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Editorial: Ethics and Equity

The Universal Declaration on Bioethics and Human Rights (UNESCO 2005) includes an article recognizing the global agreement that justice, equality and equity are recognized as human rights in every country. However, countries vary widely in the ways that they establish just, equitable and loving social support systems. This issue of *EJAIB* includes both general

papers as well as specific case studies to illustrate ways that governments can deal with these ethical principles.

Nader presents a case study of organ transplantation in Iran, which has implemented a system involving payment for receipt of organs for transplantation that makes us re-examine broader norms that such a compensation system is undesirable. The regulation of the system is interesting and worthy of study of how it could be extended. At the end of this issue is a paper by Randall that argues that a utilitarian system may be useful for measuring how to manage exploitation in research, rather than a deontological model that is dominant.

Chutatip presents a review of issues in medical ethics in Thailand, and reviews some of the laws that have been enacted to protect persons. There are examples such as a cooling off period for gender change operations, which are one of the medical services available at low cost in Thailand. Ananya looks at karma and the Buddhist perspectives on life, and how this may relate to attitudes and practice of enhancement of people.

Probably most readers are on Facebook, and this would be advised to reflect on the philosophical analysis of the concept of "Lock-in" that has been achieved by facebook, explored by Jose.

Sumaira presents a comprehensive analysis of health inequity and health care in Pakistan, that could be applied to many countries and systems. How does your system compare? This issue concludes with an essay by an Indian student on patenting of life.

EJAIB welcomes papers from a variety of perspectives to encourage dialogue. I hope readers will support that dialogue, send in commentaries or articles, and continue to support us through membership in the Asian Bioethics Association. We see in this issue the first of papers from the Seventh Kumamoto International Bioethics Roundtable, jointly organized by UNU and Kumamoto University (KBRT7), and from the 14th Asian Bioethics Conference held in Chennai. Both of these were excellent meetings with many papers presenting the results of thorough research studies that will assist us in our goal of more bioethical societies. - Darryl Macer

The ethics of organ transplantation in the Islamic Republic of Iran

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Abstract

Organ transplantation services, particularly kidney transplants, have been provided in a fairly large number and good quality in the Islamic Republic of Iran since the 1990, and there are currently more than 25 kidney transplant centers that provide transplant operations. From the ethical and religious point of view, Iran has provided a flexible and relatively regulated environment for organ transplantation, especially regarding the possibility of unrelated living organ donation. This flexibility is mainly related to the role of *ijtihad* in *Shi'a* Islam where new rulings can be extracted by *Shi'a* jurists to facilitate the use of technologies that ordinarily might have been banned by traditional Islamic rulings. The possibility of monetary compensation for unrelated kidney donors in *Shi'a* Iran has helped expand the supply of donated organs, especially of kidneys, to a number almost equal to the demand. The Supreme Leaders in Iran have issued a series of *fatwas* that played a major role in legitimization of compensated organ transplantation from unrelated living donors. The main ethical issue is the large number of donors whose primary motivation is to gain monetary compensation to deal with their financial needs, and the inability of the ethical and legal system to fully regulate the market, to maintain fairness, and enhance altruism as a motivation for organ donation. This issue is also influenced by the economic hardship affecting most people in Iran, and is not merely a consequence of medical legislation to facilitate organ transplantation.

Keywords: Iran, Kidney transplants, Medical ethics, Organ transplantation, *Shi'a* Islam.

Introduction

This paper presents the third part of a research investigation into the three layer structure of bioethical decision-making in the Islamic Republic of Iran, and is based on an analytical review of the religious and ethical system of beliefs as well as the laws and practice of medical care in contemporary Iran (1980~now). The so-called 'three layer structure' refers to the basic ethical concepts, including ethical theories and religious beliefs as the 3rd level, the bioethical principles and laws as the 2nd level, and the decisions made on bioethical issues in medicine as the 1st level.

The area under investigation in this study is organ transplantation, and thus we discuss the bioethical issues of organ transplants in contemporary Iran. Both the first and second reports, as of 2011 and 2012

respectively, provided the background information including the basic religious and ethical beliefs and theories (3rd level) of *Shi'a* in the Islamic Republic of Iran; however, issues related to organ transplantation provide an opportunity to revisit the 3rd level for a better understanding of its policy implications. Therefore we shall consider the 3rd level again but mainly in the perspective of its impact on human organ transplantation, before explaining the 2nd level and the 1st level of bioethical decision structure in organ transplantation.

The 3rd level (basic ethical concepts, ethical theories and religious beliefs)

The fundamental question at the 3rd level is about the underlying ethical philosophy. The ethical thinking of *Shi'a* Islam in Iran is based on prima facie obligations similar to the views of the British philosopher W.D. Ross (1877-1971). Thus, the underlying ethical theory is not purely deontological and actions are not simply classified as right or wrong; there are a number of obligations some of which may be more important than others.

A *shi'a* Muslim is supposed to follow with various actions he is obliged to, on the basis of a proper ranking of obligations. Most obligations may be overridden by a more important obligation, which is basically the concept of prima facie ethics. Most moral obligations are not absolute, as opposed to the Kantian ethics, and exceptions are allowed depending on circumstances. Actions may be judged ethical/unethical based on the circumstances surrounding them and the consequences of actions. Therefore, what a Muslim does depends on both the circumstances and the relative importance of various obligations.

With prima facie way of thinking, there are situations where one may need to take a 'moral risk', just as Ross mentioned in his ethical theory. *Shi'a* Muslims are strongly encouraged to make decisions by 'following' the decree of a clergy (*faqih*) who has completed years of studying and training to attain '*ijtihad*'. A decree in *Shi'a* comes from a '*mujtahed*', a *Shi'a* clergy who has extensively studied the Islamic law of '*shari'a*' and knows how to make the best decision after ranking the various obligations under the circumstances and specifics of a situation.

Under the theocratic system of *Shi'a* in Iran, during the occultation of the 12th Imam, the Supreme Leader may rule over the nation and can rightfully interpret the Islamic law (*shari'a*). Therefore almost all religious, ethical, political and other decisions in the Islamic Republic of Iran ultimately depend on the interpretations of the Supreme Leader from Islam. The decrees made by the Supreme Leader over all affairs are considered as a legitimate source for decision-making by all authorities in the Islamic Republic of Iran.

On the positive side, because actions may be judged as ethical or unethical based on the circumstances surrounding them, there is some form of 'flexibility, meaning that religious decrees need not

be very rigid and can take a unique situation resulting from new technologies into consideration to form new rulings compatible with modern needs, including those used in organ transplantation. However, on the negative side, when this flexibility extends to the extremes, it may seem to merge with ethical relativism. In the case of organ transplantation from unrelated kidney donors who are compensated with money, 'saving the life' of a recipient is considered of more significance compared with the ethical question of whether the 'willing donor' was financially coerced to donate an organ. In this situation, the 'consequence' of having 'a life saved' is deemed more important than the 'action' of paying for a human organ.

The 2nd level (biomedical principles and laws in Islam and *Shi'a* Iran)

We need to first examine the basic Islamic principles that are well recognized by the majority of Islamic thinkers, and then examine the modifications made to them in *Shi'a* Iran based on its use of 'dynamic' and 'flexible' ruling through *ijtihad*.

The most basic law underlying the ethics of organ transplantation in Islam is the 'principle of no harm' (*la zara*). This means that no transplantation would be permitted if it is known to cause harm to the donor; thus transplantation of heart as well as liver from a living donor would not be permitted at all as it leads to death and/or serious harm. However, this prohibition can be sidestepped in the 'context' of kidney transplantation for example, where there is negligible harm to the donor while the life of the recipient can be saved. This is in fact the logic based on which organ transplantation has been permitted by clerics of Islam.

The greater significance of saving a life can be implied from the following Quranic verse: *Quran (5:35)*: "... and one who gives life to a person, is as he gives life to all mankind".

However, most Islamic jurists find it unacceptable to receive monetary compensation for a human organ, even for organ transplantation to save another person's life, because there are limits on human's ownership over his/her body, God being the true owner, and it is not up to a person to treat his/her body as a commodity for financial gain.

Nevertheless, in *shi'a* Iran *fatwas* issued by the former leader, Khomeini in 1988, and later by the current leader, Khamenei in 2000, have allowed a considerable level of flexibility for organ transplantation in Iran. The widely publicized *fatwas* are related to the acceptance of brain death as termination of life, and permissibility of organ removal from brain dead individuals for transplantation. These *fatwas* became the basis of an Act called the 'Act of Organ Transplantation and Brain Death' that was approved by the Iranian Parliament in 2000, formed into executive laws by the Ministry of Health in 2001, and finally passed by the Cabinet Council in 2002 (Zahedi, 2009).

Accordingly, the Professional Codes of Organ Transplantation was issued by the Iranian Academy of Medical Sciences on February 2008 which states (Zahedi, 2009): "Since protecting the lives of human

beings is the most fundamental moral principal, the ethics committee of the Academy of Medical Sciences (IRI) declares that kidney donation from living related and unrelated volunteers is generally acceptable, and the exchange of money as a reward of gratitude or a gift for compensation is not considered unethical and should not discourage this noble act, provided that:

1- *The donor is truly willing to donate a kidney in his/her right mind, free from coercion.*

2- *The donor undergoes complete medical check-up and psychological evaluation and is found fit for the operation.*

3- *There should be no medical contraindication for the operation.*

4- *Donor should be able to get long term medical attention after donation.*

5- *The medical team should have no role in the process of donation.*

6- *Donor and recipient should be from the same nationality; tourist transplantation is forbidden.*

7- *No one under the age of 18 and over 45 is accepted for donation.*

8- *A national committee assigned by the ministry of Health and Medical Education with the cooperation of Iranian Transplantation Society will regulate and supervise the renal transplantation centers nationwide."*

Iran follows an 'opt-in' system where the patient or the patient's family must consent to the donation of the organs. The cadaveric donations have been kept altruistic and no monetary rewards have been paid to the families of donors, except for a few cases where funeral expenses were paid (Zahedi, 2009).

Iran is the only Islamic country that not only allows monetary compensation of living unrelated donors but also partially funds the payments to the donor. The justification of *shi'a* scholars would be based on the 'levels/ranks' of ethical value that were mentioned in the first report (Ghotbi, 2012); they include *wajeb*, *mostahab*, *mobah*, *makruh* and *haram*. Donating an organ is highly *mostahab* (better done but still not obligatory), so it is not wrong to pay/allow a gift or reward as it is a highly desired 'public good' that needs to be promoted by the state. Also, donating an organ incurs some pain and inconvenience on the donor though it does not seriously harm the health of 'well-selected' donors. The associated pain and inconvenience can be compensated by a reward, while cadaveric donation does not incur such problems and therefore need not be financially rewarded.

Although transplant tourism has been largely controlled by laws which require the donor and recipient to be compatriot, there have been many cases of Iranians who later became US citizens but having kept their Iranian passports, they travelled to Iran to get a kidney transplant (Ghods, 2005).

The 1st level (the practice of organ transplantation in Iran)

The Islamic Republic of Iran legalized the donation of kidneys from living unrelated donors in 1988. A system was created by the government to fund and regulate

the transplantation process through a third party called 'Association of Dialysis and Transplant Patients'. Donors would receive a gift of 10,000,000 Rial (equal to about USD 2,500~2,000 in 1990's and early 2000's, respectively) from the association, plus in many cases another agreed upon sum of money directly from the recipient's family which in average was about two times the formal amount.

In 2006, the formal pay was increased to 50,000,000 Rial to make up for the severe inflation in Iran; the value of Iranian currency has decreased from about 4,000 Rial for USD 1 in late 1990's to about 30,000 Rial for USD 1 in recent times. This has caused donors to expect a much larger amount of compensation from the recipient of the kidney because the governmental funds did not increase at the same scale. Recipients may be paid between 100,000,000 to 400,000,000 Rial (3,300 to 13,300 USD) depending on the size of demand versus supply as well as the ability to pay (by recipient) versus the need for money (by potential donors).

Because the kidney transplant system only relies on ABO compatibility (not HLA matching), it is easy for potential donors to advertise their kidney to potential recipients with just a phone number and their blood group written next to it; many photographs have been surfaced and widely shown on the Internet of such graffiti on the walls near the site of the "Transplant Association". The transplant centers have continued with their policy of only requiring ABO compatibility citing their own studies which show no statistically significant improvement when HLA compatibility was checked; this has facilitated the advertising of kidneys for sale by potential donors, as mentioned before.

The donors are supposedly under the coverage of governmental health insurance for life, but because of the nature of the insurance and the wide gap between formal fees and the private sector, this coverage may not be complete. It is worth noting that some experts have already suggested that a reward of about USD90,000 would be a fair compensation considering the required checkups and possible expenses to the donors of kidneys in the US (Matas, 2003). Apparently the important issue for these experts has been the 'fairness' of compensation, rather than the basic issue of whether monetary compensation for human organs is ethically defensible or not.

Discussion

A large number of people are being affected by chronic diseases such as chronic renal failure, which leaves them with few options to survive other than dialysis and an organ transplant from another human. The demand for human organs is much larger than the supply that can be provided through cadaver organs plus brain dead individuals who have consented to organ removal. One of the consequences of monetary compensation of donors is saving the lives of more people, but we should not ignore other social consequences such as the use of human body as a monetary asset and its being targeted for raising money by individuals in need who may not necessarily

be the donors. It would be very difficult to assure a lack of coercion especially in situations that economy is bad, loans are piling up, and there are few other options to raise revenue. This situation is already happening in Iran and the recent economic pressures have only aggravated it.

Although it is illegal to trade kidneys in most countries in the world, it is a common underground practice at least in a number of countries like Russia, Turkey and South Africa (Major, 2008). Apparently, the legal and ethically approved sources of kidney for transplant, including cadaveric donors, brain dead donors, and living related donors are not enough to meet the high demand. An especially disturbing phenomenon is the practice of 'transplant tourism' whereby rich recipients travel to a developing country where they may buy an organ, such as a kidney, from a living unrelated donor.

A kidney transplant does not significantly harm the donor even in long-term, but is associated with some risk and suffering such as those associated with bleeding, anesthesia, not having an extra kidney for possible injuries in the future, etc. Provision of life-time governmental health insurance to donors helps reduce the associated risks but does not fully eliminate them. To allow monetary compensation to cover for the pain and suffering of the donors and the small extra risk has been supported by some experts but they recommend that the level of monetary compensation should be fair enough; a few experts have suggested a figure of about USD 90,000. The amount of money that Iranian donors negotiate for is in a far smaller range of about USD 3,000~10,000 but still mainly depends on the ability of the recipient to pay, and the negotiation leverage of the donor based on unstable and ever-changing economic conditions in Iran, as well as the size of the 'supply' in the matching ABO blood group.

Tens of thousands of people in Iran have been able to follow a normal life without reliance on dialysis after receiving a kidney from an unrelated living donor. A significantly larger number of lives, those of kidney recipients, have been saved as compared with the physical harm to donors of kidneys. An ethical consequentialist may find this fact convincing enough. However, there are other 'social' consequences, for instance through a devaluation of the 'sanctity' of human body over financial needs of the donors or their families, as well as the 'deontological' issue of allowing people to sell their body organs for financial gain. The latter is a special concern in Islam and the main reason why transplantation from unrelated kidney donors is banned in all Muslim countries except for Iran.

Having said that, it cannot be denied that the flexible attitude of the Iranian government towards the use of unrelated donors may have avoided from more unethical practices such as underground clinics run by illegal human organ traffickers. Patients needing a transplant may have largely benefited from a practical solution to their 'life or death' situation, and the donors may have also been able to use the reward in a positive way without suffering from serious bodily harm; it is also hoped that in the future there will be better

solutions, as the number of cadaveric and brain dead donations increase; currently they are only about 10% of the total number of transplants. However, we cannot deny the probability that donors and recipients, as well as surgeons and the whole transplantation system might have made different decisions if they were better informed about the ethical nature of such transactions and discussed their implications for society at large in more detail. I would argue for discussions to reassess and revise the system to help keep it in line with the morals of the society and the sanctity of 'everybody's life.

