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Editorial

Protection of Substantive Life: The Challenges of Medical Ethics

"Modern medicine has unprecedented power to heal human beings of physical and mental disease, to keep them healthy, and even to improve the human race. This power can be used to humanize life or to dehumanize and destroy it. It can be used justly to benefit all, or it can be used to benefit the few at the expense of many. How to use such power is a question of values, and therefore, of individual and group decisions that are not merely technical but ethical." (Ashley-O'Rourke)

State of the Problem

The term medical ethics was often associated with the discussion on the moral principles that regulates the individual relations of a doctor with his/her patients or concerning specific medical social issues such as abortion, euthanasia, or prolongation of life. This view is rather narrow.
The term ethics, among the various meaning systems that it assumes, denotes two fundamental orientations—first: an exploration to locate people’s vision of “ought to be” and a rational language to articulate the same. This investigation is informed by the accumulated wisdom of people, their cultures and traditions, faith imperatives they have gained through their encounter with the divine as well as the vision gained through their dialogue with the political and social ideologies. The earnest in which the communities reconstruct and rearticulate the meaning of history journeys through these objective encounters. The second fundamental orientation is that of a creation of moral behavioral patterns that facilitate the actualization of the “ought to be” as an empirical reality in history. These two processes, however, are dialectically interlinked; the praxis to actualize the ought to be sparks the ethical imagination to a new consciousness regarding the goal of history while this new array of teleological imperatives warrants a radical renewal of the moral behavioral patterns that communities and people accepted as normative.

In the case of medical ethics, it means that the ethical imagination stretches out to define and redefine the concept of health and healing in relation to the ever increasing capabilities of life. The emerging visions of life, however, entail the creation of newer practical means to objectify them in the service of rendering health and healing.

Health and Healing: Towards an Understanding

The prevailing theological discussion on health and healing often recounts that a biblical understanding of brokenness is an imperative to develop a perspective in this regard. Sickness is perceived in the Bible as a state of broken relationship with God. In the empirical situation of life it delineates the reality of estrangement between people and nature; implying that healing is an act of restoration of a right relationship with God, with fellow human beings and with
nature. In the gospel narratives, healing signifies a concrete manifestation of the redemptive act of Jesus and is proclaimed as a sign and anticipation of the eschatological breaking in of the Kingdom of God (Lk. 10:9). The work of redemption, however, involves the reordering of the social structures and forces that encourage the alienation of life from its ‘original source’. It implies that healing does not mean merely the normalization of the function of a particular organ but the sanctification of life by rediscovering its authenticity and quality as created in the likeness of God. Alienation from the nexus of God – people-nature is the root of the crisis and therefore restoration of this nexus is the true act of healing.

The World Health Organization’s description of health is not radically different from the theological arguments. In its constitution, WHO defines health as “a state of complete physical, mental and social well-being.” Health care then means establishing programs towards the recovery of wellbeing. The creation of a social environment to provide social goods for people and nature is thus an essential factor that contributes directly to the total health of the people.

These definitions suggest that any evaluation of medical ethics should enquire how the practice of present health care contributes towards the restoration of the total health by reversing the process of alienation between people, nature and God.

However, the prevalent discourse in Christian ethics depicts the very practice of health care as essentially a moral act.

**Claim of Medicine as a Moral Act**

Commoditization of health care is a rather new phenomenon. Before the market mediated system of medicine, health care was considered as both a spiritual engagement and a moral act. Owing to Emmanuel Kant’s categorical imperative that “a person should treat the other as an end and not as a means to achieve one’s end,” the medical profession affixes the
concept of subsumption to the “other” as a normative structure of the relationship in the medical profession. The act of subsumption for the well-being of the other (patient) qualifies health care as essentially a moral act. A strong proponent of this view was Paul Ramsey. According to him, “medicine embodies in a particular intense form our general moral commitment to one another”.

For Ramsey, the relationship of loyalty between a medical professional and the patient represents the embodiment of a moral principle. Ramsey’s argument stems from the notion of Hippocrates, that a professional is bound to respect the autonomy of the patient. The autonomy leads to a “cannon of loyalty,” leading to a new pattern of covenant relationships in society. In the covenant relationship between the patient and medical professional, trust is built not only on the knowledge and skills of the medical professional, but also on the commonly shared moral convictions which the professionals represent. Instead of the model of a social contract, which the market society is familiar with, a moral imperative of medicine leads society to a covenant relationship of trust.

While supporting the established assumption that medicine is a moral act, Stanley Hauerwas argues that the dilemma involved in the profession of medicine makes it moral. For Hauerwas, medicine is guided by certain convictions that sustain the effort to care even in the face of death. Knowing that death is imminent, the ability to care makes this profession a moral act. The moral principles of medicine involve a passion for life, informed by a conviction that death is not the final word and that death can be arrested. The term hopelessness is counter to the medical profession and the committed practice of care approaches all terminal cases as hopeful ones. Medical science, as Hauerwas suggests, is a statement of hope and the highest form of moral science.

2 Stanley Hauerwas “Medicine as a Tragic Profession” in David Smith (ed) *No Rush to Judgment* (Indiana: Poynter Center, 1977) p. 96
Is This Claim Convincing?

It is difficult to consider these claims true in the context of the market-mediated medical care system. The object of subsumption that Ramsey had alluded to has moved from the patient to the capital market. As a result, the medical profession and its subsidiary relations have assumed the principle of selling and buying. Recently, health care has become a commodity, exchanged with the same principles as any other commodity in the world. Decisions made in prioritizing medical research as well as production of medicine are based on only one criteria—profit. Neo-liberal policies on health care create a direct conflict between the pursuit of health and the pursuit of wealth.

With the provocative caption “Millions for Viagra, Pennies for Diseases of the Poor,” Ken Silverstein conveys that “many people, most of them in tropical countries of the Third World, die of preventable, curable diseases. ... Malaria, tuberculosis, acute lower-respiratory infections -- in 1998, these claimed 6.1 million lives. People died because the drugs to treat those illnesses are nonexistent or are no longer effective. They died because it doesn't pay to keep them alive.”

A market determination on health rerouted the priority to “life-style drugs”; a euphemism for possible remedies that may one day free the world from the scourge of toenail fungus, obesity, baldness, face wrinkles and erectile difficulties. The market for such drugs is worth billions of dollars a year and the investment in research is also enormous.

Out of the 1,393 new drugs marketed between 1975 and 1999, only 16 were for diseases that significantly affect the poor and the middle class of the world.

The distribution of the world’s medical expenditures is violently uneven and appalling. A quote from the French

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3 The Nation, July 19, 1999
4 Martine Bulard “Apartheid of Pharmacology” Le Monde Diplomatique January 2000
newspaper *Le Monde* cites, “92% of the world’s population has to [be satisfied?] satisfy with only 8% of the [world’s] total [medical] expenditure”\(^5\) Therefore *Le Monde* qualifies this phenomenon as “apartheid of pharmacology.” Similarly, 500,000 women a year die during pregnancy or childbirth, mostly in sub-Saharan Africa. Maternal death rates are 100 times higher in these regions than other areas of the world. 300-500 million clinical cases of malaria are reported each year. 14,000 new HIV infections are reported every day. However, there is no serious attempt to bring medical care to those suffering due to these problems. Around the world, approximately 300 children die of malaria per day. The research expenditure for malaria is only US$ 60 million out of the US$ 73 billion spend on medical research world-wide. HIV/AIDS drug cocktail costs US$12,000 a year in Africa when the per-capita income ranges between US$ 330 to 800\(^6\).

The issue is not the absence of technology to provide better health care, or a lack of skill to produce affordable medicines. The issue is due to priority. Access to quality healthcare is a right of global citizenship, but now this basic right is violated by the rules of the market.

In the neo-liberal economic environment, medical research and medical care are privatized and have been transferred to a few multinational pharmaceutical companies. Two thirds of the world’s medicine market is controlled by about 20 large corporations. Patent rights in medicine, enforced by the WTO regime, restrict two-thirds nations from creating an equitable system of distribution. Only by cutting prices will medicine be accessible to patients in these countries. The failed attempt by Thailand’s authorities to produce the drug fluconazole, used to treat cryptococcal meningitis, a fatal disease often associated with AIDS, proves that pharmaceutical companies not only set their own prices and select the markets

\(^{5}\) *Le Monde* January 2000

\(^{6}\) www.globalissues.org
that will push their share prices up, but they oppose every outside initiative.

An often quoted warning of Abraham Lincoln is unfortunately our present reality. He prophetically exhorted,

“I see in the near future a crisis approaching that unnerves me and causes me to tremble for the safety of my country. ... Corporations have been enthroned and an era of corruption in high places will follow, and the money power of the country will endeavor to prolong its reign by working upon the prejudices of the people until all wealth is aggregated in a few hands and the Republic is destroyed.”

Corporations and the transnational capital they circulate around the globe are two major influences on people’s lives at the present time. Out of the 100 largest economies in the world, 51 are corporations. The combined worth of the world's top five drug companies is twice the combined GDP of all sub-Saharan Africa. Moreover, their influence on the rules of world trade overrules the collective will of the people for health and sanctity of life.

**Medical Nemesis**

The commoditization process goaded medical science towards the construction of a techno-genic view of human life. In this view, science has reduced the human body to the sum total of certain bacteria and minerals, assembled in different chemical formations. The decisive imbalance in the composition of bacteria and the resultant chemical formation is termed as disease.

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8 [www.globalissues.org](http://www.globalissues.org)
There are two ramifications for this mechanical approach. Firstly, the human body is reduced to the level of things which can be analyzed by the aid of technological skills. Medical professionals are people who have competence in reading the different technological instruments. Dependence on technology eventually brought an alienation of the professionals from the human body. Such alienation leads to the inability to listen to the rhythms and music of the body; and in practice this alienation amounts to the distance of a medical practitioner from the living reality of the living organism.

Secondly, a technological dependence in the medical practice has resulted in creating a subject-object relationship between medical professionals and patients where patients have been reduced to replaceable objects. The subject-object relationship is one of domination mediated by the category of power, where the patients become dependent on the professional. This it is a political relationship.

Thirdly this approach leads to the patient’s alienation from their own body, or from their own self. Science creates a sense of ignorance in ordinary people regarding their bodies, and this ignorance leads to total dependence on the so-called experts. This approach is a conscious creation of the modern medical science. An alienation of people from their own self is not solely a health crisis but also a spiritual crisis, a crisis where each is robbed of the ability to realize his or her total being.

In one of the strongest critiques to modern medicine, Ivan Illich argues that modern medicine is literally dangerous to people’s health. Professional and physician-based heath care systems do not help people’s wellbeing for three reasons: first, the system produces clinical damage that outweighs potential benefits; second, the system cannot but enhance the political conditions that render society unhealthy- on the contrary, in majority of the cases the health system contributes towards the degradation of the general health of the community; third, physician-based health care tends to mystify and expropriate the power of the individual to heal himself/herself and to shape
his/her environment, serving to perpetuate professional control over the health care system⁹.

According to Illich, medicine has become the paradigmatic form of oppression of a technological society. The tragedy multiplies because victims are unaware of their own self-imposed oppression. It is assumed that those receiving care benefit from it. Illich suggests that there is no medical remedy for the medical nemesis, as there is no technological way to control technology. Therefore Illich suggests that the only solution is for the people to regain the will to care for themselves; he believes that "better health care will depend not on some new therapeutic standard, but on the level of willingness and competence to engage in self-care." He defined self-care broadly as consisting of "personal activities [that] are shaped and conditioned by the culture in which the individual grows up: patterns of work and leisure, of celebration and sleep, of production of food and drink, of family relations and politics". Illich described this ideal state as an "autonomous and creative intercourse among persons within their environment... individual freedom realized in interpersonal interdependence and, as such, an intrinsic ethical ideal."¹⁰ He called this a state of conviviality, and his notion of its health enhancement is remarkably in tune with current views of the impact of the social environment on health.

3.2. Techno-genic View of Life

Medical technology has transformed the living human being – the homo, as a concept replete with meaning, into a manageable thing, namely, “a life.” This amounts to an abstraction which was used only in military terminology. However now it could include women, children, the unborn, embryos, old people and the dying. This newfound manageable

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¹⁰ ibid. p. 17
life has also appeared with a new form of “epistemic sentimentality,” as expressed in the much debated issue of Terry Schiavo. A techno-gentic view assumes the agency to hold the moral card of protecting “life”. The pro-life debate has created sympathy towards "technogenic constructs" like the “public fetus,” unborn fetus, vegetable bodies and many others. This approach seems to be a carefully constructed political means for the management of public emotions as well as a way to confuse the concern for one’s neighbor with sentimental attachment to a value-laden fiction.

When Jesus said to Martha, “I am the resurrection, and the life” [John 11:25], he was proposing that “life” is the ultimate value. Throughout biblical literature the substantive “life” was never equated with a stage in biological development; people were alive, they were not "lives." Life is not narrowed to the physical nature of biology. The crisis in medical ethics is the legitimacy it provides to the technogenic construct of life by devaluing the substantive life.
Medical Ethics from an African Perspective

J.N.K. Mugambi

1. Introduction

The topics commonly associated with medical ethics are those having to do with the professional decisions which doctors must make in the treatment of patients at critical points of illness. Such decisions include 1) whether, when and how life should be terminated or prolonged for people with terminal illness; 2) whether, when or how organs may be replaced or transplanted; 3) whether, when and how artificial organs should be implanted; 4) whether, when and how abortion may be

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procured; 5) whether, when and how conception and gestation should be managed with regard to couples faced with problems of procreation. This paper will not focus on these issues. Rather, the objective is to explore some of the ethical challenges arising from deterioration of medical practice away from human welfare towards technological gadgetry and financial profiteering. As a challenge for applied ethics the significance of this shift of emphasis is profound. It is manifested by the recent policy orientation of the Bretton Woods institutions (World Bank, IMF, WTO), since the end of the cold war, from Welfare State economics towards privatization and commercialization of all social services, including health care. at a time when the poor communities are becoming poorer increasing in numerically while the affluent are becoming increasingly opulent. Apparently, nobody seems to care any more about the fate of the destitute, except as objects of charitable benevolence.

The theme of Medical Ethics eludes both the medical practitioners on the one hand who focus on treatment of infected patients and the social workers on the other, who care for the affected relatives, friends and colleagues. Codes of ethics in medical practice are rare, with the exception of the Hippocratic Oath whose recitation is a routine ritual in the graduation and certification of doctors. Increasingly, the medical profession has leaned more towards industrial gadgetry and further away from social and religious welfare. In the past, medical care was closely linked to cultural and religious heritage. Most physicians were at the same time priests, monks and nuns. Today, most medical practitioners are secular in outlook, attributing their expertise more to scientific and technological competence than to divine inspiration. Healers who appeal to cultural traditions and practices are considered less qualified when contrasted with doctors trained in modern universities. While it is true that cultural methods of healing are less exact, it is also true that
laboratory-based diagnosis does not solve all problems which are the actual causes of disease. For this reason, it is reasonable to suggest complementation between *culture-based prognosis* and *laboratory-based diagnosis*. Such complementation, when it is constructively and effectively implemented, can have a great impact on the reduction of infection and survival rates among various sectors of population, especially in those areas where cultural traditions are relied upon much more than generic drugs and specialized medical prescriptions. On this point see Laurenti Magesa, *African Religion: The Moral Traditions of Abundant Life* (Maryknoll, New York: Orbis, 1997).

2. **Commercialization of the Medical Profession**

Despite the noble affirmations of the Hippocratic Oath, the contemporary commercialization of medical practice honours that Oath more in breach than obedience. Owing to competition in the profession, doctors and related professionals tend to hide their methods from each other in order to maintain a competitive edge. The limits of medical and technological knowledge are today viewed in medical circles as frontiers to be conquered through further research and more elaborate gadgetry. This approach to medical practice is subordinated to capital investment and industrial innovation. The commercialization and industrialization of the medical profession has excluded the poor majority of the world's population from access to the latest medical inventions and innovations. The pharmaceutical industry which provides drugs and other supplies to the medical profession is monopolized by a few transnational corporations accountable primarily to themselves and their shareholders. Costing of medical services, drugs and gadgetry is left to the dictates of the 'market forces'. Human life is too valuable to be the object for manipulation by 'market forces' in the interest of entrepreneurs and corporate shareholders. Competition in the marketplace cannot be a reliable method of ensuring affordability of medical services and supplies in a context
controlled by corporate cartels. From the perspective of applied ethics, it appears that under the pretext of 'progress' medical practice has become an end in itself, rather a means towards the end of restoring human well-being and combating disease.

Health Care, together with other basic social services, ought not to be commercialized. The principles of Cost-Reduction and Cost-Recovery are important, but they should be applied in such a way as to ensure affordable access to medical care for the destitute individuals and communities within a nation. The challenge is how to formulate policies which guarantee sustainable medical care for the majority of the population. Proportional taxation is the most effective way of financing national health care schemes. However, the richest sectors of the population often resist what they consider to be over-taxation to subsidize health care for the poorest sectors. Proportional taxation guarantees equity, but the rich prefer to patronize the poor through charity. Unfortunately, charity is unsustainable, because it depends on the whims and frenzies of the benefactors at the same time that it dehumanizes the poor by making them unwilling beneficiaries dependent on their patronizing benefactors. On this point see, for example, Graham Hancock, *The Lords of Poverty* (London: Mandarin, 1992).

2. Culture-based Prognosis and Laboratory-based Diagnosis

Science is organized knowledge. Technology is organized trial and error. The fruits of science are culturally shared, and the fruits of technology are culturally controlled. The word 'science' has only recently acquired restricted meaning and application. Originally it referred to all epistemological investigation, including theology and philosophy. It is for this reason that in the European intellectual tradition theology is called the 'Queen of the Sciences'. The recent dethronement and marginalization of theology by biological and physical sciences has impoverished rather than enriched human understanding of
nature and culture. Scientific reductionism has encouraged unhealthy narrow-mindedness and prevented many empirical researchers from appreciating the epistemological insights yielded by the humanities and social sciences.

Through glorification of empiricism and the denigration of religion in contemporary North Atlantic epistemology, illness and health have been reduced to the physical condition of the bodily organs. The cultural and religious understanding of illness and health, however, extends far beyond physical wellbeing. Medical doctors may prescribe drugs to cure a disease, but the sense of inner wholeness can come only from the cultural and religious domains which academic medical practice cannot prescribe. The overwhelming majority of people in Africa and Asia still rely on culture-based prognosis, followed by culturally conditioned methods of treatment. These traditional methods of healing have not prevented the populations of Asia and Africa from growing—despite the great risks to life arising from natural and socio-political factors. There is a great deal for academic medicine to learn from the cultural and religious heritage of the peoples of Africa and Asia. On this point see, for example, Vandana Shiva, "Health Care as if the Earth and Human Being Mattered", Lectures delivered 26-Feb -5 March 2006, Navdanya Farm Centre, Dehrandun, Uttaranchal, India, http://www.bijavidyapeeth.org.

3. Equity and Charity in Medical Practice

Training for the medical profession has become extremely expensive, with the consequence that only the very few who can afford it become doctors. A man or woman from a poor family can enter the medical profession only through government scholarships or sponsorships financed by voluntary benefactors. This restrictive access partly explains why medical consultancy is so expensive. Should access to medical training be restricted to those who can afford, or to those who have the aptitude,
interest and commitment? Should the medical profession be a career or a vocation?

In the traditional contexts in Africa and Asia, the knowledge about precaution, prevention, management and cure of diseases is passed on from generation to generation, and it is available to everyone as a survival kit for everyone, rich and poor, high and low. The use of plant, animal and mineral ingredients for management of various ailments is disseminated as an integral part of nurture. This partly explains how most individuals with little or no monetary income survive in most parts of Africa and Asia. Traditional medicine (as bequeathed from the past generations to the present) presupposes the principle of equity, in which all individuals and communities must have access to the basic knowledge and means essential for survival, without restriction or limitation. Contemporary professional medical practice, in contrast, presupposes doctors as specialists must be remunerated for providing consultancy services based on the restricted knowledge they have acquired during their training. As experts, they are allowed to charge professional fees as they choose. The 'market forces' determine the level of these fees, depending on the clientele and the competition between the service providers. Commercialized medical care presupposes that the poor can have specialized treatment only through charity. Without charity, they perish. The access to specialized medical treatment for everyone should be a matter of equity, not charity. On this point see, for example, Robert Chambers: *Whose Reality Counts?* (London: ITDG, 1997).

4. **Human Beings as Guinea Pigs**

Another matter of ethical concern is the use of human bodies for experimental purposes in the perfection of surgery and medication. While basic research applied to animals may help us to understand more clearly how the human body functions under specific circumstances and conditions, how can the use of human bodies in experimental research be justified?
Can informed consent on the part of the 'human object' be taken as a sufficient criterion to justify any experimental work on a patient? It may be argued that the patients on whom experimental surgery and drugs are administered would be worse off without these experiments. However, ethical justification is in doubt considering that the procedures are intended to test drugs and procedures ultimately aimed at benefiting private corporations. Commercialization of medical services and pharmaceutical industries dehumanizes human individuals who are used for experimentation to make a drug or procedure more competitive.

Too often, experimental drugs and procedures are tested in Africa and Asia where informed consent is not sought. This is unethical. A recent example is the distribution of genetically engineered agricultural products in Africa without consideration of the risks to human health across generations. These products are promoted by private corporations interested, primarily, in maximizing their own profits without regard to long-term consequences for humankind in particular and ecology in general.

Although traditional methods of treatment in Africa and Asia have been improved though trial and error for generations, and although perhaps many people may have died during those trials, nobody would have benefited commercially from these experiments. Such knowledge would have been acquired for posterity, and its ownership has remained as part of the cultural and religious heritage of the local communities. The patenting of such knowledge by individuals and corporations is both unethical and exploitative. On this point see Kofi Appiah Kubi, *Man Cures, God Heals: Religion and Medical Practice among the Akans of Ghana* (New York: Friendship Press, 1981).

5. Patenting of Indigenous Medical Knowledge

Traditional knowledge is intellectual property, even though its ownership is not pegged to a particular individual or
corporation. Unfortunately, within the context of the World Trade Organization (WTO), the protection of such knowledge and its owners is not guaranteed. Unscrupulous entrepreneurs can, and do pirate and patent items of knowledge and procedures belonging to communities in Africa, Asia and the Pacific which have no means to protect manage their cultural and religious heritage within the current international protocols. Piracy of intellectual property seems to be only one way, whereby transnational corporations complain when their patented knowledge is used without permission.

When those corporations use knowledge taken without permission and payment from the communities of Africa, Asia and the Pacific, this unethical action ought to be treated with the reciprocal seriousness. Unfortunately, the communities of Africa, Asia and the Pacific do not have the power and means to institute litigation in international courts to stop such piracy and for compensation against the culprits. The current global economic order is one-sided and tilted in favour of transnational corporations, which have the power and financial means to patent and protect inventions and innovations even without compensating the original sources of the relevant essential knowledge. This is exploitation. With regard to medical treatment, many traditional methods of healing have been incorporated into commercialized procedures without due acknowledgement and payment to the communities concerned. This problem makes it difficult for traditional healers to disclose their techniques to strangers. On this point see Martin Khor, 'Indigenous People Criticise WIPO Approach', in South North Development Monitor, October 1999, <suns@igc.org>.

