4-24-2009

Moral Concerns in Genomic Medicine Beyond GINA

Stuart Paul Reeves
University of Missouri-St. Louis, stuart.reeves@umsl.edu

Recommended Citation

Reeves, Stuart Paul, "Moral Concerns in Genomic Medicine Beyond GINA" (2009). *Theses*. 234.
http://irl.umsl.edu/thesis/234

MORAL CONCERNS IN GENOMIC MEDICINE BEYOND GINA

by

Stuart Paul Reeves
Bachelor of Arts, Philosophy, University of Texas, 2005

A THESIS

Submitted to the Graduate School of the

UNIVERSITY OF MISSOURI – ST. LOUIS

In Partial Fulfillment of the Requirements for the Degree

MASTER OF ARTS

in

PHILOSOPHY

April, 2009

Advisory Committee

Ronald Munson, Ph.D.,
Committee Chair

John Brunero, Ph.D.

Robert Northcott, Ph.D.

ACKNOWLEDGMENTS

I would like to extend a warm expression of gratitude to Prof. Ken Goodman and his staff at the Ethics Institute at the University of Miami where I began the research that would eventually become this thesis.

DEDICATION

For my father, Paul, and my wife, Karen… “the world entire.”

ABSTRACT

Genomic medicine, including pharmacogenomics, represents a potential paradigm shift in the diagnosis of disease and delivery of healthcare. Beyond the promise to address and resolve pandemics affecting specific ethnic/racial communities is the potential to develop pharmacological therapies custom tailored to the individual patient's genomic profile. However, the delivery of such promise rests on the contribution of genomic samples from individuals in communities where the culpable polymorphisms are present in high volumes. With the potential for an ever-widening disparity in overall population health among the socio-economic tiers in which these communities are often found, a theory of justice is needed to address and resolve concerns of distributive justice.

I submit Norman Daniels' application of Rawls' theory of justice as fairness can provide a framework to guide policymakers in navigating these matters and ensure that subject populations are not unjustly exploited for the sole medical benefit of those individuals that can afford such treatments, while those that contributed their specimens for the development of new therapies are left with only sub-standard treatments for the same maladies, if any at all.

Introduction

Genomic medicine represents a possible paradigm shift in the practice of medicine and the delivery of healthcare. This approach to medicine analyzes how variations in a patient's genome determine susceptibility to certain conditions. For instance, breast cancer is linked to a variation called the BCRA-1 gene found in the 17th chromosome. Researchers hope to identify and isolate culpable variations, such as BCRA-1, in hopes of developing new treatments for various diseases such as sickle-cell anemia, Tay-sachs and other malignancies. Pharmacogenomics, an emerging sub-discipline of genomic medicine, is of particular significance to this potential change in the practice of medicine. It examines how these polymorphisms affect drug efficacy and as a result will likely shape pharmaceutical research agendas. As with any new medical technology that promises to have a significant impact on society, policymakers, physicians and philosophers must critically examine the looming moral impact introducing such instruments could have on society at large. In this paper I will identify some of the moral issues that arise in genomic medicine, specifically concerning the distribution of the supposed benefits, and propose some initial solutions. The consequences this conceptual shift could bring to the practice of medicine and society cannot be overstated.

For instance, delivery systems will have to be redesigned to include genetic screening in order to select the best course of treatment. Of course, doing so raises a number of ethical concerns. First, how is the privacy of the screened patient adequately protected to prevent genetic-based discrimination? Second, if pharmacogenomics successfully gives rise to the production of drugs tailored to a patient's genomic profile, will those that cannot afford these custom designed therapies have to settle for sub-standard medical care, if any at all? Fortunately, the law has spoken on the discrimination issue with laws such as the Genetic Information Non-discrimination Act of 2008 (GINA). However, the just distribution of the benefits of pharmacogenomics, like those mentioned above, has yet to be addressed.

