to function, and health policy should aim to maintain and improve this capacity by meeting health needs. The relationship between health and economic development is two-directional. Health affects labor productivity as well as investments in physical and human capital and savings rates. In the other direction, income can affect health and demography by improving the ability to obtain food,

sanitation and housing and by providing incentives to reduce the family size.

As we are in the later part of the first decade of 21st Century, the awareness on health care has increased enormously and everyone wants to lead a healthy life. National Governments and State Governments should be positive to provide medical care for all. But, do these facilities and benefits reach out or are they available to all the citizens of the country? What are the existing draw backs and problems? How to overcome such problems to universalize the health care to all irrespective of their economical and social status? These would be discussed in the paper.

Paradigm shift: Policy to human rights approach

Our past experience over a period of more than sixty years has not given any comprehensive and universal access approach by developing selective schemes or programs. Hence, our historical experience tells us that we should abandon the policy approach and adopt the human rights route to assuring universal access to all people for healthcare. The State is today talking of health sector reform and hence it is the right time to switch gears and move in the direction of right to health and healthcare.

The right to healthcare is primarily a claim to an entitlement, a positive right, not a protective fence. As entitlements rights are contrasted with privileges, group ideals, societal obligations, or acts of charity, and once legislated they become claims justified by the laws of the state (Chapman, 1993). The emphasis thus needs to shift from 'respect' and 'protect' to focus more on 'fulfill'. For the right to be effective optimal resources that are needed to fulfill the core obligations have to be made available and utilized effectively.

Further, using a human rights approach also implies that the entitlement is universal. This means there is no exclusion from the provisions made to assure healthcare on any grounds whether purchasing power, employment status, residence, religion, caste, gender, disability, and any other basis of discrimination. But this does not discount the special needs of disadvantaged and vulnerable groups who may need special entitlements through affirmative action to rectify historical or other inequities suffered by them.

Thus establishing universal healthcare through the human rights route is the best way to fulfill the obligations mandated by international law and domestic constitutional provisions. International law, specifically ICESCR, the Alma Ata Declaration, among others, provide the basis for the core content of right to health and healthcare. But country situations are very different and hence there should not be a global core content, it needs to be country specific. In India's case a certain trajectory has been followed through the policy route and we have an existing baggage, which we need to sort out and fit into the new strategy.

Present scenario

Specific features of this historical development can be depicted as follows:

- A very large and unregulated private health sector with an attitude that the existing policy is the best one as it gives space for maximizing their interests needs to be checked. A complete absence of

professional ethics and absolute disinterest in organizing around issues of self-regulation, improvement of quality and accountability, and need for an organised health care system needs to be addressed.

- A declining public health care system which provides selective care through a multiplicity of schemes and programs, and discriminates on the basis of residence (rural-urban) in providing for entitlements for healthcare should be looked into.

- The existing inequities in access to healthcare based on employment status and purchasing power should be reviewed.

- Inadequate development of various pre-conditions of health such as water supply and sanitation, environmental health and hygiene and access to food should be taken care of.

- Very large numbers of unqualified and untrained practitioners should be checked.

- Declining investments and expenditure in public health needs special care.

- Adequate resource availability when we account for out-of-pocket expenses needs attention.

- Human power and infrastructure that are reasonably adequate, though inequitably distributed, are the needs of the hour.

- Wasteful expenditures due to lack of regulation and standard protocols for treatment should be avoided.

Thus the operationalisation of the right to healthcare will have to be developed keeping in mind what we have and how we need to change it.

Right to Quality Healthcare:

Health is one of the goods of life to which man has a right; wherever this concept prevails the logical sequence is to make all measures for the protection and restoration of health to all, free of charge; medicine like education is then no longer a trade - it becomes a public function of the State ... Henry Sigerist

The quote used as the Preamble is very relevant to the notion of right to healthcare. Sigerist said this long ago and since then most of Europe and many other countries have made this a reality. And today when such demands are raised in the developing countries, India being one of them, it is said that this is no longer possible - the welfare state must wither away and make way for global capital! Europe is also facing pressures to retract the socialist measures, with working class struggles had gained since 19th century. So we are in a hostile era of global capital which wants to make profit out of anything it can lay its hands on. But we are also in an era when social and economic rights, apart from the civil and political rights, are increasingly on the international agenda and an important cause for advocacy.

Thus health and health care are now being viewed very much within the rights perspective and this is reflected in Article 12 "*The right to the highest attainable standard of health*" of the International Covenant on Economic, Social and Cultural Rights to which India has acceded. According to the General Comment 14 the Committee for Economic, Social and Cultural Rights states that the right to health requires

availability, accessibility, acceptability, and quality with regard to both health care and underlying preconditions of health. The Committee interprets the right to health, as defined in article 12.1, as an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including sexual and reproductive health.

Understanding of health and health care

The understanding of health and health care are spelt out below:

The right to health in all its forms and at all levels contains the following interrelated and essential elements, the precise application of which will depend on the conditions prevailing in a particular State party:

(a) *Availability*: Functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party. The precise nature of the facilities, goods and services will vary depending on numerous factors, including the State party's developmental level. They will include, however, the underlying determinants of health, such as safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs, as defined by the WHO Action Programme on Essential Drugs.

(b) *Accessibility*: Health facilities, goods and services have to be accessible to everyone without discrimination, within the jurisdiction of the State party. Accessibility has four overlapping dimensions:

i) *Non-discrimination*: health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds.

ii) *Physical accessibility*: health facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups, such as ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons with disabilities and persons with HIV/AIDS. Accessibility also implies that medical services and underlying determinants of health, such as safe and potable water and adequate sanitation facilities, are within safe physical reach, including in rural areas. Accessibility further includes adequate access to buildings for persons with disabilities.

iii) *Economic accessibility (affordability)*: health facilities, goods and services must be affordable for all. Payment for health-care services, as well as services related to the underlying determinants of health, has to be based on the principle of equity, ensuring that these services, whether privately or publicly provided, are affordable for all, including socially disadvantaged groups. Equity demands that poorer households should

not be disproportionately burdened with health expenses as compared to richer households.

iv) *Information accessibility*: accessibility includes the right to seek, receive and impart information and ideas concerning health issues. However, accessibility of information should not impair the right to have personal health data treated with confidentiality.

(c) *Acceptability*. All health facilities, goods and services must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.