6. Social Medicine and Private Consultancy

In the contemporary African context there is a huge epistemological gap between the academic training of a doctor and the social environment of patients. This gap often makes it difficult for doctors to take full account of the social background
of many patients when prescribing medication. The failure of treatment under prescription in some cases can be attributed to this gap. An interesting illustration of this problem is narrated by Raymond Downing in his book *As They See it: The Development of African AIDS Discourse* (London: Adonis, 2005). The book describes the discord between North Atlantic the patronistic perceptions of the HIV AIDS pandemic and African perceptions of the problem. As long as the discordance remains, the pandemic will not be brought under control.

7. Some Concluding Observations

The Internet has become a powerful means for sharing both scientific knowledge and technological information. Those societies lagging behind in Internet connectivity correspondingly lag behind in scientific and technological advancement. In turn, this deficiency is reflected in economic retardation. According to the Annual *UN Human Development Report*, Africa as a region lags far behind other regions in Internet connectivity, and correspondingly is at the bottom of technological and economic ladder. Internet as a cultural tool can be domesticated to suit the local cultural needs of specific societies. This domestication has happened in Asia with great success. Africa has a great deal to learn from Asian countries with regard to the appropriation of the Internet for cultural modernization.

How are these insights related to culture-based prognosis and laboratory-based diagnosis of disease? Scientific research and technological innovations are always conducted within the context of specific cultural presuppositions. There is no culture-neutral science. Nor is there any culture-neutral technology. The industrial production of consumer goods in Asian countries for world distribution has been segmented in such a way that goods destined for specific countries are modified to suit the cultural particularities of each respective destination. Thus the cars manufactured in Japan for use in eastern and southern Africa are
right-hand drive, while those for North America are left-hand drive. Video cameras and players manufactured for this region are in PAL format, while those for North America are in NTSC format.

In the pharmaceutical industry, tropical Africa is prone to malaria infection, and for that reason there are several drugs in the market for the treatment of malaria. It is hard to procure malaria drugs in Europe and North America except in specialized pharmacies. Culture-based prognosis of disease is often accompanied by culture-based diagnosis and culture-based prescription. In both Asia and Africa the majority of patients are treated on the basis of this culture-specific continuum of prognosis, diagnosis and prescription. When laboratory-based diagnosis is introduced without consideration of the cultural particularity of patients, the results often fail to take full account of the symptoms, and the prescriptions often fail to cure the disease. There have been cases of patients abandoning laboratory-based prescription turning to culture-based treatment because of the failure of laboratory tests to identify the actual causes of illness, or the appropriate treatment. It is important to appreciate the significant role of culture-specific prognosis, diagnosis and prescription, while recognizing the limited place and role of laboratory-based diagnosis and prescription.

In Africa and Asia we are familiar with the use of diet, exercise, plant and mineral supplements in the treatment of various categories of disease. The knowledge of these methods of treatment has been passed on from generation to generation. These methods ought to be incorporated as complementary prescriptions, not as peripheral, optional guesses. They should not be regarded as 'Alternative Medicine', but as 'Complementary Medicine'. Most people rely on this approach either because they have no access to academic therapy, or because the university-trained doctors have failed to prescribe effective cure. The time has come for culture-based medical practices to be recognized and appreciated within the public
domain. On this point see World Health Organization, trm@who.int.

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Complex Science but Simple issue: The Roman Catholic Perspective To Genetic Engineering And Medical Ethics

Eunice Karanja Kamaara

Introduction

Scientific and technological advancements of the modern world have enabled humans to exploit available world resources to previously unimaginable levels. Such advancements as genetic engineering, the systematic manipulation of the natural genes to come up with new genetic creations, have enabled humans to venture into new levels of medical health. As with all frontiers of human knowledge, these new levels may be destructive or constructive.

1 Dr. Eunice Karanja Kamaara, is Senior Lecturer in Christian Ethics, Department of Religion, Moi University, Eldoret, Kenya. Email: eunkamaara@yahoo.com Paper presented at the Medical Ethics Conference of Formosa Christianity and Culture Research Centre. An earlier version of this paper was presented at the Bossey Seminar, Geneva held between 24-30th April 2004 on Genetic Engineering and Medical Ethics.
Throughout the ages, the Roman Catholic Church, (hereafter referred to as the Catholic Church) has a mandate to respond to any human behavior and judge it as morally licit or illicit. This response guides the Catholic faithful on Christian living in every time and place. In drawing out its moral teaching the Catholic Church recognizes two sources of authority: 1) the Bible which is believed to be the eternal and inerrant Word of God, and 2) the Oral Tradition derived from the teachings of the Church Magisterium comprising of the Pope and Bishops’ committees appointed for specific teachings. This paper seeks to present the catholic perspective on genetic engineering in the context of medical ethics.

The first section of the paper presents the official Catholic moral method. This is the method adopted at all times in determining what is moral and what is not in human actions. This section is important in providing background information to the any subject in Catholic moral theology.

**The Official Catholic Moral Method**

The Catholic Church’s methodology in determining what is moral and what is not is firmly rooted in the natural law tradition developed by Christian scholars in the Middle Ages of Christianity. Basically, natural law is based on the assumption that the human person has the capacity to reason about the observable aspects of the created order and from this reasoning, understand divine action and will. With this understanding, then the human person can determine the moral response to make. Writing on the natural law in moral theology, a renowned catholic theologian, Charles Curran, indicates that the process of an inductive approach to natural law starts with meticulous observation of human experience, then develops principles
based on the observed reality, and then arrives at moral judgment about human activity in the context of natural order.1

Following in this methodology, the official Catholic moral teaching in all instances begins from one basic affirmation that the inviolability of a human being’s right to life is implicit in God’s plan. This affirmation is rooted in the Biblical notion that all human beings are created in the image of God (Gen: 1) Consequently, the dignity of the human person not only reflects the dignity of God but also the sanctity of God’s gift of life itself.2 This affirmation presupposes the fact that all human beings are equal in value and dignity. Within this Catholic moral method, the right to life, as in many Human Rights documents, including the United Nations Declaration on Human Rights (1948), is considered the basic right of the human person, a right that is inalienable because it is granted by God and it is not dependent on recognition by society or public authority. Naturally, all rights go with responsibility. Human beings therefore have a responsibility to apply their rational nature to observe realities and consequently understand God’s will and design. Failure to do so is irresponsible behavior that reduces one in terms of humanity, reduces the image of God in every human person. Mariane Sheahan in a doctoral study of the Roman Catholic tradition of justice-as-solidarity expounds on catholic moral method.3 Although Sheahan was specific to abortion in the United States, her analysis is relevant to any moral issue.

The implication of this fundamental affirmation is that all moral judgments are made on the basis of whether the human right to life and human dignity are protected or violated. Hence while science may be complex, the issue of genetic engineering

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3 Marrianne Shenan,
is that simple. It is against this background that we discuss the catholic perspective on genetic engineering and medical ethics.

The Roman Catholic Official Position on Genetic engineering and Medical Ethics

It is essential to begin by noting that the Catholic Church, with its Episcopalian model of ecclesiology, is one of the most systematic groups of Christians. This is in terms of having clear-cut church authority in a way that one cannot confuse individual Christian opinion with the official church position. Occasionally, the church releases to the public the official teaching of the church in all aspects of practical life issues so that here is little room for individual church leaders or faithful to present their own understanding and interpretation. However, this does not mean that the faithful make no contribution on to the official Church teaching nor does it mean that there are no controversies in the church. In line with Vatican II’s call for members of the catholic laity to be active participants in the life and teaching of the church, lay catholic persons express their understanding of the design and will of God in response to human behavior, sometimes in utter disagreement with the official teaching.4

In its official teaching, the Roman Catholic Church is categorical that genetic engineering is against the natural order of things and therefore it is not morally right even in this age, for a very simple reason: human dignity and human life are threatened by genetic engineering. In no uncertain terms, the Catholic Church declares that all forms of human cloning is morally illicit and must be prohibited. In Domium Vitae I, I the Church teaches:

...the human being is to be respected and treated as a person from the moment of conception; and therefore

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from the same moments his rights as a person must be recognized among which in the first place is the inviolable right of every innocent human life.5

This teaching is restated in Evangelium Vitae and in Humanae Vitae. On many occasion, the current pope, John Paul II, emphasizes this teaching whenever he talks on anything “the culture of death” perpetuated in the name of civilization.

In L’Osservatore Romano, an official weekly bulletin of the Vatican, the stance of the church against all forms of human cloning is occasional clarified thus:6

All forms of human cloning whereby production or attempted production of a human embryo through nuclear transfer or embryo splitting is aimed at are prohibited.

Both “reproductive” cloning and “therapeutic” cloning are illicit for while the scientific procedures may be different and complex in each, both are simply about “production” of a human embryo.

From this position, it would seem that the Catholic Church is opposed to scientific progress. Not so. The Church in no uncertain clarifies this. Directly on transplant surgery, the pope observes that this is “…a great step forward in science’s service to man (sic)” and a “valid means of attaining the primary goal of medicine- the service to human life.”7 However, he stresses:

6 See for example: L’Osservatore Romano, N 33/34 13/20 August 2003
... as with all human advancement, this particular field of medical science, for all the hope of health and life it offers to many, also presents certain critical issues that need to be examined in the light of a discerning anthropological and ethical reflections.8

The Church is opposed to scientific advancements at the expense of human life and dignity. Hence the Church clarifies that it is not opposed to production of stem cells from adults or by means that does not entail the destructive use of living embryo. Removal and use of cells, tissues or other biological materials from embryos of fetuses that have died spontaneously is therefore deemed licit. So is cloning which has no intentions of producing individuals but merely of multiplying cells as in stem cells. The Church recommends that other forms of therapeutic interventions, which do not involve cloning, or use of embryonic cells. Since this is possible, as science itself has pointed out in the use of stem cells, research should pursue this direction.9

Rationale for the Catholic Position

Often, religious positions are dismissed as irrational, emotional and mysterious matters of faith. But the Catholic Church’s position is fully accessible to reason and is founded on two bases. First and foremost, the stance is based on clear recognition that scientific enquiry for human progress is fundamental and researchers’ creativity has a special place in this. It is for this reason that the Church clarifies that it is not opposed to any form of therapeutic intervention that does not interfere with the dignity and life of humans, any human. Secondly the stance is founded on recognition that there are ethical implications of genetic engineering.

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8 Ibid.
9 Ibid
Specifically, the major reason propounded by the Church against genetic engineering hinges on the fact that the practice involves nuclear transfer or embryo splitting which is killing of innocent human lives. Of course killing of innocent human lives is indisputably evil. The argument propounded by those in favour of these practices is that the embryo is not a full human person. This raises the question of who is a person? For the Catholic Church, the total person can be found in the zygotic stage of an embryo… even if it does not yet possess the fullness of capacities.9 This is a restatement of what Pope John Paul II notes in *Evangelium Vitae* indicating the need to recognize, respect, and protect human life from its earliest stage. The argument propounded is that the tendency to subordinate the condition of the human person to presence of specific biological characteristics is not rational or consistent. If a person with one arm is still a person why is an embryo not to be considered a person? Basically it is argued that an embryo or cell is not human because the functions of the central nervous systems are not functioning in a certain way. Does it mean therefore that a person who has grown senile with age is not a human person? Or is a two-year-old child not a person? How do we determine at what stage a potential person becomes a total person? For the Church an embryo is a total human person even when it consists of one cell and has equal dignity with any other person.

One of the major arguments in favour of genetic engineering is that major benefits will be accrued from such biomedical knowledge and technology for society particularly in future. But why should an individual's life be sacrificed for the sake of society? The Church reasons:

*Human rights flow from the recognition that human beings have an intrinsic dignity that is based on the fact that they are human, Human embryos are human even if they are cloned. If the rest of us are to have the rights*
that flow from the recognition of this dignity, then we must act to ban cloning in all its forms.10

The Church’s position is that a human person is not distinct from a human organism because an organism is not a part but a full living self-organism since no organism would exist in partial form. Human dignity is not about quality or quantity of life. Hence it does not matter how many diseases or disabilities may be controlled in future through genetic engineering. Every human person is dignified and should enjoy equal dignity. If we allow any prejudices and arbitrary anthropological presuppositions, we may deny the individuality of human life in many other instances. This amounts to discrimination of the weak and has appropriately been referred to as a new form of racism. In genetic engineering human beings are used as means rather than as an ends and this practice should be subjected to severe sanctions. This buttresses the understanding that ethically, the practice is deplorable and unacceptable.

Another rationale for the position of the Church is that genetic engineering leads to objectification and commercialisation of human life. Definitely there are some benefits that may be derived from genetic engineering. The practice can help relieve symptoms of various diseases and conditions. For example, infertile couples can have children through this. But the ethical questions raised have to do with who benefits at whose expense. As it were, certain people will have control of human life as a commodity that can be sold to those who can afford at the expense of those who are too weak and cannot fight for their rights. The truth is that genetic

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engineering has no real benefits given the primary end of medicine, which is service to humanity, all humanity.

An important thing to note is that in spite of lack of real benefits of genetic engineering, the practice may have grievous unforeseen consequences. The experience of Dolly, for example, indicates that clones may develop unforeseen biological complications. Would we want to risk with human life? The Catholic Church is categorical that life does not belong to us. It is a gift from God that we have to guard from any possible harm.11

The Catholic Church also reasons that genetic engineering is an assault on marriage, parenthood, family and procreative functions of a man and a woman. It is not natural to "produce" life through asexual means. Given the commonness of human error, such "production" may lead to unforeseen dangers to the humanity. Thus cloning is contrary to the dignity of life, procreation, marriage, and the family.12 This last point raises controversy because of emerging issues such as of "different sexual orientation". Moreover, it may not be clear with regard to what is natural or not natural in human beings especially since the Church accepts that "human embryos are human even if they are cloned". For want of time and space, this controversy is not discussed in this paper.

Conclusion

This paper indicates that the Roman Catholic Church perspective is that genetic engineering is wrong whether it is

therapeutic or reproductive. Indeed, the Church finds no distinction between the two forms of interventions because while the processes differ, the end result is that human life and human dignity are not recognised, respected, and/or protected. In fact it is simply murder of innocent human beings because a human embryo or cell is no less human than a mature human person.

It is clear that the Church does not just present a position that has not been thought out. Indeed, there is a rationale for the position and specific reasons are given for the position. All these are presented in this paper. It is essential to emphasize that the Church supports scientific research but this should not be at the expense of human dignity and life.
Theology and Disability

K.C. Abraham

Theology is a discourse carried out by able bodied people for the able bodied. So disability is not a theological category and there is very little material available which we may draw from for our theological reflection on disability. The materials that reflect on the experiences of the disabled: their special hardship, social pressures on them, their emotional and spiritual problems, their rights and their struggle for justice and the peculiar gifts they bring to our faith and our understanding of our spirituality are relatively few.

But thanks to the WCC ‘Programme on Persons with Disabilities’, some resources are made available. The book Disabled God by Nancy Eiesland is an outstanding contribution with its focus on the struggle of the physically disabled. There are other helpful reflections by the physically challenged. But the expression of the mentally challenged as they are not used to the conceptual discourse (they have other ways of articulating

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1 Rev. Dr. K.C. Abraham was the Director of South Asia Theological Research Institute of the Senate of Serampore and was President of the Ecumenical Association of Third World Theologians.
their experiences) are relatively fewer. Henry Nouwen’s *Reflection* on his life with the L’Arch community is an exception.

There are cultural and theological reasons why a discourse on the experience of the disabled has become difficult. The ideas of perfection and of beauty that are ingrained in our psyche and sanctioned by our culture tend to preclude any form of disability. There is no “beauty” in the disabled. Perfection is measured by physical and mental endowments that are rarely found in the experiences of the disabled. Any form of disability makes you less than human.

For this reason they are excluded from society. They are preferred not to be seen. In our churches they are seldom present. We are told that 10% of the human population has some deformity or other. Yet in our church services they are absent. In fact, our church buildings are not disabled friendly – one rarely sees a ramp or special wheelchair for the handicapped in them. As a pastor I was not aware of the presence of the disabled, until my child became mentally challenged.

Theologically speaking, a weak God is a misnomer. Our God is Almighty with exquisite beauty. We will say more about this.

**Methodology**

A theological reflection should begin with methodology. How do we do theology? The perspective from which we do theology is closely related to the “context” of theologising. All theologies are contextual. They are not reiteration of timeless truths and propositions. It is not an effort to apply a prefabricated system of ideas to a situation. Rather theological articulation arises out of our experience: experience of suffering, of humiliation and also our aspirations. Theology is faith articulated from a context. Amartya Sen in one of his writings
has drawn our attention to the importance of positional view in Astronomy – Sun when looked at from different positions will have an impact on our views. There is a parallel in our theological thinking. Reality viewed from different experiences influence our theological articulation. The experience of the disabled like the experiences of women or dalits should generate a theology of a new genre.

What we have learned from EATWOT is relevant here. Commitment is the first act of our theology. Theological reflection is only a second act. It has to start from a commitment to the struggles of the disabled – their struggle for recognition of their rights to exist, for equality and against all cultural and prejudices and stigma. Our commitment is for liberation. Without this commitment our theology is only a construct in abstraction.

**Metaphorical theology**

Theology is God-talk, discourse on God. The discourse is based on a language which is symbolic and metaphorical. It is through metaphors that we articulate the incomprehensible reality. Metaphors arise out of a cultural or social environment. We use images borne out of our experience in the family – Father. There are also political and military images such as ruler, lord, master and warrior.

All these metaphors which are cultural have a preference for patriarchal dominance. Patriarchy and hierarchy are characteristic of traditional societies. And the metaphors that maintain such order are used as controlling metaphors. Unfortunately we tend to confuse metaphor with reality. Metaphors are not literal truth. Father is a controlling metaphor as we are prone to think about the protective and caring role of a father as primordial to our life existence. This way of looking at theological language opens up the possibility of metaphors other that we commonly use. Feminists correctly point out that the
caring role of God is best expressed through the metaphor of ‘mother’ or ‘lover’.

What about metaphors that arise out of the experience of the disabled? ‘Disabled God’ is a metaphor that helps us articulate the experience of God from the perspective of the disabled. Nancy Eiesland, the author of *The Disabled God* affirms that the symbol of ‘Disabled God’ arises “in the particular situation in which people with disabilities and others who can find themselves as they live out their faith and to fulfill their calling to live ordinary lives of worth and dignity”.

She further notes that “contextualisation is that the disabled God emerges in the particular situation in which people with disabilities and others who care find themselves as they try to live out their faith and to fulfil their calling to live ordinary lives of worth and dignity. Contextualisation is an authentic process of perceiving how God is present with people with disabilities and unmasking the ways in which theological inquiry has frequently instituted able-bodied experience as the theological norm.”

Again, the symbol of Jesus Christ is that of a disabled God. “In presenting his impaired hands and feet to his startled friends, the resurrected Jesus is revealed as the disabled God”.2 In this way the disabled God, not only challenges the stereotyped stigmatisation of the disabled persons, but it is an empowering and liberating way of doing theology. It is liberating because it is “a clear recognition of the limits of our bodies and an acceptance of the limits as the truth of being human”.3 In this way theology becomes a liberating truth and re-symbolisation of God – reality can be empowering.

**The Nature and Power of God**

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3 Ibid., p.108.
One of the key questions we need to raise in this context is about the nature of God. The classical understanding especially influenced by the Greek philosophy is to describe God as impassable – beyond change. The prefix ‘omni’ is used frequently in the characterisation of God: Omnipotent, omniscient or omnipresent. All powerful, all-knowing God who is present everywhere is beyond all feelings and change. ‘God as Raw Power’ was the emphatic assertion. One may recall the concept of nirguna brahma in the Hindu philosophy. God’s absoluteness is preserved by picturing God as almighty and powerful, beyond all qualities.

Important changes have taken place in our understanding of God – thanks to our awareness of Biblical God and also the influence of personalistic and process philosophy. We discovered the prophetic insight into the power of God. To the prophets; God does not reveal himself/herself as an abstract and impersonal power but in intimate relationship.

In Isa. 63:8,9; 54:5,6; …… God as fellow sufferer, a great comforter, a husband and lover are referred to. “A re-symbolisation of divine power not as a dominative or controlling power, nor as dialectical power in weakness but as a liberating power that is effective in compassionate love” is taking place in the prophets.

The discovery of a ‘God who suffers’ is at the centre of the theological constructions of Bonhoeffer, Moltmann and Dorothy Solle. This is important for us to develop a new language of God if we take the disabled and their experiences seriously. Happily we have a strong accent on the suffering God among Asian theologians. One of the pioneers in this kind of theology is Kitamurai (The Pain of God). We also have the recent writers like C.S. Song who develops the theme of a compassionate Christ. God does not come as an absolute omnipotent God, but as a compassionate God.

Dalit theologians, especially A.P. Nirmal talks about pain pathos as the authentic experience of dalits and he discovers the face of God in it: God as relational, mutable and
also a powerful being. The God who suffers with us empowers us to fight against all experiences of marginalisation, suffering and disability. It is important to affirm this understanding of God when we theologize from the perspective of the marginalization and suffering.

II

My wife and I have the responsibility to raising our daughter, Liza now 27 years old. She was born as a normal child when we were ministering at St. Mark’s Cathedral, Bangalore, India. After two months of her birth she contracted meningitis. In spite of medical attention her brain was damaged and we were given the responsibility of bringing up a mentally challenged child. It was a traumatic experience; we like others in a similar position questioned God or rather spent time in prayer to seek God’s purposes in this seeming tragedy. Like every parent in similar situation we prayed that God may intervene miraculously and perform instant healing. She has improved a lot but remains profoundly retarded. But this experience opened our hearts to the needs of similar children and parents who have the responsibility of taking care of them. We got a glimpse of the idea of “solidarity”. Slowly we opened our home for providing care for mentally challenged. Our family is extended, our horizon of concern for God’s children enlarged. We thank God. Solidarity for us is not a mere theological jargon, but a living reality with all its joys and sorrows.

“Blessed be the God and Father of our Lord Jesus Christ, the Father of mercies and the God of all consolation, who consoles us in all our afflictions so that we may be able to console those who are in any affliction with the consolation with which we ourselves are consoled by God”. II Cor.1:3.

In this second part we will address a few questions that arise out of our experiences of growing up with out mentally challenged daughter.
The meaning of suffering

Unexpected illness, the death of a loved one, accident, loss of job and many different forms of suffering is the lot of our lives or our friends’ lives. We ask why Lord? What have I done to deserve this?

Rabbi Kushner in USA wrote a book entitled When Bad Things Happen to Good People. It became an instant best seller and went into several editions of printing. He wrote it after the tragic disease and death of his child. After discussing the question he concludes:

“In the final analysis, the question of why bad things happen to good people translates itself into some very different questions, no longer asking why something happened, but asking how we will respond, what we intend to do now that it has happened.”