I will argue that Norman Daniels' application of Rawls' theory of justice as fairness to healthcare reform addresses problems such as the just distribution of resources that accompany pharmacogenomics. Daniels believes when Rawls' theory of justice as fairness is applied to society, it creates institutions, such as healthcare in the broadest sense, that protect opportunity for its citizens and guarantee equal access to all. One should understand though that Daniels makes a distinction between *health* and *healthcare* that is particularly useful for understanding his motives for such a project. Briefly, in Daniels' view, health is an ideal state marked by the absence of disease. Health, in his view, is determined not only by those natural factors we have no control over, such as hereditary pre-dispositions, but also by some socially controllable factors, such as education, public health and economic policies. When Daniels says that Rawls' scheme describes a just distribution of healthcare, what he means is that it describes a just distribution of those socially controllable factors that contribute to overall population health. Thus, rather than attempt healthcare reform by injecting copious amounts of capitol into delivery systems in hopes of improving health, Daniels prefers a holistic approach that favors environmental hygiene initiatives, public research programs, education and the like to affect overall population health.

Laws like GINA demonstrate that our political leaders share Daniels' intuition. The act disallows the use of information yielded from genetic testing, including family medical history, in the determination of insurance coverage, including determination of premiums, as well as use in hiring, promotion or termination practices by an employer.[1] Although GINA encourages individuals to seek out potentially life saving information without fear of reprisal for their own benefit, I want to further address what can be done to encourage people to seek out this information for the greater benefit of society.

I propose the state can fulfill Rawls and Daniels' vision by subsidizing at least some portion, if not all, of the cost of voluntary genetic screenings. Doing this could solve two pressing social issues at once. First, with respect to pharmacogenomics, the problem of just distribution is that it requires collecting genomic samples from a patient or community in order to develop a treatment that, though they may need it, the patient or community cannot afford. By encouraging screening, the patient could have the necessary information to make informed health management decisions. Second, this increase in preventative measures taken by individuals could reduce the burden on scarce medical resources. Consider for example, a child screened early in its life and determined to have a genetic predisposition to Type-II diabetes. By encouraging specific

---

[1] Though the law has now spoken on the discrimination concerns, the effectiveness of the protections GINA extends to would-be patient-subjects may not be proven with the activation of its provisions in the next 12 to 18 months. A surge in the academic literature, particularly in health-care law and other public interest journals, aiming to expose the loopholes and other weaknesses in the legislation should be anticipated.

nutritional habits early in the child's life, the resources required to treat the would-be diabetic adult could instead be used to underwrite the cost of treatments for those destitute individuals and communities whose genomic information contributed to the development of a treatment for some other disease.

Genomics, Pharmacogenomics: Method and Emerging Concerns

Before Daniels' theory can be discussed in vivid detail, it is worthwhile to briefly discuss the basic method of genomic medicine, which includes pharmacogenomics, and the immediate ethical concerns each produces.

With the success of the Human Genome Project, researchers were given a working model of the genome to use as a baseline with which they could compare collected samples from various subjects belonging to diverse ethnic/racial communities in order to determine how, if at all, genomic variation determined susceptibility to disease.[2] Another promising application that emerged was pharmacogenomics.

Beyond the potential for treatments tailored to the individual patient is the promise to address pandemic health concerns in specific communities. Diseases such as sickle-cell anemia and Tay-Sachs, which historically have the greatest frequency of occurrence in specific ethnic/racial communities, could be assessed at the genomic level to identify those polymorphisms that either put the subject at high risk for manifestation,

---

[2] For example, a recent report published by researchers at the University of Texas Health Science Center, San Antonio, Texas has found a genetic variation common to people of African descent that both increases susceptibility to HIV infection, while at the same time immunizing them against a pandemic strain of Malaria. See Sansom, 2008.

or ultimately lead to onset. With such information, more efficacious therapies, or even cures, could be developed.

The ethical, legal, and social literature that emerged as this burgeoning field matured highlighted many pressing concerns. Among them was the fear that stratification of the general population by genome type could elevate social tensions and create an opportunity for discriminatory practices in insurance and employment.[3] Such practices, if unchecked, would stymie research efforts as patient-subjects would fear their participation would result in higher premiums or loss of coverage by their insurers, or termination by their employers if discovered.