The experience of Iran with kidney transplantation so far may be interesting to other nations, whether *Sunni* or *Shi'a*, Muslim or non-Muslim. I would like to recommend long-term follow-ups of both donors and recipients of kidneys to gather more reliable information about the consequences of this system in long-term. It is unfortunate that many of the papers published by Iranian surgeons involved in the transplantation system appear to deny the disadvantages of the current system and attempt to only focus on its advantages for the recipients in terms of life years saved. Fairness of the system, the long-term quality of life of both donors and recipients, as well as the willingness of the donors to recommend such a procedure to their beloved relatives, family and friends could be further investigated in Iran.

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Bioethics in Thailand: Perspective from Past to Present and Unsolved Problems

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Since the 13th century, during the Sukhothai Period, traditional and herbal medicines were used by monks and village healers to take care of the sick in Thailand. Not until the modernization period in late 19th century,

modern medicine was introduced to the country with the establishment of the first modern hospital in the country in 1886. Hospitals and medical schools followed the American model. Then Western medicine has replaced our traditional medicine. No doubt that Thai people benefited a lot from modern medicine but it raised many ethical problems. Bioethics was introduced into Thailand only 15 years ago with the American and European model, Thai modern medicine has created many problems that are difficult to solve with from the traditional and Buddhist background. The complex ethical problems concerning euthanasia, right to die and right to live, human experimentation, organ transplantation, and the new productive technologies are emerging as a result of using hi-tech medicine. Since the year 2004, Thailand has become a global hub of medical tourism with world class facilities, which had raised many ethical questions and the Thai government has to have some laws to regulate some practices.

This paper will elaborate upon the problems and what should be the solution with the Buddhist background of the people. The problem of medical health in Thailand is not only the emergence of ethical problems in bioethics but also the separation of modern medicine from morality and spiritual dimensions. Thai traditional medicine has Buddhist values as its main component. In the last hundred years many Thai doctors were trained in America or Europe and brought back modern medicine with free market ideology, which value wealth over human needs or person. The health care can benefit those who have, and those who have not cannot access the benefit. More than 70% of Thais in the rural areas cannot have good health care. This is another problem that will be discussed in this paper.

I. Present situation: health care and problems

The present situation of medical health in Thailand is separated from traditional medicine and ideology background of the country. Modern medicine is analytic, i.e. it separates the physical from the mental, and the pathological part from the other parts of human system.¹ It lacks religious values and spiritual aspects. In Bangkok, many private hospitals use the hi-tech machine and medicine to patients.

End of life care

Living Will: The National Health Act of Thailand granted that a person is given the right to make a living will to refuse public health service which is provided to prolong his terminal stage of life. This law was enacted in 2007. But not many Thais are aware of this law even now. Most of the rich relatives even the middle classes want to prolong the death of their loved ones through helping machines and other means no matter if the patients desire or not. The problem of the right to die has not been discussed among doctors and patients widely. Not understanding philosophy of Buddhism

clearly Thais are facing real dilemmas of life and death. Pulling off the plug of patients who are brain death; can this be considered as killing? With the Buddhist background and traditional belief no one wants to do the job. There are many cases also that doctors and the closed relatives use technology to prolong the life of patients without consideration of the patient's will.²

Thailand also has Hospices and Homecare as alternative terminal care programs that give strictly non-curative care. They also have palliative care program. In order to be sure that the final days of a patient are pain free and comfortable. And also support to family whose loved ones are facing an incurable illness. The desired result of all palliative care is to improve the quality of life of a patient. The professional team works with the patient and family to make sure that the patient dies with dignified and comfortable death. Through this care the patients are treated both physical ailments and psychological needs.³

Euthanasia-Killing or Letting-Go:

This is a controversial subject in all societies as it involves the ending life of a person. In Thailand, euthanasia is not expressly allowed neither is it expressly prohibited. Active Euthanasia qualifies as murder under Section 288 of the Criminal Code: *"Whoever commits murder on the other person shall be punished with death, imprisonment for life or imprisonment of fifteen to twenty years"*.

And also Physician Assisted Suicide – qualifies as assistance of suicide under Section 307 of the Criminal Code: *"Whoever practices cruelty or employs similar factors on person who has to depend on him or for substance or any other activities in order that such person shall commit suicide, or if suicide has occurred or has been attempted, be punished with imprisonment not exceeding seven years and fine not exceeding fourteen thousand baht"*.

We can see that the Thai Criminal Code, euthanasia consider as unlawful, but under the Civil Code is not necessary in the following.

"When euthanasia, whether active or passive, is performed without the patient's consent, the doctor will be charged with a tort, and is required to pay the reparation. In case where euthanasia is accomplished with the patient's own consent, the principle volunti non fit injuria is applied as a general principle of law even though the very same act would be criminally condemned".⁴

As Thai society changes, people are more involved and concerned about human rights. The problem of euthanasia are part of the expression of one's freedom of decision making about the Human Rights and Civil

² In the cases of Buddhadasa Bhikku, Dr. Pradit Tansurat, Poonperm Krairish, had been hospitalized for sometime before their death.

³ Kelly, Katherine. Mutetwa, Batsirai. Novoson, Lisa. *Palliative Care in Thailand: Hospice and Homecare: A Framework for the Assessment of Costs and Benefits*. www.wpi.edu/Pubs/E-project/Available/E-project.../Deliverable.pdf

⁴ Santivasa, A.P. *Legal Aspect of Euthanasia in Thailand: Problems and Prospects*.

¹ Ratanakul, Pinit. *'Bioethics in Thailand', Bioethics in Asia* pp.98-99 Eubios Ethics Institute 1998.

Rights laws is concern. Passive euthanasia is when the patient's death resulted from withdrawal of the necessary treatments. There are necessary consents from the patients or the relatives of the patients.

As mentioned a person is given the right to sign a living will to refuse the public health service, the person who is ill may make an "advance directive" which is a written document stating the wishes of a patient regarding medical treatment which may involve decisions such as ending his life.

*Because of the incorporation of the provision above mentioned in the National Health Act of Thailand, it became know to the world that the country allows euthanasia in its jurisdiction. Nevertheless, the battle of the legality of euthanasia in the country is still on its peak and as a country which primary religion is Buddhism, euthanasia will always reap criticisms from different sides of the society. It is a fact that pro euthanasia lobbied for the importance of a law allowing the same while those against still remain to defend the teaching of Buddhism- abstention from destruction of life.*⁵

Buddhist teaching and interpretation towards the issue will be introduced and discussed as a challenge by the problems and questioning the use of modern technological medicine, later on.

The right to live: Problem of abortion has been of great concern to public and health department since the discovery of almost 2000 fetuses in Bangkok, 2010. The event alarmed the Thai government and especially the Senate to put the Pro-life Reproductive Health Bill in the country.⁶ Article 305 of Thai Penal Code states that abortion is illegal, except in cases committed by a medical practitioner and is considered only necessary if there is a danger to the health of the mother or when the pregnancy is due to sexual offenses as rape and incest or the fetus severely handicapped.

Abortion has been considered as a sensitive issue which alarmed many interested groups such as activists and feminists. So far nothing really changed according to the law, but the issue remains a problem. Those who support abortion consider that it is not a crime when the fetus is aborted, as the fetus while inside the mother's womb is not yet considered as having any legal right as a person under law, until it was completely delivered and alive. The feminists who support abortion argued that abortion will eliminate gender discrimination in Thailand, as the law allowing abortion will promote the "right of woman to choose". It will also reduce the high rate of woman seeking illegal abortion. In legalizing abortion in Thailand according to the feminists will also reduce the rate of death among woman caused by unsafe abortion.

The problem of abortion still remains. There are many arguments from those who are against abortion, such as the life of unborn fetus should also be protected as it is given value as a being. If the law allows abortion, the whole traditional values and

customs are out of date, with the Buddhist background those who against legalizing abortion consider that abortion is a sin. The questions of abortion have to be carefully considered, from the realistic point of view, Buddhist point of view and social point view.

The Senate considered an immediate passage of the Pro-life Reproductive Health Bill which concentrated upon preventive measures that will give awareness to Thais and will give information on effective Birth Control Methods. In the Bill, the government is mandated to provide accommodation for young mothers as well as their newly born babies' for free health care. Legalizing abortion is not the solution to the high rate of population growth. They try to give effective sex education rather than amendments to legal abortion.⁷

Organ Transplantation has been practiced in Thailand since 1972 first at Chulalongkorn University Hospital. Then transplantation was gradually developed, and now bone marrow, kidney, liver, heart, and lung transplants are common. Heart and lung transplantation are undertaken in 26 hospitals around the country.⁸ Kidney is the most transplanted organ. The demand for organ transplantation has increased and disproportionately increased the demand for donation, leading to the problem of organ shortage. For example, in June 2002, there were 1,029 patients registered for organ donations, and only 200 transplantation cases were operated. It will take approximately 5 years to treat all patients on the waiting list without new registered patients.

Law and order need to step in the process of transplantation, as in 1997-2000 there were scandals about illegal kidney transplantations. The news had impact upon the transplantation system which led to many regulations on transplantation. After 1989, rumors about organ selling in Thailand and other countries gradually spread. During 1997-2000 there were scandals on kidney trafficking in a private hospital. This was reported to the public throughout the media and had major repercussions on public trust in transplantation. The number of donations and transplantations decreased significantly. Then regulation of transplantation were established, there were consumer protection in transplantation system, with rule and regulation and enforcement agencies. Patients who need transplantation must register in a hospital capable of performing transplantation at one hospital only. There were regulations set up in order to make the best and fair in transplantation.

In 1989, the Thai Transplantation Society was set up that has great concern and interest in transplantation, especially in academic and treatment aspects. The problems of transplantation in Thailand are the lack of organ donation, expensive medication and operations that the poor cannot access. There is no specific law in Thailand to control all persons

⁷ Thailand Law, thailandlaw.org.

⁸ Regulation Organ Transplants Thailand HEFP 04-03 – WPOR_03. pdf p.3

⁵ <http://www.thailandlaw.org/euthanasia-in-thailand.html>

⁶ Thailand Law, thailandlaw.org.

involved in transplantation.⁹ There are needs to increase knowledge and interest among the people and physicians that can improve the donation rate in hospitals such as from the brain death patients. The promotion of knowledge to contribute organs to the public is very important. The trust of the general population should help to increase donation and transplantation.

II. Thailand: A global hub of medical Tourism by the use of high technologies and new productive technologies: Assisted Reproduction, Gender Reassignment Surgery, Stem Cell Therapy and Research, Cloning, Face Transplants and Cancer Treatment and Research.

New advanced technologies are being used in all leading hospitals and private hospitals in Bangkok. World class facilities offering a wide range of medical treatments are now located within the country. Well trained doctors are expert in techniques of the new productive technologies, such as assisted reproduction practice widely. There are many regulations issued as follows:

Assisted reproductive technologies (ART) in Thailand: 2001-2007 results generated from the ART Registry, Royal Thai College of Obstetricians and Gynecologists. Executive Board of Medical Council of Thailand has set up an ad hoc committee that established the regulations for practicing assisted reproductive technology. The committee assigned the Royal Thai College of Obstetricians and Gynecologists to supervise and take charge of the administration and formulate an annual report in accordance with the Thai Medical Council Declaration. The regulation was finally approved on 9 October 1997. It was announced in the Royal Gazette on 26 December 1997 and since then the prescription of standard measures for ART practice has been effected. All licensed ART centers are obliged to submit annual reports on the number of patients, cycles, ART techniques and treatment outcomes to the Reproductive Medicine Subcommittee of the Royal Thai College of Obstetricians and Gynecologists. Data from all centers were aggregated and analyzed retrospectively. Despite many limitations, the data provided in this report will help patients, clinicians and policy makers understand the current situation of ART practice in Thailand.¹⁰

Gender Reassignment Surgery: Thailand is famous for the transgender surgery. There are many private hospitals and clinics that offer a variety of treatments for patients who wish to change their gender. There are regulations made by the Medical Council of Thailand in 2009, for doctors performing sex change operations to be registered with the Medical Council. And doctors must check and give treatment for any post-operative complications. Before an operation, the transgendered person must live as the opposite sex for a year while under hormone therapy,

and consult psychiatrist for the hormone too. And at least two psychiatrists must give letters of approval for the person to receive gender reassignment surgery.

Stem cell Research and Therapy: Stem cell treatments and research are regulated in Thailand by central authorities. But before 2009, no government regulations were in force. Medical institutions were responsible for regulating themselves.¹¹ After international criticism of Thai hospitals and clinics offering many unproven and potentially dangerous stem cell treatments, the Thai government decided to take action by regulating the use of stem cells by central authorities.¹² The Medical Council is the main regulatory body overseeing stem cell research. Doctors giving stem cell therapy have to be certified by the Medical Council. Any institution, public or private, wanting to do stem cell research must first get the approval of the Medical Council's ethical committee in addition to their home institution's ethical committee. And also the Ministry of Public Health which oversees the Food and Drug Administration (FDA) also has a hand in the regulation of stem cell therapy. In 2009, the FDA said stem cells and their products would be regulated as drugs.¹³ The FDA also banned the advertising and sale of cosmetic products containing stem cells, and warned against facial treatments involving stem cells.¹⁴

Cloning: We remember mostly about cloning Dolly the sheep in 1997, and after that there was a Thai movie named *Cloning* and not a popular one. In 2005, a Thai scientist began cloning super cows after the importation of U.S. Cattle was banned, and the same year The United Nations General Assembly adopted the Declaration on Human Cloning, which prohibited the use of human cloning if it violated human dignity. In Thailand, therapeutic cloning is allowed, but the reproductive cloning is banned.¹⁵

Face Transplants: This technique may not yet be happening in Thailand, but face procedures are

¹¹ "Stem Cell Therapy in Thailand," *Health-Tourism.com*, 2008, <http://www.health-tourism.com/stem-cell-therapy/thailand/>.

¹² Sirinart Sirisunthon and Pongphon Sarnsamak, "New Stem-Cell Regulation Draws Flak," *The Nation* (Bangkok, February 5, 2010), <http://www.nationmultimedia.com/home/2010/02/05/national/New-stem-cell-regulation-draws-flak-30121899.html>.

¹³ "Stem Cell Therapy in Thailand."

¹⁴ Pongphon Sarnsamak, "Medical Council to Punish Doctors Who Do Stem cell Therapy," *The Nation* (Bangkok, July 30, 2008),

<http://www.nationmultimedia.com/home/2008/07/30/national/Medical-council-to-punish-doctors-who-do-stemcell-300793600.html>; Pongphon Sarnsamak, "FDA Warns About Facial Treatments," *The Nation* (Bangkok, March 2, 2008), <http://www.nationmultimedia.com/home/2008/03/02/headline/s/FDA-warns-about-facial-treatments-30066981.html>.

¹⁵ "United Nations Declaration on Human Cloning A/RES/59/280," *Genomics Gateway*, March 29, 2009, <http://www.brad.ac.uk/acad/abtwc/gateway/HEALTH/Cloning.htm>; "GENERAL ASSEMBLY ADOPTS UNITED NATIONS DECLARATION ON HUMAN CLONING BY VOTE OF 84-34-37," n.d.,

⁹ *Ibid.*, p.27

¹⁰ The Authors. *Journal of Obstetrics and Gynecology Research*, 2010 www.ncbi.nlm.nih.gov/pubmed/21272157

common. With Google search will bring plenty of clinics and hospitals that perform cosmetic facial procedure or called facial rejuvenation. Some examples are facelift, eyelid surgery, cheek implants, jaw surgery, lip and nose surgery.

Cancer: With increasing rate of cancer, the Thai royal family has patronized cancer treatment and research facilities. Researches on cancer are the focus from many research centers, they are interested in using Thai natural products to treat and prevent the disease.