The Book of Job is an attempt to respond to the question, why a righteous God allows a righteous man to suffer? But the Book of Job, like Rabbi Kushner’s book does not answer this question. It, however, gives some perspectives on faith and suffering which will equip us to respond to the situations of suffering.

Firstly, the Book rejects the idea that suffering is God’s punishment and that our suffering is caused by our own personal sins.

This was the argument of Job’s friends who came to comfort him. He was a righteous man, but his friends strained themselves to suggest that Job would have done something wrong sometime which he would not have remembered. Job strongly defends himself and rejects their suggestion. He has not committed anything wrong. Undeserved punishment is a gross violation of humanity’s right and our God is not a despotic ruler.
Certainly there are some forms of suffering that come to us when we disobey God. If you continuously and deliberately go against the rule of nature, you will suffer the consequences. We all know that ecological crisis is caused by our irresponsible exploitation of nature. You harm your body by too much smoking or drinking and even over-eating!

But there is suffering that cannot be attributed to any apparent cause – like the innocent suffering, illness that have come unexpectedly etc. We should not think them as a punishment of God, or as the result of some mistake we committed. Such an attitude increases our suffering by increasing the burden of our guilt. Our Lord also refuted this kind of explanation when his disciples asked him the reason for the blindness of the blind man whom he healed. Was it because of his sin or his parent’s sin? They asked. Jesus refuted this view.

Secondly, we cannot always find an answer to the question why there is suffering but we can turn some experiences of suffering into an occasion for spiritual enrichment. We are called to be prophets who fight the unjust social and political structures and practices that cause suffering. It is an undeniable fact that people who became sensitive to the suffering of others were led to struggle against it. In our country, the vicious caste-system brought heinous suffering to a section of our people. It is the gospel of Jesus Christ that brought an awareness of this suffering and many people were led to fight this evil. People were liberated from the clutches of this pernicious system. Situation of suffering is turned into God’s arena of fighting for justice and dignity.

The experience of suffering will also help us to enter into the suffering of others. Solidarity with the suffering is one of the keys to understand the message of Christmas. The baby Jesus was born in the cattle shed, in poor circumstances. We are moved from apathy to empathy and sympathy. We are called to be cross-bearers in the world in solidarity with the suffering and
thus lightening the burden of others by sharing our experience of suffering.

The agony brought to us by this experience was unbearable. We asked, and continue to ask ‘God why did you do this? Have you forsaken us?’ Overcome by grief we continued to delve deep into the spiritual resources at our disposal for comfort and strength. Looking back, we can assuredly confess that it was a moment of great spiritual strength. The care for the brain-injured child opened to us a large number of similar parents whom we would not have known otherwise. The horizon of our love experience is enlarged. During the illness of our daughter our experience of God’s love through human kindness was deepened. How can we forget the kind gesture of a friend of ours, a faithful member of St. Mark’s for the last fifty years came to the hospital on the first day carrying a tiffin full of food for us. He did it everyday until we left the hospital. Yes, when we experience such kindness it enriches us spiritually. In our Liza’s Home we are continually enriched by the affection of those children who cannot do anything ‘useful’ other than loving. The world will be poorer without them.

1. Ethical concerns

The experience of living with the disabled raises some ethical concerns which are integral to our theological reflection. The foremost is the question of justice. The disabled are denied their basic human rights and they are excluded from society. To restore their dignity is to struggle for it. There has been some efforts by the physically disabled to organise themselves and fight for their rights. They critically look at the stigma that hurts them and reject them. Nancy Eiesland points out that “although living with disability is unique to each individual it is shaped by a dominant social milieu that devalues and discriminates against people with disabilities. These people are stigmatised i.e., they
are marked as bearers of spoilt identity”.

Some breakthrough is made by the physically handicapped and their organised efforts in resisting this social evil.

But in the case of mentally challenged, they are not capable of organising themselves. In solidarity with them, caregivers and others should create an awareness of their hurts and struggle for their rights.

Justice is often understood as balancing the rights of different groups. But prophets bring to our awareness the concept of compassionate love as integral to justice. For them a just relationship is possible only if all are included and cared for. Therefore the test of justice is how society treats the most vulnerable sections. They are not asking for charity, but they demand, in their own way, justice and participation. Justice that includes compassion is an enriching concept. A workshop on disability conducted by the WCC has these closing words “In sharing out compassion, we may not always do or give much but we need to do it with the attitude and compassion of Christ. That invitation goes to all people.”(Workshop on Disability Discourse, 2004)

2. Participatory Structures

Justice is realised in the creation of participatory structures for the weak. In the area of education, health, housing and other basic areas of life the State/community should evolve support structures that enable the disabled to participate fully in the life of society. They are not subjected to the charity and philanthropy of some individuals or church groups. But when the state creates them their participation is their right. Of course care givers can be enlisted to serve these structures. It is the responsibility of the State/community to provide them. In many countries in the West the State is fully involved in providing

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4 Ibid., p.61.
such facilities with the tax payer’s money. In India in other Asian countries we have a long way to go.

**Power**

Underlying every form of relationship is power, an essential category that shapes our ethics. Here again two contrasting images are given to us in the New Testament: Demon and Servant. In Jesus’ commission to the disciples they are given the charge to proclaim the good news to the poor, to heal the sick and to cast out demons (Mk. 6:7-13). The command to cast out demons is problematic to us. It is all the more difficult when we think of demon - possessed as the mentally deranged person roaming around the streets abusing everybody and sometimes people tend to include the mentally challenged in this category! Now ‘demon’ is part of the symbolic structure of the ancient world. To translate it literally is to miss the point. From the accounts of Jesus’ miracle stories of casting out demons, we see demons possessing uncontrollable power; they go about destroying themselves, others and the environment. Demons are within us, especially when we exert self-oriented power. They use power to abuse or gain control of others and nature. Power used without any accountability can end up as a destructive force. It should be transformed into power to heal, to build up the other. Mission consists in the process of transformation from demonic power to power to love. Ecological crisis is the result of the distorted, uncontrollable power humans exert on nature. It is demonic. How can this be transformed into power to care?

The command of Jesus points to the way of accomplishing this. He asks them not to take additional clothing and to accept hospitality. They should experience the powerlessness. Presenting the good news from a position of strength and dominance is abhorrent. We experience the powerlessness in solidarity with others. How true this is when
we consider ecology and the life of the disabled. We are in solidarity with the powerless nature and the vulnerable.

Precious gifts of the disabled

Living with Liza has made us conscious of the precious gifts of all the disabled. In our society the disabled seldom receive any attention. We try to avoid their company. Their awkward movements, their mannerisms and sometimes their uninhibited display of feelings become embarrassing to us – who are normal and able-bodied. In our church services we rarely see them, although they represent at least 10% of the society. But our Lord commends to us this feast of the disabled as the highest moment of his ministry. Jesus says;

“When you give a dinner or a banquet, do not invite your friends or your brothers or your kinsmen or rich neighbours, lest they also invite you in return, and you be repaid. But when you give a feast, invite the poor, the maimed, the lame, the blind, and you will be blessed, because they cannot repay you. You will be repaid at the resurrection of the just.” (Luke 14:12-14)

I see a Jesus who tenderly fondles and plays and laughs with those maimed, lame, dumb and blind. Hardly have we taken this face of Jesus seriously. The mentally challenged like our daughter deeply challenge our experience of the depth of Jesus love.

You know how profoundly retarded children like my daughter construct a world of their own. They are unable or unwilling to enter into the normal world of discourse. It is rather frustrating if you try conforming them to our way of thinking. The only way we can communicate with them is by entering into their world and becoming part of it. We have to find the right code to enter into it; not all can do this. My wife
knows better than I do what that right code to enter into my daughter’s universe and communicate with her.

Perhaps this capacity to find the right code, by identifying with our condition – that is God’s love for us. He is one with us in our suffering, our joys. This solidarity is established at the expense of all our so-called achievements. That is love incarnate, suffering love.

One more thing we need to share: when we are so much frustrated and annoyed, disappointed at the manipulations and intrigues of people in society and even in the church, we can be with our daughter. She doesn’t know the art of manipulation. Her demands or the favours she asks are simple – to play some good music or take her for a short ride in the car. For this she gives profuse kisses and a long embrace. That love is not concocted or contrived. It is infectious. It jettisons our pettiness, our hunger for power and position.

One of the spiritual disciplines that have enriched our lives is the ability to rejoice in little things and to give God thanks for small mercies. This is peculiarly true for my wife and I as we continue to relate with Liza. She has this irresistible urge to listen to music all the time. These days when there is load shedding the music stops. She could not comprehend why. She would go into tantrums, screaming and biting. Slowly, with a great deal of patience on our part it dawned on her that there is a connection between music and light. When the light goes off, the music stops, she learned. This may not be a big thing about normal children of her age. But for the children of her condition it is great. We are grateful for her achievement. An eye for little ones, and little things – that should be the experience of thanksgiving.

The little ones are sustained by God’s grace. They remind us that our lives every day, every hour and every moment are sustained by God. Jesus says,

Consider
The birds of the air,
The lilies of the field
And the grass in the fields

They are little things, yet they are important for our Lord. We are asked to learn from them. They witness to God’s care for all God’s creation, even those which we consider little. The importance given to them by our Lord raises questions to our value system and our priorities for our life. We tend to identify success with bigness; power with might; strength with capability to kill. See how our political leaders make us imagine that by exploding the nuclear bomb we have suddenly become a strong nation! Our Lord can be very sarcastic. “Even Solomon in all his splendour was attired like one of these”. When people crave Solomon’s glory, as witnessed in our rat race for success, fame and power, our Lord says, look at the little things. How God continues to sustain them and adorns them with glory.

If our Lord has found it important to learn from the little things, then we do learn God’s mystery and power by being in solidarity with the little ones / things. Plants, animals and other ‘lesser’ creations are our source of inspiration. To take care of them is God given responsibility. To pollute God’s creation, its air and rivers and destroy its forests and vegetation is to go against God’s purpose for us and for God’s world. The ‘little ones’ are the weak, disabled, powerless and marginalised among the humans. Only in solidarity with them and their struggle for liberation and wholeness can we know and experience God of love and mercy.

Permit me to end it with a quote from Henri Nouwen’s reflection on his expression of taking care of one of the members of the Day Break Community, whom he took care of.

As I think about this first part of Adam’s life, I cannot avoid seeing a close parallel with Jesus’ own life. Jesus did not come in power and might. He came dressed in weakness. The greatest part of His life was hidden, sharing the human condition as a baby, a young child, a
struggling adolescent, and a maturing adult. Adam’s hidden life was like the life of his ministry to many people, even though neither he nor his parents looked on it that way.

I am not saying that Adam was a second Jesus. But I am saying that because of the vulnerability of Jesus, we can see Adam’s extremely vulnerable life as a life of utmost spiritual significance. Adam did not have unique heroic virtues: he did not excel in anything that newspapers write about. But I am convinced that Adam was chosen to witness to God’s love through his brokenness. To say this is not to romanticise him or to be sentimental. Adam was, like all of us, a limited person, more limited than most, and unable to express himself in words. But he was a whole person and a blessed man. In his weakness he became a unique instrument of God’s grace.

He became a revelation of Christ among us.”

How true these words express beautifully our own experience of living with Liza and taking care of her.
A Reflection on the Bioethical Dilemmas from the Perspective of a Human Being as a Relational Being and the Ethics of Caring: The Case of Genetic Screening

CHEN Nan Jou

Dilemmas in Bioethics: A case

Mr. A came to see the medical doctor because of his family disease for the first time when he was twenty-five years old, single. He was healthy from his looks. Mr. A’s father suffered from a degenerative neurosis and died in the age of forty-nine. Mr. A

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1 Rev. Dr. Chen Nan Jou is Professor of Christian Ethics and Vice President at Yu Shan Theological College, Hualien. Paper presented at the seminar on Medical Ethics organized by FCCRC. A section of this paper is taken from a paper written by the same author. Please see the handbook of the 32nd Asian Christian Medical Workers & Students Exchange Program, August 4, 2001, Hualien, Taiwan.

Celia Deane-Drummond distinguished the differences between genetic testing and genetic screening. Genetic testing refers to the individuals, genetic screening to a whole population or sub-population. See Celia Deane-Drummond, Genetics and Christian Ethics (Cambridge: Cambridge University Press, 2006), 77-79. However, there are no such differences in this paper.

2 This case is taken from the handbook of a Medical Ethical Lecture which was published by the Medical College of the National Cheng Kung University dated March 19, 2002. pp. 1-3.
had one elder brother and two elder sisters. One of his elder sisters was thirty-five years old, and suffered from Autosomal Dominant Cerebellar Ataxias. The result of the genetic screening showed that she had Spinocerebellar Ataxia (SCA) genes, type I. Therefore, Mr. A came to the medical doctor for genetic screening. The report of Mr. A’s genetic screening showed that he also had SCA genes. Six months later, Mr. A took out a life insurance and a medical insurance. The insurance company asked him to have a health examination; however, it did not include the genetic screening. Mr. A agreed to the insurance contract that the insurance company has the right to read his health report from the hospital.

**Discussion:** Did Mr. A take out insurance while he is sick? Did the insurance company have the right to read Mr. A’s genetic screening report? Should the persons of the hospital tell the insurance company about the result of Mr. A’s genetic screening? Can the insurance company get the report of Mr. A’s genetic screening and refuse to pay Mr. A when Mr. A had Spinocerebellar Ataxias?

**Case:** One year later, Mr. A brought his newly married wife, 25 with 16 week pregnancy to see the medical doctor, and asked the doctor to do amniocentesis for his wife. Mr. A also asked the doctor privately to do genetic screening for the fetus, and not to tell his wife about his own medical record. After the ultrasound examination and the test of the blood pathology, the fetus was suspected to have Down’s syndrome. Then, the following amniocentesis showed the fetus was a male with normal chromosomes, and SCA genes. Mr. A asked the doctor to fabricate a reason to his wife that she might need an abortion. Nevertheless, the doctor refused to follow Mr. A’s suggestion.

**Discussion:** Can the medical persons take initiative to tell Mrs. A the truth about the examination and amniocentesis?

**Case:** Due to the doctor’s moral persuasion, Mr. A told his wife the whole story. Mr. A and his wife were struggling in a dilemma, and arguing whether the fetus should be aborted. Mr.
A did not want to have a child with SCA genes. However, Mrs. A thought that SCA is likely a late-onset disease, meaning that it may only develop thirty or forty years later when the genetic therapy might be more advanced, and wanted to keep the fetus.

**Discussion:** Should genetic screening be done in the prenatal diagnosis for those diseases which will only be late-onseted? Is a fetus having SCA genes a justified reason for abortion? To whom should the medical doctor listen? What is the suggestion that the doctor should offer in the process of consultation?

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**A Human Being is a Relational Being**

Living in the age of globalization, we are experiencing new biotechnology and its impacts almost every day. We are forced to face new ethical challenges while old ethical dilemmas are still disturbing us. All ethical decisions are related to and made in the living context, namely our society and culture. Our social and cultural contexts influence our understanding of ethical values and decisions. In order to tackle the ethical dilemmas we are facing, the foremost thing for us is to do reflection on what is the conception of human being, the moral agent in our society and culture.

Due to the rapid social changes, Han Taiwanese nowadays do not follow the traditional Confucian social ethical teachings on “the five human relationships.” However, one of the social and cultural realities reflected on the Confucian social ethics, namely, emphasizing relationship, is still the living context of today’s Han Taiwanese. This is to say that Han Taiwanese, influenced by Confucianism, think that a human being is a relational being. It is even more crucial to talk relationship in the age of globalization.

According to the interpretation of modern Confucian scholars such as Liang Shu Ming, Ambrose Y. C. King, the society of Han People is neither individual centered nor society
centered. It is a relational oriented society.\textsuperscript{3} This means that in the Han people’s social life, a human being is understood from his or her personal relationships. A human being is a relational being. Whether a conduct is moral or not is understood from his or her personal relationships. Y. C. King quoted an expression of Fox Butterfield, a columnist of \textit{New York Times} in China and said that Han people distinguish people into two catalogues instinctively. One is fixed relationship; the other one is non-fixed relationship. Han people live in this social relationship and network, and make their ethical decision in this relational context.\textsuperscript{4}

In fact, “a human being is a relational being” is not a unique understanding of human beings in Han people. The Taiwanese Indigenous people also have similar social thought. Though the Taiwanese Indigenous people do not have philosophy well developed like Confucianism, they do also have very clear and strict social norms. And according to the Taiwanese Indigenous scholars, in the Indigenous society, whether a conduct is moral is very much determined in the context of relationship. It is moral if a conduct is done by a person in relationship; otherwise, it is not moral.\textsuperscript{5}

In short, “a human being is a relational being” is a common understanding of Han Taiwanese and the Taiwanese Indigenous about human beings, and is also a criterion for ethical decision. Therefore, when we discuss the medical ethical dilemmas in the Taiwanese social and cultural context, “a human being is a relational being” should be taken into account.

\textsuperscript{3} See Ambrose Y. C. King, Chinese Society and Culture (Hong Kong: Oxford University Press, 1993), 9-10. quoted from Liang Shu Ming, The Essence of Chinese Culture (1974), 94
\textsuperscript{5} Chung-Cheng Pu (Basuya Poichehnu), The Oral literature of the Taiwanese Indigenous People (Taipei: Formosa Folkways, 1996), 226-227.
Understanding the Christian Faith in Terms of Relationship

If the social ethics of a society is to understand a human being from the context of relationship, is it in conflict with the understanding of human beings of the Christian faith? Or, is “a human being is a relational being” also a Christian interpretation in Taiwanese social and cultural context when he or she is making an ethical decision?

When we interpret the Bible from our living context, namely a human being is a relational being; we find that “relationship” is also the motif of the Bible. “The righteousness of God through faith in Jesus Christ”, the salvation offered to humankind by God in Jesus Christ, the translation in Today’s Chinese Version is “to have right and appropriate relationship with God in Jesus Christ”. The central theme of the Bible and the Christian faith is the relationship between human beings and God. The purpose of Incarnation, God became a human being, is to restore the relationship between all creation and God, to put human beings into right and appropriate relationship with God. In fact, we can also say that the relationship with God is the main motif of the story of creation and the Fall in the Book of Genesis. God created human beings in God’s image, and asked human beings to take care of the creation. This is an expression that the existence of human beings depends on the relationship with God. Human beings live in the context of relationship with God and with all creation. And the story of the Fall also points out that death, the result of sinning against God, is the break of relationship with God. Christian ethics is therefore based on the relationship with God. Human beings make their ethical decisions in the light of their relationship with God.

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But, how do people understand and experience the relationship with God in Christian faith? Human relationship! We surely know that the human beings’ relationship with God is not reflected only in their relationship with others; however, the relationship with others is the foremost dimension of human beings to demonstrate their relationship with God. In Christian faith, “repentance goes to the roots in the human heart and manifests itself through actions and relationships”. This means that a person, who turns to God, must also be a person who turns to neighbors. Christians demonstrate their turning to God, their new relationship with God, by turning to their neighbors." To love God and to love neighbors are closely interrelated. God has come to us to express His/Her love through Jesus Christ, but how do we express our love to God? The answer is to love our neighbors. This was precisely the teaching of the prophets in the Hebrew Bible. The prophets tried to let the Israelites understand that practicing religious rituals was not the only factor for human beings to be accepted by God; human beings’ social life was also one of the most crucial and important factors. The prophets judged the relationship of the Israelites with God through their personal and social relationships. The human beings’ personal and social relationships were the foremost criteria for prophets to evaluate their relationship with God.

In the Sermon on the Mount, Jesus told the crowds that when people are offering their gifts at the altar and remembering that their brother or sister has something against them, they have to leave their gifts there before the altar and go to be reconciled to their brother or sister, then come and offer their gifts. It

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10 See NRSV, *the Gospel according to Matthew 5:23-24.*
shows that Jesus also emphasized the co-relationship between the relationship among human beings and relationship between human beings and God.

Thus, when we interpret the Bible from our living social and cultural context, we come to a conclusion that “a human being is a relational being” is also a Biblical understanding of human beings. Christian faith emphasizes human beings’ relationship with God, but this relationship is to be comprehended through human beings’ personal and social relationships. This means that when a Taiwanese Christian is making an ethical decision, the social and cultural understanding of human beings that “a human being is relational being” does not conflict with Christian faith, but rather it is a necessary consideration in terms of Christian praxis in the Taiwanese social and cultural context. Besides, “relationship oriented” social thinking may fall into the dangers of “ethnocentrism”; therefore, the Christian understanding of human beings, that is to understand human relationships through their relationship with God, and to understand the relationship with God through the relationship with others, can be the checking point of the praxis of social and cultural understanding of human beings independently of the limitations of emphasizing human relationships.

The Ethics of Caring

What is the core of Jesus’ understanding on the relationships among human beings which reflects the relationship between human beings and God? It is “caring”. In fact, the character of Jesus’ ethics is caring.\(^{11}\) We may learn this from the parables of the sheep and the goats,\(^{12}\) the rich man and Lazarus,\(^{13}\) and the parable of the Good Samaritan.\(^{14}\) Those who

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\(^{12}\) See NRSV, *the Gospel according to Matthew* 25:31-46.

care for the people who are suffering from poverty, hunger, thirst, injustice, and are marginalized, are caring for Jesus. Jesus is in the human relationships. Jesus cares the relationship; Jesus expects that human relationships express caring. When you care for others, you are right in the relationships, having not only right relationship with others, but also right relationship with God. “Caring” is usually construed as a virtue. However, using the words of Nel Noddings, it is “a relationship that contains another, the cared-for that the one-caring and the cared-for are reciprocally dependent.”15 In the ethics of caring, “the essential elements of caring are located in the relation between the one-caring and the cared-for.”16 Thus, if we have to make an ethical decision in terms of relationship, we have to be aware that caring is the core of relationship. And if we approach ethical issues with caring, we have to be aware of the relationships involved.

Reinterpreting the bioethical Principles from the Perspective of a Human Being as a Relational Being and the Ethics of Caring

There are four basic and well-accepted principles when we discuss the biomedical ethics, namely: autonomy, non-maleficence, beneficence, and justice.17 Since “a human being as a relational being” is the ethical conception from the Taiwanese society and culture, and is also an interpretation of Christian ethics about human beings, and caring is the core of relationship, reinterpreting these four basic medical ethical principles from

14 See NRSV, the Gospel according to Luke 10:25-37.
15 See Nel Noddings, Caring: A Feminine Approach to Ethics & Moral Education (2d ed.; Berkeley: University of California, 2003), xiii.
the perspective of a human being as a relational being and the ethics of caring in the light of the dimension of relationship with God may give us new insight in the discussion of bioethical dilemmas.

1. **Autonomy**: This principle, on the one hand, points out that any ethical decision basically should be the autonomous choice and decision of the moral agent; on the other hand, it asks for respect for the decision making of the moral agent. Therefore, this principle emphasizes personal autonomy and respect for the ethical decision. The ethical norm of “informed consent” is precisely derived from this principle.