(d) *Quality*. As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality. This requires, *inter alia*, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation. (Committee on Economic, Social and Cultural Rights Twenty-second session 25 April-12 May 2000)

Universal access to good quality healthcare equitably is the key element at the core of this understanding of right to health and healthcare. To make this possible the State agencies are obligated to *respect, protect and fulfill* the above in a progressive manner:

The right to health, like all human rights, imposes three types or levels of obligations on State parties: the obligations to *respect, protect and fulfill*. In turn, the obligation to fulfill contains obligations to facilitate, provide and promote. The obligation to *respect* requires States to refrain from interfering directly or indirectly with the enjoyment of the right to health. The obligation to *protect* requires States to take measures that prevent third parties from interfering with article 12 guarantees. Finally, the obligation to *fulfill* requires States to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realization of the right to health. (Ibid)

State parties are referred to the Alma-Ata Declaration, which proclaims that the existing gross inequality in the health status of the people, particularly between developed and developing countries, as well as within countries, is politically, socially and economically unacceptable and is, therefore, of common concern to all countries. State parties have a core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights enunciated in the Covenant, including essential primary health care. Read in conjunction with more contemporary instruments, such as the Programme of Action of the International Conference on Population and Development, the Alma-Ata Declaration provides compelling guidance on the core obligations arising from Article 12. Accordingly, in the Committee's view, these core obligations include at least the following obligations:

(a) To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups;

(b) To ensure access to the minimum essential food which is nutritionally adequate and safe, to ensure freedom from hunger to everyone;

(c) To ensure access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water;

(d) To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs;

(e) To ensure equitable distribution of all health facilities, goods and services;

(f) To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population; the strategy and plan of action shall be devised, and periodically reviewed, on the basis of a participatory and transparent process; they shall include methods, such as right to health indicators and benchmarks, by which progress can be closely monitored; the process by which the strategy and plan of action are devised, as well as their content, shall give particular attention to all vulnerable or marginalized groups.

The Committee also confirms that the following are obligations of comparable priority:

(a) To ensure reproductive, maternal (pre-natal as well as post-natal) and child health care;

(b) To provide immunization against the major infectious diseases occurring in the community;

(c) To take measures to prevent, treat and control epidemic and endemic diseases;

(d) To provide education and access to information concerning the main health problems in the community, including methods of preventing and controlling them;

(e) To provide appropriate training for health personnel, including education on health and human rights. (Ibid)

The above guidelines from General Comment 14 on Article 12 of ICESCR are critical to the development of the framework for right to health and healthcare. As a reminder it is important to emphasize that in the Bhore Committee report of 1946 we already had these guidelines, though they were not in the 'rights' language. Thus within the country's own policy framework all this has been available as guiding principles for now 56 years.

The growth over the years of healthcare services, facilities, human power etc. has been inadequate and the achievements not enough to make any substantive impact on the health of the people. The focus of public investment in the health sector has been on medical education and production of doctors for the private sector, support to the pharmaceutical industry through states own participation in production of bulk drugs at subsidized rates, curative care for urban population and family planning services. The poor health impact we see today has clear linkages with such a pattern of investment:

- The investment in medical education has helped create a mammoth private health sector, not only within India, but in many developed countries through export of over one-fourth of the doctors produced over the years. Even though since mid-eighties private medical colleges have been allowed, still 75-80% of the outturn is from public medical

schools. This continued subsidy without any social return is only adding to the burden of inequities and exploitation within the healthcare system in India.

- Public sector participation in drug production was a laudable effort but soon it was realized that the focus was on capital goods, that is bulk drug production, and most supplies were directed to private formulation units at subsidized rates. It is true that the government did control drug prices, but post mid-seventies the leash on drug prices was gradually released and by the turn of the nineties controls disappeared. Ironically, at the same time the public pharmaceutical industry has also disappeared – the little of what remains produces a value of drugs lesser than their losses! And with this withering away of public drug production and price control, essential drugs availability has dropped drastically. Another irony in this story is that while today we export 45% of our drug production, we have to import a substantial amount of our essential drug requirements.

- Most public sector hospitals are located in urban areas. In the eighties, post-Alma Ata and India ratifying the ICESCR, efforts were made towards increasing hospitals in rural areas through the Community Health Centres. This was again a good effort but these hospitals are understaffed by over 50% as far as doctors are concerned and hence become ineffective. Today urban areas do have adequate number of beds (including private) at a ratio of one bed per 300 persons but rural areas have 8 times less hospital beds as per required norms (assuming a norm of one bed per 500 persons). So there is gross discrimination based on residence in the way the hospital infrastructure has developed in the country, thereby depriving the rural population access to curative care services. Further, the declining investment in the public health sector since mid-eighties, and the consequent expansion of the private health sector, has further increased inequity in access for people across the country. More recently a facility survey across the country by the Ministry of Health and Family Welfare clearly highlights the inadequacies of the public health infrastructure, especially in the rural areas. This survey is a major indictment of the underdevelopment of the public healthcare system - even the District Hospitals, which are otherwise well endowed, have a major problem with adequacy of critical supplies needed to run the hospital. The rural health facilities across the board are ill provided. (MOHFW, 2001)

- Family planning services is another area of almost monopolistic public sector involvement. The investment in such services over the years has been very high, to the tune of over 15% of the total public health budget. But over and above this the use of the entire health infrastructure and other government machinery for fulfilling its goals must also be added to these resources expended. This program has also witnessed a lot of coercion and grossly violated human rights. The hard line adopted by the public health system, especially in rural areas, for pushing population control has terribly discredited the public health system and affected adversely utilization of other health programs. The only silver lining within this program is that in the nineties immunisation of children and

mothers saw a rapid growth, though as yet it is still quite distant from the universal coverage level.

Then there are the underlying conditions of health and access to factors that determine this, which are equally important in a rights perspective. Given the high level of poverty and even a lesser level of public sector participation in most of these factors the question of respecting, protecting and fulfilling by the state is quite remote. Latest data from NFHS-1998 tells the following story:

- Piped water is available to only 25% of the rural population and 75% of urban population.
- Half the urban population and three-fourths of the rural population does not purify/filter the water in any way.
- Flush and pit toilets are available to only 19% of the rural population as against 81% of those in towns and cities.
- Electricity for domestic use is accessible to 48% rural and 91% urban dwellers.
- For cooking fuel 73% of villagers still use wood. LPG and biogas is accessed by 48% urban households but only 6% rural households.
- As regards housing 41% village houses are *kachha* whereas only 9% of urban houses are so.
- 21% of the population chews *paan masaala* and/or tobacco, 16% smoke and 10% consume alcohol.

Besides this, environmental health conditions in both rural and urban areas are quite poor, working conditions in most work situations, including many organized sector units, which are governed by various social security provisions, are unhealthy and unsafe. In fact most of the court cases in India using Article 21 of the Fundamental Rights and relating it to right to health have been cases dealing with working conditions at the workplace, workers rights to healthcare and environmental health related to pollution.

Other concerns are related to the question of economic accessibility. It is astounding that large-scale poverty and predominance of private sector in healthcare have to co-exist. It is in a sense a contradiction and reflects the State's failure to respect, protect and fulfill its obligations by letting vast inequities in access to healthcare and vast disparities in health indicators, to continue to persist, and in many situations get worse. Data shows that out of pocket expenses account for over 4% of the GDP as against only 0.9 % of GDP expended by state agencies, and the poorer classes contribute a disproportionately higher amount of their incomes to access health care services both in the private sector and public sector. (Ellis et al, 2000; Duggal, 2000; Peters et al, 2002). Further, the better off classes use public hospitals in much larger numbers with their hospitalization rate being six times higher than the poorest classes, and as a consequence consume an estimated over three times more of public hospital resources than the poor (NSS-1996; Peters et al, 2002).