Medical Tourism and Practice: People from all parts of the world are drawn to Thailand for good medical care and comparatively cheaper rates. The cost of surgery in Thailand can be one-tenth or less of what is in the United States or Western Europe. Thailand also has at least 450 hospitals with internationally trained medical staff that specialize in neurosurgery, dental surgery, heart surgery, and cosmetic surgery. Under the Thaksin regime, June 2004 the government tried to promote medical tourism, created a strategic plan that would offer medical services to at least two million tourists by the year 2008.¹⁶ This focus on big business has led to the privatization of many Thai hospitals in four major collaborations: Bumrungrad, Bangkok, Thon Buri, and Phayathai are now the leading medical tourist centers.¹⁷ For example, the Bangkok Dusit Medical Services is a major collaborative group with the chain of 14 hospitals of the Bangkok Hospital Group. That offers a deluxe service and amenities on par with five stars hotels. The ethical problems and results of the medical tourism in Thailand will be discussed later.

III. The Problems and Solutions of Bioethics in Thailand from Social and Buddhist Perspective

In Buddhist ethical thinking, **compassion and interdependence** (the connection of all) are two fundamental values. Compassion implies: first, respect for the right of an individual to make choices or express **autonomy**. Second, one will act the best with the interests of other in mind that is being **beneficence**. Third, **non-maleficence**, with compassion one will do no harm for others. And fourth, **justice** that one can give fair treatment equal to all. Beauchamp and Childress already stressed these in their *Principles of Biomedical Ethics*. These ideologies included the concepts and respect of human dignity and human rights as well. One has to have compassion to oneself which enables one to have dignity and know one's rights. One also needs to understand the concept of interdependence thoroughly. The interesting concept of *interdependence* does not lead the self to be isolated and autonomous, but with the relationship to others, the fellow humans, society and nature are unlimited of time and space. As it means one can exercise

individual rights with respect and consideration of its effects on the others, so called responsible individualism.¹⁸ The Buddhist based Thai approach is holistic: human beings are seen as being comprised of physical, mental, emotional and spiritual elements. These aspects are interwoven with one's social and physical environments. Health is viewed as the harmonious interplay of all the forces in accordance with the eightfold path of Buddhism. Disease is considered as an expression of disharmony, which prevent a person from living in a holistic way.¹⁹

In the old Thai Buddhist approach, disease may result from surrogate agents such as ghosts, demons, who may possess or afflict the person. There will be a series of rituals which are performed by shaman or some Buddhist monks who mediates between human and spiritual world. The Buddhist concept of *karma* (one's own action) contributes also to individual's state of health and illness. That health and disease are interpreted as the effects of positive or negative *karma* which may be accumulated from the previous act or pass life. Thai Buddhism prescribes that human beings practice morality (*sila*), discipline (*Samadhi*), and wisdom (*panna*) in order to live the life well, able to diminish the negative karma and have good health.

Death and dying: Thai Buddhist accepts death as part of their life with no difficulty as common words are usually represented about life: 'being born, getting old and die'. But the question of how to die is more important. Active euthanasia is certainly rejected both by law and Buddhist morality (*sila*, the first principle is not to kill). But passive euthanasia or letting go of life is more acceptable to take into consideration. In the sense of letting go or let die is to let go of the person in the natural process, and can be an act of compassion, not to go against nature and prolong the suffering of the patient or relative, especially the patient total brain death and no hope for recovery.

Hospice and Living Will: The hospice care is accepted well in Thai Buddhist society as it is a natural end of life. It shows holistic approach to health care that focusing on the entire person. Buddhism considers the last stage of life that is calm and conscious states are meaningful to next life or the reincarnation. *Dying with consciousness is important for the next stage of life. "Buddhist literature emphasized the importance of meeting death mindfully since the last moment of one life can be particularly influential in determining the quality of the next rebirth."*²⁰

Doctors and nurses with the practice of compassion provide palliative care, lead the patients to have less pain and ready to go; patients can have a meaningful life at the end. The 'living will' is able to help one die

¹⁸ Ratanaku, Pinit. *Bioethics in Thailand: An Update* <http://muse.jhu.edu/login?auth=0&type=summary&url=/journ>.

¹⁹ _____, Buddhism, health, disease, and Thai culture. In: H Coward and P Ratanakul, editors. *A cross-cultural dialogue on health care ethics*. Waterloo, Ontario; Wilfred Laurier University Press: 1999. p.17-33

²⁰ Hughes, James J., Keown, Damien. *Buddhism and Medical Ethics: A Bibliographic Introduction* <http://www.changesurfer.com/Bud/BudBioEth.html>

¹⁶ Saniotis, Arthur. Changing ethics in medical practice: A Thai perspective. *Indian J Med Ethics* 2007;3:24-5.

¹⁷ _____. A Medical bioethics and medical tourism in Thailand. Paper to be published in 2007 in *Journal of the Thailand Medical Association*.

with dignity. Hospice and 'living will' enable one to have humane treatment that is still possible in the society. More and more people are also aware of 'living will', and wish to die naturally in the last stage of their life, as they believe this is the Buddhist way to face the inevitable death.

Right to live: The tragic event in Thailand in 2010 that 2000 fetus were found showed that Buddhist ideology had been ignored by many young people. Thai traditional Buddhist believed that the transmigration of consciousness occurs at conception and therefore that all abortion incurs the karmic burden of killing.²¹ Any killing is successfully done consisted of three parts, **first the mental effort, second the intensification of the desire to kill, and the complete act of killing** the victim, stated by Buddhaghosa, the well know Theravada Buddhist Monk. He further said that the karma of feticide would be greater than that of killing villains in self defense.²² As we saw above mentioned that abortion in Thailand is against the law, what we need in Thailand is good sex education and methods of contraception. There should be movies and stories to youngsters and teenagers about prevention of pregnancy, abortion, and the effect upon the mother physical and psychology and the fetus. There are many stories that the event can never erase from one's memory, which are painful and brought great suffer to the mother and those surround even with to those who had a lawful abortion.

Thailand: Medical Hub and High Tech Medication benefit to whom?

Many people from all countries come to Thailand for medical treatments. Doctors and nurses are concentrated in those high quality world class hospitals to serve foreigners and well to do patients. Is the idea of leading the country into a medical hub a wrong one? This neglects those who live in the countryside which are more than 70-80% that lack good medical care. The much higher medical expenses and better professional care in private hospitals are beyond the financial capacity of most Thais. And also the shortage of medical practitioners, only 25,815 physicians were filled out of 31,039 in 2005.²³

This consuming and capitalistic society drives people to have more than what are necessities, Thai people are also the victims of the system. Even if the King of Thailand always stresses sustainable development, and the "sufficiency economy" has become a global dialogue for many nations. And his ideas became a great model for this ecological problem of the world. But it seems to have little concern for those commercialists and politicians. As Socrates said,

'Those who never know who they are can never be satisfied with themselves.'

Buddhism in Thailand is interesting, as according to the survey there are about 90% Thais are Buddhist. Thais observe and practice Buddhist rituals and rites but to really understand the philosophy of Buddhism or not is the question. Had the Thais known the philosophy of Buddhism, many high tech technologies that are being use now will be irrelevant, such as transgender surgery, face transplants, cosmetic surgery etc. Buddhism can lead people to understand life and accept life as it is. There is no need to have sex change, as one should be satisfy with oneself. Face transplants, cosmetic surgery also come from dissatisfaction of one self. Right now we have so many *kathoeys*, after the sex reassignment surgery, (they are more beautiful than many ordinary Thai ladies).

*Thai Buddhism links physical beauty to "moral purity" improving upon one's physical appearance can have added spiritual benefits.*²⁴ This understanding is upside down from true Buddhist philosophy. According to Buddhism, those who practice well both in morality (*sila*), maintain discipline (*Samadhi*) and gain wisdom through practice of meditation (*panna*) are good looking, and maintain one's dignity in life. But those who want to have sex change are willing to pay multiple and expensive surgeries for their relentless pursuit of pseudo physical beauty.²⁵

How can the Thai doctors, nurses and public be fully aware of the linkages between modern medicine in bioethical problems? The Thais also have to learn how to apply Buddhist philosophy and ethical principles to the problems. What is lacking in Thailand is a systematic reflection on these problems within Thai/Buddhist cultural framework.²⁶

Highly advanced technologies in Thailand such as assisted reproduction, gender reassignment surgery, stem cell therapy and research, cloning, face transplants etc. are important for the Thais to investigate how these high technologies are appropriate to their life. Do Thai Buddhists understand life in a holistic way or not, that physical, mental emotional and spiritual cannot be separated. To live in harmony with nature, not against it, to understand that one's action (*karma*) effects upon one's life.

As mentioned before many Thais hardly understand and practice Buddhist philosophy, they do not realize that they are responsible for their own actions not matter what they do. And to understand that all things are interdependence or Dependent Origination, all things arise in dependence upon multiple causes and conditions. This is the basis of the key concept of Buddhism. Buddhist wisdom is one that can gain through meditation is the realization of the three characteristics of reality-impermanence, suffering and no-self. But it will take time and great effort to be able

²¹ Ibid., p.4

²² Hughes, James J. Buddhism and Medical Ethics: A Bibliographic Introduction p.5
<http://www.changesurfer.com/Bud/BudBioEth.html>

²³ Saniotis, Arthur. *Changing ethics in medical practice: a Thai perspective*, Indian Journal of Medical Ethics Vol. IV No1. January-March 2007.

²⁴ Saniotis, Author. *Changing ethics in medical practice: A Thai perspective*. *Indian J Med Ethics* 2007;3:p.25

²⁵ Ibid., p.25

²⁶ Ratanakul, Pinit. *Bioethics in Asia*.
<http://www.eubios.info/ASIAE/BIAE98.htm>

to realize these characteristics. If the Thais truly understand Buddhist ideology the country will progress the way it is now. They will not measure success by material gain, but by morality with compassion. They will not prolong death by only using high technologies, they will not have euthanasia and abortion, as nature will take life itself. They will live a life in harmony with nature, not to control it. They will accept who they are, not who they want to be, so there will be no sex surgery, face transplant. They will have a good distribution of health care to all, not only concentrate in big cities like Bangkok.

The urgent problem: the limited of health care resources. The basic health care services are still inadequate for 78% of the Thai population who live in the rural areas. These people are poor and in need of health care services more than affluent people in the cities like Bangkok. The fair distribution of health care to all sectors in the society is needed.

Conclusion

Education is able to lead for the better in the society. Bioethics courses are being offered in Thai universities that can lead people to be more aware of the problems in bioethics. The country has gone too far to realize the problem and solve in a Buddhist way. The real obstacle is that the Thais are not truly understand Buddhism. They only call themselves Buddhist as it is registered as their "official" religion but many do not follow the philosophy. They do not understand sustainable development as a way of life. Bioethical problems of the Thais are very difficult to solve, as the people have to think for themselves, to understand their situations, and to have the knowledge to be able to see the whole structure of life, the whole world, and philosophy. How are things related and connected to all? At the moment, they are like blind persons walking in the mist of a fog not knowing and seeing things clearly, and they do not know what direction they should take. By the time they reach the end, they will realize the vanity of life itself. High technologies that were invented are like a knife, one can use for one end that can be very useful, and the other end one can kill oneself. If the Thais understand the meaning of life and death, the *interdependence* in all things, the values in life, *compassion* to everyone, technologies in their hands can be used to help one another for the better.

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A Buddhist perspective on genetic enhancement

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What is enhancement?

Human enhancement has emerged in recent years as a blossoming topic in applied ethics. With continuing advances in science and technology, people are beginning to realize that some of the basic parameters of the human condition might be changed in the future. One important way in which the human condition could be changed is through the enhancement of basic human capacities.

Human genetics has evolved to a level where we have been able to manipulate the genetic constitution of an embryo to a certain extent through genetic engineering. The knowledge of human genetics has led us to be able to enhance the positive traits in humans while removing the negative ones. The various interesting aspects of human genetics have unfolded the mysteries of the physical and psychological characteristics of humans and opened doors to the betterment of human life. The boundary between "good" and "bad" human genetic engineering depends on whether or not the embryo is considered to be "animate".

The ethical problem of surplus pre-embryos

The fate of the other fertilized ova is an ethical problem, since they will soon become "sentient beings", if not already. But, we hear different views from different Buddhist teachers. In the end, your own motivations are one of the main deciding factors for the morality of actions. A general principle is, it is better to be aware of the problem and admit that your actions are not completely pure, than pushing the problem aside and defending all your actions even to yourself. If you develop compassion and make prayers for the beings you "have" to kill (the worms you kill if you grow vegetables or build houses, the parasites you kill to help your child or pet, and so on) you will diminish the negative karmic effects from killing those beings. Using the awareness developed in meditation it is possible to have a fuller understanding of oneself, other people, and of life itself. Buddhists do not seek to 'evangelize' or coerce other people to adopt their religion, but they do seek to make its teachings available to whoever is interested, and people are free to take.

In view of Buddhist teachings on rebirth, the sentient being is counted from moment of conception (the meeting of three things: the sperm from the father, the ovum from the mother, and the subtle consciousness that is a continuum continuing from a preceding life). Buddhist ethics are all about trying to help others and especially trying to not harm them. The greatest harm is of course killing someone. When discussing fertility treatments, abortion, stem cell research. Generally, Buddhism doesn't clearly state that "you must" or "you're not allowed to" this or that. Instead it explains the functions of cause and effect also in psychological and moral matters, which is called the "law of karma". The teachings tell you what the consequences are if you harm or take the life of another sentient beings, and then it's up to you if you want to take the consequences or not, and if the good outweighs the bad.

In general, fertility treatment is a positive thing from a Buddhist point of view, since you are encouraged to use all the techniques you have on hand (spiritual practice, common sense, science, modern technology, and so on) to help sentient beings. One problem is when you fertilize several ova, and then only use one of them; we freeze the others – maybe one day to discard.

Buddhism in Thailand

Nowadays, Western visitors to Thailand have displayed an increasing interest in our national religion. Buddhism asks "Who was the Buddha?", "What did he teach", "What do Buddhists believe about life after death, good and evil, and the beginning of the world?" Let us consider these in the context of what a good life, "eubios", should mean. The word "Eubios" was coined in 1990 from the Greek Eu=good; Bios=life, to mean "good life".²⁷

Buddhism sees life as a process of constant change, and its practices aim to take advantage of this fact. It

means that one can change for the better. The decisive factor in changing oneself is the mind, and Buddhism has developed many methods for working on the mind. Most importantly, Buddhists practice meditation, which is a way of developing more positive states of mind that are characterized by calm, concentration, awareness, and emotions such as friendliness. Buddhism is a way of life based on the training of the mind. Its one ultimate aim is to show the way to complete liberation from suffering by the attainment of the Unconditioned, a state beyond the range of the normal untrained mind. Its immediate aim is to strike at the roots of suffering in everyday life.

All human activity is directed, either immediately or remotely, towards the attainment of happiness in some form or other; or, to express the same thing in negative terms, all human activity is directed towards liberation from some kind of unsatisfactoriness or dissatisfaction. Dissatisfaction, then, can be regarded as the starting point in human activity, with happiness as its ultimate goal.

Dissatisfaction, the starting point in human activity, is also the starting point in Buddhism; and this point is expressed in the formula of the four noble truths of Buddhism which set out the fact of dissatisfaction, its cause, its cure, and the method of its cure.

The Buddha's teachings can be understood on two distinct levels. One is logical and conceptual and is concerned with an intellectual comprehension of humankind and the external universe. It is on this level that the above questions are more easily answered.

The second level is empirical, experiential and psychological. It concerns the ever-present and inescapable phenomena of everyday human experience, love and hate, fear and sorrow, pride and passion, frustration and elation. And most important, it explains the origins of such states of mind and prescribes the means for cultivating those states which are rewarding and wholesome, and diminishing those which are unsatisfactory and unwholesome. It was to this second level that the Buddha gave greater emphasis and importance.

Karma is a word that most everyone has heard of, but few people know the true meaning. It's often mistakenly thought of as a punishment and reward system, and is used as a curse on those who do bad things. "You'd better watch out for Karma!" as if it's a voodoo police force of the universe. Karma is most importantly, understanding. It is neither good nor bad, just whole. If a person does good deeds, helps others, and lives an honest life, they can still get "bad karma." If that person does all those things, but then judges others who they say they are evil, then they will soon find themselves on the opposite side of that fence.

