Commentary: Differential Human Life Value Perception, Guatemala Experiment and Bioethics

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Abstract

The objective of this opinionated paper is to reflect on the potential of perceptions of different values of human life in influencing ethics violations particularly in health and medical research. It is posited that sometimes members of the research community perceive their own lives as being more precious than other lives. The factor discussed for bioethical violations is the perception of different levels of importance of human lives of people of different races, cultures, regions, countries or ethnic origins in the minds of fellow humans. The experiments carried out on Jews in Nazi camps, African-American people in The Tuskegee experiment, and Guatemalans in The Guatemala Syphilis experiment point to this perception. More often than not, the learned medical scientists know what morally sound medical research is, as is brought forward by an example of Guatemala study; however, sometimes they resort to bioethical violations presumably influenced by their perception of value for other human lives. The researchers for clinical or experimental trials are often drawn to inhabitants of underdeveloped or developing nations as they perceive that if in case there is any harm to the clinical subjects’ health, there won’t be any big payouts; as the worth of those subjects is less than clinical subjects in a developed country. In some of the unethical human experimentations, the affected populations were vulnerable due to their social or economic conditions: being war personnel, mentally depressed or being inmates in prisons. This vulnerability of the subjects makes the researcher throw away the concept of ‘equality in the value of human life’. It is the opinion of the author that as long as this mentality of different values of human life persists, it will have the potential to feed into ethical violations in spite of regulations or laws.

KEYWORDS: Bioethics, research, human life, Guatemala, syphilis

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Differential Human Life Value Perception, Guatemala Experiment and Bioethics

Medical research is an integral part of discovering and evaluating new cures for diseases that affect humans. The research community should make sure that they do not resort to bioethical violations in their zeal to achieve the objectives of the research. However, it has been seen repeatedly that bioethical violations do occur, though their frequency has drastically reduced due to increased awareness.

Recently, an atrocity against medical science perpetrated by United States Public Health Service physician, John Charles Cutler, in Guatemala over 60 years ago has come to light. US Presidential Commission concluded that ethical standards of the time were disregarded but was silent on the reason why they were disregarded (President’s Commission for the Study of Bioethical Issues, 2011). This bioethics violation was uncovered by Professor Susan Mokotoff Reverby of Wellesley College. Reverby (2011) found the documents in 2005 while researching the Tuskegee Syphilis study, in Cutler's archived papers. U.S. Secretary of State Hillary Clinton and U.S. Secretary of Health and Human Services Kathleen Sebelius issued a formal apology (Clinton & Sebelius, 2010) to the Guatemalan government for the experiments in which Guatemalan prisoners were intentionally infected with syphilis and then treated with antibiotics.

The premise of this paper is to ponder the factor - ‘the value of human life’ and how it might have led to the bioethics violations in health research.

Is the life of a human being precious? What is the intrinsic value of humans? It is opined here that sometimes the research community only believes ‘their own life’ to be precious enough and not others. Here, ‘their own life’ may include being of the same race, ethnicity, community, region, religion, country or from a similar economic status. All ‘other lives’ are perceived to have minimal value. The value with which one weighs other individuals modifies his/her
behavior and actions towards them. The experiments carried out on Jews in Nazi camps, on African-American people in The Tuskegee experiment, and on Guatemalans in The Guatemala Syphilis experiment point to this perception. Not only is this true in clinical medicine research but also in the international business and political setup. A life lost in The Bhopal accident is considered to be less precious than the livelihood loss due to The BP oil spill. The value of life or the earnings value of those in the third world countries (India’s in case of Bhopal accident) or other ethnicities (Jews in case of Nazi Experiments) appear to be irrelevant.

The economic principles and economic perceptions have also fueled the exploitation of the vulnerability in disease research. A few medical scientists sometimes want to achieve fame and economic power, even if it is at the cost of human lives or harm to humans. The medical research community and the pharmaceutical industry clamor for new disease cures and yet want to have financial gains. Researchers and the pharmaceutical industry try to have the least financial costs for clinical trials and sometimes resort to non-ethical studies (“The Ethics Industry,” 1997). This leads them to countries where the cohort is relatively poor and uneducated, and the scientific labor is cheap. It gives them access to naive people who are suffering from the disease being investigated, but are not taking medicines for other diseases. This population which is uneducated, socially backward, and having meager resources of livelihood are often targeted as the researchers and the pharmaceutical companies know that neither these guinea pigs nor their families have the resources to fight in local courts, let alone International courts or courts in the countries where the principal investigator or the main headquarters of the pharmaceutical company is located. Thus, researchers for clinical or experimental trials are drawn to inhabitants of underdeveloped or developing nations to decrease overall cost of development of drugs. Albeit, they perceive that in case there is any harm to the
clinical subjects’ health, there won’t be any big payouts; as the worth of those subjects is less than clinical subjects in a developed country.