Related to the above is another concern vis-à-vis international human rights conventions' stance on matters with regard to provision of services. All conventions talk about *affordability* and never mention

'free of charge'. In the context of poverty this notion is questionable as far as provisions for social security like health, education and housing go. Access to these factors socially has unequivocal consequences for equity, even in the absence of income equity. Free services are viewed negatively in global debate, especially since we have had a unipolar world, because it is deemed to be disrespect to individual responsibility with regard to their healthcare. (Toebes, 1998, p.249) For instance in India there is great pressure on public health systems to introduce or enhance user fees, especially from international donors, because they believe this will enhance responsibility of the public health system and make it more efficient (Peters et al, 2002). In many states such a policy has been adopted in India and immediately adverse impacts are seen, the most prominent being decline in utilization of public services by the poorest. It must be kept in mind that India's taxation policy favours the richer classes. Our tax base is largely indirect taxes, which is a regressive form of generating revenues. Direct tax revenues, like income tax is a very small proportion of total tax revenues. Hence the poor end up paying a larger proportion of their income as tax in the form of sales tax, excise duties etc on goods and services they consume. Viewed from this perspective the poor have already pre-paid for receiving public goods like health and education from the state free of cost at the point of provision. So their burden of inequity increases substantially if they have to pay for such services when accessing from the public domain.

The above inequity in access gets reflected in health outcomes, which reflect strong class gradients. Thus infant and child mortality, malnutrition amongst women and children, prevalence of communicable diseases like tuberculosis and malaria, attended childbirth are between 2 to 4 times better amongst the better off groups as compared to the poorest groups (NFHS-1998). In this quagmire of poverty, the gender disparities also exist but they are significantly smaller than the class inequities. Such disparity, and the consequent failure to protect by the state the health of its population, is a damning statement on the health situation of the country. In India there is an additional dimension to this inequity – differences in health outcomes and access by social groups, specifically the scheduled castes and scheduled tribes. Data shows that these two groups are worse off on all counts when compared to others. Thus in access to hospital care as per NSS-1996 data the STs had 12 times less access in rural areas and 27 times less in urban areas as compared to others; for SCs the disparity was 4 and 9 times, in rural and urban areas, respectively. What is astonishing is that the situation for these groups is worse in urban areas where overall physical access is reasonably good. Their health outcomes are adverse by 1.5 times that of others (NFHS-1998).

Another stumbling block in meeting state obligations is information access. While data on public health services, with all its limitations, is available, data on the private sector is conspicuous by its absence. The private sector, for instance does not meet its obligations to supply data on notifiable, mostly communicable,

diseases, which is mandated by law. This adversely affects the epidemiological database for those diseases and hence affects public health practice and monitoring drastically. Similarly the local authorities have miserably failed to register and record private health institutions and practitioners. This is an extremely important concern because all the data quoted about the private sector is an under-estimate as occasional studies have shown. The situation with regard to practitioners is equally bad. The medical councils of all systems of medicine are statutory bodies but their performance leaves much to be desired. The recording of their own members is not up to the mark, and worse still since they have been unable to regulate medical practice there are a large number of unqualified and untrained persons practicing medicine across the length and breadth of the country. Estimates of this unqualified group vary from 50% to 100% of the proportion of the qualified practitioners (Duggal, 2000; Rhode et al, 1994). The profession itself is least concerned about the importance of such information and hence does not make any significant efforts to address this issue. This poverty of information is definitely a rights issue even within the current constitutional context as lack of such information could jeopardize right to life.

Finally there are issues pertaining to acceptability and quality. Here the Indian state fails totally. There is a clear rural-urban dichotomy in health policy and provision of care; urban areas have been provided comprehensive healthcare services through public hospitals and dispensaries and now even a strengthened preventive input through health posts for those residing in slums. In contrast rural areas have largely been provided preventive and promotive healthcare alone. This violates the principle of non-discrimination and equity and hence is a major ethical concern to be addressed.

Medical practice, especially private, suffers from a complete absence of ethics. The medical associations have as yet not paid heed to this issue at all and over the years malpractices within medical practice have gone from bad to worse. In this malpractice game the pharmaceutical industry is a major contributor as it induces doctors and hospitals to prescribe irrational and/or unnecessary drugs. All this has drastic impacts on quality of care. In clinical practice and hospital care in India there exist no standard protocols and hence monitoring quality becomes very difficult. For hospitals the Bureau of Indian Standards have developed guidelines, and often public hospitals do follow these guidelines (BIS, 1989; Nandraj and Duggal, 1997). But in the case of private hospitals they are generally ignored. Recently efforts at developing accreditation systems has been started in Mumbai (Nandraj et al, 2000), and on the basis of that the Central government is considering doing something at the national level on this front so that it can promote quality of care.

First Steps Towards a Right to Healthcare:

To establish a right to healthcare with the above scenario certain first essential steps will be compulsory:

- equating directive principles with fundamental rights through a constitutional amendment;
- incorporating a National Health Act (similar to the Canada Health Act) which will organize the present

healthcare system under a common umbrella organization as a public-private mix governed by an autonomous national health authority which will also be responsible for bringing together all resources under a single-payer mechanism;

- generating a political commitment through consensus building on right to healthcare in civil society;
- development of a strategy for pooling all financial resources deployed in the health sector; and
- redistribution of existing health resources, public and private, on the basis of standard norms (these would have to be specified) to assure physical (location) equity

As an immediate step, within its own domain, the State should undertake to accomplish the following:

- Allocation of health budgets as block funding, that is on a per capita basis for each population unit of entitlement as per existing norms. This will create redistribution of current expenditures and reduce substantially inequities based on residence. Local governments should be given the autonomy to use these resources as per local needs but within a broadly defined policy framework of public health goals.
- Strictly implementing the policy of compulsory public service by medical graduates from public medical schools, as also make public service of a limited duration mandatory before seeking admission for post-graduate education. This will increase human resources with the public health system substantially and will have a dramatic impact on the improvement of the credibility of public health services.
- Essential drugs as per the WHO list should be brought back under price control (90% of them are off-patent) and/or volumes needed for domestic consumption must be compulsorily produced so that availability of such drugs is assured at affordable prices and within the public health system.
- Local governments must adopt location policies for setting up of hospitals and clinics as per standard acceptable ratios, for instance one hospital bed per 500 population and one general practitioner per 1000 persons. To restrict unnecessary concentration of such resources in areas fiscal measures to discourage such concentration should be instituted.
- The medical councils must be made accountable to assure that only licensed doctors are practicing what they are trained for. Such monitoring is the core responsibility of the council by law which they are not fulfilling, and as a consequence failing to protect the patients who seek care from unqualified and untrained doctors. Further continuing medical education must be implemented strictly by the various medical councils and licenses should not be renewed (as per existing law) if the required hours and certification is not accomplished.