By judging someone negatively, one is actually asking the Universe for the understanding that made that person behave that way. Common examples are in traits that are misunderstood. If a person says another is too controlling, then pretty soon, they will be accused of the same. They may not even notice, because to them, they were only being helpful, or looking out for someone, but most certainly not being controlling! Only

²⁷ Macer, DRJ. *Shaping Genes*. Eubios Ethics Institute 1990.

after the karmic shoe is on the other foot do they gain the insight as to why the person they judged seemed to be acting in a controlling way

There are different kinds of love, and these are variously expressed as family love, sensual love, emotional love, sexual love, selfish love, selfless love, and universal love. If people develop only their carnal or selfish love towards each other, that type of love cannot last long. In a true love relationship, one should not ask how much one can get, but how much one can give. It is not easy to live life sometimes, and face the world with a smile when you are crying inside. It takes a lot of courage to reach down inside yourself, hold on to that strength that's still there, and know that tomorrow is a new day with new possibilities. But if you can hold on long enough to this, you will come out a new person. Stronger, with more understanding and with a new pride in yourself from knowing that you made it. Just because you fell apart doesn't mean you're broken. Have Faith and never, ever give up. It may appear that Karma is happening to us, as if some outside force is causing good things or bad things to come to us. However, it is really our own inner conditionings and processes that are leading us to experience outer effects or consequences in relation to our own actions.

One of the thorny and most difficult things we humans are ever called upon to do is to respond to evil with kindness, and to forgive the unforgivable. However justified you may be, or however enormous the hurt, it is always possible to forgive. Why teach children about the penalties that life has to offer when you could just as easily teach them about the rewards? Fear based education is negative and faith based education is positive. Simply put, this means that whether we are fearful or faithful, just what we expect to have happen will. Our expectations create our realities, and through our own choosing we create our character, and our character creates our destiny. Even though this is an easy concept to state it is a hard concept to understand, internalize, and put into action.

True happiness can be broadly defined as a mind-state. The characteristics of a mind-state include a sense of universality, continuity and endurance. The mind-state we call true happiness is not temporary, not hit-and-miss; it is not grounded in purely sensual gratification; it does not deal in extremes. It is constant and all-pervasive, and above all it is that which can be borne with ease.

Rebirth with Karma, as there is no soul to transmigrate from one body to another, "Rebirth" occurs when the karma created by a past life carries over to another life. Most schools of Buddhism teach that conception is the beginning of the process of rebirth and does, therefore, mark the beginning of a human being's life. One way to explain rebirth is to think of all existence as one big ocean. An individual is a phenomenon of existence in the same way a wave is a phenomenon of ocean. A wave begins, moves across the surface of the water and then dissipates. While it exists, a wave is distinct from ocean yet is never separate from ocean. In the same way, that

which is reborn is not the same person, yet is not separate from the same person.

Turning our attention to the modern world, it is not difficult to identify the psychopath who lacks any measure of conscience and empathy—a person whom we might characterize as being "cold and calculating". One troubling aspect of a psychopath is that they seem to be quite sane. But in reality they are anything but sane. They have an insatiable appetite to be in positions of power in order to control others and psychically harm them. Virtually, every hierarchical system is riddled with psychopaths. Probably, the first recorded evidence of psychopathic came at the beginning of the 19th century.

How the psychopath gains power over those with a conscience is perhaps more disturbing? One of the most troubling of modern ironies is that those who believe they have a conscience often permit themselves to be undermined and ruled by psychopaths who have no conscience. This, it could be argued, is the main cause of every form of modern injustice and abuse culminating in the holocaust during the Second World War.

From a Buddhist perspective, those who believe they have a conscience might be slowly and imperceptibly transforming into subconscious, that is, psychopaths. They are like someone driving the getaway car for a gangster who, while never actually committing the bank robbery, was nevertheless an important element in the success of the robbery.

Everything that we see, hear, smell, taste, touch, feel, think, remember, and imagine has a cause. If we are in physical pain, that pain has been caused by something; if we are mentally upset, then that mental pain has a cause.

The law of Karma cannot be negated. There is no effect that is not subject to the law of Karma. Just as no negative effect can be brought about without a cause, similarly no positive effect can be brought about without a cause. Positive and negative thoughts, feelings, sensations, experiences, and so on and so forth, do not occur in a vacuum. They originate at 'sometime' and take place 'somewhere'. In other words, they occur in time and space.

Applying Buddhism to Enhancement

Should we enhance life? Scientists tell us that life started on this planet, somehow, about 4 billion years ago, and since then life has expressed itself in many diverse forms. But no one has observed the "beginning." We living beings are manifestations of an unbroken process that has been going on for 4 billion years. In that context we should consider enhancement.

Positive Perceptions of enhancement

The International Bioethics Survey (Macer et al.)²⁸ revealed very positive views of enhancement in Thailand in 1993, which is illustrated in the three tables below extracted from the paper. These were in

²⁸ <http://www.eubios.info/Papers/HGT95.htm>

response to the question: "Q28. *How do you feel about scientists changing the genetic makeup of human cells to:* ++ Strongly Approve + Somewhat Approve - Somewhat Disapprove - - Strongly Disapprove DK Don't know". There are comparisons to the public in New Zealand (NZ), Australia (A), Japan (J), India, Thailand, Russia (R), Israel and to an earlier US survey.

Public										
	NZ	A	J	India	Thai	R	Isrl.	US86		
e. Improve the physical characteristics that children would inherit										
++	10	15	12	36	54	16	10	16		
+	14	13	16	27	29	20	12	28		
-	17	19	35	11	11	12	34	22		
--	47	44	16	15	3	38	42	31		
DK	12	9	21	11	3	14	2	3		

Public										
	NZ	A	J	India	Thai	R	Isrl.	US86		
g. Make people more ethical										
++	14	18	14	31	68	19	10	-		
+	13	16	10	25	18	12	22	-		
-	12	10	32	12	11	7	24	-		
--	43	34	21	16	6	44	32	-		
DK	18	22	23	16	7	18	12	-		

Public										
	NZ	A	J	India	Thai	R	Isrl.	US86		
f. Improve the intelligence level that children would inherit										
++	11	15	13	41	48	18	6	18		
+	13	12	13	29	26	17	16	26		
-	21	21	35	10	16	11	32	22		
--	46	41	19	13	6	38	38	31		
DK	9	11	20	7	4	16	8	2		

In India and Thailand more than 50% of the 900+ total respondents in each country supported enhancement of physical characters, intelligence, or making people more ethical. It could suggest several things: that poor living standards and infectious disease make people more pragmatic about "improvement", or that people in those countries have not thought about the implications (even though they were relatively highly educated samples). It is interesting if this is a general trend in developing countries, as it could have significant implications for international policy.

It is not surprising that so many Thai people undergo cosmetic enhancement as discussed in the preceding paper in *EJA/IB* by Chutatip Umavijani (Nov. 2013).

Conclusions

If we have some condition should we stay in that condition and bear it – even at times suffering, or should we try to improve ourselves by spending money and using technology. We may spend our money and time to work hard to study and take education. A Buddhist perspective may be to take a middle way, and have a thankful heart working hard for the good of others. There could be more research done to examine why so many people in Thailand appear to embrace enhancement using new technology, as we approach the genetic revolution.

Further Reading and References

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Jaron Lanier's Lock-In as Exemplified by Facebook

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Abstract

Jaron Lanier, renowned computer scientist who is credited to coin the term "virtual reality" (VR), empathically states that persons must beware of digital lock-in. According to him "The brittle character of maturing computer programs can cause digital designs to get frozen into place by a process called lock-in. This happens when many software programs are designed to work with an existing one. The process of significantly changing software in a situation in which a lot of other software is dependent on it is the hardest thing to do. So it almost never happens." Thus, Lanier also contends that "lock-in... is an absolute tyrant in the digital world." This paper contends that the

ubiquitous, and also seemingly indispensable, Facebook, has locked-in its users. From its creation in 2004 by Harvard sophomore Mark Zuckerberg, Facebook has become a monolith with a global 1.2-billion-plus strong (and still growing) members at present. A monolith, which, has been showing signs that it is becoming a runaway “absolute tyrant in the digital world.”

Keywords: Digital lock-in, Facebook, data mining, digital tyranny

The Beginnings and Evolution of Facebook

Facebook was created in February 4 2004 by Mark Zuckerberg, a Harvard University sophomore, under the name “Thefacebook.com”. In 2005, having purchased the domain name for US\$200,000, “The” was dropped, and “facebook.com” became the official domain name of Facebook.²⁹

“Facebook” originally referred to the publications that some colleges in Harvard give out to students at beginning of the year to help students know each other better. Zuckerberg designed his electronic version of Facebook still with the same aim, however Harvard students access them via the net. Initially, exclusively for Harvard students, but in matter of months became so popular, that the next year, 2005, was offered to high school students, and offered to general public in 2006. The trajectory of Facebook use was indeed astounding. On its first launch in 4 February 2004, there were “somewhere between twelve hundred and fifteen hundred registrants.” By August 26, 2008 (around 4 years and 6 months from its 2004 launching), Facebook had its 100 million active users (An “active user” is defined by Facebook as a user who has visited the website in the last 30 days). By April 8, 2009, Facebook already hit 200 million active users; by September 15, 2009 already 300 million; by February 5 2010, up to 400 million; by July 21, 2010 already half a billion active users; January 5, 2011 already 600 million; May 30 2011 already 700 million; September 22, 2011 already reached 800 million; April 24, 2012, up to 900 million active users; October 4, 2012, reached its 1 billion users; by March 31, 2013, already 1.1 billion. Of course, according to David Cohen, even Facebook that the said numbers may also even include invalid accounts (duplicates 5%; improperly classified 1.3%; fake .9%)³⁰, but that still leaves us at least 1 billion active users of Facebook. Given such number, it’s worth noting that the population of Facebook’s active users is only exceeded in the world by the national populations of China (1,360,940,000)³¹, and India (1,236,160,000). The United States is a distant fourth with its population of 317,22,000, and such figures are as of 08 November 2013.

Digital Lock-in According to Jaron Lanier

Jaron Lanier, renowned computer scientist who is credited to coin the term “virtual reality” (VR), also

nominated in TIME magazine as among the 100 most influential people³², and recognized by Encyclopedia Britannica as one of history’s 300 greatest inventors³³, empathically speaks that persons must beware of digital lock-in. According to him: *“The fateful, unnerving aspect of information technology is that a particular design will occasionally happen to fill a niche and, once implemented, turn out to be unalterable. It becomes a permanent fixture from then on, even though a better design might just as well have taken its place before the moment of entrenchment...(p.8) The brittle character of maturing computer programs can cause digital designs to get frozen into place by a process called lock-in. This happens when many software programs are designed to work with an existing one. The process of significantly changing software in a situation in which a lot of other software is dependent on it is the hardest thing to do. So it almost never happens. (p. 7)”*

And according to Lanier such entrenchment is further cemented by the computers’ power to grow exponentially as essayed by the Moore’s law³⁴. *“Computers have gotten millions of times more powerful, and immensely more common and more connected. It’s as if you kneel to plant a seed of a tree and it grows so fast that it swallows your whole village before you can even rise to your feet.”*³⁵ Thus, Lanier contends that *“lock-in... is an absolute tyrant in the digital world.”*

The Facebook, since its inception, as the numbers above show, have also exponentially grown, similarly along the lines of the Moore’s law. So much so, that contrary to Lanier’s view that Facebook, though “with commercial intent, but without, as of this time of writing, commercial achievement,”³⁶ Facebook eventually had filed for its IPO (initial public offering) on February 1, 2012. The IPO gained Facebook US\$16 billion. Around 18 months later, as of August 2013, according to Brian Womack³⁷, Facebook is worth at least US\$100B. And the profitability of Facebook is still expanding. In the same article, Womack further states that: *“The market is gaining confidence that Facebook is going to be a viable profit-generating machine in the future,”* said Laurence Balter, an analyst at Oracle Investment Research in Fox Island, [Washington](#). *“People are*

³² http://en.wikipedia.org/wiki/Jaron_Lanier

³³ Jason Lanier, *“You Are Not a Gadget: A Manifesto,”* Allen Lane – Penguin Group, Penguin Books, Ltd. 80 Strand, London W C 2 R ORI, England, 2010, Preface

³⁴ **Moore’s law** is the observation that, over the history of computing hardware, the number of transistors on integrated circuits doubles approximately every two years. The law is named after Intel co-founder Gordon E. Moore, who described the trend in his 1965 paper.[1][2][3] His prediction has proven to be accurate, in part because the law is now used in the semiconductor industry to guide long-term planning and to set targets for research and development. [4] http://en.wikipedia.org/wiki/Moore's_law

³⁵ Lanier, p. 8

³⁶ Lanier, p.16

³⁷ <http://www.bloomberg.com/news/2013-08-26/facebook-market-value-tops-100-billion-amid-mobile-ad-push.html>

²⁹ http://en.wikipedia.org/wiki/History_of_Facebook

³⁰ http://allfacebook.com/form-10q-invalid-accounts_b122538

³¹ http://en.wikipedia.org/wiki/List_of_countries_by_population

checking their Facebook page more and more all the time.”

The Facebook Lock-in

As stated above by Lanier, Facebook, from its genesis, was intended by Zuckerberg primarily as a profit-making venture, a commercial entity. To keep such commercial edge, Facebook thus has to install its own version of lock-in, which: “...once implemented, turn out to be unalterable. It becomes a permanent fixture from then on, even though a better design might just as well have taken its place before the moment of entrenchment.³⁸... Every element in the system –every computer, every person, every bit- comes to depend on relentlessly detailed adherence to a common standard, a common point of exchange.”³⁹

And such lock-in-ness is fundamentally embedded in Facebook’s “Statement of Rights and Responsibilities.” Meaning, that, as in any digital program or application, one can only have access to such program or application if first of all one clicks “Agree” to the said terms and conditions, or “Rights and Responsibilities.” And such is categorically essayed as a provision says: “*This Statement of Rights and Responsibilities (“Statement,” “Terms,” or “SRR”) derives from the [Facebook Principles](#), and is our terms of service that governs our relationship with users and others who interact with Facebook. By using or accessing Facebook, you agree to this Statement...*”⁴⁰

Then such categorical statement is followed by a short, but a motherlode provision: “**Privacy** Your privacy is very important to us. We designed our [Data Use Policy](#) to make important disclosures about how you can use Facebook to share with others and how we collect and can use your content and information. We encourage you to read the Data Use Policy, and to use it to help you make informed decisions.”

We say motherlode, because this provision captures the essence of the lock-in-ness of Facebook. “Your privacy is very important to us,” makes a blanket statement decidedly meant to assuage a very basic concern of any internet user: privacy. With such a statement, thus Facebook gives a putative (if not at least implicit) assurance to its users that their very fundamental rights and concern to privacy is being warranted by Facebook. That is, if the statement is taken univocally, meaning, that the said provision is to be interpreted in only one and the same way, which is indeed, because privacy is important for the users, thus Facebook assures the users that their privacy will be appropriately protected by Facebook. However, this “Your privacy is very important to us” provision may also be looked from another angle, or that it may also be taken analogously. That is, as the phrase stands, it can actually also be taken to mean another thing, depending on one’s vantage point, in this instance, skewed towards Facebook. Meaning that whatever it is that a user holds important because it’s private, is also

held important by Facebook, for the simple reason that because of the *private matters that its users bring into* Facebook, Facebook is able to generate revenue from.

And that’s the reason why, the next sentence makes clear sense, again advantageous to Facebook when it says “We designed our [Data Use Policy](#) to make important disclosures about how you can use Facebook to share with others and how we collect and can use your content and information.” The word “designed” clearly essays that from the time one becomes a user of Facebook, whatever one brings into Facebook will only be according to such “design,” thus, locked-in to the will and decisions of Facebook. Thus, from the very outset, Facebook is indeed proving itself to be totalitarian, absolutist.