Sobering to the potential for such harms, the scientific community began to lobby for legislation that would forbid such practices. After 13 years and numerous revisions, GINA was signed into law in May 2008.[4] Though potential discrimination concerns were certainly important to resolve early in order to ensure research could proceed unabated, we must continue to seek resolutions to other pressing social and ethical concerns that could further stall not only medical and scientific progress, but social progress as well. Disparity in the levels of access to healthcare is not a novel revelation. One of the results of setting the US healthcare system in a market based, capitalist scheme is that geographic and socio-economic factors, as well as particular cultural views on medicine

---

[3] Peterson-Iyer, 2008

[4] Hudson, 2008

lead to unequal access to the opportunity to purchase healthcare, or even insure oneself against the risk of requiring *institutionalized healthcare*.[5]

Observing the correlation between socio-economic status and level of access to care leads one to affirm a true irony of medical research—those who would volunteer to become a test subject in a trial may very well not be able to afford the treatment that information gathered from their participation would yield. Now consider the ends of pharmacogenomics and the problem becomes even more disconcerting.

The methodology assumes by gathering multiple genome samples from communities in which a given malady occurs with high frequency, the culprit variation can be isolated, studied, and a treatment or cure developed. To appreciate the notion of how many samples would be required one must consider that it is not tens, or even hundreds that are needed. It could be as many as thousands. The realization that a member of a community could not afford the treatment their own genetic information contributed to the discovery of should strike us as properly unjust. Moreover, it would seem to violate any intuitive sense of fairness.

One might be inclined to respond that there is no such foul occurring here. It could be suggested that one's labor does not entitle them to the fruits of that labor. For instance, even though a surgeon may spend his career performing hundreds of life saving procedures, it does not entitle him to a free triple by-pass. However, to take this position on the value-added labor argument is to ignore what makes medicine different from most

---

[5] By *institutionalized healthcare*, I mean institutions such as hospitals and care clinics other than emergency care centers which are required by federal law to treat all patients in need of acute care.

professions and health from most natural goods. The special moral significance of health, and the practice of medicine by extension, is that it protects access to opportunity by maintaining the function necessary for a person to achieve their rational goals.[6] It could be argued that society moved along well enough without computers, diamonds or automobiles. However, I contend, all social activity would cease without healthy individuals motivating society and social institutions. If one segment of society's participation in society entails to some degree maintaining the health, and therefore the functioning, of another segment, it seems that we have an obligation to consider some form of compensation lest we find ourselves accepting an ever widening disparity in the aggregate health of the population.

I do not, however, take for granted that the manifestation of some diseases and malignancies may be hastened by the choices made freely by individuals, such as the link between tobacco use and multiple forms of cancer. Genomic medicine operates on the assumption that there exist law-like relationships between individual genomic profiles and the patient's environment that play a significant causal role in the onset of disease. While some patients' predispositions may hasten the development of a malignancy, those that opt not to indulge in the use of a particular carcinogen-containing product may nonetheless develop the same malignancy. To reject the intuition concerning injustice I have expressed here because of the actions of a probable minority seems shortsighted. Though these same individuals in society may ultimately benefit from the contribution of these donors of interest, penalizing those that act autonomously and choose to consume

---

[6] Daniels, 2008

these products or engage in risky behaviors is a separate legislative and philosophical issue altogether and beyond the scope of this discussion.

Ultimately, a framework or theory of justice is called for to inform a prudent public policy to address the disparity I am concerned pharmacogenomic research creates. What distinguishes this call for distributive justice in access to healthcare from previous efforts is unlike those proposals that simply looked for charity for those that would contribute nothing to the healthcare system but take from it, so called *free-riders*, here is a situation where whole communities could contribute to the body of medical and scientific knowledge and yet have no access to the returns. Even on a commodity-based view of healthcare, this seems improper. However, the framework I offer here is just that, a framework. It is not meant to, nor could it, fill the content of any potential law. That is a procedural matter that could only be resolved through the work of a politically recognized legislative body. Here, justice appears to demand, for Rawls and Daniels at least, that we recognize the distributive challenges that emerge from genomic medicine and its ilk, and make positive steps to address them. Proposing that Daniels' application of Rawls' theory of justice as fairness to this issue in healthcare resolves these concerns and making a plausible case for such a claim is but an early-step in fulfilling that obligation.