   Autonomy is one of the basic foundations for the ethical decision of a responsible self. Reinterpreting this principle from the perspective of “a human being as a relational being” and the ethics of caring, autonomy should not be an arbitrary decision of an individual. The emphasizing of autonomy of a moral agent does not deny the fact that human beings are living in the context of relationship. An autonomous person’s decision has to be autonomous with caring in the context of his or her relationship with relatives, friends, even communities. He or she has to make his or her own decision, but the decision has to be made in the context of his or her relationship with others in acting caring. Reinterpreting the principle of autonomy from the perspective of a human being as a relational being and the ethics of caring, on the one hand, avoids the ethical approach of the absolute individualism. On the other hand, it is free from the domination of the community and society which the moral agent belongs to. The autonomies of the one-caring and cared-for are both taken seriously. In this process of decision making, the absolute autonomy becomes relational autonomy.

2. **Non-maleficence**: This principle emphasizes the motivation of any ethical decision should be non-malicious, and the result of an ethical decision has to avoid the causation of harm.
Reinterpreting the principle of non-maleficence from the perspective of a human being as a relational being and the ethics of caring, gives us an alternative understanding on what may do harm to the patient. “Harm” has to be understood in the context of relationship and the ethos of caring. One decision may be thought harmful from the third party; however it may be acceptable to the patient and his or her families and relatives. Therefore, making an ethical decision from the context of relationship offers more possibilities of choice. “Relationship” may change or reshape our understanding of the ethical issues and the application of ethical principles and norms. Those who are caring for others will avoid doing harm.

3. Beneficence: This principle can be stated as a positive expression of the principle of non-maleficence. Beneficence points out that providing benefits and welfare for others is not only a virtue, but also our ethical obligation. However, we all know that there is a limitation regarding obligation of beneficence. We do not have obligation to sacrifice our lives to act for the benefit of others.

Reinterpreting the principle of beneficence from the perspective of a human being as a relational being and the ethics of caring, may encourage us to bring the effect of this principle to its full function. “Relationship” produces positive effect that people act for the benefit and welfare of others, even to sacrifice our own benefit. Beneficence as an obligation is more obvious in the context of relationship. And to care is to identify with the cared-for. Caring moves people to act beneficently spontaneously.

4. Justice: This principle refers to the fairness, equality, and appropriateness of the biomedical policy and the distribution of the medical resources. It concerns issues such as “Are the medical resources mainly accessible by the rich?” “Are the benefits of the minority groups concerned about?”
Reinterpreting the principle of justice from the perspective of a human being as a relational being, on the one hand, reminds us that human beings tend to misinterpret “relationship” and to distort justice in terms of its process and contents, on the other hand; it urges us to be just in the context of relationship, to overcome the temptation of individual centrisms. Moreover, if the principle of justice is patterned in accordance with the ethics of caring, then the medical resources can be utilized to “enhance human well-being and self-acceptance and communal fellow feeling without asking first whether people have deserved what they received.”

We certainly know that “human relationship” can be misinterpreted and abused. Therefore, I would like to emphasize that the understanding of “a human being is a relational being” should include human beings’ relationship with God. This means that we do not sacralize the human relationships. Human relationship with God is the foundation of the relationships between human beings. It is also the checking point of human beings’ relationships with others to prevent abnormal human relationship and the distortion of human relationship from an authoritarian or arbitrary person. The ethics of caring which emphasizes Jesus’ understanding of caring will also help people move away from an ego-centric understanding of human relationship.

**An Example: Ethical Dilemmas with Genetic Screening**

I am convinced that the ethical dilemmas with genetic screening can be discussed more comprehensively in the lights of the perspective discoursed above.

The genetic screening may be taken as a means to diagnose those genetically determined diseases. If genetic screening is done without respecting the autonomy of the one whom genetic

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screening is performed on, it not only violates the principle of autonomy, but also breaks the relationship between the medical doctor and the patient. It is at the same time not an action of caring. It hurts the patient’s feelings, intrudes upon the patient’s privacy, and damages his or her individual welfare. The harm will be very true if the result of genetic screening is taken illegally by the insurance company or any other party.

What can a pregnant woman do if she finds her fetus is known to be suffering from a particular genetic disease through the prenatal genetic diagnosis? Is it an excuse for her or her family to determine the termination of the pregnancy? The decision may be different because of her or her family’s religious faith or philosophy of life. For me, the debate between the perspective of pro-life and pro-choice does not make too much sense in this situation. From the perspective of the ethics of caring, all lives should be cared for, the pregnant mother’s life and the fetus’ as well. When a medical counselor is asked by the woman or families who are facing this ethical dilemma, the medical counselor may help the client think of the dilemma from the perspective of “relationship”. What kind of decision will be helping her to keep harmonious relationship with others? Does the existing relationship, personal and social relationships provide the network and socio-medical welfare system to support her decision? These discussions also apply to the dilemma raised by pre-implantation genetic diagnosis.

A person’s genes come from his or her parents, namely from two families. Someone’s genetic screening result reveals not only his or her personal genes, but also his or her families’. This means that one’s genetic screening may affect the families related. Therefore, in the light of a human being as a relational being and the ethics of caring, to do genetic screening and to reveal the result of genetic screening should not be one’s personal arbitrary decision.

Genetic screening has its positive dimension and negative as well. In terms of positive dimension, some genetic diseases may get early therapy through genetic screening. Even with the
so-called “un-therapeutic” or late-onset genetic diseases, the patient and his or her families may want to plan their life career as earlier as possible. Nevertheless, the result of genetic disorder may also bring negative psychological impact on the patient, or stigma from the society where he or she belongs. The individuals and the society as a whole should think of genetic screening from the perspective of a human being as a relational being and the ethics of caring. Are we human beings biological determinate? Are we going to accept the perspective offering by genetic determinism?

**Conclusion**

When we talk about life, we have to be aware that besides biological life, we have interpersonal-social life and spiritual life. Our Lord Jesus Christ said: “Those who find their life will lose it, and those who lose their life for my sake will find it.”\(^\text{19}\) Christian faith does not count the human biological life as an absolute value; its survival is not the final goal of a human life. The purpose of the biological life is to fulfill the goal of spiritual life, to have the vision of God, and to glorify God. Our life has to be responsible to God, and it is demonstrated through our social relationship.

God requires human beings to live out the meaning and the value of their life in the living context, namely, in our social relationship. “A human being as a relational being” and ethics of caring give us a more comprehensive approach to interpret life and ethical principles, and to make ethical decision in the midst of a more and more complex society because of globalization.

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\(^{19}\) See NRSV, the Gospel according to Matthew 10:39
Contemporary Challenges of The Physician-Patient Relationship

Huang Yeewen

Introduction

The physician-patient relationship has undergone major and increasingly rapid changes over the past 50 years. It has moved from being a relationship based on physician paternalism, to patient autonomy, in which both patients’ and physicians’ authority and control over care are facing significant threats from outside sources. National Health Insurance, HMOs, legislative proposals for Surrogate motherhood, Death with dignity acts and multi-national insurance industries are few among these outside forces. We have to ask the critical question: What are physicians for? Is medicine merely an industry, a technique, just another consumer-wants-satisfaction enterprise? Is medicine a way for people does business and gain prosperity? Or is medicine a profession of human service, an unconditional service provided by one human being to another?

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Physicians used to be strong advocates for patients’ well-being and benefit, now they are forced by managed care systems to be the gatekeepers who guard against “wasting” medical resources. Physicians are pressured to set aside their traditional Hippocratic duty of serving the patient’s good instead serve the financial good of the health care system. Profit has tended to replace service. Professional values are no longer emphasized in the medical school education. Instead, medical knowledge and technique are the only indispensable qualifications for medical students. When students begin their medical careers, the goal is to bring home a fat check every month. Our question is: Is there anything that can be done?

The Importance of the Physician-Patient Relationship

The principles of veracity, loyalty, and respect for autonomy define the conditions of the physician-patient relationship. German philosopher-psychiatrist Viktor Emil von Gebsattle (1883-1974) warned against a dehumanization of medicine when the “person” of both patient and physician are not explicitly present in their relationship. His warning remains valid, notwithstanding the modern emphasis on respect for patient and provider autonomy. Studies show that both the nature and quality of the physician-patient relationship and the physician’s professional skills are key dimensions in the patient’s “consumer satisfaction.”

The negative consequences of physicians’ failure to establish and maintain personal relationships with patients are at the heart of the humanistic crisis in medicine. Physicians leave

3 Welie JV.:” Viktor Emil von
4 Calnan, Katsouyinnopoulos, Ovcharov, Prokhorskas, Ramic, & Williams: “Major determinants of consumer satisfaction with primary care in different health systems” Family Practice. 11(4):468-78, Dec. 1994
the educational system with a predisposition to deal with problems from a biomedical perspective. They are unaware that, by the very nature of the physician-patient relationship, they possess considerable ability to effectively intervene in the psychosocial area. Evidence indicated that effective dealing with physician-patient relationship will improve patient compliance and outcomes.⁵

The problems of modern physician-patient relationship

The growth of profit-driven medicine and managed care, as well as the increasing technological focus of Western medicine, has stimulated much reflection on the fundamental values of the medical profession and on the meaning of being a “good physician.” These changes have created serious concerns about the fate of the physician-patient relationship among a host of physicians, patients, and other professionals in the medical community.⁶

Recently, the physician-patient relationship has undergone a major structural change due to the growing pressure from the ethic of personal autonomy on a paternalistic “helpful healer” tradition. The autonomy ethic gives patients greater control over their own lives, while the paternalistic approach lets the physician to determine what should be done. The traditional relationship of the patient with his/her physician-as-friend-and-counselor has replaced by the informed consent documents. As a consequence, there is enormous tension between the physician and the patient, and the changes have some negative consequences regarding the quality of medical practice. In a study done in Korea [Kim, et al.] the researchers found that the transitional change in the physician’s professionalism could be related to the ubiquitous perception of the patient’s rights in

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⁵ Lieberman: “Compliance issues in primary care” *Journal of Clinical Psychiatry*. 57 suppl. 7:76-82; discussion 83-5, 1996
physician-patient relationships. Such phenomena are believed to have caused physicians to think that their status has declined in recent years and will continue to decline in the future. Clinical concerns are centered around the relationship between these two parties and no one seems to be a winner in the conflict. As a result of a 10-year retrospective study done in an emergency department, Ooi reported from Singapore that 71.3% of the complaints in the Emergency Department were due to physician-patient relationship problems. Another study of 45 malpractice suits revealed that problematic relationship issues were identified in 71% of the depositions. Four themes emerged in these suits: deserting the patient (32%); devaluing patient and/or family views (29%); poor delivery of information (26%); and failing to understand the patient’s and/or family’s perspective (13%). These misfortunes would have been avoided if more attention had been paid to the physician-patient relationship.

Many factors may be responsible for having a poor physician-patient relationship. Relationship difficulties may occur due to the character of the patients. In a study of 4 primary care clinics, physicians rated 15% of their 627 patients as ‘difficult’. This study concluded that the ‘difficult’ patients are prevalent in primary care settings and they show signs of having psychiatric disorders, functional impairment, health care utilization, and are dissatisfied with the care. Poor communication is another major factor in poor physician-patient

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relationships. Studies showed that physicians who had a history of frequent malpractice claims tended to have more patients who felt being ignored, rushed, and/or ill-informed. These complaints were signs of high patient dissatisfaction. Poor communication skills of the physicians are at the root of this problem. Extensive empirical data often suggests the inequality of power in relationships between physicians and their patients. Salmon and May found in their case studies that patients sometimes have their own ways of gaining control over the physician’s decision by organizing strategies which include the presentation of emotional and social distress around biological somatization complaints. Sato, et al., found that the risk factors for physician are strongly associated with the chronic conditions of the patients and the state of physician-patient relationship.

When the physician-patient relationship encounters problems, patients often turn to nurses. Tabak observed that the patient may seek the nurse’s counsel because he/she feels insufficiently informed by the physician, or because the nurse becomes aware of inadequacies in the information-giving process. Seldom do patients go to their physicians to discuss the issue of the relationship directly.

The poor relationships between physicians and their patients may also be due in part to the medical system in which they are working. In their follow-up study of 551 breast cancer patients.
patients, Holli and Hakama found that patients met an average of 10 different physicians during their 5-year follow up treatment, impairing the possibility of having continuity of the physician-patient relationship. They suggest that consulting the same physician would probably improve the quality of life among cancer patients. Unfortunately, it appeared that other considerations of the health management system make this suggestion unappealing.\textsuperscript{16}

The Role of Humor in Physician-Patient Relationship

However, there is a given logic for both physicians and patients to pursue a better relationship between them. Beauchamp and Childress urged physicians to take the initiative to improve their relationship with the patients. They suggested four fundamental virtues that can provide guidance for physicians in medical practice: compassion; trustworthiness; discernment; and moral integrity.\textsuperscript{17} Abramovitch and Schwartz proposed a new model of physician-patient interaction with an objective to resolve this crisis. Based on Martin Buber’s philosophy of dialogue, their model shows how the physician may successfully combine the personal (I-Thou) and impersonal (I-It) aspects of medicine in three stages. These three stages include: 1. An initial Personal Meeting stage, which initiates the physician-patient relationship and involves mutual confirmation; 2. An Examination stage, which requires a shift from a personal to an impersonal style of interaction; 3. An integration through dialogue of “Healing Through Meeting” stage, which involves the integration of the impersonal medical data into the ongoing

\textsuperscript{16} Holli, & Hakama: “Continuity of the doctor-patient relationship during the routing follow-up of a breast cancer patient” \textit{Supportive Care in Cancer.} 1(5):263-5, Sep.1993

\textsuperscript{17} Beauchamp and Childress: \textit{Principles of Bioethic Ethics} 4\textsuperscript{th} Ed. (Oxford University Press, New York, 1994) p.466
dialogue between physician and patient as a base for shared decision-making.\textsuperscript{18}

If this is too theoretical, Wender’s article suggested something more practical; humor. He argued that the role of humor in medicine is becoming increasingly apparent. Humor helps individuals to narrow their interpersonal and cultural gaps, to communicate difficult messages, to express frustration and anger, and to cope with anxiety. He urged that primary care providers should learn to interpret humor used by patients and the art of using humor to create a healing environment. Humor plays an important role in the improvement of the physician-patient relationship.\textsuperscript{19}

Other authors have argued for the centrality of empathy in the physician-patient relationship. In his article in \textit{Theoretical Medicine}, More wrote that empathy should be a core of ethically sound responsible therapeutics, and that empathy can be the center in the physician-patient relationship.\textsuperscript{20} The physician has to learn to use empathy to understand patients’ concerns. Wright suggested the development of friendship between physician and patient, stating that such friendship enriches the physician’s professional life without detracting from the physician-patient relationship.\textsuperscript{21}

Communication skills are a cornerstone of the physician-patient relationship.\textsuperscript{22} A Kansas study conducted by Twemlow and Bradshaw found that patients who rated themselves as more needy and were unsatisfied with their care have marginal relationship with their physicians, and those whose physicians

\begin{thebibliography}{9}
\bibitem{19} Wender: “Humor in medicine” \textit{Primary care: Clinic in Office Practice}. 23(1):141-54, Mar. 1996
\bibitem{21}Wright: “Frank” \textit{Australian family Physician}. 14(5):757, 755, May 1995
\bibitem{22}Marine, & Kohen: “The power of words: Communicating effectively with young patients” \textit{Journal of the American Osteopathic Association}. 96(7):410-2, Jul. 1996
\end{thebibliography}
called them by their first names tended to be more content.\textsuperscript{23} Although pharmaceuticals and scalpels can address disease, Roger Bulger argued that something else is required to heal the illness and begin to reduce the suffering. He said that “something else” is the physician’s communication to the patient—by words, body movement, or other means of commitment—that he or she cares. This kind of communication can be rendered best by a caregiver who can decipher both the verbal and nonverbal messages conveyed by the patient, and who knows how to respond to them appropriately.\textsuperscript{24} A 1994 ruling by the Pennsylvania Supreme Court\textsuperscript{25} underscores the importance of explaining the benefits and risks of treatment alternatives to patients. Poor communication often leads to malpractice lawsuits and loss of confidence in physicians. Aside from oral patient education, physicians can convey information by handing out videotapes and supplements from national specialty societies. Engaging, empathizing, and educating are the rules behind better communication between the physicians and their patients. The Physician Insurers Association of America has collected data on 96,000 malpractice claims, and estimates that up to 30% of the cases are the result of the lack of an informed consent or failure to instruct the patient properly. A University of Rochester, N.Y. Highland Hospital study of 140 depositions in malpractice suits indicates that “failure to provide an explanation” was cited in 35% of

\textsuperscript{23} Twemlow, Bradshaw, Coyne,&Lerma: “Some interpersonal and attitude factors characterizing patients satisfied with medical care” \textit{Psychological Reports}. 77(1):51-9, Aug. 1995
\textsuperscript{24} Roger Bulger: “The forgotten ingredient in health care reform” \textit{The Western Journal of Medicine}. Dec 1997 v167 n6 p443 (14)
\textsuperscript{25} General surgeon R. Douglas Cassel of Harrisburg diagnosed a cyst on a patient’s spleen and performed a splenectomy. The patient developed a series of complications culminating in bilateral deep vein thrombophlebitis. His subsequent suit against Cassel alleged negligence and lack of informed consent.
them. Law suits and unnecessary conflicts between physicians and patients are often avoidable if both parties pay more attention to their communication skills. Miles Institute teaches physicians the four Es to better communication: engagement; empathy; education; and enlistment of patients in their own health care.

Davies, et al., designed a first-year course for personal and professional growth that focused on helping the students become aware of student, patient, and family issues that may impact the physician-patient relationship. They hope that courses like this will help students gain deeper insights into issues that impact them, their patients, and the physician-patient relationship.

The Issues: Trust Issues in Physician-Patient Relationship

Trust is also essential to the physician-patient relationship. An emphasis on the physician’s fiduciary ethic, however, has made the physician plausible as a protector of patients’ interests. The rise of managed care is often seen as undermining the fiduciary ethic and lessening the trustworthiness of care. Gray suggested four possible sources of trustworthiness in managed care: ethical standards in the managed care industry; nonprofit organizations; physician control; and performance monitoring by purchasers. The other side of the trust issue is the truthfulness of the patients. After a half day clinic session, Woolley and Clements asked 44 residents about their impressions of each patient’s truthfulness. The residents doubted patients in 54 of 277 encounters (19.5%).

26 Ken Terry: “Telling patients more will save you time—explanation of risks and benefit of treatment options” Medical Economics, July 25, 1994 v71 n14 p40(6)
28 Gray: “Trust and trustworthy care in the managed care era” Health Affairs. 16(1):34-49, Jan-Feb1997
In the same study, senior physicians doubted patients in 16 of 183 encounters (8.7%). Both groups had more negative than positive emotions towards such encounters. The study suggests that family physicians question patient’s truthfulness fairly often. Because such feelings may contribute to inadequate patient care, the investigators suggest that further research is warranted to understand the contributive factors and to guide the development of the resident and student education programs in this neglected area of the physician-patient relationship.

Informed Consent and Physician-Patient Relationship

For historical reasons, much of the analysis of the physician-patient relationship has been based on the concept of informed consent. The concepts of information and consent are both problematic. As a result, consent forms and advanced directives often undermine the goals that led to the consent doctrine. A better ethic can be derived from stressing the connection between physicians and patients and determining how that connection can be fostered.

A belief in the validity of informed consent is one of the most important consequences of the doctrine of autonomy in medical ethics. Truly informed consent requires full disclosure of all relevant information by the physician. The Hippocratic oath demands that the physician “will use treatment to help the sick according to his/her ability and judgment” and s/he will come to his/her judgment by collecting all possible data about the patient’s condition, including data put aiming to the interests of the patient and respect of his/her autonomy. Truly informed consent also requires the patient’s ability to appreciate what the information signifies, understanding of the facts and issues,

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voluntary choice, and autonomous authorization for treatment or entry into a trial. These elements serve two functions. They serve to ensure that the patient’s will is fully expressed in the process of decision making, and they help the clinician to arrive at a decision that s/he believes will best benefit the patient. In this way, the physician can fulfill his obligation under the Hippocratic Oath and respect the patient’s autonomy at the same time.

In summary, for a patient to give and a physician to receive properly informed consent, several requirements must be met. 1. The physician must give the patient all relevant information about the nature and the purpose of the procedure, its risks and benefits, and the risks and benefits of any alternatives --including the alternative of no treatment. 2. The patient must understand the information, whether it is given orally or written in a consent form. 3. The patient’s consent must be given voluntarily, without coercion or undue influence from health care personnel or others. 4. The patient must be mentally competent to give consent.

However, the patient’s right to self-determination is not absolute. In situations involving the interests of society or in which the patient’s own welfare is at stake, a physician is not required to obtain informed consent. Such situations may include public health emergencies, medical emergencies, and the invocation of therapeutic privilege.

**Referral and Physician-Patient Relationship**

The physician has a duty to know the limitations of his/her specialty and service. This is particularly true now that the subspecialty medical system is part of the main stream. While a physician in one specialty may become an expert in his/her own field, s/he has only limited knowledge in other fields of medicine. Referral and consultation are required if the physician is truly the patient’s advocate. The Hippocratic Oath requires that physicians refer their patients suffering from stone
without hesitation to the surgical experts. The action of referral and consultation does not mean that the physician is incompetent; on the contrary, it takes true knowledge for a physician to know his/her own limitations and to identify the best referral.

This issue becomes complicated in the managed care system. It is not uncommon for new patients to ask primary care physicians for referrals to physicians who have previously treated them. This is, in fact, the most common complaint of primary care physicians who work in managed care setting. Patients only come to primary physicians for referrals to specialists whom they have trusted before. The physician may think: “My patient considers me as a rubber stamp to give permission to meet a specialist, most of which are unnecessary. This action shows a lack of respect towards the physician.” On the other hand, the patient also may have different thoughts that the primary care physician acts as a strict gatekeeper with possessive and inflexible attitude. Request for referrals usually leads to unhealthy conflicts, damaging the relationship between the physician and the patient severely.