Such totalitarianism has actually also found expression by way of the work of the philosopher Emmanuel Levinas, especially on his thoughts about the egoistic “self,” or the “I” as he calls it. The “I,” or *Il y a*, as expounded by Emmanuel Levinas, literally is, “*il*”, meaning “it”, “*y*” meaning “there”, and “*a*” meaning “has”. Crudely further put, “it has there”. Correctly put, *il y a*, is the *there is*, the verb “to be” of Being. In other words, referring to the *existence* of that which exists, and not to that which exists itself. The *il y a* is akin, if not derivative of Martin Heidegger’s *Dasein*, the *there-being*. The notion of the *il y a* is significant because for Levinas this is the grounding of all beings, of anything that exists. Meaning, anything which exists cannot but exist. It *has to* exist for it to be an existent. There is the persistence of the Being (act of existence) of a being or beings (the one/s existing), or the insistence of the verb of the noun. This there-being of existence, at the first instance however, is impersonal, or that the notion of the term Being is impersonal. Thus Levinas says that, “Being is essentially alien and strikes against us. We undergo its suffocating presence like the night, but it does not respond to us.”⁴¹ It is not that there is nothing there, but rather that what is there is some kind of a void, or maybe an amorphous entity, akin to being something which is there which is anonymous part of the landscape. However, amorphous being/s may be, it/they still cannot but persist in its/their Being. And this mode of existence is also taken on by the “I”, the “self”, the “ego” the human being.

The human being, or the “I” or the “self”, is one of the beings which has Being, or which exists. And just like any existent, it would also like to persist in its Being: “*For man is able to take up an attitude with regard to his very existence. Already in what is called the struggle for life, over and beyond the things capable of satisfying our needs which that struggle intends to acquire, there is the objective of existence itself, bare existence, the possibility of pure and simple existence becoming an objective... But the notion of the struggle for existence is not enough to grasp the relationship of an existent with its existence as deeply as we would like. When taken at the level of the time of the economic order, as it ordinarily is envisaged, it*

³⁸ Lanier, p. 16

³⁹ *Ibid.*, p.15

⁴⁰ (<https://www.facebook.com/policies/>)

⁴¹ Emmanuel Levinas, Alfonso Lingis (trans.) *Existence and Existents*, (The Hague: Martinus Nijhoff, 1978), p. 23.

appears as a struggle for a future, as the care that a being takes for its endurance and conservation. It is a struggle for an already existent being for the prolongation of its existence. It is not a continual birth, understood as a distinct operation by which an existent takes over its existence, apart from what it may do to conserve it.⁴²

This ontological persistence plus the impersonality of the *il y a* thus makes for a highly self-seeking, egoistic, self-centered, human being, institutions, in our case, Facebook. This inflicting persistence of being is also termed by Levinas as *totality*: "A being that has life in the totality exists as a totality, lives as though it occupied the center of being and were its source, as though it drew everything from the here and now, in which it was nonetheless put or created. For it the forces that traverse it are already forces assumed; it experiences them as already integrated into its needs and enjoyment."⁴³

If we notice, the said, totality or persistence in being is a self-sufficiency that is not a total absence of need for being or beings other than itself. As the above citation says the forces other than "I" are "forces assumed... integrated to its needs..." Its selfishness consists in simply assimilating others, as if embracing others in an octopoidal dance of death, simply for its own purpose, for its own interest. Even the word "interest", etymologically dissected denotes such egoism. "Inter," meaning inside, interior, within; "est," is. Inter-est therefore refers to what is inside, meaning, that which is not found outside or does not go outside. Meaning that in totality, everything **goes back into** the "I", the "self", and not to those other than itself. Ergo, in totality, the human being, can be likened to the black hole of physics. A black hole absorbs into itself anything approximate it through its very strong magnetic energy. The aforementioned persistence in being can be likened to the said magnetic energy of the blackhole, and as physicists would surmise, nothing escapes a blackhole, and so nothing will also be allowed by the totalizing self to slip from its self-serving grasps. Ergo, it is because of such totalistic propensity that therefore, there is that aforementioned state of war or violence among human beings, a war that therefore casts somekind of a darkness between human beings: "The state of war suspends morality; it divests the eternal institutions and obligations of their eternity and rescinds ad interim the unconditional imperatives... In advance its shadow falls over the actions of men. War is not only one of the ordeals -the greatest- of which morality⁴⁴ lives; it renders morality derisory. We do not

need obscure fragments of Heraclitus to prove that being reveals itself as war... that war does not only affect it as the most patent act, but as the very patency, or the truth, of the real. In war reality rends the words and images that dissimulate it, to obtrude in its nudity and in its harshness. Harsh reality (this sounds like a pleonasm!), harsh object-lesson, at the very moment of its fulguration when the drappings of the illusion burn, war is produced as the pure experience of pure being. The ontological event that takes form in this black light is casting into movement of beings hitherto anchored in their identity, a mobilization of absolutes, by an objective order from which there is no escape. The trial by force is the test of the real. But violence does not consist so much in injuring and annihilating persons as in interrupting their continuity making them play roles in which they no longer recognize themselves, making them betray not only commitments but their own substance, making them carry out actions that will destroy very possibility for action."⁴⁵

Levinas also states that such natural proclivity to totality, the "self's" absorption of the other, can have several expressions. And one of them is in labor, or as Levinas would say, the transformation of matter or the elements by man. According to the Pentateuch, Yahweh created man in his image and likeness. According to Levinas, the "self", also transforms the world or elements in his image or likeness. The material world, or the "elemental" as Levinas calls it, is there for the my taking, for my mastery.

The elements remain at the disposal of the I -to take or to leave. Labor will henceforth draw things from the elements and thus *discover* the world... This primordial grasp, this emprise of labor... arouses things and transform nature into a world...⁴⁶

I get myself a lump of clay. I knead it, I mold it, I shape it according whatever shape I want it to have, then I put into the furnace, then taking it out of the furnace, and after letting it cool, I paint it. As finishing touch, as if not yet satisfied, I either stamp my insignia on it or manually put my signature on it. The "I" therefore simply makes that piece of clay a copy of the "I", an imago, thus the other still becomes me. Thus, if applied to Facebook, everything, and anything that is in, and transpires in Facebooks, is in and transpires in Facebook, according to the "image and likeness" of Facebook

Through labor, the "ego" or "I" does not only transform matter or the world. It also takes possession of the world. Thus it can be noted, that one says "This is house is the fruit of my labor," "This piece of special paper used to be just a lump of grass was made by me," and so on and so forth. We identify ourselves with our labor, with our transforming of matter, and by so doing we also end up appropriating the fruits of our labor. "This finished product is mine because I made

⁴² Ibid., pp 23-24.

⁴³ Emmanuel Levinas, *Collected Philosophical Papers*, Alfonso Lingis trans., (Boston: Martinus Nijhoff Publishers, 1987), p.25.

⁴⁴ This is the other term which Levinas uses for ethics, which on author says is "a metaphysical responsibility, an exorbitant and infinite responsibility for other human beings, to care not for being, for the unravelling of its plot, but for what is beyond and against being, the alterity of the other person." Emmanuel Levinas, *Ethics and Infinity (Conversations with Philippe Nemo)*, Richard Cohen

trans., (Pittsburgh, Pennsylvania: Duquesne University Press, 1985), p.3.

⁴⁵ Levinas, *Totality and Infinity*, *ibid.*

⁴⁶ Levinas, *Totality and Infinity*, pp.156-157.

it." Again, the "I" simply agglomerates the other into the same. And how more can Facebook manifest such proprietary totality than by its being out and out profit-oriented.

For such lock-in-ness or totality, to date, therefore Facebook is at the very least known of the following problematics according to Rosa Golijan⁴⁷: "**Facebook collects more data than you may imagine.** For example, did you know that Facebook gets a report every time you visit a site with a Facebook "Like" button, even if you never click the button, are not a Facebook user, or are not logged in?"

Your data is shared more widely than you may wish. Even if you have restricted your information to be seen by friends only, a friend who is using a Facebook app could allow your data to be transferred to a third party without your knowledge.

Legal protections are spotty. U.S. online privacy laws are weaker than those of Europe and much of the world, so you have few federal rights to see and control most of the information that social networks collect about you.

And problems are on the rise. Eleven percent of households using Facebook said they had trouble last year, ranging from someone using their log-in without permission to being harassed or threatened. That projects to 7 million households — 30 percent more than last year."

However, Levinas himself also prescribes that the Other can actually resist the totalizing proclivities of the egoistic "I", i.e., the "ego", comes to be aware that though he usually is able to assimilate other beings, and there also are some which sometimes resist such assimilation, there really is *that other* which *totally or absolutely defies* his totalistic predilection. That there has been so many things of this world that he has enjoyed, has appropriated, provided him nourishment, been made into his image and likeness, yet there is that something which it cannot and will not allow it so. And during such moments of resistance, of defiance that the Levinasian moment of ethics -the epiphany of the Face or the Other- happens.

The ethical moment, the moment in which the "ought" shows itself, is found, for Levinas, on the level of sensibility when the egoist self comes across something that it wants to enjoy, something that it wants to make part of itself, but cannot. That which the self wants to enjoy but cannot is the other person. The reason that it cannot enjoy the other person is ... in the other person who pushes back, as it were, who does not allow himself to be consumed in the egoism of my enjoyment. The presence of the other, on this level, is not, properly speaking, known.⁴⁸

Thus, though locked-in, a Facebook user can also have still reasonably choose to remain within the domains of Facebook as it also has its attendant

advantages. Among the most salient being that as a social networking tool, it capacitates one linking with people. Facebook has also become a democratic platform for individuals or groups to express their ideas whether it be in politics, science, technology, commerce, economics, and anything and everything as long as they are acceptable according to the locked-in *design* of the Facebook. For all its problematics, this author can't help but praise Facebook for having been a fast and ubiquitous or accessible gateway of information, specially for emergencies, as in disasters, calamities, etc. Messages seeking help, sympathy, aid, can easily reach multitudes of Facebook netizens at a digital speed. Thus, it can be deemed that the following can also be observed by Facebook users so as to minimize the totalizing impact of Facebook's lock-in, of course, in a very digital manner⁴⁹:

Think before you type. Even if you delete an account (which takes Facebook about a month), some info can remain in Facebook's computers for up to 90 days.

Regularly check your exposure. Each month, check out how your page looks to others.

Review individual privacy settings if necessary. Protect basic information. Set the audience for profile items, such as your town or employer. And remember: Sharing info with "friends of friends" could expose it to tens of thousands.

Know what you can't protect. Your name and profile picture are public. To protect your identity, don't use a photo or use one that doesn't show your face.

"UnPublic" your wall. Set the audience for all previous wall posts to just friends.

Turn off Tag Suggest. If you'd rather not have Facebook automatically recognize your face in photos, disable that feature in your privacy settings. The information will be deleted.

Block apps and sites that snoop. Unless you intercede, friends can share personal information about you with apps. To block that, use controls to limit the info apps can see.

Keep wall posts from friends. You don't have to share every wall post with every friend. You can also keep certain people from viewing specific items in your profile.

When all else fails, deactivate. When you deactivate your account, Facebook retains your profile data, but the account is made temporarily inaccessible. Deleting an account, on the other hand, makes it inaccessible to you forever.

To end, let me once again quote Jaron Lanier: "*We have to think about the digital layers we are laying down now in order to benefit future generations. We should be optimistic that civilization will survive this challenging century, and put some effort into creating the best possible world for those who will inherit our efforts.*"⁵⁰

⁴⁷ <http://www.nbcnews.com/technology/consumer-reports-facebook-privacy-problems-are-rise-749990>

⁴⁸ Anthony F. Beavers, *Introducing Levinas to Undergraduate Philosophers* (http://cedar.evansville.edu/~tb2/trip/levinas_intro.htm, 23 March 2001), p.2

⁴⁹ <http://www.nbcnews.com/technology/consumer-reports-facebook-privacy-problems-are-rise-749990>

⁵⁰ Lanier, p. 20

NOTE. I offer this humble paper in memory of my fellow Filipinos who perished and are still suffering due to the onslaught of the typhoon Haiyan/Yolanda. I also offer this as a salute to everyone (Filipinos and non-Filipinos) who unselfishly extended themselves to our country in this time of direst need. I know, together, with God's grace, we shall prevail. **[Ed.- Readers may be interested to join the Eubios Youth Looking Beyond Disaster (LBD) programme, with the LBD4 occurring in the Philippines, 2-6 April 2014. See the website of Facebook pages!!]**

Framework for Advancing Health Care in Pakistan

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Abstract

Health inequity is prevalent in developing countries and despite of showing success in terms of national averages health attainment in developing countries has not reached up to the mark of desired outcome. Patterns of these inequities can be seen in our country and society in both the directions i.e. horizontal and vertical. Inequity in the domain of health is vital as it is considered as a significant factor for human life and development. Moreover, these inequities in health lead to other inequities prevalent in our society that contributes again in health inequity. Therefore it can be said that inequities in health are the consequences of various factors i.e. Individual factor, social inequities, economical inequities, cultural value and beliefs, environmental conditions, system factors and discriminatory beliefs. In order, to overcome these inequities 'health equity' is a perfect approach to address.

In this paper a framework for advancing health equity is discussed. In part I of this paper an attempt would be made to understand health inequity and factors that contribute and precipitate. In part II, solutions and recommendations will be proposed and discussed that will be effective for developing health equity in our country. This part will focus two areas i.e. understanding health system governance matrix of Pakistan, its strengths and weaknesses at central and Ministry Of Health (MOH) policy level; secondly, promotion of public health and human rights in Pakistan.

Key Words: Health equity, disparity, social justice

1. Understanding disparities

It's been more than 60 years, since that Pakistan has got independence and citizens are enjoying the freedom of being independent nation. Many years have been passed since Pakistan got affiliation with human rights bill. However, the pattern which is very evident in

this country is that the better-off is becoming better day by day and the less well-off are being deprived from their needs more with the passage of time. It is because that the better-off, more educated, more powerful, and wealthier in society have much greater capacity to improve their health than do the less well-off. This is the reason because of which the condition of inequity is becoming persistent and a pattern of resistance is becoming evident amongst them. Besides human right bill affiliations, it doesn't seem that this country will be able to achieve Millennium Development Goals (MDGs), in which the aim is to reduce hunger and poverty, and to address various issues in our society i.e. gender inequality, access to education, access to health care, access to safe water and safe environment. Thus, it can be said that the condition of inequity is existent and is becoming persistent in many developing countries also including Pakistan. This pattern of these inequities can be seen in our country and in our society in both the directions i.e. horizontal and vertical. I stated here inequities prevalent in our country in horizontal and vertical directions i.e. these inequities can be seen in every spectrum of our society, for example, inequities prevalent among men and women, urban and rural areas, working class, social class, health, education, income, working conditions, disabilities and death. Although, the inequities or disparities that are mentioned above are avoidable and are unnecessary.

2. Understanding health inequity

Health inequity can be defined as differences in health which are not only unnecessary and avoidable but, in addition are considered unfair and unjust. Health inequity is prevalent in developing countries as comparative to developed countries and despite of showing success in terms of national averages health attainment in developing countries is not up to the mark or the desired outcome. Let us see this concept with the help of an example of Pakistan's infant mortality rate (IMR). Pakistan is a country where life expectancy is lowest and IMR is highest. Moreover, Maternal Mortality ratio (MMR) is more than 500 per 100000 live births. Almost 300 to 550 per 100000 women die annually from child birth process. A point to ponder is that those deaths are avoidable with the provision of certain facilities and by taking simple measures of prevention but despite of this fact these deaths are prevalent and are rising day by day. These statistics rings various questions in one's mind that why such pattern is being observed in our country? Why it is not avoidable? Does this pattern is related with the other causes i.e. individual, social, cultural and etc?

Looking at the statistical analysis of health indicators it can be said that amongst all the disparities, inequity in the domain of health is vital as it is considered a significant factor for human life and development. Moreover, these inequities in health lead to other inequities prevalent in our society that contributes again in health inequity. Therefore it can be said that inequities in health are the consequences of various factors i.e. Individual factor, social inequities,

economical inequities, cultural value and beliefs, environmental conditions, system factors and discriminatory beliefs. In order, to overcome these inequities 'health equity' is a perfect approach to stop these inequities.