- Integrate ESIS, CGHS and other such employee based health schemes with the general public health system so that discrimination based on employment status is removed and such integration will help more efficient use of resources. For instance, ESIS is a cash rich organization sitting on funds collected from employees (which are parked in debentures and

shares of companies!), and their hospitals and dispensaries are grossly under-utilised. The latter could be made open to the general public.

- Strictly regulate the private health sector as per existing laws, but also an effort to make changes in these laws to make them more effective. This will contribute towards improvement of quality of care in the private sector as well as create some accountability.
- Strengthen the health information system and database to facilitate better planning as well as audit and accountability.

Carrying out the above immediate steps, for which we need only political commitment and not any radical transformation, will create the basis to move in the direction of first essential steps indicated above. In order to implement the first-steps the essential core contents of healthcare have to be defined and made legally binding through the processes of the first-steps. The literature and debate on the core contents is quite vast and from that we will attempt to draw out the core content of right to health and healthcare keeping the Indian context discussed above in mind.

The Core Content of Right to Healthcare

In the words of Chapman: "*Operatively, a basic and adequate standard of healthcare is the minimum level of care, the core entitlement, that should be guaranteed to all members of society: it is the floor below which no one will fall*" (Chapman, 1993). She further states that the basic package should be fairly generous so that it is widely acceptable by people, it should address special needs of special and vulnerable population groups like under privileged sections (e.g. scheduled castes and tribes in India), women, physically and mentally challenged, elderly etc it should be based on cost-conscious standards but judge to provide services should not be determined by budgetary constraints, and it should be accountable to the community as also demand the latter's participation and involvement in monitoring and supporting it. All this is very familiar terrain, with the Bhole Committee saying precisely the same things way back in 1946.

We would like to put forth the **core content** as the Primary care services that should include at least the following:

- General practitioner/family physician services for personal health care.
- First level referral hospital care and basic specialty services (general medicine, general surgery, obstetrics and gynecology, paediatrics and orthopaedic), including dental and ophthalmic services.
- Immunisation services against all vaccine preventable diseases.
- Maternity and reproductive health services for safe pregnancy, safe abortion, delivery and postnatal care and safe contraception.
- Pharmaceutical services - supply of only rational and essential drugs as per accepted standards.
- Epidemiological services including laboratory services, surveillance and control of major diseases with the aid of continuous surveys, information management and public health measures.

- Ambulance services.
- Health education.
- Rehabilitation services for the physically and mentally challenged and the elderly and other vulnerable groups.
- Occupational health services with a clear liability on the employer.
- Safe and assured drinking water and sanitation facilities, minimum standards in environmental health and protection from hunger to fulfill obligations of underlying preconditions of health.

The above listed components of primary care are the minimum that must be assured, if a universal health care system has to be effective and acceptable. And these have to be within the context of first-steps and not to wait for progressive realisation – these cannot be broken up into stages, as they are the core minimum. The key to equity is the existence of a minimum decent level of provision, a floor that has to be firmly established. However, if this floor has to be stable certain ceilings will have to be maintained toughly, especially on urban health care budgets and hospital use (Abel-Smith, 1977). This is important because human needs and demands can be excessive and irrational. Those wanting services beyond the established floor levels will have to seek it outside the system and/or at their own cost.

Therefore it is essential to specify adequate minimum standards of health care facilities, which should be made available to all people irrespective of their social, geographical and financial position. There has been some amount of debate on standards of personnel requirements [doctor: population ratio, doctor: nurse ratio] and of facility levels [bed: population ratio, PHC: population ratio] but no global standards have as yet been formulated though some ratios are popularly used, like one bed per 500 population, one doctor per 1000 persons, 3 nurses per doctor, health expenditure to the tune of 5% of GDP etc.

We are at a stage in history where political will to do something progressive is conspicuous by its absence. We may have constitutional commitments and backing of international law but without political will nothing will happen. To reach the goals of right to health and healthcare discussed above civil society will have to be involved in a very large way and in different ways.

The initiative to bring healthcare on the political agenda will have to be a multi-pronged one and fought on different levels. The idea here is not to develop a plan of action but to indicate the various steps and involvements that will be needed to build a consensus and struggle for right to healthcare. We make the following suggestions:

- Policy level advocacy for creation of an organized system for universal healthcare
- Research to develop the detailed framework of the organized system
- Lobbying with the medical profession to build support for universal healthcare and regulation of medical practice
- Filing a public interest litigation on right to healthcare to create a basis for constitutional amendment

- Lobbying with parliamentarians to demand justice be protected in directive principles
- Holding national and regional consultations on right to healthcare with involvement of a wide array of civil society groups
- Running campaigns on right to healthcare with networks of peoples organizations at the national and regional level
- Bringing right to healthcare on the agenda of political parties to incorporate it in their manifestoes
- Pressurizing international bodies like WHO, Committee of ESCR, UNCHR, as well as national bodies like NHRC, NCW to do effective monitoring of India's state obligations and demand accountability
- Preparing and circulating widely shadow reports on right to healthcare to create international pressure

The above is not an exhaustive list. The basic idea is that there should be widespread dialogue, awareness raising, research, documentation and legal/constitutional discourse. CEHAT has developed an action plan towards facilitating the realization of this agenda collaboratively with a range of civil society actors through a national initiative on right to health and healthcare in India.

Overview

It is evident that the neglect of the public health system is an issue larger than government policy making. The latter is the function of the overall political economy. Under capitalism only a well-developed welfare state can meet the basic needs of its population. Given the backwardness of India the demand of public resources for the productive sectors of the economy (which directly benefit capital accumulation) is more urgent (from the business perspective) than the social sectors, hence the latter get only a residual attention by the state. The policy route to comprehensive and universal healthcare has failed miserably. It is now time to change gears towards a rights-based approach. The opportunity exists in the form of constitutional provisions and discourse, international laws to which India is a party, and the potential of mobilizing civil society and creating a socio-political consensus on right to healthcare. USIBC President Ron Somers said: "Access to effective and affordable healthcare is essential to ensure India's remarkable growth," while announcing the initiative of the body representing over 250 of the largest US firms investing in India and about 25 of India's largest global companies.

Government is only part of the solution. We must harness the dynamism of the private sector for this effort to be successful. The goal is to make patient outcomes as good in India as they are in any other part of the world. India's healthcare system is quickly expanding, but faces considerable challenges – to be expected in a country rapidly transitioning into a global economic power. It must satisfy the rising demands and expectations of the burgeoning middle class, while addressing the needs of those not benefiting from economic development. Nevertheless, India has an opportunity to avoid the problems that healthcare

systems in many developed countries are experiencing by transforming financing and delivery, redefining the accountabilities of stakeholders, and improving quality and access.