It is not that the learned and powerful medical scientists do not know what morally sound medical research is or that they are intellectually immature to differentiate between ethical and non-ethical biomedical research. This is also true irrespective of bioethical codes and Acts. Several international codes provide guidance on the ethical conduct of clinical research including the Declaration of Helsinki, Council for International Organizations of Medical Sciences (CIOMS), International Guidelines for Biomedical Research, and the UNAIDS Guidance Document on Ethical Considerations in HIV Vaccine Research. All the research proposals go through IRB or equivalent committees. How well do the members of these committees follow the actual violations in the trial? Does any member ever visit the actual patients and talk to them? Even if there are violations, these codes are recommendations, not legal imperatives. More often than not, no documentation is provided to the subjects if they have any legal course in case something adverse happens.

It is the opinion of the author that the main factor for bioethical violations is the perception of different levels of importance of human lives among people of different races, cultures, regions, countries or ethnic origins in the minds of research scientists and fellow human beings. This was probably one of the reasons that the Guatemala Syphilis experiment was not conducted in North East America but in Guatemala at the behest of The U.S. government. Dr. John C. Cutler of The United States Public Health Service, the Principal-Investigator for The Guatemala experiment knew that the study was not morally sound. As you can imagine, Cutler reported to his colleague, “We are holding our breaths, and we are explaining to the patients and others concerned with but a few key exceptions, that the treatment is a new one utilizing serum
followed by penicillin. This double talk keeps me hopping at times.” In a second letter he repeated his concerns that “a few words to the wrong person here, or even at home, might wreck it or parts of it….” PHS physician R.C. Arnold, who supervised Cutler from afar, was more troubled than Cutler about the ethics of the project. Eight months after the “Doctors’ Trials” at Nuremberg had ended, he confided to Cutler, “I am a bit, in fact more than a bit, leery of the experiment with the insane people. They cannot give consent, do not know what is going on, and if some goody organization got wind of the work, they would raise a lot of smoke. I think the soldiers would be best or the prisoners for they can give consent. Maybe I’m too conservative….Also, how many knew what was going on? I realize that a pt [patient] or a dozen could be infected, develop the disease and be cured before anything could be suspected…In the report, I see no reason to say where the work was done and the type of volunteer.” (Reverby, 2011).

This shows that the United States Public Health Service doctors and officials were well aware of the lack of bioethics in the experiment, turned a blind eye to the immorality and went ahead with the experiment nevertheless. On a certain level, the Guatemala experiments surpassed Nazi experiments in the sense that these were carried out on citizens of another country after taking permission from Guatemala’ government in exchange for money and aid. In Nazi experiments, Jews were their own citizens. In lieu of aid from the US government, the Guatemalan’s authorities at that time turned a blind eye to the details and protocols of the trials thereby ignoring the value of the life of the prisoners.

The Guatemala Syphilis medical experiments took place in 1948, about the time that U.S. officials were prosecuting Nazi officials for subjecting human beings to gruesome medical experimentation (Hornberger, 2010). The US government which was actively pursuing cases
against Nazis for conducting medical experiments on an ethnic population thought that it would be fine if they carried out similar experiments in Guatemala as long as the world did not know about them. As one might imagine, efforts were made to keep these shrouded in the veil of secrecy. It was basically a different set of rules for you; a different one for me; a different life value for Nazi’s subjects and a different life value for Guatemalan experiment subjects.

Another fundamental reason for most of these unethical human experimentations, as it comes out, is that the effected populations were vulnerable. They were vulnerable due to their: social or economic conditions, inability to fight a stronger enemy, being war personnel, mental patients, or being inmates in prisons. This vulnerability makes the researcher throw away the concept of ‘equality in the value of human life.’

So, let us go back to the basic question of perception of value of life and start to evaluate answers to some questions. Is the ‘value of life’ of a Caucasian of one country different from the value of life of a Caucasian from another country? Is the value of life of a Caucasian different than the value of life of an African-American (The Tuskegee experiment) in the same country? Or, is the value of life of a citizen of a developed country equal to the value of life of a citizen from an underdeveloped country? Was the value of life of a Jew less than that of a German in the 1940’s; or, is the value of life of a Jew more than the value of a life of a Palestinian in 21st century? Is the value of life of a person of one religion equal to value of life of a person having other religion? Is the value of life of a rich CEO of a multinational company equal to the value of a life of a spiritual person in a third world country? Is the value of life of a medical researcher more than the value of life of an experimental human subject in an underdeveloped nation? As long as the answers to these and similar questions provide an unequal life value in the minds of
the people even though outwardly they may exclaim- all humans are equal; it is the opinion of
the author that it has the potential to feed into ethical violations in spite of regulations or laws.

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