3. Factors that contribute to Health Inequity

In this part an attempt will be made to highlight some of the factors that contribute or leads to health inequity. Because framework to advance health equity can not be discussed in isolation as it is related to other various factors. In other words, it can be said that health inequity is a result of interaction of multiple factors. These factors can be categorized as individual factors, social inequities, economical inequities, cultural value and beliefs, environmental factors, system factors and discriminatory beliefs.

Individual factors:

Individual factors effect directly on health and influence it. To say that there are inequities in health and the responsible for these inequities is only system is a wrong assumption and statement because individual factors also contribute in inequities in the domain of health. These factors include an individual's age, genetics, health behaviours and chronic illnesses.

Social factors:

Other than individual factors, social factors also play a vital role in health inequity. Social factors are also referred as Social Determinants of Health (SDH). These social inequities are a life long process. I am referring this as life long process because it starts from the day a person is born and continues through out life in different domains, for example, education, work and etc. These social inequities exist in our society because of the different classes that we have in our society as the people who are well to do can enjoy every benefit that they can afford or buy, on the contrary poor class only suffers and bears the burden of diseases. Besides this, these social factors also leads to lack of access to education, lack of access to health care facilities, race discrimination, class discrimination and gender inequity.

- **Education and Health:**

If we refer to lack of access to education and its impact on health inequity then we observe globally a uniform pattern i.e. the pattern of disparities in health among the people who are not very privileged to have access to education as comparative to those who are well educated because education is one of the factor that plays a significant role in decreasing social inequities because it creates awareness amongst the people and also provides way to live life effectively and productively for oneself and for society. However, on the other hand, if we see the system of education in Pakistan then it can be said that it is one of the weakest system not in terms of its planning and paper work but in terms of its actual field application and monitoring. If we look facts and figures then it reveals that the adult literacy rate of Pakistan is 49.9% which is very low comparative to other developing countries as

well for example the literacy rate of our neighbour country i.e. of India is 61%. The reason of stating these statistics here is just to highlight the difference which is the result of the issue of priority setting in terms of expenditure. In Pakistan, education is the domain which gets low priority and hence less funds are allocated to this domain for expenditure. The data on public expenditure on education reveals that Pakistan gives low priority to education: it spends relatively less on education, 2.3%, compared to other countries.

The statistics mentioned above provide the overall global picture of the education and its impact on health inequity, but if we see within our country then also disparities exist amongst the provinces where the main domain is urban and rural population difference. The schooling system of rural and urban areas is also distinct from each other. The facilities, environment and education provided in rural setting are different from the urban setting. The facilities that I am referring to here are the facility of water, sanitation and many more. These all eventually results in weaker performance on equitable distribution of educational opportunities.

The point of discussing these all facts here is that these inequities in health impact significantly on health as it is directly related with income and employment through which the cost of health care facilities can be afforded. In addition, educated people's approach to life and risk taking behaviours is different because of the level of awareness that they possess. Moreover, people who are less or uneducated, work in the areas which are highly risky to the health and life; for example, workers of cement, cloth and cotton industries are prone to develop respiratory tract diseases, workers of mines and automobile workshops are vulnerable to accidents and deaths, workers of transport industries are prone to accidents, sexual abuse and developing sexually transmitted diseases. Let us understand this concept with the help of an example, i.e. think about a person who belongs to low socio-economic class of our society and because of which they are unable to get education. Later on, when they grows up and starts their own family then definitely they have to earn income. Because the person is uneducated, therefore they are unable to do any such job that is limited to qualified persons and they end up doing certain kinds of job that involve risks, for instance, a driver, worker in a coal mine or cotton industry or etc. Hence, education is the only means by which health status can be enhanced and uplifted.

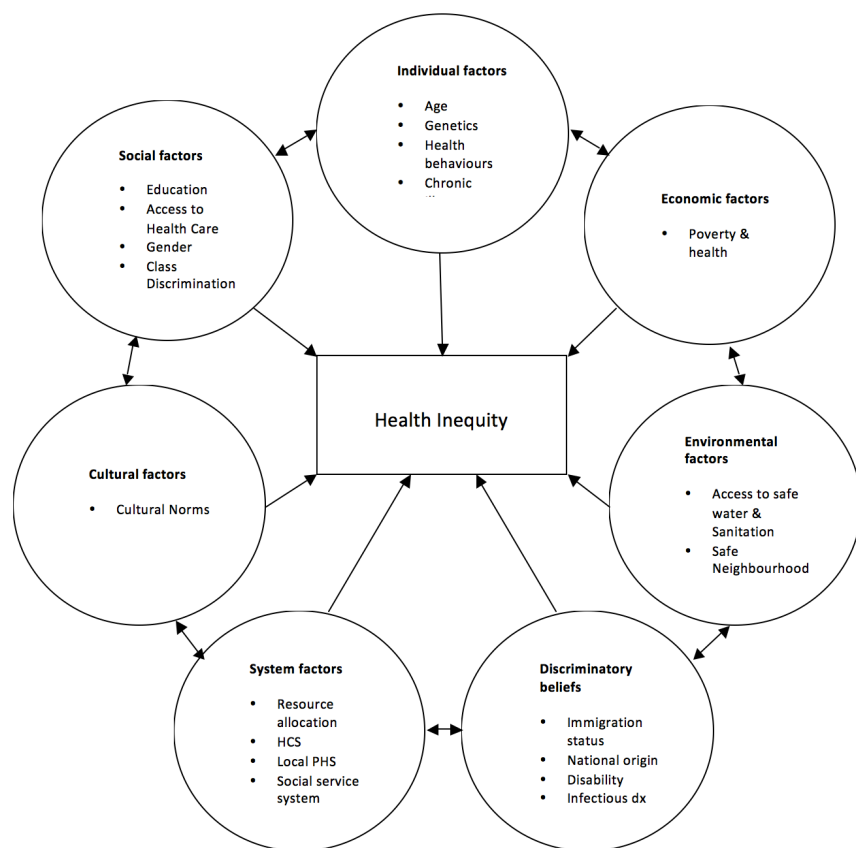
- **Access to Health care:**

Inequities in health care also exist because of another important social factor which is lack of access to health care. In Pakistan, the setup of health care provision is well formulated in terms of its paper work but if we see the implementation of that system that this body is non-functional. I would like to elaborate this thing more in detail that the government system of health care provision is well formulated in terms of planning the setup for example in urban areas the concept of Primary Health Care Centres (PHC), Secondary Health Care (SHC) and Tertiary Health

Care (THC), and in rural areas the concept of Basic Health Care Centres (BHU) and Rural Health care Centres (RHC). However, if we refer to the availability of doctors or paramedical staff or the supplies that these setups should have then this becomes questionable and this thing is because of the same reason i.e. the issue of monitoring. Thus, if in a village there is only a building of BHU or RHC but no doctor, no paramedical staff and no or inadequate supplies then how people can get benefit out of it. On the other hand, the issue of affordability comes with Private hospitals.

Consider a situation, if a person residing in a village suffers from any disease that demands proper health care and he is brought to BHU or RHC then we can think of that what he is going to get out of this paralyzed system. As a result, he will be referred to THC but the issues that surround this situation are the issue of access to health care, affordability of it and then delay in the provision of health care which is because of system failure.

Figure 1: Summary of some factors linked to inequity



• **Gender and Health:**

Gender discrimination and its impact on health is a significant issue of women of Pakistan, which they face in their every day life and in every spectrum of it. The women of Pakistan start facing these issues even before they are born and it continues through out their life. It is their fate and a bitter reality to face this discrimination from education to employment, from domestic violence to social injustice and etc. Although, in Pakistani parliament, the proportion of women representation is higher as compared to some other

countries but the fact is that only some women enjoy life and health at the highest level but on the other hand other women are deprived of their basic rights. The social system of Pakistan is structured in such a way that restricts women from the equal right to education, access to health care, deprived of nutrition, lack of awareness of their rights and many more. Because of this situation women are more vulnerable to diseases, violence and every type of crime. They are the ones who are prone to domestic violence, sexual abuse, harassment, rape, injustice, forced marriages, honour killing and etc. These all things not only affect their physiological health but also psychological, mental and emotional health and well being.

• **Class Discrimination:**

Class discrimination is the major determinant of health inequity because the health care system provides same opportunity for every one. In Pakistan, the class system is very evident, not only amongst people it prevails amongst societies and communities as well. In addition, the concept of the free market economy has been diminished which is the result of the capitalist. As in capitalist society, neither the oppressed people have control nor do they have choice to use the resources. Moreover, the rich people who are in position to afford health and health care services are able to do so while, on the other hand poor people cannot even think about buying the basic health care needs as it is out of their affordability. Therefore, while determining any policy regarding health the concept of horizontal and vertical equity should be considered carefully i.e. equals should be treated equally and unequal should be treated unequally.

The social factors discussed in the above mentioned paragraphs affect significantly on the health equity and this concept of their interaction can also be easily understood by the visual illustration in Figure 1. From the illustration it is clear that the social factors affect directly health equity and also affect other factors, in a two way process that both the factors are related and influenced by each other. Thus, it can be said that unequal provision of health facilities, unfair distribution of resources and violation of human rights, cause the outcomes which are unacceptable and unfair. Consequently, the people who are rich enjoy the benefits and those who are poor bear the burden of diseases and premature deaths. Suppose a scenario of a young person who is suffering from any chronic illness. Because he is not well therefore his ability to work is decreased and he is unable to earn as much as he was able to earn previously when he was in his good condition in terms of health. His low earning capacity will definitely affect the economy of his family, resulting in poverty, which will further lead him to ill health. Because of his condition, his own as well as his

family life is affected. Thus, it is a vicious cycle which can only be broken by implementing policies that address health equity because if that person will be in his good health then only the needs of the family can be met. These inequalities are resulting in the poor health and other health related problems. So it is the need of the time to rethink about these determinants.

Economical inequities

After social factors, the other factor that affects health is the economic factor. As mentioned above these two factors have their own independent interaction which is two way process.

- **Poverty and Health:**

Income is the fundamental reason which is linked with health care affordability in the absence of a formulized and functional system of health care by government. The people, who are poor, are unable to avail the right to health look at it as luxury rather than as necessity or right. These are the people who did not get enough chance to be educated which leads them to get lesser chances for good income and secure jobs. They are the people whose social life and social status is also diminished so how they can think of health in such a miserable condition. That's the only reason to say that poverty is the root cause of inequity in every spectrum of life including the domain of health. Moreover, inflation in the prices of every item makes their condition more miserable. Consider the situation of a women residing in rural area that is dying because her family is unable to afford the transportation charges of a vehicle that can take her to a hospital where she can have health care and her life can be saved. Therefore, the main reason here is not in terms of health care affordability but the issue starts from the transportation expenses and so on. Also, the issue comes here of inadequate nutrition because of poverty that leads them to illnesses which are curable. Thus, poverty is a significant factor that contributes in health inequity.

Cultural factors:

Beside economic factors, cultural beliefs also play a significant role in terms of health and health care accessibility. These cultural beliefs and norms of a particular community come from their ancestor and are practiced as religion therefore, the practices which are formulated as a result of their cultural belief are unable to change or even modify. Consider a community having cultural norm not to visit a doctor when they are ill rather to see a Hakeem. Just imagine that how many mothers are dying because of the births attended by Traditional Birth Attendants (TBAs) whose skills are questionable. These are the reason of having high mortality in our country.

Environment factors:

Communities with no education, no good job and poor income in the end results in to living in an environment which have no good conditions in terms of access to safe water, sanitation, safe neighbourhood and etc. These poor people have to live in the areas

which are unclean and full of waste products that make their condition more miserable and make them vulnerable to the diseases which are caused by residing in such an unhealthy environment.

Systems Factors:

The first system factor that affects health equity is of "Resource allocation". The reason of health inequity is not always resource allocation some times it is also the result of poor resource allocation for example in terms of availability and allocating the number of doctors or nurses per unit population, quality and types of medical treatment available and etc. It has been found that the issue of proper resource allocation has been found prevalent in the societies which have inequity in health. In addition, the inequity result not only from the shortage of resources but the misuse of resources and this is also the world wide reason that is leading to the poor health. Pakistan spends less on health and education combined than on military. Less spending of resources generates inequities in health, which affects those people who are either poor or unable to access to the healthcare institutes. Other than resource allocation, health care system itself is another reason leading to health inequity and details about it are provided in the paragraph access to health of this paper in detail.

Discriminatory factors:

Discriminatory factors are the beliefs that a particular community have regarding a particular group of people which marginalize that group of people from rest of the population. These discriminatory factors include immigration status, national origin, disability and infectious diseases.

Up till now we have discussed in detail the factors which lead to health inequities. These factors are individual, social, economic, cultural, environment, system and discriminatory. The above mentioned illustration of these factors also provides the way these factors interact with each other.

After understanding the factors the next step is to discuss the ways by which this problem can be overcome. Below is an attempt to address this issue of health inequity.

4. Understanding Constitution and Law

For any country the constitution and law is of greater significance as it is a key factor by which a government run itself. Besides government, the constitution is also needed by people for their fundamental rights that include social, economic and cultural rights. It is very important for a nation to know the countries constitution or law so that they can claim and ask for their right. In the absence of this knowledge right about it cannot be claimed. On the other hand, parliamentarians should have equal knowledge about health equity and basic human rights.

Let us examine the above mentioned concept with the help of an example i.e. the constitution of Pakistan talks about basic human right which is the right of dignity of humans and prohibition of torture but if we

see the actual existing system then the gap is found because there is no such implication. We see police torturing ordinary citizens for no reason but the question is who knows it and who is addressing it? In addition, this is affecting an individual's physical and mental health. So the key factor that can bridge this gap is that the people of this nation should know the constitution so that they are aware about their rights as a Pakistani citizens along with the responsibilities. Until and unless people of this nation will not make an effort to know their rights they can not exercise it and bring about change. Therefore, it can be said that the problem is with the implementation of the constitution which can only be done by creating awareness because the constitution was build by the people like us. Referring to health and health care in our constitution things are written in black and white but are not implemented the way it should be. Thus, to make equity in health there should be efforts for humans to have equal access and opportunity for their health and health related issues

Understanding Health Policy:

Health policy is the means by which people's standard of living can be maintained. These policies not only affect the health of an individual but also affects significantly on employment, education, housing and etc. Some of the important features that should be kept under consideration while developing health related policies are that it should be evidence based, focused on the desired outcome and most importantly it should be beneficial for the people for whom the policy is being developed. Therefore, it should be targeted to improve overall quality of life of people, if a policy is unable to do so then that policy should not be made or should be modified according to the need of people. In the following paragraph an attempt is made to identify strengths and weaknesses of our current health system governance.

• Health system governance matrix of Pakistan; Strengths and weaknesses:

The strengths of Health system governance matrix of Pakistan at central level are that it promotes social safety nets for the poor and vulnerable; and there is increase in role of the media and NGO's in protecting people's health. At the level of MOH policy, firstly, the preparation of draft bills to update health legislation. Secondly, there is rapid emergence in role of the Pakistan health policy forum as a civil society organization. Thirdly, stable turnover of health policymakers during the last six years has been observed which a positive element is. Fourthly, increase in public private interaction has been observed. And lastly, preventive programs, especially the LHW Program which has a strong community as well as equity dimension.

On the other hand some of the weaknesses with the health system governance matrix of Pakistan at central level are that the lack of participatory decision making and culture of accountability has been observed. Parallel streams of bureaucracy and technocracy do not seem to work in unison and adherence to rules and

procedures is considered as an end rather than as a continuous process. Also, there is lack of consumer protection act delays or deny justice. At the level of MOH policy, firstly, short-term objectives were set which override the need for focus on health outcomes. Secondly, health equity is not high on the policy agenda although it should be. Thirdly, mechanisms to monitor transparency of decisions do not exist. Fourthly, decisions are often tinged with personal preferences, not evidence-based. Fifthly, legislation on minimum standards of care is absent with lax regulation and enforcement capacity. Sixthly, policy, planning, health information and surveillance units are weak. Seventhly, there are delays in release and utilization of funds. Eighthly, accountability systems focus on procedure instead of performance and lastly and the most important that bioethics is not on the policy radar of MOH. At the level of policy implementation some of the weaknesses are that there is minimal protection against hazards from personal health services. Also, gaps exist in policy and practice for recruitment, posting and promotion of staff and rules favor seniority over meritocracy. Instruments for evaluation of staff performance are improperly used and responsiveness of public sector health services is not monitored. The important point is that the physicians turned managers lack understanding of administrative matters while bureaucrats lack health orientation. The most commonly practice observed in our context is that physicians and allied staff extensively engage in private practice outside and often within public institutions. Support systems function inefficiently and code of ethics exists with the professional associations but not practiced.