India has had notable health achievements since Independence in 1947. The country's population has increased from 361 million 1951 to 1.13 billion in 2007 (a 313 percent increase). Life expectancy has more than doubled (32 years to 68.6), infant mortality rate has decreased 76.3 percent (146 per 1000 babies to 34.6) and crude death rate has fallen 73.7 percent (25.1 per 1000 population to 6.6).

Other achievements include eradication of some diseases (small pox and guinea worm) and near elimination of others (for example, leprosy and polio).

India's doctors and hospitals are also increasingly receiving recognition for the quality of care they provide. Their services cost a fraction of those of their India's burgeoning middle class has greater access to excellent healthcare, but the vast majority of citizens have limited access to basic healthcare of varying quality. While government health services are by law free, patients must often pay for drugs out-of-pocket to get sustained treatment. More than 40 percent of hospitalized patients borrow money or sell assets for medical care and 24 percent become impoverished due to medical crises.

An examination of healthcare systems in other countries underscores the importance of achieving a value-based, affordable, sustainable healthcare system in India. In a recent study by the IBM Institute for Business Value demonstrated that unrelenting pressures are pushing many healthcare systems along an unsustainable path. If left unaddressed, many countries will reach a breakpoint in their current paths, forcing immediate and major forced restructuring. What does this mean for India? Without significant changes, an unsustainable path for India could have public health, economic, social and political ramifications. For example, the healthcare infrastructure will remain fragmented, focused on acute, reactive, episodic care and will be inaccessible, particularly in rural areas. There is also the potential impact on premature morbidity/mortality due to unaffordable, inaccessible and inconsistent quality of healthcare. And the IBM Global Business Services insufficient healthcare delivery capacity would exacerbated, as providers are burdened by such issues as workforce shortages, costs of treating the uninsured and overcrowding. There are other ramifications of the *status quo*. Economically, continued depletion in the quality and quantity of general work force and lead to lower national output in national income. Between 2005 and 2015, for example, heart disease, stroke and diabetes are expected to account for Rs 1,040,800 crores (US\$ 236 billion) in lost productivity. Socially, there would likely be a reduced transfer of skills and wealth across generations and continued developmental losses for children. Politically, India could fail to deliver healthcare as a fundamental public right for all citizens. Moreover, there would be a possible loss of global competitiveness as the country's health status is unable to effectively support its ambitious economic growth plans.

Conclusion

Everyone born in the world should live a full human life. To make this possible, a health care system and hygienic environment and effective livelihood need to be assured for all citizens. In the world today medical advancement is progressing very fast and the quality of life is on the increase, thereby making people live longer and longer. While the medical advancement in the industrialized countries is making progress the availability of medical facilities in many developing countries are abysmal. It is the responsibility of the State to provide with adequate health care especially for the children who are the future hope of the nation and the globe.

In the first place the people, especially those in the rural areas, should be given awareness with regard to health care especially preventive measures to be taken to avoid infection and diseases. Health cares should be not only accessible but affordable – The State should come to the rescue of the poor in providing effective health care system. Primary care centers should be given priority and in State run medical centers all facilities should be extended without any difficulty – Strict laws should be enforced against corruption in providing medical aids and negligence of duty in emergency.

The neighbourhood outreach programme could be introduced in educational institutions especially in medical institutions where the students spend considerable time with the poor, in the slums in cities and rural areas, teaching them hygiene and helping them have health care facilities. The medical students could be asked to spend a couple of years of their service in the rural areas.

Also traditional medicine, such as herbal, Ayurvedic, Sidha etc, could be encouraged by the State which could give effective medical facilities at much lower cost of care. The State should make it clear that the people are the wealth of the nation and health is the first concern as well as area of investment for any nation.

Do the Developing Countries with High Disease Burdens Need to Take a More Active Role in Defining Health and Disease?

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Do developing countries with high disease burden need to take a more active role in developing, or adhering to, a conceptualization of health and disease that is more relevant for them? This paper argues that there are number of reasons to make a rather compelling case to answer in the affirmative.

First, the facts. There can be no doubt that great health disparities still persist among the countries in the world. In spite of great advances in medical technology, medicine, and treatment, and high-spirited initiatives such as Alma Ata (1978), the disparities in health status remain stark between the populations of the developed countries and the developing countries in particular. To date, the poorer countries, as a matter of fact, see more of death, disease and disability.

The WHO fact sheets show that the developing countries in Africa and Asia bear a disproportionately high disease burden from an array of major fatal communicable and endemic diseases. For example, though incidences fell in certain countries, WHO reports that in 2008 Malaria is endemic in 109 countries and *preventable* deaths from Malaria is close to a million lives, with mostly that of children under 5, in Africa³². The 1.2 billion people who are at high risk from Malaria are mostly living in the developing nations of Africa (49%) and Southeast Asia (37%). Similarly, the WHO tuberculosis (TB) 2009 report³³ mentions twenty-two high-burden countries, covering 80% of world's TB cases, which almost without exception belong to the developing world. The report also mentions that the co-infection of HIV-TB and the drug-resistant variety of TB in some of these countries are matters of great concern, as one out of four TB deaths in 2007 was HIV-related. Since the burden of non-communicable diseases was found to be no less on the developing

³² WHO. World Malaria Report 2008. Geneva: WHO. Available at: <http://apps.who.int/malaria/wmr2008/> [Accessed on 29 May 2009].

³³ WHO. Key Points: Global TB Control 2009. Geneva: WHO. Available at: www.who.int/tb/publications/global_report/2009/key_points/

countries, WHO has named the burden of the developing countries the 'double burden'³⁴ of diseases.

Although the recent global outbreaks such as the 2009 global spread of *A H1N1* flu showed that the risk from a global pandemic is a great leveler for the countries across the globe, epidemiological models predict that the impact may be more severe for countries with weaker health systems. In case of an influenza pandemic analogous to that of 1918, it is claimed that the maximum loss of life would occur in two developing regions: Sub-Saharan Africa and South Asia³⁵, two of the world's poorest regions with weakest health systems. The risk disparity is underscored by the fact that the lower income countries with high-disease burdens usually have weak public health infrastructure, poor and inefficient healthcare delivery services, whereas most developed countries have highly sophisticated health systems equipped much better to provide specialized care and protection from bio-risk.