Confidentiality and Physician-Patient Relationship

The understanding that the physician will not disclose private information about the patient provides a foundation for trust in the therapeutic relationship. Dodek argued in his article that although patient confidentiality has been a fundamental ethical principle since the Hippocratic Oath, it is under increasing threat. The main area of confidentiality is the patient record. Physicians must be able to store and dispose of medical records securely. Patients should be asked whether some information should be kept out of the record or withheld if information is released. Patient identity should be kept secret during peer review of medical records. Provincial legislation outlines circumstances in which confidential information must be divulged. Because of the "team approach" to care, hospital
records may be seen by many health care and administrative personnel. All hospital workers must respect confidentiality, especially when giving out information about patients by telephone or to the media. Research based on medical-record review also creates challenges for confidentiality. Electronic technology and communications are potential major sources of breaches of confidentiality. Computer records must be carefully protected from casual browsing or from unauthorized access. Fax machines and cordless and cellular telephones can allow unauthorized people to see or overhear confidential information. Confidentiality is also a concern in clinical settings, including physicians' offices and hospitals. Conversations among hospital personnel in elevators or public cafeterias can result in breaches of confidentiality. Patient confidentiality is a right that must be safeguarded by all health care personnel.31

In 1974, Wright reported that up to 40% of patients in one practice preferred not to discuss personal anxiety, family problems, or sexual problems in the presence of a student.32 Recently, Cooke, et al., concluded from a questionnaire survey that only 3% of patients had negative views about the presence of a student.33 Norma, et al., report that 95% of 335 patients from London and Newcastle were happy for student to be present during an examination, but their consent was dependent upon the clinical setting. More than 95% of the patients were happy to have a student present if they had complaints of a sore throat or a chest infection. 67-70% would agree if the consultation were for emotional problems. Only 50% would agree to a student’s presence if an internal examination was required and less than 50% would agree if they were consulting

the physician because of a sexual problem. They urged that patients have the right to choose whether to participate in the training of medical students. In many cases, however, patients’ permission to have a student present during the consultation was sought at the last moment, making it difficult to refuse. They recommend that consent be sought when the appointment is made.\textsuperscript{34}

The confidentiality issue is important for adolescent patients. Physicians may either neglect to discuss confidentiality with their adolescent patients or incorrectly promise unconditional confidentiality. Ford, et al., found that among 786 board-certified physicians in California specializing in family practice, internal medicine, obstetrics and gynecology, and pediatrics, 53\% reported that they discussed confidentiality with their adolescent patients. 64\% of physicians incorrectly promised unconditional confidentiality.\textsuperscript{35}

**Euthanasia and Physician-Assisted Suicide and the Physician-Patient Relationship**

The legalization of euthanasia creates a certain tension when it is compared with those traditional medical principles that seem to embody respect for the sanctity of life. It also creates a real need for us to explore what we mean by harm in relation to dying patients. When we consider that we must train physicians to be virtuous in their practices, it is imperative that we provide a sound ethical basis during their training. We can only do this by conveying a real sense of the needs of the patient and by creating a moral attitude that enable them to relate to the patients as people and not as problems. Such attitudes take shape

\textsuperscript{34} Norma O’flynn et al : “Consent and confidentiality in teaching in general practice: survey on patients’ views on presence of students” \textit{British Medical Journal}, Nov 1, 1997 v315 n7116 p1142

\textsuperscript{35} Ford & Millstein: “Delivery of confidentiality assurances to adolescents by primary physicians” \textit{Archives of Pediatrics & Adolescent Medicine}, May 1997 v151 n5 p505(5)
in a training program in which practical situations are explored and discussed, and the limits of scientific medical responses to those challenges are exposed.\textsuperscript{36} Are euthanasia and physician-assisted suicide favors done by physicians for their patients? Or are they the terminators of the traditional values of medical professionals? The Oath clearly stated that the physician would not give poison to anyone though asked to do so, nor would the physician suggest such a plan. It is one thing to read this statement in the ceremony without pausing to ponder upon its meaning; it is a totally different thing to put this statement into practice in a clinical setting. The physician has to refer to the early section of the Oath for counsel: “I will use treatment to help the sick according to my ability and judgment, but I will never use it to injure or wrong them.” It is up to the physician and his/her patient to decide what is harmful and what is best to the patient. This consensus can only occur in the context of a well-established physician-patient relationship characterized by sharing of values and interests.

**The Changing Nature of the Health Care System and the Physician-Patient Relationship**

The ‘for-profit’ medical system and the managed care system have introduced ever new interests into the physician-patient relationship.\textsuperscript{37} A study conducted by La Puma suggests that managed care and managed competition challenge physicians’ roles as trustworthy patient advocates. He argued that fortifying physician-patient relationships in managed care would be prudent and wise, and would help to achieve the ethical allocation of limited resources. By protecting patients’ personal medical interests and empowering patients to do the same, physicians can attempt to safeguard trust. Both

\textsuperscript{36} Gillett GR “Learning to do no harm” *Journal of Medicine & Philosophy*. 18(3):253-68, Jun. 1993

physicians and patients want to have strong, personal, values-oriented relationships, even under the tension of the current managed care system. Dewberry argued that health care reform threatens to jeopardize the role of physicians in deciding what an appropriate care is for their patients. Factors outside the physician-patient relationship, such as a global budget and limited access, will exert increasing influence on the decision making process. Dr. Dewberry suggests that physicians take an uncompromising stance against the malfunctioning system.

Managed care has been perceived by many as creating an environment that places the physician in a situation of a conflict of interest, wherein he/she is expected to accept responsibilities toward society at large, as well as fulfill the traditional role of advocate for the individual and specific patient. Angell described the current dilemma well. She noted the pressures for physicians to become “double agents” (they are being asked to act as agents for society and not simply advocates for their patients). Angell argued that physicians must work “unstintingly” for each of their patients, and that physicians should at the same time work for the health care reform to guarantee universal access under a global budget. How can this double duty be possible? Although Angell did not comment on this issue, it is clear that there must be a lot of tensions and frustrations.

Many have noted with concern the increasing influence of these external factors on the physician-patient relationship. The traditional physician-patient relationship is inevitably changing and being eroded by these social, philosophical, and economic forces. These stressors to the physician-patient

relationship exist in some form in all Westernized countries. Access to care and the relationship between physicians and patients are major issues in nearly all countries; they are affected by particular aspects of culture, religion, and social structure.

**Conclusion**

In this pluralistic world, everyone should be respected. Concept of pluralism is based on the idea that every voice counts. People bring into the system whatever they see fit. They practice whatever appears acceptable to them as long as they do not interfere with others’ rights and interests. This is a picture in which variety and freedom are highly valued. However, this is also a world in which people can easily get lost. Because it is pluralistic, no one direction is the direction; no one way of managing things is the way. This chaos is even evident in the realm of medicine. There seem to be so many options in the physician-patient relationship that only leads to confusion.

What make the profession of medicine different? Does the practice of medicine require more than the practice of other professionals? How much does a physician have to invest in his profession? To answer these questions, I have turned to the study of the Bible. The Philippians 2:15 says: “…that you may be blameless and innocent, children of God without blemish in the midst of a crooked and perverse generation, among whom you shine as lights in the world,” I found that the whole person of the physician must be involved in the practice of medicine. The physician is dealing with several different dimensions of relationships, both vertical and horizontal. S/He has to deal with herself/himself first, charging herself to be pure and holy. The physician will then deal with others: his/her colleagues, his/her teachers, and his/her patients. The physician will then deal with his/her society; s/he will start with the commitment to doing no harm and trying to do good. S/He will protect the society as a whole, protecting their integrity and interests by observing the rules set forth by the Law and common moral sense. S/He will
finally face her/his God. S/He is, therefore, accountable to her/his colleagues, her/his patient, her/his society, herself, and most of all, to her/his God. When a person enters the career of medicine, he/she is called to enter a career of morality.
Market-driven Biomedical Research:
A Major Challenge to “Everyday Bioethics”

Chan Chee Khoon1

Frontier bioethics has been focused almost exclusively on recent developments in biomedical sciences, for instance [in] organ transplantation, genetic therapy, cloning, use of stem cells, pre-implantation diagnosis, and transgenic technologies, which lead to unheard-of events and new moral categories. Everyday bioethics, less remote from the experience of ordinary people concerns the daily persistent conditions of most of the world's population, often difficult and sometimes tragic. [Even] among people who ignore the latest progresses of science, moral reflections on birth, gender relations, justice and autonomy, disease and health care, the interdependence of species, and death have a very long history - as long as that of humanity. These reflections guide today, wittingly or unwittingly, the decisions of all individuals, social groups, and communities, because "it must be shown that all men (sic)

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are ‘philosophers’, by defining the limits and characteristics of the 'spontaneous philosophy' which is proper to anybody”.

Giovanni Berlinguer
Lancet (September 18, 2004)

1. Some Pertinent Questions from the SARS Epidemic

In the SARS epidemic of 2002-2003, the microbial agent involved (SARS coronavirus) was swiftly identified and sequenced in a remarkable collaboration between otherwise highly competitive laboratories in Asia, Europe, and North America2.

These early exchanges however very soon gave way to a mutual wariness at the point when intellectual property claims were filed for the pathogen’s sequences and other patentable findings with commercial potential3.

Notwithstanding the rapid success in isolating 4 and sequencing 5 the SARS coronavirus, the epidemic quickly subsided in the absence of reliable diagnostics, vaccines, or efficacious therapies.

WHO gave much credit to institutional responses such as isolation, contact tracing, ring fencing, and quarantines (i.e. centuries-old techniques)6, with lesser mention of personal risk

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6 Gro Harlem Brundtland, Director-General, World Health Organisation “... SARS can be contained despite the absence of robust diagnostic tests, a vaccine, or any specific treatment. When awareness, commitment, and determination are high, even
avoidance and the possible contributions of seasonality effects or cross-reacting immunity from related endemic micro-organisms.

Most importantly, the economic and financial stakes involved ensured that SARS would not be a “neglected disease”.

A number of pertinent questions arise from these observations, which could be asked more generally of emerging biomedical technologies:

how important are biomedical advances (incl. genomics) to population health and to patient care (distinguishing perhaps between knowledge-based practices and coping responses, as opposed to consumable commodities?)

what is the relative significance of genetics in the etiology (and social ecology) of health and disease?

what are realistic expectations of the advances that genomics can contribute to disease control, diagnostic aids, and treatment? in what ways can pathogen genomics be most useful in epidemic control strategies?

what are the likely trajectories of genomics R&D in the foreseeable future, given the current modalities for funding of biomedical research, the associated regimes

such traditional control tools as isolation, contact tracing, and quarantine can be sufficiently powerful to break the chain of transmission ...” (WHO website, accessed on July 5, 2003).


9 while vaccines and efficacious therapies were not speedily available at the time (1998-1999), the knowledge that *Nipah encephalitis* was linked to a newly recognised *paramyxovirus* which could be transmitted through close proximity to live, infected pigs but not via insect vectors, fomites and suspended airborne particulates, or contact with raw or prepared meats (ascertained from virological studies, field epidemiology, and clinical medicine), allowed for its rapid control in humans, even as this control decimated the pig farming industry in parts of Southeast Asia.
of patents, intellectual property rights, and market-driven product development, and the chronically unresolved problems of neglected diseases of the poor?

what would be an enabling environment for the realization of the useful potential of genomics? for an equitable harvest of benefits and a humane deployment of genomic technologies that can avoid the emergence of a marginalized genetic underclass and the imposition of arbitrary, constructed norms?

what are acceptable processes and institutions for dealing with these policy and ethical issues, at the community, national, and international levels?

2. The Social Ecology of Health and Disease

Among public health practitioners, it is by now conventional wisdom that there is only a modest overlap between the “healthcare sector” (in the narrow sense), and the “determinants of health”10.

In 1962, Thomas McKeown advanced the thesis that the historical decline of infectious mortality in the 19th century (among the early industrializing countries) owed little to medical science and its derived technologies11.

In England and Wales for example, the mortality rate from a major killer, respiratory tuberculosis, had declined by more than 85% between 183812 and 1945, well before the discovery and isolation of streptomycin in 1947 by Waksman and Schatz (one of the early antibiotics effective against the

12 Tuberculosis mortality in England and Wales in 1838 was nearly 4000 deaths per million population (age-adjusted to the 1901 population).
tubercle bacillus\textsuperscript{13}) and well before the widespread availability of BCG vaccination from the 1950s onwards.

Clearly, other factors had been paramount in the decline of TB mortality in England and Wales, and McKeown and others went on to identify food intake and nutritional status, and from about 1870 onwards, potable water supplies and environmental hygiene as the key factors in the secular decline of infectious mortality\textsuperscript{14}.

Mortality by itself of course is an inadequate metric of population health status. Nonetheless, the recent efforts to invent more discriminating measures of disease burden which take into account morbidity, disability and functional capacities, and quality of life (Daly’s, Qaly’s, Hale’s for example) have not seriously undermined McKeown’s thesis, notwithstanding the evident efficacy of some modern therapeutics and procedures when used under controlled, favorable circumstances.

\begin{itemize}
  \item Robert Koch’s discovery of \textit{Mycobacterium tuberculosis} in 1882 had little effect on the rate of decline of TB mortality.
  \item RC Lewontin gives lesser weight to potable water supplies and sanitation, at least among the early industrializing countries, but may have downplayed the synergistic effects of diarrheal disease and malnutrition on childhood mortality, especially in poorer countries: “The history of tuberculosis is the history of nearly all the major killers of the nineteenth century. Whooping cough, scarlet fever, and measles, all with death rates in excess of 1,000 per million children, and bronchitis, all declined steadily with no observable effect of the discovery of causative agents, of immunization or of chemotherapy. The sole exception was diphtheria which began its precipitous decline in 1900 with the introduction of anti-toxin and which was wiped out in five years after the [US] national immunization campaign. The most revealing case is that of measles which killed about 1,200 in every million children in the nineteenth century. By 1960, despite the complete absence of any known medical treatment, it had disappeared as a cause of death in Britain and the US while in much of Africa it remains the chief cause of death of children. The causes of the tremendous decline of mortality from infectious diseases in the last 100 years are not certain. All that is certain is that "scientific medicine" played no significant part. Water supply and sanitation are not involved, since water-borne diseases have not been the major killers. The suggestion that a reduction in crowding may have reduced the rate of transmission of respiratory diseases is not altogether convincing, since measles remains pandemic although it kills virtually no one in advanced countries. The most likely explanation, both for the historical trend and for the differences between regions of the world today, is in nutrition, although hard evidence is not easy to come by”. (New York Review of Books, January 25, 1979).
\end{itemize}
Biomedicine (in the sense of consumable commodities as opposed to knowledge-based practices and coping responses) at best has contributed modestly to improvements in population health in the course of human history.

Even when effective therapies exist for responding to major public health emergencies, there can be non-technical political and economic barriers to these available options, most dramatically revealed by the ongoing campaigns for affordable essential drugs, in particular, for anti-retroviral treatment for people living with HIV/AIDS.

A broader perspective on etiology and the coping responses of human societies towards illness and infirmity was clearly needed and it was articulated at the International Conference on Primary Health Care (PHC) in Alma-Ata, USSR in September 1978.

The Primary Health Care vision and the practical requirements for its implementation were of course the distillation of prior cumulative experiences from countries such as China, Bangladesh, Cuba, and India.

Its intellectual lineage however (one branch of it, at any rate) was already evident in the writings of Rudolf Virchow15, and this has been further enriched in the last several decades by diverse influences from Thomas McKeown16, Rene Dubos17,
Richard Levins, Paul Farmer, Michael Marmot, Vicente Navarro, and others.

Along with this increasingly sophisticated and nuanced understanding of etiology, the “multi-sectoral approach” - the institutional and somewhat bureaucratic expression of the “new public health” - now appears as overly static, rigid and compartmentalized.

A social ecology of health and disease captures better the dynamic, interactive complexity, and the interpenetrating unity of the social, natural and created environments which embed the health and disease experience of individuals and populations.

3. Molecular Medicine: Justifiable Exuberance or Premature Genohype?

Dr Francis Collins, Director of the US National Human Genome Research Institute had earlier declared that the benefits from mapping and sequencing the human genome

“would include a new understanding of genetic contributions to human disease and the development of rational strategies for minimizing or preventing disease phenotypes altogether” 26, with further prospects of “genetic prediction of individual risks of disease and responsiveness to drugs...and the development of designer drugs based on a genomic approach to targeting molecular pathways that [have] been disrupted in disease [pharmacogenomics]” 27.

Five years on, in October 2004, the US National Academy of Sciences (Institute of Medicine) convened a conference in Washington, DC on Genomics and the Public's Health in the 21st Century at which participants reflected upon the modest progress which had been achieved in the interim.

On cancer treatment, where hopes had been raised for dramatic advances in therapy, Dr. Gilbert Omenn, a cancer specialist and president-elect of the American Association for the Advancement of Science was quoted as saying that despite an “avalanche of genomic information...cancers remain a largely unsolved set of medical problems [for which] we continue to rely on highly toxic drugs” 28. Herceptin, for HER2-positive metastatic breast cancer, and Iressa, for non-small cell lung cancer were two recent additions to the cancer armamentarium which had benefited from advances in molecular cancer biology, but these new therapies were not free from potentially life-threatening complications either. More

28 Patients have yet to benefit from genome research (Miami Herald, 12 October 2004) http://www.miami.com/mld/miamiherald/news/nation/9895562.htm
generally, genomics had made little impact on primary care medicine.

Indeed commentators like Richard Lewontin and others have argued that aside from the relatively rare Mendelian disorders such as cystic fibrosis, phenylketonuria, and Huntington’s disease where high penetrance genotypes are involved and allow for easier study of the associated molecular genetics, the overwhelming bulk of common chronic diseases (diabetes, coronary heart disease, cancers) have much more complex etiology which may include a familial component in addition to social, economic, psychological and biological factors.

The relationship between genotype (DNA sequence at the gene locus of interest) and phenotype (manifest traits) therefore becomes correspondingly murky and contingent so that the proportion of cases that can be attributed to susceptibility-conferring genotypes in a given population is typically small for common diseases such as breast cancer and colon cancer.

Even when the molecular genetics are tractable, the translation of knowledge of molecular pathogenesis into efficacious treatments is quite unpredictable. It took 70 years for instance for streptomycin to become available for TB treatment, from the time Mycobacterium tuberculosis was identified by Robert Koch as the microbial agent involved. More encouragingly, protease inhibitors (used in combination

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therapy along with reverse transcriptase (RT) inhibitors for treating HIV/AIDS patients) became available in the mid-1990s, i.e. about 10 years after the discovery of HIV-1. On the other hand the molecular (genetic) basis of sickle cell anemia was elucidated in the 1950s31, and palliative therapy has only recently become available32.

Similarly, there has been little advance in the treatment of cystic fibrosis (CF) fifteen years after the cystic fibrosis transmembrane regulator (CFTR) gene was identified and cloned in 1989 and details of the molecular pathogenesis worked out. By 1993, gene therapy treatments for CF patients had begun and early studies reported some success with adenoviral vector-mediated gene transfer. On subsequent review and further testing however, the earlier findings now appear equivocal in the wake of more stringent study protocols which did not replicate the earlier results 33.

4. Market-driven Biomedical Research and Product Development

Given that there has been quite limited success thus far with gene-based therapies, and few promising candidates on the horizon, commercial interest is likely to shift towards genetic testing for “disease susceptibility” alleles in line with a “paradigm shift” towards “predictive medicine” (genetic profiling of individuals for assessing risk of future illnesses). This has the added attraction that mass markets are involved, since the genetic testing for “disease susceptibility” may be applied in a routine manner as part of well-person (or well-child)

care and screening. Accompanying this almost certainly will be corporate R&D aimed at producing “pills for the healthy ill” (the worried well) to carve out sizeable new markets not just for screening tests but also for “prophylactics” for those deemed to be “at risk” and consequently anxious for the availability of some (commodifiable) risk reduction options.

As early as 1996, Hubbard and Lewontin had cautioned that

“serious difficulties arise from the relative ease with which information on DNA sequences can be acquired, when adequate knowledge of its correct interpretation is lacking. This can be seen in relation to the so-called breast-cancer genes BRCA1 and BRCA2. These two DNA sequences have both been linked to increased susceptibility to breast or ovarian cancer. To date, more than 100 variants of BRCA1 and several variants of BRCA2 have been identified. Only a few of them

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35 In anticipation of this expanded re-definition of “diagnosable disease”, global re-insurers are now shying away from insurance packages which provide guaranteed lump sum payments upon diagnoses of designated critical illnesses (typically, about 36 in number). The president of the Life Insurance Association of Malaysia (LIAM) KH Chia. stated that re-insurers worldwide had stopped providing guaranteed premium terms, and local insurers would follow suit in 2004 by adjusting premiums on a year-to-year basis in accordance with their claims experiences: “This trend is already happening in countries such as Hong Kong, Taiwan, Britain, Canada, Singapore, Australia, New Zealand, and South Africa... Since diagnostic techniques have been improving significantly due to continual medical research, it is now possible to detect conditions earlier which are not necessarily life threatening. This leads to early payout of claims for a risk [for] which the protection is not intended to [cover].” (The Star, December 20, 2003). The Consumers’ Association of Penang however sees this as a convenient pretext for prematurely raising premiums, merely on the expectation of hypothetical and quite unpredictable future claims experiences (The Star, December 21, 2003).

36 Hubbard & Lewontin (1996) ibid
however have been shown to be associated with tumor growth. They have been found predominantly among the small percentage of women who belong to families in which there is an unusually high incidence of one or both types of cancer or in whom breast cancer develops at an unusually young age. Yet about 90% of women with breast or ovarian cancer do not fall in these categories... it is not clear what a woman should do if she tests positive, since there are no effective measures of prevention (even such extreme measures as “prophylactic” bilateral mastectomy or oophorectomy provide no assurance that a tumor will not develop in the residual tissue).

Despite the biologic uncertainties and the potential for discrimination and other social and personal problems, biotechnology companies have begun to develop tests for DNA variants thought to be linked to “cancer susceptibilities”...worried patients, encouraged by overly optimistic claims by researchers, biotechnology companies, and the media, may want to have genetic tests performed whose validity has not been established. At the same time, physicians may legitimately feel at sea about the meaning, reliability and predictiveness of the tests. [Given] the underlying uncertainty associated with the tests themselves and their actual prognostic value, [usually] no practical consequences can be drawn from the information gained, however the test comes out.

37 more recent evidence suggests that among women with a BRCA1 or BRCA2 mutation, prophylactic bilateral total mastectomy reduces the incidence of breast cancer at three years of follow-up (H Meijers-Heijboer, et al. 2001. Breast Cancer after Prophylactic Mastectomy in Women with a BRCA1 or BRCA2 Mutation. N Engl J Med 345:159-64). In another study where BRCA1/2 carriers underwent bilateral mastectomy (as well as oophorectomy in some cases), the incidence of breast cancer was also markedly reduced after an average follow-up of 6 years (TR Rebbeck et al. 2004. Double Preventive Mastectomy Lowers Risk in Women with BRCA1 or BRCA2 Mutations. Journal of Clinical Oncology, March 15, 2004)
In the meantime, the test results can have disastrous implications for the psychological well-being, family relationships and employability and insurability of those tested.

While busily seeking to create markets for its commodifiable biomedical outputs, market-driven R&D and its corporate sponsors will continue to ignore and bypass the diseases of the poor, a scandalous situation which has been well documented by Médecins Sans Frontières (MSF):

of the 1,393 new drugs approved between 1975 and 1999, only 16 (or just over 1 percent) were specifically developed for tropical diseases (such as malaria, sleeping sickness, Chagas’ disease, kala azar) and tuberculosis, diseases that account for 11.4 percent of the global disease burden.

