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Ethics and Genomics

It can be said, and has been said, that science, on the whole, proceeds faster than ever, while the questions of morality and justice remain to be answered or perhaps even addressed. Are the ethicists twiddling their thumbs, while the scientist labor away at harnessing human destiny? It is difficult to tell whether there will ever be any clear-cut answers to our moral dilemmas, but one thing is clear; with the advancement of science these questions must at the very least be addressed, in a very real world context. What was once thought to be purely hypothetical is now very factual, so the stakes of the ethical game are raised and the urgency increases.

In this paper, I will not *theorize* about what is right or wrong, for this tends to be neither efficient nor convincing. Instead, I will draw from what I see as being common practice. In other words, while there do not seem to be any concrete "right" or "wrong" actions (even murder is allowed in our society depending on circumstance), we still hold the members of our society responsible for their actions based primarily on whether or not they had control over those actions. *Intention*, as well as *potential*, seem to mean as much as the action itself. This has inevitable consequences in the debate of genetics, its usefulness, and application. I am going to address some of the tensions that arise due to our new found scientific capabilities. As well as, convey my personal point of view on our actions, our capabilities, and our moral responsibilities relative to the human genome project and genetics in extremely general terms. There are two tensions which I plan to

focus on: whether or not we should continue studying genomics and the societal problems that might result from both the end of genetic research and the advancement of genetic research.

Our control of the situation determines our moral responsibility. At least as commonly practiced in our legal system. Holding someone guilty for a crime which they had no control over seems far from our idea of justice. In terms of genetics, parents are not held responsible for the transmission of a "bad" gene, which might later result in the death of their children. Ideally, we convict only those who in "good mind," vague as that may be, committed a crime. Of course, this does not imply that those who accidentally break the law are not held responsible for their actions. Depending on the degree of the crime and whether or not the action could have been prevented, many people are punished for something they did unintentionally. For example, if a child accidentally kills him or herself with a gun that he or she found in his parents bedroom, it is generally conceded, depending on the circumstances, that the parents are guilty of what we call "negligence." Evidently, our science of morals and our system of laws are anything but precise. Many cases push and pull on both systems forcing us to either redefine or modify them. Genomics brings to mind many such cases. So much so that whether or not we should continue to study genomics has become an ethical issue in and of itself.

So, should we continue research in the field of genetics? Here, I stress the importance and subjectivity of the word "should." It implies not only the fact that we have a choice, but also that our decision will be determined on ethical grounds, as opposed to "practical" or physical limitations. So, what are the issues that must be addressed when deciding whether or not to continue our journey into the world of

genetics? There are many. Everything from meddling in "God's domain," to the destruction of embryos, to the exacerbation of already existing social and economic inequalities can be considered as "ethical issues" that stem from genomics. Yet, "calculating" the costs and benefits of genomics appears incredibly complex. Therefore, I am instead going to address the question; "Do we have a moral responsibility to continue genomics?" in the same way we appear to have a moral responsibility to prevent or abstain from crime.

With respect to genomics and its ethics the arguments are both for and against advancement. If we have the ability to prevent the suffering or deaths of countless future lives, is it not grossly negligent to ignore that potential? Yet, at the same time, can we be held responsible for the deaths of those people even though they seem to be out of our control? Not to mention, the countless actions that genomics imply (embryo research, possibly propagating social inequalities, creating a society structured based on genetic ability, taking "nature" into our own hands, eugenics, etc. etc.).

If we hold the members of our society responsible for what is in their control, for what they do and what they do not do (which appears to be the case), then can we be held morally responsible for our decision to either continue or end our study of genomics? We appear to have complete control over whether or not we continue, therefore it appears that we bare the complete moral responsibility of either action. If we view our actions in this light, the situation takes on a different form.

For example, if a couple had the ability (in every sense of the word) to *prevent* their child from having a disease it seems negligent for them not to do so. The same kind of negligence as leaving a loaded gun lying on the kitchen table. If a couple *chooses* to

modify their child's DNA, such that he or she is born blind, it seems difficult to *not* hold these people responsible for blinding their child, but to hold someone who abuses their child under a similar belief that it is for the child's benefit.

What is ethical becomes a question of not only what you do, but also of what you do not do. We are therefore held responsible for everything that is in our control. If we then take into account the exponential potential that genomics carries with it, it becomes difficult to even consider ending the study of the human genome.