Social Justice

After having looked at the constitution and policy's strength and weaknesses the other approach by which health equity can be achieved is by enhancing social justice. Because health equity is best thought of not as a social goal in and of itself, but as intrinsically imbedded in a more general pursuit of social justice. This social justice in healthcare can be achieved by two means i.e. one by promoting health and secondly by promoting human rights.

• Health Promotion:

For promotion of health equity and to reduce social inequalities in health, the first step is health promotion and public health. Although, if we look at our health system in terms of policy development that it can be said that the policies are well formulated for school health service, safe water and sanitation, family planning, control of communicable diseases and etc. Moreover, the outcome of these policies is not just limited to individual's health but the actual goal behind all these policies is to promote health equity by reducing social inequalities in health and empowering communities. However, the issue that comes here is at the level of implantation and continuous monitoring for which adequate efforts were not made. This is the only reason which is of great hindrance in promoting health equity. If this gap is tackled skillfully then only health

equity can be achieved.

- **Human Rights Promotion:**

Many of the inequities in health sector can be reduced by enhancement and promotion of human right awareness. As health is vital to life and plays a central role therefore, if an individual is healthy then only he and his family can survive and make efforts for their production and growth. That is why it is said that Health is Wealth. If we refer to the various declarations on human rights then they address health as human right. These declarations include, Article 25 of Universal Declaration of Human Rights, Articles 7, 11 and 12 of 1, Articles 10, 12 and 14 of Convention on the Elimination of All Forms of Discrimination Against Women, Article 5 of Convention on the Elimination of All Forms of Racial Discrimination, and Article 24 of Convention on the Rights of the Child. Moreover, the WHO constitution also mentions that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being...." Thus, all the declarations that refer to human right also state health as one of the human right. However, on the other hand, in today's world the arena of debate is shifted from the question that is health a human right? To how much health care is human right? Before determining any answer to above mentioned question, I think first we should find out that what defines or makes anything as right? Or what are the criteria for saying anything as a "right"? For example, by what criteria it is determined that food, shelter and clothing are right and why in that list health is not there? I think that one criteria can be the difference of necessity and luxury. The thing that is defined as necessity makes it right and the one that comes under the domain of luxury is not a right, rather it is a privilege. However, I see two issues in this approach, first is the question here comes that who makes demarcation between necessity and luxury that will determine it as right or privilege, i.e. Grand sez who? Secondly, the term necessity and luxury can be different for different people, society, culture, gender or etc. In addition, if universal standard is being set then who sets that standard, for whom and how? Thus, the question remains the same that what is right and what is not right? Similarly, the question "is health a human right?" remains same. But it cannot be neglected that human rights are directly linked with health and provision of human rights is considered as one important factor leading to health equity.

5. Conclusion

In a nutshell, it can be said that by only looking at the constitution, policy and promotion of health, we can move towards equity in health. But actually we have to think and rethink about the factors that are leading to these inequities in health as it is the root cause. If we are able to deal with these root causes then only equity in health can be achieved. The concept is health equity should not be limited to only provision of health but also should address the other domains i.e. social determinants of health. Beside this, state has also a huge responsibility to promote universal and equitable

access to health care for all humans without regard to race, creed, colour, religion, socio-economic status and etc. Which is in true terms the message of Islam therefore should be followed by the Islamic Republic of Pakistan.

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Exploitation in Research: Utilitarian Considerations

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Few doubt the benefits of medical research; the advances made in the twentieth century reduced human suffering and extended lives. New techniques, technologies, and pharmaceuticals have been so successful that many people suffering from disease believe that cures for their diseases are on the way if they can simply live long enough to benefit. The value of research is so great that most people agree it is worth some risk of suffering or even death to reap the great benefits new treatments can produce. Millions of animals are sacrificed to medical research each year, but large numbers of humans are also negatively

impacted by research, including some who lose their lives.

While some individuals are willing to risk their health for the greater good of humanity, most individuals will not expose themselves to great risk unless they feel they will benefit from it in some way. Further, most people will expose themselves to minimal risk with no personal medical benefit only when they are compensated for time, effort, and inconvenience. These two conditions create a dilemma for researchers. In order to obtain research subjects, researchers must either convince subjects that the research is so beneficial to society that it is worth risking the health of the subjects, or researchers must offer sufficient enticements to encourage research subjects to participate. The third alternative is unseemly—researchers might be tempted to coerce research subjects in a variety of ways. Research can be conducted on captive populations such as prisoners or soldiers, or it can be conducted on vulnerable populations such as those living in extreme poverty.

This paper attempts to determine when inducements may or may not be coercive and dehumanizing. Most guidelines for the protection of vulnerable populations are written in Kantian, or at least deontological, language. I will argue that a Utilitarian, or teleological, framework is more consistent with the general language of research ethics and offers a vigorous method for evaluating the potential for exploitation and dehumanization in research. In particular, I am interested in research involving those who are extremely disadvantaged economically. Extreme poverty in and of itself can be conceived of as a social injustice. To exploit extreme poverty for the benefit of the affluent would appear, on the face, to be an outrageous injustice. Indeed, all ethical codes for research include protections for such vulnerable populations. When someone's life and health are threatened by poverty and hunger, even minor inducements can be coercive. Many people are in a position that makes it impossible for them to reject any offer that might bring them food or basic medical care. I will argue, however, that payments or other material benefits for impoverished research subjects are sometimes not only morally acceptable but required.

Protection of vulnerable populations is generally based on a conception of "respect for persons." Although Kant is not always invoked by name in ethical discussions of research involving vulnerable populations, the language used is generally Kantian. At the least, arguments for how to protect such populations are deontological in nature. The Belmont Report states that the principle of "respect for persons" makes two distinct moral demands: "the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy."⁵¹ Poverty diminishes autonomy, and extreme poverty or disease can reduce

people to the status of objects, albeit objects demanding our care and attention. The Belmont Report also expresses concern for vulnerable populations in terms of justice. Injustice occurs, according to the report, when someone is denied a deserved benefit or unfairly forced to endure an unequal burden.⁵² As an example of unjust distribution of burdens and benefits, the report mentions that nineteenth-century research was often conducted on poor ward patients with private patients receiving most of the benefit. Principles of justice demand a fair distribution of benefits and burdens. Any groups that risk harm should be likely to receive benefit as a result.

Violations of respect for persons or autonomy expressed in deontological terms do not permit justifications based on outcomes. It is not acceptable to violate the autonomy of one research subject even if the research will benefit millions of people. In this sense, deontological protections seem to be in direct contradiction of teleological concerns for research that focuses primarily on outcomes.

Generally, research is justified when the possible benefits of the research outweigh the risks of harm that may result from the research. In an ideal world, the research will yield benefits in the form of cures for devastating diseases and greatly alleviate suffering. Much research has been aimed at curing or eliminating diseases such as polio, small pox, AIDS, and cancer. Researchers have enjoyed enough success that people with life-threatening or extremely painful conditions (another vulnerable group) will often demand to be included in research protocols, thinking experimental treatments are the best treatments available. In some cases, they are the best available, but the purpose of research is to confirm this, so individuals seeking experimental therapies may inadvertently be demanding to receive a dangerous substance.

Research protocols are justified on utilitarian grounds. When a researcher proposes research on an experimental therapy, the proposal must identify the possible goods that will result from the therapy. Research that has no anticipated benefit or that poses great risks should not be considered worthwhile. At the least, experimental protocols should enhance scientific knowledge with an aim to developing beneficial treatments in the future. The fact that treatments are sold for profit complicates the calculation of risk and benefit. In order to increase profits, a pharmaceutical manufacturer may make only slight changes to an existing drug to make it easier to swallow or more convenient to store in hopes of increasing profits through new patents and licensing agreements. A manufacturer may see a protocol for such a drug as providing great benefits in the form of increased profit with little risks to research subjects as the research subjects are taking a drug almost identical to an existing drug. The primary benefit is not the alleviation of suffering and disease or even medical knowledge but an improved marketing of a known substance.

⁵¹ Belmont Report in *The Ethics of Research Involving Human Subjects: Facing the 21st Century*, ed. by Harold Y. Vanderpool (Frederick, MD: University Publishing Group, 1996), 439.

⁵² *Ibid.*, 441.

Such research protocols are frequently approved. Another complication is that manufacturers sometimes develop therapies for niche markets.

While profit is seen as a legitimate benefit for manufacturers, it is not seen as a legitimate benefit for research subjects. In fact, the use of financial incentives for research subjects is problematic for most ethicists. The concern is that financial inducements may be coercive and cause impoverished individuals to take risks they would not take if they were more affluent. In the worst case, researchers would be exploiting the desperation of the poor to benefit the affluent. In fact, in many cases drugs are tested on the poor with little chance of ever benefiting the poor. For example, Havrix was tested as a vaccine for hepatitis A in Thailand on poor school children.⁵³ The primary goal of the researchers was not to find a way to eliminate or even reduce hepatitis A among school children in Thailand. Rather, although the researchers made a verbal commitment to pursue registration of Havrix in Thailand, the researchers' primary intent was to market the vaccine to travelers as protection from hepatitis A when visiting Thailand.⁵⁴ Nonetheless, Thai citizens benefited from the research in some ways. Some children did receive the Havrix vaccine, and all children in the study were vaccinated against hepatitis B. Also, clinics and storage facilities were improved in order to store the vaccine, and the research team visited schools with hepatitis outbreaks to identify improvements that could help prevent the spread of the virus. Those who objected to the study complained that there was no plan to provide Havrix to Thailand at a free or reduced rate, Thai researchers were not adequately involved in the study, and Thai caregivers were not given adequate training to reduce the incidence of hepatitis.

Some would argue that the Havrix trial promotes the principle of utility. Citizens of Thailand received some benefit from the trial, and others will continue to benefit from the development of a vaccine for hepatitis A. The use of children in Thailand might be justified by the benefit to a greater number of people in the future. Objections to the study seem to be rooted in principles of "respect for persons" and justice while justifications for the study are utilitarian. It appears that anyone evaluating the ethics of the research must operate in two moral worlds: one for justifying research and another for protecting subjects. I argue that a Utilitarian framework can consistently be used to justify research but also provide consistent arguments for the protection of subjects. The advantage of adopting a Utilitarian perspective is that it does not require ethicists to jump from one foot to the other when evaluating protocols.

The arguments for the Havrix trial are, indeed, utilitarian, but they do not meet the requirements of a philosophically grounded Utilitarian standard. Utilitarian

moral theories are often expressed as advocacy for the greatest good for the greatest number. Indeed, Utilitarians do claim that morality should attempt to promote the greatest good possible, and it may occasionally involve sacrificing a few in order to promote good for many. As an example, many civil rights workers in the United States in the past have sacrificed their leisure, their liberty, and their lives to ensure a future where racial equality might become a reality. Many of these workers knew they would not live to see greater equality, but they felt the sacrifice was justified. As formulated by Jeremy Bentham, the utilitarian calculation of benefit for the greatest good demands an impartial examination of the good for everyone involved with equal consideration given to all.

The conflict between these two calculations is often described as a conflict between Act Utilitarianism and Rule Utilitarianism. Act Utilitarianism is said to be the belief that individual actions are deemed morally acceptable if they provide more pleasure or happiness than unhappiness. Critics can easily provide crude and horrifying counter examples. Gang rape might be justified because several people derive pleasure from the violation of only one person. Faced with such examples, Utilitarians are expected to slink away in shame for having offered such a preposterous theory. In response, some have claimed that Rule Utilitarianism is a more consistent and intuitively acceptable theory. Rule utilitarianism holds that actions are laudable when they conform to behavioral rules that tend to promote happiness for everyone. Rule utilitarians recognize that individual actions cannot be isolated from overall social consequences. Gang rape is now prohibited, as any rule that permitted rape would create a hostile climate for anyone who might become a victim of a sexual assault, and such potential victims make up the majority of the population. Utilitarianism is restored, but it seems to have taken on a deontological character. Some would argue that this is a way of being a Kantian while wearing a Utilitarian mask.

Such confusion with Kantianism is not necessary, and divisions between Act and Rule Utilitarianism are superfluous. The basic utilitarian principle is that we must seek to promote the greatest overall satisfaction for everyone affected. An Act Utilitarian who failed to consider future consequences or social consequences would be failing as a Utilitarian on the surface. The assertion of Rule Utilitarianism is only necessary when Utilitarianism is misapplied. At the most, Rule Utilitarians remind Act Utilitarians of the demand for equal consideration. Whether Utilitarianism in this form is Kantian specifically or deontological generally is a more difficult question. Deontologists claim to promote a morality that is right and good regardless of desirable or undesirable outcomes. A famous example comes from Elizabeth Anscombe, who said it is never acceptable to boil a baby, even to save a thousand lives. This is a stark admonition to ignore the outcome of an action and follow inviolable moral rules. It is hard to imagine any deontologist, however, saying that following such rules would make life less enjoyable for the majority of people. In fact, the purpose of morality

⁵³ Jennifer S. Hawkins and Ezekiel J. Emanuel, *Exploitation and Developing Countries* (Princeton: Princeton University Press, 2008), 55.

⁵⁴ *Ibid.*, 56.

in whatever form is to promote peace and happiness for most people. If murderers, thieves, and liars are less happy for our moral codes, then so be it.

With regard to research that may be exploitative, utilitarianism demands consideration for the interests of all involved, including the most vulnerable. Being reduced to extreme poverty is a bad thing in itself. Further, promoting the dignity and well being of those in poverty is a good thing. Researchers have an opportunity to either exploit the dignity of the impoverished or take actions to enhance dignity and also relieve their poverty. The concept of dignity is not easily defined, but I will simply say that we act to promote dignity when we recognize the interests of others and attempt to help promote their interests. Mutual engagement and inclusivity promote feelings of dignity. Actions that reduce people to mere means violate principles of respect for persons but also violate principles aimed at promoting general welfare.

The divergence between Kantian respect for persons and utilitarian concern for the interests of all is smaller than some expect. The principle of utility is derived from what promotes happiness. Hume asserted that our moral beliefs or intuitions are based on sentiment. When we make moral judgments about the wrongness of murder or lying, we are making a judgment about what pleases or displeases us. When we recognize what makes us disgusted or uncomfortable, we express the sentiment as a moral rule. We then use reason to further develop formal moral rules that reflect our sentiments or passions. Kant demands that reason operate independently of emotion. For Kant, we should examine the rightness of our actions by whether they can be willed to be universal. This sounds quite different, but given that Utilitarians assume that humans share a common aversion to pain and suffering, Utilitarian considerations will also be universal. Utilitarians demand concern for others because each individual wants concern for herself. Kant also says that the person who denies love and compassion to others will be choosing to deny love and compassion for himself. Utilitarianism and Kantian ethics each conclude that we must be concerned for our fellow sufferers in life. With respect to research ethics, I prefer a utilitarian framework, as it is consistent with the language of justification for research.

If we accept the general utilitarian principle that everyone should be concerned for the well being of everyone else, it stands that the goal of medical research should be to relieve as much pain and suffering as possible. Bringing a sense of dignity to those who have been robbed of their dignity is a noble goal. Medical research can do this in a number of ways: 1. Research might cure diseases that plague individuals, restoring them to autonomous and independent lives. 2. Research might involve individuals in a process that can help improve conditions for others, thereby giving a sense of purpose and meaning to their lives. 3. Researchers may help to alleviate extreme poverty.