These diseases mainly affect poorer communities in countries of the South, which do not constitute a valuable enough market to stimulate adequate R&D by the multinational pharmaceutical companies.

An indication of their priorities was provided by the president of the Malaysian Organization of Pharmaceutical Industries (MOPI), Mr Lee Yee Chong who stated at a 2002 national health conference that the two top-selling patented

38 for 13 out of those 16 drugs, two were modifications of existing medicines, two were produced for the US military, and five came from veterinary research. Only 4 were developed by commercial pharmaceutical companies specifically for tropical diseases in humans (Michael Kremer & Rachel Glannerster, "Creating a Market for Vaccines", New York Times, June 1, 2001).


40 Health Ministry management conference - Facing the Challenges of Globalisation and the New Trade Agenda, October 10-12, 2002, Penang, Malaysia. Pfizer (Malaysia) when contacted by phone (Jack Lee, December 3, 2003) acknowledged that Viagra was its top-selling lifestyle drug, but that other product lines such as Lipitor (cholesterol lowering drug) had larger sales volumes. Mr Jack Lee however declined to rank Viagra’s sales volumes (or its profitability) among Pfizer’s
drugs in Malaysia at that time were sildenafil (Viagra) and orlistat (Xenical, a slimming supplement), i.e. two lifestyle drugs.

5. Responding to Market Failure: Public Patents & “Open Source”

Prompted by this persistent market failure and the harm and misery caused by the neglect, MSF has recently launched the Drugs for Neglected Diseases Initiative (DNDi), a consortium that currently includes MSF, WHO/TDR, Oswaldo Cruz Foundation/Far Manguinhos (Brazil), Indian Council of Medical Research, Institut Pasteur (France), Kenya Medical Research Institute, and the Ministry of Health (Malaysia) as founding partners.

A principal aim of the consortium is to take the development of drugs for neglected diseases out of the marketplace and to encourage the public sector to assume greater responsibility for a needs-based research and development agenda.

In the US, Congressman Dennis Kucinich is engaged in an admirable but uphill struggle against Big Pharma. He intends to take it beyond research and development in proposing legislation

“that would create a new network of government labs for the research, development and manufacture of pharmaceutical products and biologics... When discoveries are made, the patents would be held by the government and nonexclusive licenses would be attached to them. This would allow companies to compete to manufacture pharmaceutical products, just like generic drug companies do now. This would radically bring

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down the cost of drugs [and would also] increase the affordability of cures worldwide... We have watched the pharmaceutical industry fail on three counts: submitting fewer and fewer drugs to FDA for approval, creating "copycat" drugs instead of truly new cures, and raising drug prices higher every year. Our current patent system is what encourages artificial improvements and keeps prices high. It seems clear that one of the keys to public health is establishing public patents.

The European Commission (Research Directorate) is also a significant funder of international collaborative research in the health sector, through its INCO program. Researchers and research managers from the South have proposed that the fruits of such international collaborations could perhaps be similarly vested in international agencies (trustees) such as the World Health Organisation (WHO), to keep the prerogatives within the international public domain.

43 on September 3, 1999, US activists Ralph Nader, James Love, and Robert Weissman wrote to Harold Varmus, Director of the US National Institutes of Health “to ask that you enter into an agreement with the World Health Organization (WHO), giving the WHO the right to use health care patents that the US government has rights to under 35 USC Sec 202 (c)(4) of the Bayh-Dole Act or under 37 CFR 404.7, for government owned inventions. Under the regulations concerning government-owned inventions, the US government has an “irrevocable, royalty-free right of the Government of the United States to practice and have practiced the invention on behalf of the United States and on behalf of any foreign government or international organization pursuant to any existing or future treaty or agreement with the United States. 37CFR404.7(a)(2)(i)” With respect to government's rights in inventions funded by the US government through grants and contracts to Universities and small businesses under the Bayh-Dole Act, the US government has worldwide rights to practice or have practiced inventions on its behalf (37CFR401.14), and it may require that foreign governments or international organizations have the right to use inventions, under 37CFR401.5(d). As you must know, the US government has rights to a large portfolio of health care inventions that were invented with public funds. These include inventions in many HIV/AIDS drugs, such as government-owned inventions on ddI, ddC and FddA, and university and contractor inventions such as d4T, 3TC and Ritonavir, as well as drugs to treat malaria and many other illnesses. The private pharmaceutical companies that have obtained exclusive rights to market
At the moment, the EC’s policy objectives are geared more towards the R&D needs of SMEs (small and medium enterprises), which lack the in-house R&D capacity of larger firms. SMEs, many of them innovative and dynamic, are viewed as the preferred vehicles for commercializing the outputs of EC-funded research in science, technology, and development.

This is not necessarily incompatible with the publicly-held patents and nonexclusive licensing as envisaged in the Kucinich initiative, or with other scenarios which the “open source” movement is actively deliberating, experimenting with, and promoting for knowledge-intensive industries. (The stereotypical model was pioneered by software writers for open-source applications such as the Linux computer operating system, but the generic ideas are now making inroads as well into the scientific publications and communications arena).

6. Concluding Remarks

Recent experiences with emergent and resurgent infectious diseases have cautioned us to retain a sense of proportion when considering disease etiology as well as society’s coping responses to such challenges.

A sense of proportion is also essential for constantly reminding ourselves of our troubling capacity for selective

definitions, including persons in the United States and Europe. Most seriously, the hardships are particularly difficult in developing countries, where countries do not have high enough national incomes to pay for expensive medicine”. Dr Varmus, in his reply dated October 19, 1999, stated that “Congress enacted the Bayh-Dole Act and the Stevenson-Wydler Technology Innovation Act (with later amendments, including the Federal Technology Transfer Act of 1986) to encourage the transfer of basic research findings to the marketplace. The primary purpose of these laws is economic development: specifically, to provide appropriate and necessary incentives [through exclusive licenses] to the private sector to invest in federally funded discoveries and to enhance US global competitiveness”. A subsequent request dated March 28, 2001 and addressed to US Secretary of Health and Human Services Tommy Thompson was similarly denied.

44 during the SARS epidemic, there were loud laments about a societal (or individual) “overreaction” in the risk avoidance responses to the outbreak, with the resultant
anesthesia 45, for “normalizing” human health disasters especially when they occur among marginalized communities with limited “voice” – most glaringly, 3.1 million AIDS deaths (2.3 million of them in sub-Saharan Africa) in 200446, more than one million malaria deaths annually in poorer countries, and similarly high fatalities from tuberculosis, waterborne diseases (most importantly, diarrhea), malnutrition, and other preventable diseases of poverty often acting in concert.

A social-ecological perspective of health and disease47 teaches us to be wary of the extravagant claims of genohype, i.e. genomics as all-round panacea for the major health (and social) problems of humanity.
THE NATURE AND MEDICAL IMPLICATIONS OF HUMAN GENETIC INFORMATION

Kon Oi Lian

The aim of science is not to open the door to infinite wisdom, but to set a limit to infinite error.
Bertolt Brecht (1898 – 1956)
The Life of Galileo

Genetic information is most readily associated today with the human genome sequence that was effectively completed in April 2003, 50 years after the double helical structure of DNA itself was discovered. Completion of the genome sequence is widely celebrated not only as a technical tour de force but equally, for the strong and visionary leadership of an exceptional international collaboration that involved 20 laboratories in the USA, UK, France, Germany, Japan and China.

The human genome: sequence and topography

The genome sequence is a linear readout of four bases, A, C, G and T (adenine, cytosine, guanine and thymine) that is, at first sight, completely incomprehensible as the following snippet from human chromosome 22 illustrates:

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aaggactctg tacctcctat ccacgtcaga gatttcgatt
ccacgtcaga gatttcgatt ttagttctt cctctgggca
aggagagaggctg gcactgggg agggacttgg tgaagtcagt
ggcaggccct gggtctaacct ggaagtcagt ggggccctgag
ctggtgtagg tgctgaatgc ttcctgcata tcctgcata
tccagcgct ggctggcaag gtcctacgct
tccaaaaggctttcctgacc
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The genome sequence is, in fact, arranged chromosome by chromosome and can be ‘read’ in 24 ‘chapters’ – each chapter being an autosome or a sex chromosome. The total number of ‘letters’ (or bases) in all chapters is about 3,000,000,000 and is freely available from websites of the International Human Genome Sequencing Consortium (www.ncbi.nlm.nih.gov/genome/guide/human/; www.ensembl.org/Homo_sapiens/; genome.ucsc.edu).

The sequence lends itself naturally to linguistic and literary analogies. Thus, it has been likened to a blueprint, parts list, history book, future diary, instruction manual and even, the ‘Book of Life’. Unlike conventional texts however, the genome ‘language’ is like no other yet known to humankind. The information content of the genome is embedded in a language whose vocabulary, syntax and architecture is well encrypted. To date, only the lexicon of the triplet genetic code, features required for gene splicing and basic motifs of some regulatory (gene controlling) elements are known.

Notwithstanding these limitations, the reference sequence of the human genome has already revealed certain features of our species. The feature that has arguably attracted most
publicity is the surprisingly modest gene count - currently estimated to be about 25,000 genes, which places Homo sapiens somewhat above a worm (Caenorhabditis elegans, 19,820 genes) and on par with a mustard plant (Arabidopsis thaliana, 25,498 genes). It should be noted, however, that current gene annotations of the genome sequence rely heavily on computational predictions and comparative genomics, and that the true inventory of human genes awaits experimental validation.

Other evident features are the ‘lumpiness’ of our genome and the predominance of non-coding DNA. Almost every known topographical feature, such as genes, GC content and repetitive DNA, is spread unevenly across the genome landscape. Thus, there are gene-rich regions (e.g. 22q13) as well as gene deserts (e.g. 21q21), GC-rich and GC-poor regions. Unlike the genomes of many other species, about 97% of the human genome sequence is non-coding i.e. does not specify a protein or RNA product. Repetitive DNA sequences form a substantial part of the entire genome and are, in part, the palaeontological detritus of our species.

**Genomic variations are informative**

While much of the information that specifies our species (and each person) is at present locked up in a largely unparsed text, it is equally true that we already have a tentative inventory of human genes, a growing catalogue of gene variants, disease-causing mutations and other apparently innocent variations. As gene mutations are reviewed elsewhere in this volume, other genetic and genomic variants that are not conventionally regarded as mutations will be considered here.

Human individuals are estimated to differ in 0.1%, or 3,000,000 base pairs, of their genome sequence. There are several molecular forms of genomic variation, namely simple sequence repeats, sequence insertions, sequence deletions, insertions-deletions (indels) and single nucleotide polymorphisms (SNPs). Of these, SNPs have attracted most interest to date because of their occasional but medically relevant association with human biological responses and functions. A SNP is like a spelling variation that may or may not change the meaning of the word. In the example below, two base positions are variable among four persons.

| Person 1 | ATTGA TAGGAT... CCATC GGA... CTAA |
| Person 2 | ATTG C TAGGAT ... CCATC TGA ... CTCA |
| Person 3 | ATTGA TAGGAT... CCATC GGA ... CTCA |
| Person 4 | ATTG C TAGGAT ... CCATC TGA ... CTCA |

The human genome is a surprising cornucopia of about 10 million different SNPs. As such a large number would be extremely challenging (if not impossible) to analyse by current technology, it is a fortunate happenstance that groups of SNPs closely located in the same chromosome are co-inherited as blocks (boxed in the examples below) known as haplotypes. It is estimated that haplotypes number about 500,000, making SNP analysis for linkage and association studies more manageable.
SNPs and other variations effectively form an infinite number of combinations. Each combination, known as a genotype, resembles a product barcode in which each stripe of the barcode represents a haplotype, sequence insertion, deletion or indel.

Given the large number of SNPs alone, the combinatorial possibilities effectively make each person’s genotype unique and distinguishable from all other persons, with the possible exception of monozygotic twins. This useful fact was quickly recognised many years ago and led to the early adoption of genotype information in forensic genetics.

Why SNPs are interesting

Single base substitutions and other variations that are not mutations could easily be an esoteric footnote in genome science but for the fact that some SNPs are associated with specific phenotypes (external manifestations of characteristics or function) of medical relevance. The following examples illustrate reasons for the high degree of medical interest in inter-individual genomic diversity.

It is common experience that different people may respond differently to the same chemical agent or medication. The biological basis for this is becoming clear from investigations of inter-individual genomic variations. It is well known, for example, that pain control is variable in different people treated with the same medication such as codeine. The therapeutic effect of codeine requires its metabolic conversion to morphine by an enzyme known as CYP2D6. At least 77 different CYP2D6 alleles (variant forms of a gene) are known, most of which harbour SNPs and some which reduce the efficiency of codeine conversion to morphine. Those who inherit such alleles (7-10% of Caucasian populations) are known as poor metabolizers and are liable to experience poor pain relief from codeine.

Polymorphisms (variations) in non-coding sequences may also correlate with phenotypes. The SLC6A4 gene encodes a transport protein for re-uptake of serotonin (a neurotransmitter or brain signalling chemical) at nerve endings, thus terminating its action. The promoter of the SLC6A4 gene carries an insertion/deletion polymorphism, giving rise to two allelic variants – the long (L) and short (S) variants. Two hundred and four Caucasian college students in the USA were genotyped at the SLC6A4 promoter and also questioned about their alcohol consumption behaviour. The results showed that the overall amount of alcohol imbibed was comparable
among students with the L or S allele. However, those with the S allele were significantly more likely to engage in binge drinking and to drink with intent to inebriation. This and other association studies can be investigated beyond empirical correlations to uncover the biological substrate of social and cognitive behaviour. Tracking down culpable genes from genotype-phenotype associations exploits the conceptually simple principle of guilt by association. Identification of disease genes and genes that shape the diversity of human responses and behaviour has accelerated with recourse to high resolution genome maps and the genome sequence.

What’s special about genetic information?

Awareness of genetic information has spread among the public almost as rapidly as genome science itself has advanced, thanks largely to intense media interest. Genetic information is widely regarded as being more penetrating and far reaching than any other type of medical information, and therefore potentially more threatening and sinister.

Several unique characteristics are imputed to genetic information. A person’s genotype not only reports on his present state but may be informative of his past and likely future as well. The spectre of predictive genetics with the attendant risk of being numbered among the healthy sick is naturally disquieting. The much publicised potential of genetic tests to forecast a person’s future state of health or disability may explain why the high level of public interest in medical genetics is not, in general, matched by equal enthusiasm for being personally genotyped.

The reach of genetic information does not stop with individuals because genotypes, being inherited, are also informative of families, communities and ethnic groups. Thus, genotyping families as social units may uncover genetically unrelated individual family members. Genotyping communities and ethnic groups could provide information on past population migration patterns and traits of medical significance e.g. disease susceptibility and drug response.

Owing to the far-reaching ramifications for yielding a wealth of medically important information, genetic databases have substantial value to the pharmaceutical and biotechnology industries for drug and diagnostics development, while genotypes are sought by insurance companies to improve risk assessment of clients. However, although it is probably premature to predict accurately the future returns to industry and to quantify the commercial value of genetic information, it is important even now to allay fears of exploitation of and disrespect for human volunteer research subjects whose collective genotype and medical data are essential for medical progress.

Of all the purported special characteristics of genetic information, what is arguably unique about DNA-derived information is that the source material may be rendered indefinitely accessible, with or without the subject’s knowledge. Immortalisation of lymphocytes (a type of white blood cell) has long been practised in family and populations studies for selected individuals who are deemed to have particular value to the investigation or elderly subjects whose death may compromise the quality of the study.

Sources of genetic information

Rehearsing the characteristics of genetic information above without qualification reflects a naïve, and possibly disingenuous, view that calls for urgent correction. A highly pervasive misperception, even among medical professionals, is to regard DNA-based tests as the only
source of genetic information whereas, in truth, almost all other forms of medical information have substantial genetic content. Examples abound but a few should suffice to prove the point. Haemoglobin analysis is not generally thought of as a genetic test, yet is the clinical \textit{sine qua non} for diagnosing a large group of genetic diseases i.e. thalassemia, sickle cell disease and other haemoglobinopathies. We readily submit to blood cholesterol tests without realising that the result could well be informative of our genotype. Similarly, blood glucose levels may be as genetically informative as the result of a breast cancer gene test, while some genetic diseases are immediately identifiable simply on plain radiographs or even, from photographs of a person’s external appearance. An especially rich source of genetic information is obtained from interviews that take a careful family history of disease prevalence and past drug responses.

It behoves us to dismantle the false dichotomy between DNA-derived information and all other sources of medical information because this has given rise to the current two-tier approach to safeguarding confidentiality of patient information. Thus, DNA-derived data are treated with procedurally elaborate and physically stringent security measures while at the same time, laxity in handling all other medical records and information is tolerated, and indeed considered quite acceptable. If one accepts that all medical information has actual or potential genetic content, it follows that to establish highly stringent procedures to protect DNA-based information from illicit access and disclosure while concurrently accepting considerably lower standards of protection for other sources of medical information is irrational, and more important, negligent.

Retreat from reductionism

Severely reductionist models of human biology are in retreat as human genome science advances beyond sequence to function. Notions of genetic determinism are disabused by increasing evidence from investigations of gene-environment and gene-gene interactions, especially in the context of disease occurrence. A recent example of such evidence emerged from a study of more than 1000 women who were carriers of breast cancer gene (BRCA1 or BRCA2) mutations, and their families.\cite{4} The study confirmed that female carriers have higher than average lifetime risks of developing breast and ovarian cancer. This finding in itself was unsurprising because BRCA1 and BRCA2 are well known cancer susceptibility genes. What was surprising was the marked difference in cancer risk of women by their year of birth. Women born before 1940 had a 24\% risk of developing breast cancer by age 50, whereas women born after 1940 were at 67\% risk. This striking difference demonstrates that even among individuals of known genetic risk, interacting non-genetic factors are likely to significantly influence eventual cancer development.

Single-gene (monogenic) disorders such as thalassemias, cystic fibrosis, inherited colorectal cancer, have been regarded until recently as simple genetic models of one gene-one protein-one disease. This view must now be nuanced to accommodate indubitable evidence that individuals of the same family who inherit identical single gene mutations may manifest quite different severity of the same disease. Where these phenomena have been investigated, it transpires that other genes modulate the effect of the dominant disease-causing gene. As examples of gene-gene interactions in human diseases increase, we may eventually be led to conclude that diseases are rarely, if ever, monogenic, but rather that all diseases result from the interplay of at least a few genes (oligogenic) or many genes (polygenic). Some degree of retreat from reductionism is inevitable and should temper our current naiveté of predictive medical genetics, diminish unwarranted fear of genetic information considered \textit{in vacuo}, alleviate the
anxieties of individuals for whom genotyping is clinically indicated and contribute to non-discriminatory use of genetic information.

**Genomic medicine**

Human genome science has already begun to transform medical practice that will increasingly fit the descriptor, genomic medicine. By deepening our understanding of human biology, genetic and genomic information will spawn new strategies for preventive medicine, and drive the development of superior diagnostics and therapy. Among recent trends are new disease taxonomies based on gene expression and genomic signatures. Biologically more precise disease classification, in turn, enhances diagnosis, identifies novel drug targets and broadens the options for effective treatment.

The template for bespoke medicine requires sound understanding of how individual genotypes correlate with medically significant phenotypes. The prospect of treatment individually tailored to one’s genetic constitution – already a reality - has great appeal but also clear implications for healthcare economics. It is obvious that reaping the societal and commercial fruits of genomic medicine demands appropriate but not excessive rewards for commercial research and development that nearly always have strong roots in publicly funded research. An equitable balance of interests and needs could be achieved through enlightened public policy that places high priority on preventing the emergence of a new underclass of citizens without access to genomic medicine.

**Bioethics redux**

The ever-increasing incursions of genome science into clinical practice have practical consequences for medical ethics. A discontinuity in ethics has become apparent with the rise of genome science and its application to medicine. At the very least, these developments compel re-examination of several norms of traditional medical ethics. These include determining the proper boundaries of confidentiality of medical information between physician and patient, and between patient and family, developing clinical and research databases for society’s benefit while protecting individuals from stigmatisation, achieving equipoise of individual and community rights and interests, resolving increasing inequity from the high cost of genomic medicine, rewarding human research volunteers appropriately, recruiting research subjects in the true spirit of informed consent by means of culturally appropriate processes, and developing an ethically coherent framework for collaboration between public and private sector research. Dealing well with these and other issues demands considerably higher genetic literacy than currently exists, openness to a diversity of views and willingness to engage all thoughtful stakeholders.

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Medical Ethics: The Challenge of HIV/AIDS

Augustine Musopole

Introduction

In a paper titled “Protection of Substantive Life: The Challenges of Medical Ethics”, presented to the Formosa Christianity and Culture Research group, M.P. Joseph stated, “An evaluation of medical ethics should enquire how the practice of the present health care system contributes towards the restoration of the total health by reversing the process of alienation between people, nature, and God.” It is the purpose of this paper to continue the discussion especially in relation to HIV/AIDS in the world generally, and Malawi in particular, with a view to drawing some lesson for medical ethics in general.

In this paper, I propose to proceed in the following manner. I will start by placing the discussion in a theological context by focusing on the relationship between theology and the scientific enterprise; then I will move on to discuss issues

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1 Rev. Dr. Augustine Musopole is Professor at Chang Jung Christian University and at Tainan Theological College and Seminary.
2 Paper presented at a seminar on Medical Ethics, Formosa Christianity and Culture Research Centre. Tainan.
related to health and medical ethics before looking at HIV/AIDS and the challenges it poses for medical ethics.

Towards a Scientific Theology for Medical Ethics

The debate on the relationship of theology and science, or broadly put, between religion and science has been on-going for the over three centuries now. When the regal status of theology as the queen of the sciences was challenged leading to its dethronement through the Enlightenment period, the ascendancy of science leading to the success of the industrial revolution, a new scientific world was born with practically no room for theology. Since then theology has been on the defensive against the power of the scientific method and outlook as they both contended for the human soul. However, very often the debate has remained a monologue as each party championed its position without paying much attention to what the other was saying.

The Place and Role of Theology in Medical Ethics

Joseph hinted on the relationship between theology and medical ethics when he asserted that the Biblical view of sickness had to do with brokenness of relationship with God and that healing is understood “as the restoration of the right relationship with God, and with fellow human beings, and with nature.” Then he went on to state,

…healing does not mean merely normalization of the function of a particular organ but the sanctification of life by rediscovering its authenticity and quality as created in the likeness of God. Alienation from the nexus

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3 This is the basic meaning of the Hebrew word Shalom, often translated as peace. Peace has to do with healing, restoring to wholeness, and keeping it that way. Peace in not simply absence of conflict or pain, but restored relationships.
of God - people - nature is the root of the [medical ethics] crisis and, therefore, restoration of this nexus is the true act of healing.

He then went on to draw our attention to the definition provided by the World Health Organization that understands health as a state of complete physical, mental, and social well-being.

Joseph went on to challenge the group by asserting that it is not only the human body that requires healing since its brokenness is part of a greater brokenness involving the entire cosmos. Therefore, it is only in the context of the restoration of the entire cosmos that medical ethics can be comprehensively discussed.