If we consider these key differences among the developed and developing countries in health and disease status, and in the capability of the health systems, consequently in the health needs, a question rises whether given their own contexts the lower income countries should become more involved in articulating how they want to conceptualize 'health' and 'disease'. The question is both timely and pertinent. For, health sector reforms and health policy formulation have been and are at present on the agenda of many developing countries. Though some studies³⁶ regard them as being driven and directed primarily by the conditions laid down by the World Bank credits, the efforts at health sector reforms are likely to affect positively the provision, financing, human resources, and overall healthcare management. India, for instance, is in the process of making some major changes in the health sector. In 2005 the National Rural Health Mission was launched by Government of India to provide accessible, affordable, and quality health services to even the poorest in remotest rural regions by directing increased government financing to the state public health systems. The latest review (2008) of the Mission finds that, among other things, there has been a general improvement in the utilization of public health services³⁷. The Ministry of Health and Family Welfare, India, has also initiated a National Bill on 'Right to Health'³⁸ which is at present at the drafting

stage but when passed would arguably confer on every citizen an entitlement to health and healthcare. Apparently China also has launched health-sector reform plans³⁹. Similar efforts are on in different stages of development in many of the African countries, such as Nigeria, Zambia. Thus, at this stage bioethical deliberations among the developing countries on the nodal concepts of 'health' and 'disease' will be of constructive assistance.

It is a question of ethics also; for, a definition of health, even an operational one, is necessary as a guiding principle for the health sector reforms. Similarly, we need a definition of 'disease'. Definitions of these key concepts shape the vision on which public health policy may be formulated and public health system may be organized. The implications of the definitions cover, among other things, the conditions under which budgetary increments will be allocated to healthcare resources and services, how the healthcare priorities are to be set nationally in terms of research and intervention programs, and who will be treated in need of care and who will not be.

However, like many other abstract concepts, e.g. 'peace', 'welfare', the concepts of 'health' and 'disease' too have many available definitions. The panoply of various definitions of health could be appreciated from the following observation of Hood et al:

*"...health is difficult to define. Health is described in various sources as a value judgment, a subjective state, a relative concept, a spectrum, a cycle, a process, an abstraction that cannot be measured objectively. In many definitions, physiologic and psychological components of health are dichotomized. Other sub-concepts that might be included in definitions of health include environmental and social influences, freedom from pain or disease, optimum capability, ability to adapt, purposeful direction and meaning in life, and sense of well-being."*⁴⁰

As for 'disease', at least two approaches, a normative or evaluative one advocated by Engelhardt Jr⁴¹ and an objective or value-neutral one offered by Boorse⁴², are well-established in the literature.

This indicates, among other things, that the concepts are open to interpretation. It also suggests that the differences in the available definitions of these concepts, like in case of other definitions, largely reflect the differences in the social and political milieu from which they emerged and in the interests that have driven them. For example, preoccupied traditionally with the task of prevention and medical solution of the problem of diseases and disease-causing agents ('germs'), the *clinical* or the *medical* model naturally found health in the simple dichotomy as 'the absence of

³⁴ WHO. Surveillance of noncommunicable disease risk factors Available at:

<http://www.who.int/mediacentre/factsheets/fs273/en/e>

³⁵ C.J.L. Murray, A.D. Lopez, B.Chin, D.Feehand, K.H.Hill. Estimation of Potential Global Pandemic Influenza Mortality on the basis of Vital Registry Data from 1918-20 Pandemic: A Quantitative Analysis. *Lancet* 2006; 368: 2211-2218.

³⁶ Shiner, A. Shaping Healthcare in Tanzania-Who is pulling the strings? *Lancet* 2003; 362:829-830.

³⁷ Ministry of Health and Family Welfare, Government of India. 2008. *Second Common Review Mission*. National Rural Health Mission. New Delhi, India: Govt of India. Available at: <http://www.mohfw.nic.in/NRHM.htm> [Accessed on: 25 May 2009]

³⁸ Ministry of Health and Family Welfare, Government of India. The National Health Bill. 2008. Available at: http://mohfw.nic.in/nrhm/draft_bill.htm

³⁹ Chen, Z. Launch of the Healthcare Reform Plan in China. *Lancet* 2009; 373 (9672): 1322-1324.

⁴⁰ Hood, Lucy, J. Susan Leddy, J.Mae Pepper. 2005. *Leddy and Pepper's Conceptual Bases Of Professional Nursing*. 6th Ed. Lippincott Williams and Wilkins, 203-204.

⁴¹ Engelhardt, Tristram, Jr. The Disease of Masturbation: Values and the Concept of Disease. *Bulletin of the History of Medicine*, 1974; 48 (2): 243-248.

⁴² Boorse, C. On the Distinction between Disease and Illness. *Philosophy and Public Affairs* 1975; 5 (1): 49-68.

disease'. The straightforward but narrow focus of this definition obviously misses out the social, environmental, the genomics, and other determinants of health, but it remains true to its point of interest: To define undesired, treatable conditions as disease, and to restore health by eradicating disease. The ecologically dedicated *environmental model* of health, similarly, depicts health as the state of equilibrium or adjustment between human and natural environment. Obviously, there can possibly be different interpretations of what counts as 'equilibrium' or what are the necessary conditions for such 'adjustment'; but the model is able to draw our attention to the place of humans as just another member in a larger ecosystem. The WHO, on the other hand, because of its commitment to positive health, and not merely to 'absence of disease', has tried to define health as holistically as possible: as *a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity*⁴³. This highly idealized and too wide a definition has been criticized by many. However, it has accomplished its goal of including many *well-being needs* under *healthcare needs*. As Beauchamp and Walters put it, 'The broader the conception of health, the broader the potential list of needs'.⁴⁴ Boddington and Raisanen⁴⁵ claim that there is also a political dimension to this widening of the definition in the post-world war days. They argue that health as a human right requires a huge commitment of resources, and with the broadness in the definition using a larger context, the resources could come, not just from standard health care, but from many different social, economic and political sectors. The Alma Ata (1978) declaration pronounces a similar holistic definition of health as a 'world-wide social goal'. Similarly, the concept of 'disease' also is interpretable. From the viewpoint of healthcare professionals, it may be a pathological condition, a deviation from normal functioning; while some may interpret it as a deviation from socially expected roles or from social etiquettes.

Given that contextual interpretations and interests shape definitions, it may be more fruitful if the developing countries, specially the ones with high disease burdens, draw from their own contexts to enrich the international deliberations with inputs about which conceptualizations of 'health' and 'disease' would be more suitable for them. These inputs could also help us to understand developing world bioethical issues better. We generally assume that we as a society are obligated to promotion of health and protection from disease and disability; and expect that governments as important machineries would translate this collective will into action. From the perspective of developing world bioethics, it would be interesting to find out how exactly

the high burden developing countries would own and justify this obligation.

Lately, in the developed countries, there have been many theoretical discussions on health, healthcare, and macro-allocation and micro-allocation issues in health policies at different levels. There are debates about how to ground the social obligation towards health on a sound ethical theory. Many consider it purely a matter of social justice. Drawing from Rawls' theory of justice, Daniels, for example, has chosen to view health as 'normal functioning' or '...absence of ...deviation from the natural functional organization of a typical member of a species'⁴⁶ to argue that health is of *special moral importance* because of its connection to social justice. He argues that health, when understood in the abovementioned sense becomes the precondition for enjoying the 'normal opportunity range' (NOR) or the total range of reasonable life-plans in a given society that the society's members with relevant skills and competence can pursue⁴⁷. A just society should have an obligation to protect the individual fair share of NOR, i.e. 'the set of plans of life a person functioning normally could pursue, given her talents and skills (developed under just conditions)'⁴⁸. Thus, Daniels contends, a just society should have an obligation to protect the health of its members.