Using genomics we can (have) change(d) medicine as we know it. We can facilitate the creation of antibiotics. We can prevent disease. We can diagnose the probability of disease. We can prevent complications with drug reactions. We can help create drugs specific to each person. We, in theory, will be able to do everything from stop aging to design our offspring.

But, notice that this is a list of that which is now in our control and not a list of what should be done. Yet, the list does imply that we are now morally responsible for these things. If we can save a person's life, but decide not to do so, are we morally responsible for it? Yes and we commonly are. If we can stop someone from suffering, but choose to ignore their suffering, can we be held morally responsible? Again yes and again we commonly are expected to do so.

Does this mean that continuing genomics is a purely morally correct thing to do? No. Nothing seems to be "purely" morally good. Continuing genomics means that we might have to destroy some embryos, it means that we will be directing resources towards science, instead of towards people who are currently suffering. So then are we to be held morally responsible for these things too? Yes, but in a different way.

We cannot simply state that genomics is "for the greatest good" of society and give unlimited freedom to its practice. Simply because continuing the study of genomics seems to be our best option, in terms of saving lives and combating disease, does not mean that there should be no remorse for the loss of countless lives in the process. This idea is of utmost importance, because it does not trivialize the costs, simply because they are less than the benefits. The costs are very high, but we are morally obligated to continue our study. For us to stop would be to eliminate the potential to do good that comes with genomics, but again the ethical costs must be felt and minimized. We are morally obligated not only to do everything in our power to aide those who are in need, but also to prevent injustice.

As for the tensions that come from the continuation of genomics, these must also be viewed in terms of their ethical implications. For example, the idea of eugenics seems to weigh heavy in opposition to the continuation of genomics. Also, the idea of exacerbating the socioeconomic gaps that already exist in society comes to mind. However, these problems do not seem to be a "result" of genomics itself, but rather a symptom of much greater problems within our society.

The fact that a parent would want to modify his or her child to be "more beautiful," or "taller," or "more intelligent," seems to be more a reflection of the parents insecurity and/or mis-education. Neither of which can genomics be held responsible for. The fact that the higher up the social ladder you are, the better your health care, also seems to be a result of societal structure, rather than our study of genomics. In other words, you cannot hold the tool responsible for what the agent has done or does with it, nor for the environment (in this case capitalism) for which it was created. How often do

we see knives on trial for murders or for being too expensive for some to purchase? While, I must concede that the absence of knives, *might* decrease the facility with which the agent killed its victim or one instance of economic inequality, but it is hard to believe that without knives there would be no murders and no inequities. Genomics seems to be another tool that can be used for many purposes, but we must keep in mind that the responsibility rests in the hands of those using the tool.

Interestingly enough, I feel like our analysis of genomics has lead us right back where we began. In the driver's seat, with complete control, not only of what is happening and what is going to happen, but of what is not going to happen. Personally, I feel morally obligated to promote and aide the continuation of genomics and the whole world of technology that comes with it. But, I am also very saddened at the fact that that implies a whole world of problems. Which, I am fully aware that I am also responsible for and am also obligated to fight against. It is like I said, I am obligated to not only to do everything in our power to aide those who are in need, but also to prevent injustice.

In the end, it appears that what determines whether or not something is "punishable" or "praiseworthy" appears to be whether or not we have or had control over the action. With this held firmly in mind, some of the issues that come up in conjunction with our growing knowledge of the human genome become less troublesome. We will be/are still responsible for that which is in our control; social inequality, prejudice, eugenics, the destruction of embryos, and everything else our deliberate actions imply or cause. Which means that we are also responsible for what has now come into our spectrum of control; preventing disease and suffering of those genetics can help.

In other words, in terms of ethics, genomics *must* procede. Yes, destroying embryos (if scientist even decide to use the embryos) is wrong. Yes, social inequalities are bad. Yes, eugenics and prejudice are great evils. But, how is our *ignorance* of the human genome going to help anyone? How can someone fight for the lives of unborn children and simultaneously against the lives of children suffering from inherited diseases? The science of genomics, like any other tool, in and of itself, is not morally wrong. What we do with genomics, on the other hand; that *is* very much either blame or praiseworthy.