Thomas Torrance⁴ points to the fact that the universe requires redemption from disorder. He states, “In Christian theology, that redemption of the universe is precisely the bearing of the cross upon the way things actually are in the universe of space and time. It represents the refusal of God to remain aloof from the disintegration of order in what he has made, or merely to act upon it ‘at a distance’. It is his decisive personal intervention in the world through the incarnation of his Word and love in Jesus Christ. In his life and passion he who is the ultimate source and power of all order has penetrated into the untouchable core of our contingent existence in such a way as to deal with the twisted force of evil entrenched in it, and thereby to bring about an atoning re-ordering of creation.”⁵

Alister McGrath⁶, the author of the book on T.F. Torrance, comments, “This atoning re-ordering of creation’ is to be understood as an engagement with the ‘source of disorder’. The resurrection of Christ is understood as the means by which God

⁴ Emeritus Professor of Theology at Edinburgh University and has written much on science, theology, and theology as a science.
⁵ Alister McGrath; T.F. Torrance, Edinburg: T&T Clark, 1999 p. 226
⁶ He is Professor of Theology at Cambridge university and author of many books on historical theology.
‘triumphs over the forces of disintegration and disorder in the cosmos’. Redemption can thus be understood as re-ordering – that is, restoring the God-given order in which the cosmos came into being.” While this disorder affects humanity in particular, nevertheless, redemption must be understood to embrace the whole created order which had fallen into disorder.

This cosmic dimension gets forgotten often when we speak of salvation and healing. These two last words are meant to imply each other when their meanings are properly delineated. There is need for being constantly reminded that God deals with humanity in Christ within a cosmic context. St. John, in his gospel states, “For God so loved the world that he gave his one and only Son, that whoever believes in him shall not perish but have eternal life.” So too St. Paul writes, “The creation waits with eager expectation for the sons of God to be revealed. For the creation was subjected to frustration, not by its own choice, but by the will of the one who subjected it, in hope that the creation itself will be liberated from its bondage to decay and brought into the glorious freedom of the children of God.” The poet Max Ehrmann also reminds us of this fact of being involved in the cosmic relations when he writes in a famous poet called “Desiderata”

“You are a child of the universe, no less than the trees and the stars; you have a right to be here. And whether or not it is clear to you, No doubt the universe is unfolding as it should. Therefore, be at peace with God, Whatever you conceive Him to be, And whatever your labors and aspirations, In the noisy confusion of life, Keep peace with your soul.

7 Alister McGrath; op.cit. p. 227
8 John 3:16
9 Romans 8:19-21
With all its sham and drudgery, and broken dreams,
It is still a beautiful world.
Be cheerful. Strive to be happy.”

McGrath observes, “For Torrance, humanity has a special – indeed, unique – place within creation. Not only has humanity been created in the image of God; redeemed humanity has also been entrusted with the task of exercising a ‘priestly and redemptive role in the world’. Once healed of its internal disorder and disunity, humanity may undertake this role.”

Therefore, theologically this understanding has serious implication for the human vocation in the universe of which it is a very critical part in terms of what one might call our community of life in God, with God, and under God. To this end, we must say with McGrath, “the fact that God has taken the way of becoming man in allying himself with contingent existence and thereby effecting the redemption of the creation from within its ontological foundations, immensely reinforces the unique place of man in the universe. And in that it is redeemed man who is established at the head of the whole system of inter-level interaction throughout the created order, man’s priestly function in the universe now takes on the pattern of a redemptive mission to nature.”

According to McGrath, Torrance takes the position that, “it is in this light that Christian theology must regard man’s God-given role in the natural scientific enquiry, that is, not only to be the constituent element in the universe whereby it unfolds and expresses its inherent rational order, but to be the instrument under God whereby physical evil and disorder are rectified and made, contrary to what they may actually be, to serve the whole created order. However, it is only as man himself is healed of his own inward split that he may exercise a truly integrative and

10 Max Erhmann, Desiderata, 1952
12 ibid. p. 227
re-ordering role in the world around him.”¹³ Torrance thinks it important that theology and science should collaborate in order to have a better understanding of human existence and to serve that existence in a rational manner. He finds that relationship in a common understanding of the scientific method that goes beyond the realm of the natural to embrace the supernatural.

Therefore, one of the most important tasks that Torrance faced was the neutralizing of the notion that science and theology were in conflict. However, this could not be done within the traditional theological understanding of the universe and methodologies because as Torrance perceived two problems with the traditional approaches to theology. The first is that there was as he put it “an unresolved epistemological dualism, whose roots could be discerned in Augustine, that lay behind much of western theology” Such a dualism was both improper in itself, and inhibited the dialogue with the post-Eisteinian natural sciences which deliberately eschewed such dualistic approach.¹⁴ The second problem was that Eistein’s unitary way of approaching nature was characterized by its integration of empirical and theoretical factors, so that ontology and epistemology were wedded together. Theology as traditionally done was perceived by Torrance as presenting difficulties in relating spirit and matter.

Therefore, for Torrance, science and theology were not to be understood as two non-interacting disciplines, as if each could exist in hermetically sealed compartments of the mind. He states, “It is the same mind which carries on the two different tasks, and at the back of the mind in each case there is a belief in the ultimate consistency of things as they are in themselves . . . In science the scientist concerns himself with natural causality. In religion we have to remember that the will of God entered into events . . . Indeed, it may be said to be the prerogative of religion to see and live by the fact that everything is viewed

¹³ ibid. p.227
¹⁴ ibid. p.142
within the operations of providence.\textsuperscript{15} There was need to restate the meaning of science in order to overcome the apparent obstacles that seemed to persist in the relationship between science and religion that was having an adverse effect on disciplines as medical ethics. Torrance came up with two related senses of the term science: (1) Science as the general concept of careful and impartial investigation proceeding by carefully defined method; (2) that activity of the mind which investigates by certain well defined methods the world of empiric actuality, the world of phenomena in abstraction from its relation to individual and personal situations and values. Of these two understandings of science, Torrance takes the first one as primary and basic understanding of what science in general should be. It is not restricted to any one particular field, but applies to all fields of knowledge—religion included. Unfortunately, the current view of science has restricted itself to the natural observable phenomena which Torrance finds to be too narrow an understanding and part of the problem. Therefore, only in the first sense of science can theology find its scientific role and thus contribute to human knowledge in a meaningful and rational manner. In this way rationality and faith would not be antagonistic to each other, so too revelation and scientific research.

What would be the relationship between science and theology given this new understanding that is not dualistic? What follows is a summary of Torrance’s view of a theological science:

Theology is a human discipline which aims to use human reason, to the extent that is possible, an ordered account of what can be known of its object. It shares this desire to yield an ordered account of things with other sciences. Theology alone recognizes the self-revelation of God in Christ as its object, and hence as the sole foundation and criterion of its affirmations.

\textsuperscript{15} ibid. p. 201
From this it follows that “Theological science may thus be conceived as “rational recognition of and willing submission to the claims of objective reality upon us and of obligation towards the truth laid upon us by the truth itself.’. Epistemology thus follows ontology, in which it is rooted and upon which it is dependent. Theological science is thus to be understood as based upon an ‘ontological anchoring of belief in reality transcendent to ourselves’, which thus necessitates the recognition of and the response to that which is independently and universally true.”\textsuperscript{16}

For Torrance the epistemological center and focus of responsible Christian theology is Jesus Christ. He states, “We direct our minds to the self-giving of God in Jesus Christ and allow our minds to fall under the power of the divine rationality (wisdom rather) that becomes revealed in him. It is a rationality inherent in the reality of the incarnate Word before it takes shape in our apprehension of it (aposteriori), but as we allow it to become disclosed to us under our questions and find that it opened out before us in an objective depth that far transcends what we can specify of it in our formulations.”\textsuperscript{17}

By developing its own methodology in order to get to grips with the reality thus experience in revelation of God in Jesus, theology can be scientific and be in dialogue with other scientific undertakings in other fields. In Christian theology, Torrance maintains, “Christ is thus like a lens, allowing us to see the created order in its proper light and from its proper perspective.” Theology develops from movements of thought in which we seek to know God strictly in accordance with his own nature (my emphasis), and in terms of God’s own internal

\textsuperscript{16} ibid. p. 218  
\textsuperscript{17} ibid. p. 219. I consider the term rational to be of a secondary epistemological level to wisdom. The preferred biblical word is wisdom. St. Paul refers to Jesus as the Wisdom of God and not the rationality of God. Wisdom is closely associated with life and hence it has also an ontological implications part from its epistemological implications. Jesus is both life and wisdom of God. It is with this understanding that the Johannine prologue should also be understood. The logos understood in the context of Hebrew thought and not Greek thought only.
relations are disclosed through the incarnation. Without Jesus
knowledge of God lacks an ontological basis in personal human
experience. This divine touch enlightens the human condition in
a way that science can never do being limited only to the
empirical world of nature. Therefore, Torrance asserts,

Science only informs us what light is thrown upon reality
by empirical observation of the facts of external nature.
When science claims that this is all that can be said, it is
no longer science but species of philosophical theory
called naturalism. . . When applied to man, science
interprets his nature in terms of chemical constitutions,
physics and biology. This is certainly one side of the
truth, but it is not the whole truth. (It is partial Christian
truth). But religion will not allow us to rest on this side
of truth as if it were the truth. But revelation comes in,
and we are disturbed. We are not allowed to adopt the
naturalistic view of ourselves. We are challenged by a
transcendental claim from God upon us. . . . Naturalism
cannot be answered but by revelation . . . Unless God
speaks to man, he is nothing more than an chemical
episode. 18

While the natural science have been very successful in
unlocking the vault of natural knowledge, the human existence
seems to point to a realm beyond the natural, but that takes the
natural seriously. After all is said, both theology and natural
science are based on some form of faith, either faith in a rational
God or a rational natural world and the difference will be seen in
how adequately each informs human existence.

Theology and Medical Ethics

18 ibid p.201-202
So what role do we assign to theology in medical ethics? Medical ethics is not beyond the purview of theology and both according to Terrance, being sciences rationally grounded can be mutually illuminative. Medical ethics needs to face the ultimate questions related to human existence, meaning, and destiny if it is to be adequately relevant to human existential needs, of which health is one of them. Medical ethics need to situate itself into the universal understanding and need for healing. Theology needs to take seriously the material aspect of human existence and not simply the spiritual aspect. Human beings are existentially wired into the cosmos and are affected by it—in terms of seasons, movement so the moon, stars, the sun, the air and the water, etc. as testified by many religious traditions. Theology has to realign its methodology to an understanding of the cosmos that is ordered and unified even though broken by human alienation. Therefore, medical ethic is being challenged to widen its horizons of theoretical understanding by taking in the whole of reality including God because to limit itself to the natural and the human is to adopt a narrow agenda bound to distort reality.

Understanding the concerns of Medical Ethics

The Hippocratic ethical code for physicians was a professional code to which physicians pledged their allegiance in the performance of their duties. Among other things, they pledged to work for “the benefit of the sick according to my ability and judgment.” It is the patient who is the primary concern as they carry out their services in and to the community. Following from this code various countries have developed professional ethical codes that include the following ethical concerns: rendering service to humanity; confidences to individuals and communities; services with compaction; respect for human dignity; commitment to rights of patients; health and safety of patients; interest of society; cross-cultural differences; preventive vs curative medical practice; dominant virtues:
strength, fortitude, wisdom, understanding, honest, modesty, merciful, objectivity, humanness, compassion and filial piety; commitment to poor; covenanting vs contracting; by which authority are moral decisions arrived.

Robert Veatch observes that “The concept of rights, totally alien to the Hippocratic ethical tradition, has its roots in liberal political philosophy.”\(^{19}\) Medical ethics is no longer the preserve of medical practitioners, but the concern of all who are beneficiaries of healthcare providing services. This lays obligations on all concerned living together as a community of mutually dependent person and as each other’s keeper. In a pluralistic society, various people are informed by various ethical principles and this can lead to much conflict and misunderstanding. Robvert Veatch states, “Whatever the principles in the bio-medical ethics are called, they represent the following sorts of moral considerations:

1. Obligations to respect the wishes of the competent persons (respect for persons and autonomy)
2. Obligations not to harm others, including not killing them or treating them cruelly (non-maleficence)
3. Obligation to benefit others (beneficence)
4. Obligation to produce a net balance of benefits over harms (utility)
5. Obligation to distribute benefits and harms fairly (justice)
6. Obligations to keep promises and contracts (fidelity)
7. Obligations of truthfulness;
8. Obligations to disclose information
9. Obligations to respect privacy and to protect confidential information (confidentiality) (Veatch: p.32)
10. Obligation having to do with research: targets, methodologies, experiments, and results,

\(^{19}\) Robert Veatch, *Medical Ethics*, Boston: Jones and Bartlett Publishers, 1969: 15
James Childress raises some important questions related to these obligations. He writes,

The difficult questions of biomedical ethics do not concern whether to invoke and to apply principles and rules. Rather the difficult questions are which principles and rules should be adopted, how should they be interpreted, how much weight and strength should they have, which should have priority in cases of conflict, and in what relations and situations do they apply? Answers to these questions are not easy, but seeking answers in the context of science, medicine, and health care is the fundamental task of biomedical ethics.\(^{20}\)

Can the narrow scientific approach provide answers to these questions since they go beyond the competence of such a science. This is where the acceptance of theology as a scientific field with its own methodology and even content can be of some help.

**Ethical Implications of Views on Sickness and Disease**

Arthur Caplan in a chapter on “The Concepts of Health and Disease” argues for the need to come up with clear definitions and understanding of the concepts of disease and sickness in order to make sense of the ethical implication of healthcare provision. For Caplan, it is not just the principles that present problems, but also the very understanding of what constitutes sickness, disease, and wellness. He discusses the concept of disease in America of the 1980 when he says, “Sickness and disease often signify disability and dependence – states that are abhorred by a nation with a can-do ethic and belief that life finds greatest value in the expression of individual choice and action. If , as some commentators suggest,
Americas define themselves by their work or occupations as much as by any other criteria, then health is crucial to our self-perception since it is a necessary means to the achievement of productive work and thus, self-respect.”

Therefore, medical ethics is not just limited to the body, but has implication for other areas of our existence as well, for instance, mental health, social welfare and wellbeing, and human self-fulfillment or destiny.

He goes on to state, “The alleviation of disease and disability and the promotion of health are important political and cultural goals for our society for the same reasons special priority is given in our social policies to the provision of education, shelter, and food. All these factors influence the extent to which equality can legitimately be said to exits with respect to opportunities and, therefore, to the extent to which the inequalities which necessarily result from a free market approach to the distribution of social resources can be viewed as morally palatable.”

The matter of equalities and inequalities is related to matters of justice. The critical question is how do we ensure fairness in a market controlled economy in the distribution of healthcare services? When it comes to urban versus rural population, men and women, young and old, poor and rich, educated and uneducated who gets the bigger share of the services? Who is supposed to see to it that the services are equitably distributed? Therefore, medical equity has become an urgent issue in Malawi that needs to be addressed as the idea of cost-sharing is introduced courtesy of World Bank and IMF. In the end it is not the need but rather powerful political players who decide where a health facility is going to be.

Caplan is of the opinion that disease is devalued in the American society because it is seen as a threat to equal opportunity and undermine social commitment to equity of competition and fairness of the market as efficient methods for distributing social resources. Capitalistic societies, according to

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21 Arthur Caplan in Robert Veatch, p. 52
22 ibid. p. 53
Caplan, do not seem to even question the ethics of the market. Such societies only consider the cost and not the lives affected. Is the market really fair? Does it take into account the reality of disease not simply as an economic factor, but an ontological one? What price can one put on life itself and one’s well being? These are some of the questions that need to be taken on board in discussing medical ethics. Caplan speaks of a state of fundamental inequities and serious but remediable differences that is incompatible with socio-economic orientations that seek to reward striving, performance, and individual achievements. Such major contradictions have to be addressed by medical ethics and not accepted as fait accompli.

For Caplan, it is too simplistic to view health and disease, as many health-care professionals do, as logical opposites. This attitudes, he argues, leads to regarding health as no more than absences of disease, and disease as the impairment in a person’s sense of well-being or fitness. Caplan says that “health consists in the functioning of any organism in conformity with its natural design as determined by natural selection.” Important to this definition or understanding is the use of statistics in health services that looks at what is the mean. Therefore, disease and health are viewed in terms of deviation or no deviation from various norms of species-typical functioning. This can be termed the objective view of health scientifically based. However, he goes own to remind us that according to Culvert and Gert, it is not the dysfunction but the perceived evil associated with the dysfunction—the loss of capacity, the onset of pain, and the risk to life itself which makes us disvalue this particular deviation from functional normality—that is at the heart of understanding health and disease.” In other words, while statistics may be helpful, they cannot measure the way people feel about themselves. There is a subjective element to our view of sickness, disease, and well being.

23 ibid. p. 53
24 ibid. p. 56
25 ibid. p. 59
Nevertheless, Caplan warns,

Unless medicine and the other health-care professions used definitions of disease and health that are clear and univocal, there is grave danger that uncertainties will exist on the part of both health-care providers and patients as to the aims, goals, expectations, and hopes they bring to medical encounters. If health and disease are nothing more than socially determined, culturally mediated and individually subjective concepts, then there will be little if any possibility of either placing medicine on a firm scientific footing or finding consensus among experts and patients as to the proper limits of medical concern. Objectivity, univocity of meaning, clarity, precision, and universality are at the heart of efforts to define health and disease.

Are we expecting too much of science based on mathematical formulas and statistical data? Where is the place of compassion that points to our humanity? Medical ethics cannot sacrifice human meaning to values of the market and statistical means even as useful as these methods might be.

In view of what Torrance says about the limits of objectivity of the scientific method that limits itself to phenomena and the human reality that transcends itself in and through God because it is related to God, Caplan’s restricted definition is inadequate in addressing the medical ethical questions that affect our human existence. Therefore, only a collaboration of theology and science would cover the ground adequately even to address some of the questions that have been raised in the light of the Ultimate reality.

Medical Ethics and Social Obligations

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26 ibid. p. 60
The definitions of disease and health play a pivotal role in establishing the boundaries of not only medical concerns and professional control but also social obligations. Caplan explains,

*Physicians are now able to control access to a wide variety of social and economic resources by the use of their authority as gatekeepers of eligibility for a wide spectrum of public and private programs. Getting a job receiving life insurance, admission to school, entry into and out of the armed services, and the ability to marry and raise a family are all controlled to some extent by physicians. Similarly, decisions about who will or will not be forced to receive medical care in hospital or institutional settings and what is or is not an acceptable form of medical treatment are controlled by physicians and other health-care personnel.*

It follows from this that (1) physicians and other health-care providers not only have the authority to enfranchise some members of society with social benefits or privileges; (2) they also have authority to excuse behaviour that, without medical exculpation, might be the object of educational or judicial attention. In this way they are involved in a very critical social role because (a) the disease label excuses certain behaviour that might otherwise be viewed as criminal, sinful, or both; (b) disease labels while often exculpatory in terms of liability or responsibility, carry other burdens such as the stigma, attached to illness and the assumption that those who are ill or diseased require treatment and cure from legitimate experts. It is this last point which is very relevant in our discussion of HIV/AIDS. Therefore, medical ethics has implications not only for social justice, but also social relations.

**Malawi and HIV/AIDS**

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27 ibid. p. 54
Returning to Malawi in 1995 after ten years in the USA, it was like returning to a war zone due to the impact of HIV/AIDS. I returned to a country where death had become a daily occurrence. The first case had been reported in 1986 and since then, many of my friends had died within the ten-year period, and the number of orphans was increasing exponentially. During my stay in the USA, HIV/AIDS was the disease of the gay community and was just beginning to spread to heterosexuals. Some of our fellow students had fallen to the disease and even some of the church members in the church I was attending. However, it was never on the scale that I found in Malawi. In our hospitals, sixty percent of the beds were taken by those suffering from HIV/AIDS related illnesses, the mortuaries were field to capacity with dead bodies and there were long lines of people coming to collect the bodies of their loved ones. Cemeteries in the urban areas were filling up very fast. All people were being affected by it. We all knew someone who was either dying or had died from it.

The churches were either condemning the victims as suffering the just punishment for their sins or were simply in a state of indifference. The only time one heard about HIV/AIDS was at the grave-site as the dead were being buried. The pulpit was not used to disseminate information on the pandemic. Statements on HIV/AIDS were aimed at condemning the wholesale distribution of condoms by NGOs. It was the church hospitals that were left to deal with the problem of the spread of HIV/AIDS. The government itself was in denial and had no national policy to deal with HIV/AIDS until into the late nineties. It was only in 1989 that the Malawi Council of Churches produced an official policy statement of HIV/AIDS encouraging churches to bring the matter in the pulpit and that there was some legitimate use of condoms—under medical direction. For many church leaders, the matter of HIV/AIDS was neither a medical nor a theological and missiological matter, but rather a moral issue that had been justly visited by God.
There was one young medical worker who quit working in the hospitals because he could not stand seeing so many patients dying. He confessed that he had been trained to cure patients and not to supervise their dying. Every week there were new faces in those hospital beds not because the other group had been cured, but had died. He was overwhelmed by the high mortality rate of those who were admitted. For him, HIV/AIDS raised some very fundamental questions related to life. What does one do in the face of persistent death as a medical provider when healing is not happening and medicines prove impotent? For the young medic, it was his own purpose in life that was tested to the limit and could not sustain it in the face of death.

This is why neither the market nor the science laboratories are adequately equipped to deal with such question of the purpose of life for all concerned—affected and affected—in the face of terminal illnesses. The challenge is to see beyond the functional view of medicine to life itself. Is life indeed a useless passion as Paul Jean Sartre had intimated? If it is, what medical ethics can we develop for the sustenance of such a useless passion—an attitude many are tempted to adopt—in the face of death itself without being victims of nihilism? Without a transcendental view of life and healing, HIV/AIDS presents a serious medical ethical problem related to meaning of life and its social dimensions.

Ronald Nicolson, in his book, God in AIDS\textsuperscript{28} raises the question, “But why make AIDS so important? He quotes from the Economist magazine, “Many more people die of motor accidents in the USA than of AIDS. More women die of breast cancer. In the Third World, widely though AIDS has been spread, it is still not the greatest killer. More children die of tuberculosis that of AIDS.”\textsuperscript{29} He goes on to answer his own question by suggesting that it is important to keep AIDS in proper perspective because the issue can get misrepresented for political propagandist purposes. Then he clarifies by stating,

\textsuperscript{28} London: SCM Press, Ltd., 1996
\textsuperscript{29} ibid. p. 5 quoting The Economist 1991:32
“There are many dreaded diseases in the world. The decision to focus on AIDS, the definition of AIDS as an epidemic or pandemic, is a decision made by persons in authority for political reasons, perhaps reflecting their disapproval of what they see as aberrant life-styles and their agenda of reinforcing a more traditional sexual ethic.”  