In a similar line but focusing more on the social obligation to remove health disparities within a society, Anand *et al*⁴⁹ has brought out the equity aspect of social commitment in public health. Extending Sen's *capability approach*⁵⁰ to human development, Nussbaum⁵¹ too has understood human development in terms of development of not just the GNP but of ten basic human capabilities, which includes bodily health. In contrast to these theories in which health has been promoted as *instrumental* for making other important life-choices, WHO, however, has claimed health as an *end*, or a human value in itself, in its declaration of health as a human right.

These efforts are indeed valuable, but these are yet to take place in the developing countries. This invites the question whether the developing countries should simply 'borrow' the thoughts. Is it necessary for them to do so? It appears that there may be practical and conceptual difficulties in assuming so, and we do not just mean the operational problem of implementing a typical western concept and a western approach in a non-western culture, though with the example of Australian aboriginals Boddington and Raisanen have argued that ideas of health and disease may vary in different cultural contexts and the notion of importing an

⁴³ WHO, 1947. Available at: <http://www.who.int/about/definition/en/print.html>

⁴⁴ Beauchamp, T.L. & L.Walters. Eds. Contemporary Issues in Bioethics. 3rd Ed. Belmont, CA: Wadsworth Publishing Co, 73.

⁴⁵ Boddington P & U.Raisanen. Theoretical and Practical Issues in the Definition of Health: Insights from Aboriginal Australia. *Journal of Medicine and Philosophy* 2009; 34: 49-67.

⁴⁶ N.Daniels. 2008. *Just Health: Meeting Health Needs Fairly*. New York: Cambridge University Press, p.37.

⁴⁷ *Ibid.* p.36.

⁴⁸ *Ibid.*, p.37.

⁴⁹ S. Anand, F.Peter, and A.Sen. Eds. 2004. *Public Health, Ethics and Equity*. New York: Oxford University Press.

⁵⁰ Sen, A. 1985. *Commodities and Capabilities*. Oxford: Oxford University Press.

⁵¹ Nussbaum, Martha C. 2000. *Women and Human Development: The Capabilities Approach*. Cambridge University Press, Cambridge.

external idea sits uneasily on a community⁵². We think that the systemic differences between the two kinds of societies are large enough to be skeptical about supposing what a developed society finds suitable as a pursuable notion of health and acceptable notion of disease would naturally be appropriate for a less developed one also.

For instance, consider Daniel's version of 'health' as a precondition for protection of 'normal opportunity range' (NOR) that an individual may enjoy in a society. This depiction, however, seems to presume that an exercisable NOR, or a set of life-choice plans, exists (should exist) for every individual member in any given society. Perhaps that presumption is correct in most developed societies. But, how safe is that assumption in case of hugely populated developing countries, where the available basic NORs can not exist for every individual because necessarily there are more takers, with relevant skill and talent, than opportunities? Most individuals in many such societies simply do not have the luxury to exert individual choices over life-plans, or over the career path, that they *want* to pursue. Instead, they follow just whatever opportunity by 'natural lottery and social lottery' becomes available. And, with that decision usually there is very little connection to the considerations of the state of 'natural functional organization' of one's bodily system. It is a survivability issue.

Daniels' theory appears to rely upon a 'decent minimum' threshold of just distribution of Rawlsian primary opportunities and liberties in a society as a prerequisite. Based on that, he views health as a necessary condition for living a chosen life in that society. However, in many developing countries, for a variety of reasons it may not be possible to socially guarantee that minimal threshold for everyone. There, the onus often is largely on the individual to ensure that welfare remains above a certain threshold at all times. Since the applicability of the pivotal concept of individual's fair share of NORs is doubtful, the grounding of Daniel's approach within the context of developing countries becomes questionable. Though Daniels has claimed his theory is globally applicable, the process of its real-world applications remains largely unclear.

This is *not* to argue that developing countries must never follow the precepts from the developed nations. Rather, the point is that it is not safe to assume that they must always blindly do so.

So, how should the high burden countries proceed? One initial suggestion may be that, as has been already discussed above, diseases and disabilities, more than health, seem to be relatively weightier considerations for these countries. At least given the fact of large number of lives lost in these countries because of preventable, treatable diseases, perhaps they should start first with how they would like to approach the concept of 'disease' and may consider making 'absence of disease' a more ethical and pragmatic priority in their health policies. 'Health' may follow as a subsequent goal.

This may sound to some as just verbal jugglery; they might ask, what is 'absence of disease' if not health? In

response, let us remind ourselves that 'absence of disease', except for medical model, is not health. A person who is generally dissatisfied with life and therefore cannot keep up his performance at job does not have to have a disease, but may not be healthy either. Someone who has only one kidney has absence of health but need not be considered diseased. An aged person may not be in health, but need not be diseased. In fact, the concepts of 'health' and 'disease' need not be mutually exhaustive. Hoffman, for example, has interestingly suggested a *disjunctive model* in which 'health' and 'disease' are opposite but partly disparate concepts with 'epistemological, taxonomical, etymological, axiological and practical differences'⁵³ between them. Explorations are necessary to find out what would suit the developing world health policies and action plans better.

Finally, one might object that if all the countries, developed and developing, do not commit themselves to a universal and common understanding of 'health' and 'disease', then particularly the developing countries with high disease burdens may suffer. For, they then would disassociate themselves from the purview of the universal discussions, such as health as a human right, and that of universal policies, such as increased financing in the health sector to ensure global health security. To this, the response could be that this is *not* a proposal for high burden countries to delink themselves from the international discourse on health and disease. Rather, this is to urge them to carve their own niche within the discourse. Also, for many developing countries engaging themselves in the task of defining, or choosing a definition of, crucial concepts such as 'health' and 'disease' for themselves could augur the beginning of a realization about accepting the larger responsibility of health and healthcare for their general populace. The possibility always remains that health reform efforts, when done purely under external pressure, be it the compulsion of complying to the conditions laid down by increased international finances, or pressure from international bodies and grassroots NGOs, may not be sustainable in the long run. As such the distance between having effect on the policies and having effect in actions is long; imposition of concepts could make it more difficult to traverse that distance.

Darwinism and Humans

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Recently, in August 2008 we have celebrated 150th anniversary of publication of the Darwinian Principle of Natural Selection. 2009 is the year for celebrating the 200th birth anniversary of Charles Darwin. Darwinism is for the life system on the Earth. It has relevance to

⁵² Boddington, P., & U.Raisanen, op.cit., note 14, pp.62-63.

⁵³ Hoffman, B. Simplified Models of the Relationship between Health and Disease. *Theoretical Medicine and Bioethics* 2005; 26: 369.

human problems as well. In this communication an effort is being made to make out this relevance to human civilization.