Impoverished individuals may have few opportunities to feel they are making a meaningful contribution to society. The opportunity to enhance medical or scientific knowledge can give them a sense of meaning and productivity. In order for their participation in research to preserve or augment their feelings of self-worth, though, several conditions must be met. Individuals must be fully informed of the goals of the research and participate in a fully engaged manner. This is not to imply that they must share the expertise of the researchers but only that they must be seen as partners or joint venturers in a project that can benefit society as a whole. The researchers must recognize that the subjects have their own individual goals that motivate them to participate. Beyond recognizing those goals, researchers must work with the research subjects to help them understand the progress of the research.

In addition, as in all protocols with all populations, researchers must fully inform potential research subjects of the risks of participating and any possible benefits they might accrue. Deception or withholding of critical information is never acceptable. Finally, researchers should attempt to leave all subjects in no worse shape than they were in before they began the research. In addition to making every effort to leave individuals in no worse shape than they were in at the beginning of the research, investigators must also make every effort to leave communities at least as well off as they were at the beginning of the research. Obviously, adverse events are not predictable in experiments, but researchers must do their best to minimize adverse events.

In 1994, researchers discovered that zidovudine (AZT) could prevent transmission of HIV from mother to baby. Pregnant women would begin taking AZT in the second trimester and take it for a minimum of 12 weeks at a cost of about USD10,000. Most HIV-infected pregnant women lived in developing countries, and approximate spending on health care in those countries was about USD10 per person annually. In Uganda, annual spending was less than USD3 per person. In the hope of reducing costs, researchers proposed doing research in developing countries such as Tanzania, Ethiopia, Kenya, Uganda, and Zimbabwe to test whether a short-term AZT-treatment might be effective in preventing maternal-fetal HIV transmission. All but one of the trials used placebo controls and 9 of 16 were funded by the National Institutes of Health and the Centers for Disease Control.⁵⁵

In a 1997 letter to the U.S. Secretary of Health and Human Services and following commentary in the *New England Journal of Medicine*, Peter Lurie and Sidney Wolfe condemned the trials as unethical because the use of placebos was not justified given that another treatment was known to be more effective (longer-term AZT). Defenders of the trials argued that the research subjects would not receive any treatment in the absence of the trial anyway, and were therefore no worse off. Critics noted that the trials would be

⁵⁵ *Ibid.*, 1 – 2.

unethical if conducted in the United States as regulations would prohibit the use of placebo when effective treatments were available. Defenders claimed that the poor economic conditions of the countries where the trials were taking place made the research more necessary. If shorter-term treatments were shown to be effective, treating women in developing countries could prove to be more affordable. Nonetheless, sponsors of the AZT trial made no guarantees to offer the treatment at an affordable cost posttrial.⁵⁶

The *International Ethical Guidelines for Biomedical Research Involving Human Subjects*, published by the Council for International Organizations of Medical Science (CIOMS), states that any research carried out in underdeveloped countries be "responsive to the health needs and the priorities of the community in which it is to be carried out."⁵⁷ Furthermore, in commentary to guideline 15, the document says, "As a general rule, the sponsoring agency should agree in advance of the research that any product developed through such research will be made reasonably available to the inhabitants of the host community at the completion of the successful testing."⁵⁸ It may be argued that the therapy was complete upon the birth of the baby, so that continued treatment was not necessary for any individual participating in the trial. The question then is whether the research is responsive to the health needs of the host community. If the goal of the research is to find affordable alternative treatments for developing countries, then there can be little defense of the research if the host countries cannot afford even short-term therapy, which would cost approximately USD50 per person.

If this trial was begun in order to find affordable therapies for underdeveloped countries, it seems unreasonable to begin the trial knowing that the communities involved could not continue even the relatively inexpensive treatment. If the trials were actually developed in hope of finding improved treatments for women in developed countries, the trials certainly constituted exploitation. This seems unlikely, however, as most HIV-positive pregnant women lived in developing countries.

It is possible to argue that participants in the research did benefit from the research in that some babies were protected from HIV infection. Babies in the control group who became infected were not harmed by participation, as they would have become infected in the absence of the trials. Some argue that communities should benefit from participation in research, but that it is not necessary for access to treatment posttrial be one of the benefits. According to Hawkins and Emanuel, such critics argue, "What is a requirement is that the host community actually benefit fairly from the conduct and/or results of research. But providing

medication post-trial is *not* the only way the community might benefit."⁵⁹

I would argue that if the sponsors of the research cannot reasonably provide treatment posttrial (in some cases, the treatments are not proven effective after one trial and in other cases the sponsors have no reasonable method for distributing the treatments), then it may be reasonable to offer other benefits in exchange for participation. Regarding payment for participation in research, the CIOMS guidelines say,

Subjects may be paid for inconvenience and time spent, and should be reimbursed for expenses incurred, in connection with their participation in research; they may also receive free medical services. However, the payments should not be so large or the medical services so extensive as to induce prospective subjects to consent to participate against their better judgment.⁶⁰

This requirement is intended to prevent unscrupulous researchers from using incentives as a form of coercion to compel subjects to expose themselves to risks that more empowered individuals would not consider. Alternatively, the guidelines could say that no research should be conducted that entails risk so great that no affluent person would give consent. In other words, the research should not be conducted on the poor simply because it is too risky for the wealthy. If this condition is met and researchers have sought to minimize risks for all participants, then restricting the amount of payment that is permissible only constrains the liberty of participants. Further, compensation that is too low may make participation available only to comfortably well off subjects. While excessive payment may be coercive, insufficient payment can be exclusionary.

One does not need to be desperately poor to be subject to inducements. Many people who live fairly comfortably are willing to take risks to their lives in exchange for higher pay. For example, some are drawn to completing construction contracts in war zones partly for the high pay and partly for the excitement they derive from participation. When people agree to work in a war zone, they generally understand that they are involved in extremely risky activity, but individuals in drug trials often do not seem to fully understand the risks. In 2006, the U.S. drug company, Parexel paid eight men about USD3,500 to participate in phase I research of TGN1412. Within hours, all six men receiving the active drug suffered organ failure. The men were not poor. One victim was raising money to pay for his wedding.⁶¹ Another of the victims was a college student who just wanted to earn some extra cash. A family friend said he did not think there would be any problems.⁶² These men did not choose to

⁵⁹ Ibid, 10.

⁶⁰ Vanderpool, 504.

⁶¹ Rob Sharp, "Elephant Man' cancer victim breaks his silence," *The Observer*, August 6, 2006. Guardian.co.uk accessed 12/19/08.

⁶² Dani Veracity, "TGN 1412 drug trial update: One patient may lose fingers and toes due to drug side effects,"

⁵⁶ Ibid., 2 – 9.

⁵⁷ Vanderpool, 506.

⁵⁸ Hawkins and Emanuel, 9.

participate because they could not afford to refuse. They chose to participate because they did not fully understand the risks, probably because the sponsors of the trial also did not understand the risks and did not expect any serious adverse events. If the risks had been accurately stated and everyone involved understood that using experimental drugs always has a risk of serious side effects, then the agreement to participate would be justified, and a higher payment for a higher risk would be reasonable.

In underdeveloped countries, ethicists raise more red flags, though. There is concern that participants will lack the understanding of the trial necessary to make an informed decision. It is conceivable that in some cases, the prospective participants have no way of understanding what research is or what the risks of participating may be. When such prospective participants are identified, they should not be permitted to participate in the research; however, sponsors should not assume that poverty in itself negates one's ability to understand and negotiate contracts. Justice demands that participants understand that they are involved in research that entails risks, that the research may not or will not (when this is known) benefit them therapeutically, and that they be engaged with researchers throughout the trial in a manner that continually emphasizes the nature of the research project.

In the case of the AZT trials, Utilitarian considerations would demand a number of conditions for the research to take place. First, the goal of the researchers must be to reduce disease, suffering, and death. It appears that this may well have been the case, but the long-term effects of the trial were not adequately considered. If the treatment was designed primarily for women in countries that could not afford the treatment at any cost and the sponsor could not provide the treatment for the countries involved, the research had no justification for taking place. If this is not true, and the research was intended to benefit women in affluent countries who could afford the treatment, then it is an unjust distribution of burden and benefits.

Second, research sponsors should ensure that communities and individuals participating in the research will benefit from their participation. Benefits could come in a variety of forms. Fully informed subjects might agree to participate simply for the opportunity to contribute to the greater good of society. So long as they agree with full understanding that they are sacrificing their time and risking harm in hope of benefiting others, it is laudable to provide an opportunity to include them in a productive and meaningful activity.

Third, when researchers are not providing therapeutic benefit to the community, it is possible for the community to benefit from improved comfort care, improved training for healthcare providers in the community, and improved health care facilities or

technology that will stay in the community. In such cases, the participants may not benefit from the treatments being researched, but they will still benefit from improved care. Sponsors should make every effort to maximize benefits.

Fourth, researchers should make every effort to leave both communities and individuals as well off as they were before the research began. Some adverse effects cannot be predicted as was apparently the case in the Parexel trial, but the long-term effects on the countries participating in the AZT trials seem predictable. Ironically, negative effects on the community were the result of the success of the treatment. Demonstrating the effectiveness of a treatment that will not be available to the community can only have a demoralizing effect. Beginning a clinical trial knowing that this is the best outcome possible violates the principle of equipoise at the community level. Although some babies were spared HIV infection, the overall effect on the community was negative.

Finally, when researchers discover a possible therapeutic benefit, they should make every effort to make the treatment available to as many individuals and communities as possible. How therapeutic benefit will be maximized should be explicitly stated and negotiated before any clinical trial begins. The AZT trials had a stated goal of finding more affordable treatments, but no long-term plan for financing treatment was negotiated or, apparently, even discussed.

A September 2008 article in the *Journal of the National Medical Association* examines the ethical issues of conducting genetic studies with African immigrants as the subjects. The article notes that these immigrants are classified as a vulnerable population by the Department of Health and Human Services Agency for Healthcare Research and Quality because they face culture shock, language barriers, prejudice, an unfamiliar legal system, and economic hardship. One issue raised in the article is profit sharing. The authors note that discoveries from genetic research could yield millions of dollars. Failing to share the profits with the individuals providing the genetic information necessary for developing the treatments amounts to "biopiracy" or "biocolonialism" according to some critics of such research. The authors conclude, "It is possible that a promise to share financial gain with research participants may provide more incentive for potential subjects to participate in research and change the prospect of future research."⁶³ Rather than asking whether it is ethical to use payment as an inducement, researchers should ask whether it is ethical to withhold payment when enormous profits may result from the willingness of research subjects to participate. Shared

⁶³ Gordon Gong, Sade Kosoko-Lasaki, Gleb Haynatzki, Cynthia Cook, Richard O'Brien, and Lynne E. Houtz, "Ethical, Legal, and Social Issues of Genetic Studies with African Immigrants as Research Subjects," *Journal of the National Medical Association*, Vol. 100, No. 9 (September 2008): 1075 – 1076.

ownership in the research project is one way of enhancing a sense of dignity and empowerment in participants, but one might ask whether it is ethical for pharmaceutical companies to generate (or retain) such enormous profits in the first place. The relief of poverty is of utmost concern to most Utilitarians. If companies will generate enormous profit, it makes sense that economically disadvantaged research subjects should share in some of the profit, but a robust Utilitarianism would demand that the profits be used to alleviate poverty to the greatest extent possible. This would certainly be an unpopular position, but ethicists should not take positions based on how popular they will be with corporations. Instead, concern for the welfare of our global community should motivate both our ethical positions and our behavior.

The purpose of this paper is not to refute deontological theories of ethics or justice as I believe both deontological (especially Kantian) and teleological (especially Utilitarian) theories demand concern for social justice and compassion for vulnerable populations who are possible victims of exploitation. I do claim that Utilitarianism can provide a consistent framework for both the justification of research and the protection of human subjects. It is not necessary to toggle between theories when discussing research protocols. Further, I assert that when research protocols are designed well, payment for participation is a matter of fairness, not exploitation, and payment may help promote human dignity.

On the patenting of life: Ethical, medical, and economic repercussions

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The genes in your body are shared with virtually every other human being in the world, and are a part of the common heritage of humankind. Your genes are a product of nature, as are the clouds in the sky, the water in the sea, and the air you breathe. None of those things can be patented, so why is it that over one-fifth of your genes already are (Jensen & Murray 2005)?

By letting biotechnology firms own the genes in our bodies, we are allowing them reduce those genes to mere commodities, letting them be bought and sold as if they were nothing but a pair of gloves or boots. Treating such a fundamental piece of the heritage of our species as private property is regarded as an insult to our fundamental human dignities and freedoms, and an affront to decades of genetic research. The whole notion of patenting genes, however, seems totally paradoxical. The very definition of a patent suggests

that it is for the protection of an invention. In contrast, genes are quite the opposite of an invention; they are a product of nature. Yet biotechnology companies have still obtained patents on them by stating that their sizable investment during the research and development of the gene should be rewarded with complete intellectual property rights to it (Crichton 2006).

What's worse is the fact that many of these companies are allowed to patent an entire gene just because they've extensively researched a very specific application of it. It's as if I can patent computers because I've spent the last 25 years researching their use in playing video games. Sure, computers are used for many other purposes, but since I was the first researcher to ask for a patent, I got it. Because I have a complete monopoly over the use of computers now, it means that companies that produce and sell keyboards, mice, computer components, and computers themselves are going to have to pay me a (rather handsome) royalty because their products directly rely on computers for their applications. Not only that, but you will need to pay me a fee to use your computer; otherwise I can fine you and send you to jail for violating my patent. Though all this may seem utterly ridiculous, it is exactly what is happening in the strange world of gene patents.

However, it is important to keep in mind that there are more than just ethical and philosophical dilemmas to the patenting of genes; the real world effects of these patents are catastrophic for patients and their families. Gene patents delay the development of life-saving treatments, greatly drive up the costs of drugs and tests, and hamper the progress of medical research. This is not at all what should be happening with patents.

A patent should first and foremost be used to foster innovation within the scientific community, not hinder it. When one research group patents a method A for diagnosing breast cancer, another research group would quickly begin working to find a method B. This competition creates additional methods of diagnosing the cancer (a valuable second opinion), and helps significantly reduce treatment costs for the patient (Borger 1999). With gene patents however, that is not the case. As a gene is not something that can be invented, granting a patent on one would shut the door closed to other researchers. This severely limits the study of that gene, and raises costs for treatments associated with it as the owner of the patent can charge whatever he likes due to the lack of competition (Crichton 2007).

A very alarming example of how gene patents hinder research was during the outbreak of the SARS in 2003. During the outbreak of the virus, researchers were hesitant to study the disease because of confusion surrounding three separate patent claims to it (Rimmer 2004), and the fear of facing charges of patent infringement. The virus ended up killing over 700 people; some of whom might have been saved if researchers had had quick and unrestricted access to the virus, without fears of expensive patent-

infringement litigation. This “tragedy of the anticommons”, in which competing interests prevent progress and development, greatly slows down biomedical research, which in turn means patients will have to wait longer for new methods of medical treatments (Heller & Eisenberg 1998). This is most evident today with statistics showing that over half of all laboratories have stopped development of diagnostic tests because of concerns over infringing patents, and one in four laboratories are forced to abandon a clinical test in progress because of conflicting gene patents (Holman 2008).

However, gene patents are not only hurting independent laboratories, they are also hurting patients. A key example would be for a test for mutated versions of the breast cancer related genes BRCA1 and BRCA2. This test could easily be done by independent laboratories for under \$1000, yet today it has an asking price of over \$3000 because Myriad Genetics (the owner of the gene patent) does not let anyone else offer the test, giving Myriad a monopoly over pricing for tests for those genes (Andrews 2002). Even worse, the tissue samples used for the testing become the property of Myriad, and anything of interest found in that sample can be used commercially and even patented in itself, all without your permission or knowledge (Bovenberg 2005). If you don't like that, then you can't take the test, and as there are no other places to go for testing, you are left unaware as to whether or not you are developing cancer.

Gene patents pose an enormous threat to medical research. Because of these patents, costs for needed tests and treatments have skyrocketed, and competition has been removed. This lack of competition directly affects many researchers working to find new methods of saving lives, causing the speed and intensity of their research to greatly decelerate. When their research and progress suffer, our future suffers. It is time to put patients before patents.

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