For Nicolson, HIV/AIDS is more than simply a disease. It is a global political issue with all that it implies. It is about power and life. It is about who lives or does not live and in this battle health providers have a critical stake. This being the case medical ethical discourse must be earnest and holistic otherwise health providers become accomplices in “genocidal” politics generated by the market. It is not only health providers, but even politicians. President Thabo Mbeki may be a case in point in the latter category.

Since it is about life, then theology cannot be left out of the discussion of any aspect of HIV/AIDS, but how is theology to carry out its own engagement? To this question Nicolson responds by saying, “If we are to respond theologically to AIDS, then it is very important the theologians also try to be as honest and objective about it as possible, for otherwise our theology is merely reflecting biases which already exist in the community. We cannot avoid unconscious bias, but we can do our best to be as well informed as possible.”

He shares the concerns of Caplan for an objective criterion in understanding the phenomenon called HIV/AIDS. HIV/AIDS brings a challenge not only to ethics, but to theology itself. He quotes approvingly a statement by Professor Bonganjalo Goba of South Africa who has said, “For the AIDS epidemic deconstructs, challenges all our philosophical or theological presuppositions. To encounter those who have openly come to terms with the challenge of AIDS is to participate in a deep spiritual pilgrimage which attempts to define the ultimate meaning of human existence.”

Nicolson makes the following comment, “By deconstruction is

30 ibid. p. 6-7
31 ibid. p. 10
32 ibid. p. 10
usually meant the idea that the confident assertions of Western philosophy and theology have within them the seed of their own unraveling, so that grand theories of meaning and metaphysics are no longer possible. Goba suggests that AIDS in Africa has the effect also of making grand theories untenable, so that we are left with more questions than answers.” (p. 10) Science narrowly understood is at the heart of some of the grand theories, however, this is true of all traditional myths and theories that have sustained human life in all cultures.

Now coming back to the question that was raised above as to why HIV/AIDS should be privileged above other diseases. Nicoloson gives the following as some of the reasons:

1. AIDS has disastrous effect on health and the economy.
2. AIDS kills off those who are economically productive, the people whom a developing country most needs, and on whose training and education precious resources have been spent.
3. AIDS is a disease that affects young men who are sexually active
4. AIDS confounds our economic plans
5. AIDS hits poorest countries hardest. It is reported that drug companies in the West are withdrawing funds for the development of an AIDS vaccine. Among the reason is the such a vaccine would be used in the Third world where they would not be able to pay. There would be little economic return. The other reason is failure to find an effective drug and the cost of investment would be too high to justify. No work is being done on the virus that is prevalent in Africa –type B. AIDS only compounds the hardships in which the poor find themselves.
6. AIDS destroys our sense of order and control. AIDS represents the frightening world of chaos, disorder, and non-meaning from which we hoped our faith had delivered us. AIDS is a plague in a modern era when
plagues should have no power. The AIDS pandemic recreates for us the frightening world of the earlier church where we do not control the elements and are in a place between creation and redemption in what the old salve Regina prayer used to call a ‘vale of misery.

7. AIDS raises for modern theology, just as for modern science, the fear that there is no answer, only silence. Surprisingly little has been written about a theology of AIDS. Perhaps this is because AIDS forces us to face three issues with which the modern church feels profoundly uncomfortable: death, sexuality and otherness.

8. Although gradually the church in America and elsewhere has begun to come to grips with the pastoral demands which AIDS makes upon us, the response was slow, and sometimes judgmental and unhelpful.

9. AIDS is not only a medical problem, nor only a social problem. It affects the whole person in every aspect of personality. Part of the problem in western society is that we often divide life into compartments, each to be dealt with by its own panel of experts. Medical people want to treat AIDS by medical means: vaccines, prophylactics, condoms. Social workers want to concentrate on housing and financial care for people with AIDS. But AIDS is part of an overall system in which we live which includes family, housing, economics, health, and everything else. We cannot separate of the biology from the psychological or from the social. AIDS has been primarily re-searched as a medical problem.”

10. AIDS requires the sharing of research concerns between medical and social scientists, and also to include religion and spirituality. Spirituality and theology can help bridge the gap between mind and body. The theology of the whole church needs to take AIDS into account.
11. AIDS also raises in a sharp way some crucial issues about human rights and legal ethics.\textsuperscript{33} No other disease has impacted humanity in the same way as HIV/AIDS or challenged the optimism of scientific progress as this one, and not to name medical ethics.

**Challenges of HIV/AIDS for Medical Ethics**

HIV/AIDS challenges us on very many fronts and medical ethics is only one of them. However, in considering the medical ethics related to HIV/AIDS we need to widen our horizons beyond the disease itself and see it in terms of the transcendental vision of the God of life and of the future of humanity. By referring to the God of life, we are talking about a God whose very being is love; who has created us in love and out of love and for love; who has redeemed us in love in Jesus Christ and through whose resurrection we have been born a new to a living hope.\textsuperscript{34}

It is only in the light of this theological vision that science can be empowered to ethically play its role in mitigating against this pandemic. It is in the light of this vision that we can address issue of the meaning and purpose of life, the meaning of sexuality, spirituality, socialization, stigmatization, discrimination, medical resources, justice distribution of health care, condom use, poverty, cultures, personal and social responsibility, the injustices of the market that dis-empower medical professionals from discharging their duties adequately and responsibly, and the issues of legality and ethical responsibility. What is legal may not always be ethical and hat is ethical may not always be legal.

One of the biggest challenges of HIV/AIDS has been stopping its spread especially in Africa where it has been said that it is through hetero-sexual sex that it has spread, even though careless use of needles by health providers at a certain

\textsuperscript{33} ibid, p. 18-21

\textsuperscript{34} 1 John 4:8; 1 Peter 1:3.
The recommendation has been a three pronged strategy: (a) Abstention; (b) Being faithful; (c) Condom use, also called the ABC approach. While governments have expressed their priority in that order, they have encouraged the third as the only hopeful one for stopping the spread of HIV/AIDS. The church and traditional leaders have denounced promotion and indiscriminate distribution of condoms as the promotion of immorality. One approach has used the authority of science while the other the authority of Divine revelation or theology. As a result of this disagreement people have been getting mixed messages. There is need to clear the air and clarify the issues and methods through discussion. Therefore, beginning with the relation of science and theology is not an irrelevant attempt, but rather to start where the intellectual conflict begins leading to existential mixed messages when it come to praxis.

There is a general assumption that science is working against God’s revelation and that medical practice has been aligned with science against God. This assumption is heard by people in both camps. It is important that we clear this mistrust between science and theology and with Torrance see how they can collaborate.

There is a dualism that has been already mention as affecting traditional theological thinking, but which has affected the development of science which is informing and misleading the discussion on science and theology, and within theology on spirituality and sexuality, spirit and matter, soul and body. This dualistic thinking has been at the core of the battle between theology and science. Its removal would go a long way to clarifying and reconciling the two subject areas for mutual

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35 I do remember that even after the first case of AIDS had been diagnosed in Malawi, one needle filled with chloroquin was being used to inject many patients at times without sterilization. Once the virus was in the blood, then it became sexually transmitted. For some victims of HIV, it had nothing to do with being immoral. The immorality was the improper use of the injection by medical personnel.
enlightenment. Opposites can also be complementary realities and not always antagonistic.

There is a challenge of stigma that comes with HIV/AIDS because of the threat to life that the disease is associated with, also because of the moral implication as to how the disease is contracted, the sense of shame that the victim feels, the disfigurement that the disease brings, and long suffering that some have to endure. However, it is also true that there are many wives, children, and even men who are victims. Can medical ethics contribute to the alleviation of such guilt and shame? Attempts have been made to define HIV/AIDS as a normal disease and sickness like malaria for which there is no moral questions raised.

The condom, as a scientific tool, has often proved not to be culturally relevant and not one hundred percent reliable. It may be tested in the factory, but not in the cultural ways in which various peoples understand sexuality and the role it plays in their existence. There is need to harmonize the people’s world views and medical science, if their health needs are going to be met adequately. As Torrance says, humanity is more than simply biology, chemistry and physics. Healing humanity has to go beyond these natural limits. The approach has to be as holistic as possible.

Life, ARVs, and Money

President Mbeki of South African has been severely criticized for insisting that HIV/AIDS was related to poverty and not to some virus, and for being not willing to make the ARVs available for his people who continue to die of HIV/AIDS. While ARVs are improving the quality of the life of the sufferers, they are not cheap and not everyone can afford them. So it is also true that poverty is a major factor in the spread of HIV/AIDS and it is hoped that its alleviation would contribute to the stopping of the spread of the disease. The irony is that companies that were willing to make generic drugs I order to
bring down the cost were prevented from doing so by the rules of the market. Profit considerations were more important than the lives of the poor because they have no monetary value—rightly so, but for the wrong reasons.

**Fatalism**

One other challenge in the struggle against the spread of HIV/AIDS in Malawi is a fatalistic attitude towards life. When people have little to live for and when even the little they have is taken away from them within the global market fatalism sets in. Life becomes cheap and who cares how it expires. People see themselves as victims of time, diseases, wars, and events. To everything there is a time and even for AIDS.\(^{36}\) Fatalism comes from a naturalistic attitude that sees life as embedded in nature and is a victim of nature from which humanity cannot escape. Life is part of the natural circles of nature moving nowhere. In a way there is some truth to it, but unless human consciousness rises above nature enough as to interact with nature in a meaningful way, people will continue to be fatalistic. In this way medical interventions are seen as temporally measures. There is little that one can do about fate, in this case, as manifested in HIV/AIDS. Medical ethics has to deal with this attitude if medical services are to be accepted as efficacious, but it needs theological and anthropological insights to address such matters.

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\(^{36}\) Cf. Ecclesiastes 3:1-8. The song in Malawi talks of “Zonse ndi nthawi basi” meaning, “the bottom line is that everything has its time”. There is nothing that one can do to alter one’s fate. Even the very young say that all was written and sealed. They never stop to ask who has written and sealed their fate. Of course, it is assumed it is God. This is a result of either bad theology or lack of theology.
Ethical Challenges of HIV/AIDS

Malhia Joshua

Introduction

Ever since the first AIDS {Acquired Immunodeficiency Syndrome} patient was identified in the year 1981 that resulted from infection with the HIV {Human Immunodeficiency Virus}, the epidemic has presented several ethical moral challenges relating to human life and dignity. The HIV is spread through sexual intercourse and exchange of infected body fluids like semen, vaginal fluid, and it can also be transmitted through nonsexual means, usually involving a contaminated blood transfusion or doctors/nurses sticking themselves with a needle used on an HIV-positive patient. The virus can damage many types of cells, especially white blood cells of the immune system. It can also attack other tissues including the vagina, cervix, male and female urethra, rectum, and brain. In the cells of these tissues, HIV is incorporated directly into the DNA, which stores the genetic

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code. Once infection takes place, it may be a long time before the patient actually gets AIDS.

**HIV/AIDS Statistics**

HIV/AIDS has severely affected most of the nations shaking their developments achieved through technology and science. The gap between the developed and developing countries has widened. Over 70 percent of the cases have occurred in homosexual or bisexual men; 20 percent in intravenous drug abusers; 2 percent in people who received contaminated blood; 1 percent in people with hemophilia; and the remainder in heterosexual or persons who died before complete histories could be obtained. About 95% of all HIV/AIDS infected people are living in developing countries where they are worst affected by poverty, illiteracy, stigma and discrimination. By the end of 2005 it was estimated that worldwide 40.3 million people were living with HIV/AIDS. In the same year around 5 million adults and children became infected with HIV. Although HIV/AIDS can affect all ages, about a half of new infections occur in young adults before they are 25 years old and who, if untreated, will die within ten years of contracting the infection. HIV deaths continue to increase, with an estimated 3.1 million during 2005 alone.

This paper makes a re-look into the ethical issues that revolve around HIV/AIDS, focusing on the attitude towards the affected people, doctor patient relationship, gender difference, resource allocation and vaccine research with special reference to the conditions prevailing in the developing countries.

**Stigma Related to HIV/AIDS**

Ever since scientists identified HIV and AIDS the epidemic has been accompanied by social responses of fear, denial, stigma and discrimination. The individuals affected have been rejected by their families, their loved ones and communities and this
phenomenon has equally been reported both from the rich as well as from the poorer countries. Stigma, a powerful tool of social control can be used against certain individuals or groups like ‘homosexuals,’ ‘drug users,’ and ‘sex workers,’ and in most cases they are denied of any care by the society. Factors that contribute to HIV/AIDS related stigma can be summarized as:

- it is a life-threatening disease
- religious and moral beliefs that contracting the disease is the result of perverted morality
- people look down on the HIV/AIDS affected people as social nuisance.

In some societies HIV/AIDS has been considered as a public health risk. In such societies, laws, rules, and policies can increase stigmatization of people living with HIV/AIDS by way of including compulsory screening and testing, as well as limitations on international travel and migration. In such societies laws that insist on the compulsory notification of HIV/AIDS cases, that leads to the restriction of a person’s right to anonymity and confidentiality, as well as the infected people’s right to movement, have been the examples of stigmatization.

Ignoring the existence of HIV and AIDS, negligence towards the needs of the infected people, coupled with the failure to take precautions to check the spread of the epidemic in the belief that ‘it can never happen to us’ portray the infected people as abnormal and exceptional.

**Women and stigma:** In many developing countries where women are often economically, culturally and socially disadvantaged and lack equal access to treatment, financial support and education the impact of HIV/AIDS is acute. An HIV positive woman who heads the Assam network of Positive People and submitted an application in the month of March 2006 to run for an assembly seat in the Indian state of Assam has said that she was denied the Congress Party nomination because of stigma and discrimination. In most of such societies
women are portrayed as the main transmitters of sexually transmitted diseases. Such beliefs are the basis for the further stigmatization of women who are affected with HIV/AIDS. The husbands who infected their wives with the disease often abandon them.

**Families:** Family members provide primary care to sick members in the majority of developing countries. HIV/AIDS infected members of the family in such countries can find themselves stigmatized and discriminated against within the home.

**Employment:** Vast majority of employers tend to terminate their employees who live with HIV/AIDS or refuse employment for fresh candidates. To check the intake of such candidates many industries evolve pre-employment screening. Employer-sponsored insurance schemes are increasingly under pressure in countries that have been seriously affected by the disease. The result is the denial of employment to people with HIV/AIDS.

**Stigma in health care:** Many studies reveal the reality of withheld treatment, non-attendance of hospital staff to patients, HIV testing without consent, lack of confidentiality and denial of hospital facilities and medicines.

**HIV TESTING**

The ethical issues have to be faced even before the blood is tested for the HIV and process continues through different stages of caring the patients.

**Informed Consent for the HIV Testing of Blood:** The ethical practice of medicine requires the informed consent of HIV testing of blood of a given individual. Experts argue that when patients get admitted voluntarily to hospitals or clinics for investigation and treatment of disease, specific informed consent for HIV testing is not necessary provided strict confidentiality is
maintained. They may argue that such consent is not necessary because the test is noninvasive and involves no physical harm to the patient. Many tests on blood products are routinely carried on at the hospital without securing the informed consent of the patient. If it is not required in these routine areas, it ought not to be required in the context of AIDS. The AIDS victims do not usually wish to be tested for varied reasons:

- increased risk of being thrown out of their jobs or losing their insurance coverage if the information on their HIV status will leak out
- fear of being ostracized from their respective families and communities
- fear of discriminatory reactions on the part of the hospital or the health care provider if the test is positive

As these concerns are genuine, maintaining confidentiality is essential in preparing the health care plan. In practice, however, informed consent is essential. There are no specific provisions for testing of HIV in prisons. A question may arise in view of the statutory provision (section 24, Prisons Act), whether a non-consensual HIV test can be conducted in prisons.

**Disclosing Personal History:** Patients are expected to be truthful in disclosing the details of his/her personal history to the treating physician. Such an attitude will help health professionals in preventing the spread of the HIV infection to the community and to themselves.

**Prenatal HIV Testing:** The ethical concerns surrounding prenatal HIV testing are different in developing countries. The cost of antiretroviral prophylaxis has been prohibitive and therefore, for the most part, pregnant women do not receive it. Although knowing their HIV status may be helpful in guiding decisions concerning breast-feeding, in many circumstances, bottle-feeding is not a feasible option because of cost and lack of access to clean water. Accordingly, determining HIV status may be of limited benefit. Moreover, such determination could
subject women to risk of physical harm or loss of housing and support. The benefit of testing will increase as prenatal antiretroviral prophylaxis, along with support services, becomes increasingly available.

**Respecting the Patient’s Privacy:** Once the diagnosis of HIV infection is made in a patient admitted to hospital or nursing home, the information often reaches all staff members. The change in their attitude toward him/her is immediately obvious to the patient. Some clinics paste posters near the patient’s bed informing all of the patient’s HIV status. This is especially tragic when the poster remains in place during the hours when friends and relatives visit patients. Other clinics print in bold letters the HIV status on the cover page of the patient’s case chart, all times underlined in red. When questioned, doctors and administrators offer the explanation that this measure was to ensure that everyone “takes the necessary precautions when handling the patient.”

**Informing the Spouse:** Human rights activists argue that the right to marry is constitutive of one’s right to life and this right cannot be qualified on the basis of the health status of the person. The public health staffs are not only accountable to those with HIV infection but also to those partners/prospective partners who may not have the virus. The question is, is it ethically right to hold back information from the partner, which has direct bearing on his/her health? Since the spouse may contract the disease from her infected husband, how is she to be informed of the very real danger she faces? One of the studies makes the consideration of this issue of vital importance: 57% of individuals in rural South Africa would not tell their wives about their having contracted sexually transmitted disease. If infected by HIV, 66% would withhold information from their wives. 71% of men would not inform their casual partners about their HIV infection. The same study showed that a majority of women claimed a right to know if a man was infected. There is
every reason to believe that a comparable study in India would show similar results. But there are no clear guidelines to tackle this problem in India.

**Duty to warn:** Though confidentiality is rooted in the right to privacy, and is a matter of personal autonomy the protection of third parties vulnerable to potential serious harm must be given priority. The Supreme Court of India ruled that the right to privacy and confidentiality is not absolute; it may be lawfully restricted when third parties are at risk. There are issues related to partner notification. The poor, the uneducated, and the unemployed require special consideration and partner notification may be especially important in these groups.

**Pre-employment Medical Examination:** There is a long-standing practice of requiring prospective employees to undergo a medical examination before they are appointed. This is for two reasons – one, to make sure that the employee will be able to work and the productivity will not be reduced by frequent medical leave. Secondly, they don’t want to be burdened with the cost of treating an employee. Already in several countries law has been proposed to eliminate discrimination against women. This has to be extended to persons with HIV.

**HIV testing for life insurance:** The decision by an insurer to test for HIV in a given population is based in part on the risk that the insurer is prepared to take in that class of insurance applicants. The requirements for confidentiality of results, and pretest and posttest counseling should ensure that HIV antibody testing by the insurance industry is a closely monitored activity.

**Refusal of treatment:** The law does permit any doctor to refuse to treat any patient provided such refusal is not likely to result in irreversible harm or death. By using this provision if the doctor acts legally not treating a HIV infected person it will be against all ethical and moral norms. Again, if the doctor insists on every
one of his patients to get him/her tested for HIV and show him the result, is it not reasonable for him to get tested for HIV and declare/announce the results to each of his patients?

**Research Ethics**

Global efforts are continuing to develop vaccines to prevent infection among persons exposed to HIV (prophylactic) and to prevent HIV infected persons from progressing to AIDS (therapeutic vaccines). Research with human participants raises several ethical concerns as it involves risks and inconveniences, the outcome being scientific knowledge and the benefit of others. Vulnerability is particularly important in the context of HIV related research. The higher risk groups of HIV infection like homosexuals, injection drug users, minorities and women are more likely to be socially and economically vulnerable due to historical attitudes and enhanced discrimination. Hence special attention should be given to protect potentially vulnerable research participants while conducting HIV related research.

**Vaccine Research:** HIV vaccine research is different from other biomedical research in developing countries because

- the harm under discussion results from sexual activity or injecting drug use, not from any ill effects of the vaccine itself
- Vaccine trials involve healthy participants, who are presumed to participate for altruistic reasons, not because of any potential direct personal benefit
- The HIV epidemic threatens the very fabric of society in most regions
- Such research is intended to benefit the community under study.

Despite concerted efforts being made in the prevention and treatment of HIV/AIDS in recent years developing a safe and effective vaccine has been in snail slow pace. While it is a grave
necessity to develop a successful AIDS vaccine it poses not only scientific challenges but also ethical and legal issues.

**Beneficence:** Since more than 95% of HIV positive people live in the developing countries, and only less than 8% of those needing anti-retroviral therapy \( \{ \text{ART} \} \) receive it – compared with 84% in the West, developing countries in Africa, Asia, and Latin America should be vastly in vaccine trial. “Beneficence” as an ethical principle is the obligation to minimize possible harms and maximize possible benefits, and from this perspective, researchers argue that antiretrovirals should be provided to trial participants who become infected on a priority basis. The question is should the best standard of care be provided, or the best available standard of care? Again, if antiretrovirals are provided only to infected trial participants, wouldn’t it create inequities in communities? Wouldn’t it be unreasonable inducement to participate in clinical trials?

**Informed Consent:** The concept of informed consent in many of the developing countries is interpreted differently from developed countries. For example, in rural African countries it is a form of communitarianism rather than individualism. In this context, research is an endeavor that is aimed primarily at the benefit of the communities and societies rather than the individuals. Language problems and the lack of familiarity with scientific terminology and concepts often limit volunteers’ understanding of the research project.

**Community Involvement:** As a remedy to informed consent issues emerging from language and other cultural barriers, the UNAIDS guidelines for HIV vaccine research recommend a process of consultation between community representatives, researchers, sponsors, and regulatory bodies to design an effective informed consent strategy and process. Such a participatory process of decision-making may enhance the
prospects of achieving a fair balance in the distribution of nation’s biomedical research resources.

**Justice:** The principle of “justice” refers to the fair distribution of the benefits and burdens of research which means the access to safe and effective vaccines. The UNAIDS ethics guidelines recommended that any HIV vaccine demonstrated to be safe and effective should be available as soon as possible to all research trial participants, as well as other populations at high risk of HIV infection in a priority basis.

Research funding in developing countries has also been a subject of attention today. The Global Forum for Health Research has pointed out that less than 10% of the world’s research resources are earmarked for 90% of the health problems. Hence there is the need for promoting equity in health research globally and to strengthen the capacity within developing countries to undertake research that is relevant to them.

**CONCLUSION**

The ethics of health care and medical research are increasingly getting related to basic human rights, provision of equitable health care, assurance of safety and benefits to the communities, while protecting privacy and confidentiality and ensuring global justice in all these endeavors. The challenges have to be shouldered by the policy makers, health care providers, bio-medical researchers, pharmaceutical industry and behavioral scientists. There is no easy solution possible and the formulation of universal ethical standards is a remote possibility and hence decisions are to be taken to suit the local needs and considering the socio-cultural traditions and practices.