Sociobiology

Application of Darwinism to the organization and behaviour of social species, including the humans, is referred to as Sociobiology. Sometimes it is also called Social Darwinism. Sociobiology, when dealing with human problems and affairs, has to answer two questions, often asked, viz.

- (1) Whether humankind is still evolving?
- (2) What are human races, and if there is any basis for racial prejudices?

Whether humankind is still evolving?

By evolution we generally mean speciation, i.e. formation of new species. In that meaning humans are not evolving. During the past 150,000 years, no speciation has taken place; *Homo sapiens* has continued as a single species. The following two factors have been mainly responsible for no further speciation, viz.

- (1) Human technology,
- (2) Human's restlessly migratory habit.

Human technology allows us to invade different environments without evolving any bodily adaptations. Our technology allows us to live successfully in desert areas as well as in polar regions or tropical forests without undergoing any organic change in himself.

Humans have been migratory since their very beginning. Soon after their origin in East Africa, more than 80,000 years back, they moved out of Africa to the Middle East, and thence to the rest of the world. Thousands of years ago, when the modern means of transport were not available, Buddhism, after its Indian origin, could reach China and Japan. Islam after its foundation in the Middle East, spread to South East Asia, including Malaya and Indonesia. Christianity, also having its origin in the Middle East, swept through Europe and even reached the New World. Because of such migratory human tendency, allopatric populations were never formed, and as per the Natural Selection Theory, allopatry, among populations of a species, is necessary for further speciation.

In humans intraspecific evolutionary changes do occur. A good example of such evolutionary fluctuations is in Remmert's book on Ecology (1980): *"It is a regular feature of the leafing out of woods in spring that certain individual trees are ahead of the main group and others are far behind. In favourable years without late night frosts, the leaders are genetically at an advantage, because they have the opportunity for greater production. In years with late frosts they are in danger of producing nothing at all, for their buds and leaves are irreversibly damaged. The extreme individuals also represent genetic reservoirs upon which the species draws in adjusting to long term changes in climate. As the growing season shortens or lengthens over centuries, the population can respond without requiring a single (new) mutation."*

A number of examples of such intraspecific evolutionary fluctuations among humans may be cited.

Verma and Saxena (2000) have mentioned the following example: *"In 1960s the Time magazine conducted a survey of I.Q. among children born in a university campus, and noted that there was literally a burst of I.Q.. Several children were having I.Q. close to that of Newton. But this did not result in formation of a superintelligent human species, as the population in the university campus was not isolated from the rest of the US population."*

Some factors dampen such intraspecific evolutionary changes among humans. They include:

1. Egalitarianism, i.e. equal rights for all.
2. A fine and detailed distribution of labour in a human society, as a result almost every individual is able to find a suitable niche to serve and survive.
3. Medical help. For example, a child with proclivity to develop phenylketonuria, if this genetic tendency is detected early, may be kept on a diet free from the amino acid phenylalanine, and, therefore will not suffer from the disease. A myopic person may be prescribed suitable glasses for his spectacle, and will do well in the society.

Because of such factors a lot of variation has accumulated in the human populations. *Homo sapiens*, and their domestic animals and cultivated plants present much more variability than any other species.

Applying Darwin's Natural Selection concept to humans is a very complex task, and this had been in a way foreseen by Darwin, who, in his book *"Descent of Man"*, published in 1871, said, *"It must not be forgotten that although a high standard of morality gives but a slight advantage to each individual man and his children over other men of the same tribe.....an increase in the number of well-endowed men and an advancement in the standard of morality will certainly give an immense advantage to one tribe over another."*

Taking cue from the above opinion of Darwin, Wilson and Wilson (2007) have formulated a hypothesis about evolution among humans. They say that evolutionary changes in humankind are multilayered. Such changes occur both at the individual level as well as at the group level. The hypothesis further says that in a group or a society there are some individualist members and some altruistic ones. An individualist considers only his individual gains and not the social needs. He may take even to tortuous ways for personal benefit and ignore the social ethics. He may well provide his family and afford costly education for his children, who will inherit the traits from their parents, and theirs will be a prosperous family. Thus this family will be positively selected at the family level, but will contribute little to or even harm the social structure. An altruist will concentrate on social needs, will keep in view the laws of the land and the religious ethics, but may do not much for his family. In this family there will be, in comparative terms, a negative selection at the family level, but at the group or social level evolution theirs will be a positive contribution and selection. Thus both individualists and altruists have to face a "trade off". If in a society altruists dominate, this society will do better and will be more progressive than another society, in which individualists have dominance. A society with the

former constitution will be positively selected at the society/group level.

In the preceding paragraph inheritance by children in the family has been mentioned. It may be kept in view that among humans inheritance is not only genetic but also cultural, because of a long post-natal association with parents and the rest of the family, and an extra long period of psychological immaturity.

The hypothesis by Wilson and Wilson (loc. cit.) has been well supported by several computer generated models considering all the relevant factors.

Altruism is a need for a functional and healthy society not only among humans, but also among social insects. A number of bees, ants and wasps have in their workers' sting barbs, curved towards their body. When the workers, defending the colony, sting the attacker, the shaft of the sting cannot be pulled out from the flesh of the attacker, and, therefore, through autotomy, it is left there. The worker after the autotomy dies. The defending workers of a number of ant and termite species rupture their abdomens to release a sticky fluid to entangle the attacker. Tofilski et al. (2008) have described a regular and extreme case of altruism in a Brazilian ant species. At dusk some workers of this species close the mouth of their subterranean nest by kicking the loose earth, which has been arranged neatly in a mound near the mouth, when opening of the nest mouth is done in the morning. During the closure a number of workers take part, but, when the mouth is nearly closed, some get into the nest, and a few remain outside. The latter get killed during night. All this has been carefully recorded by videography by the authors.

After a long discussion on their hypothesis Wilson and Wilson (loc. cit.) put their inference in a 'nut shell' in the following words: "*Selfishness beats altruism within groups. Altruistic groups beat selfish groups. Everything else is commentary.*".

About human races and racial prejudices

Often we talk of races in humans. But 'race' has no taxonomic recognition. Several authors have used the term 'race' in place of the taxonomically recognized term 'subspecies'. Mayr and Ashlock (1991) have pointed out that geographical subspecies be named only when they differ "taxonomically, that is, by sufficient diagnostic morphological characters", and that the breeding ranges of the two subspecies of the same species do not overlap. Geographically varying human populations cannot be regarded as subspecies, because we cannot point out taxonomically significant and consistent differences among them, and also because their distributional/breeding areas broadly overlap. Oliviera and Ferreira (2004) have correctly pointed out that the racial concept is "imprecise" and "subjective". They have also said that through "extensive genetic studies of several human populations from different continents.....it was verified that the human diversity was higher inside the "racial" or geographic groups than among them".

In view of all this the human populations in different geographical areas be taken only as geographic variants, and we should shed our 'racial' prejudices.

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