Daniels and Just Healthcare

Rawls' theory of justice includes the axiom that no one person should gain any social benefits or suffer any detriment as the result of the *natural lottery*. That is, every citizen should have equal access to the opportunity to compete for jobs in specific trades, public office, or even acquire wealth regardless of those biological and circumstantial factors that are beyond their control, such as the socio-economic tier into which they were born, and arguably, the genetic predispositions that historically occur in the ethnic/racial group of which they are a member. Daniels seized this principle of equality of opportunity and built his theory of just health care around it.

Daniels argues that medicine's moral significance is found in its efforts to protect the normal functioning of individuals, which in turn protects the range of opportunities open to any citizen. Doing so allows these citizens to enjoy those liberties that are to be guaranteed to all under Rawls' first principle. It can be seen from this assumption that *disease* and *harm* take on special meanings in the theory. Daniels relies on Boorse's view of disease, which treats disease as any condition that affects species typical functioning in a way that prevents the affected individual from enjoying the opportunities that would otherwise be available to him.[7] Since a *disease* is a deviation from the natural function of a typical member of a given species, *health* then is defined merely as the absence of *disease*. *Harm*, then, occurs when any block in access to such activities is caused by the manifestation of a *disease*.[8]

---

[7] Daniels, 1985, 2007

[8] This view is controversial for its use of *function* as the standard for *health*, among other reasons. Critics often allege that function-based accounts of disease lead logically to the conclusion that homosexuality is a disease since, perhaps trivially, homosexual partners cannot reproduce with one another. However, I believe such critics are taking a far too narrow interpretation of function in this account. As the classical literature suggests, the function of human beings is not solely to procreate, but to exercise reason. Therefore, considering any condition that compels reason to direct humans to seek a remedy to restore *species-typical functioning* seems to me to be a much more productive view to adopt concerning this naturalist account of disease. See Aristotle, NE Book I 1098 b 5.

Daniels came to accept that various social goods and cumulative experience can affect the collective health of a community, and further claimed that Rawls' principles of justice described a fair distribution of these social determinants of health.[9] In Rawls' account, every citizen is afforded the same set of basic liberties such as participation in political discourse, including but not limited to lobbying for community interests and voting. Further, any social or economic inequalities that emerge in a society must satisfy two conditions. First, all citizens must have fair and equal access to the opportunity to compete for all offices and positions. Any citizens with approximately the same skills and ability to use them should have the opportunity to do so regardless of social status. One could not be prevented from entering a trade, though soundly qualified, because of the social tier in to which they were born. Second, any such inequalities must be to the greatest benefit of the least advantaged members of that society. This Difference Principle is not meant to imply a trickle down scheme for wealth. Rather, it permits individuals to earn varying and competitive wages across trades owing to factors such as the cost of training and education. Presumably, however, in Rawls' scheme all citizens have access to social institutions such as primary and secondary schools. It could be argued that seizing the opportunity for a relatively cost-free education at the primary and secondary level could allow for greater opportunities for citizens down the road.

Rawls, however, did not include health among those primary goods his principles are meant to describe the just distribution of. Primary goods are those things that every

---

[9] Daniels, 2001, 2007

rational man is presumed to want.[10] Rawls distinguishes between two kinds of primary goods—social and natural. In his description of primary social goods, Rawls intentionally simplifies the list to include rights, liberties, opportunities, income and wealth. In short, those things a man might need to carryout his own ends. Primary natural goods include health and intelligence. What distinguishes these sets of goods from each other, according to Rawls, is that the latter may be influenced by the basic structure of society, but ultimately may not be determined by it.

Looking at the lexical ordering of the principles of justice, we can make some sense out of Rawls' claim here as it plays within his own scheme. One cannot blatantly deny basic liberties to any individual merely for the sake of claiming that any disadvantage the violation would create would benefit the least advantaged. Given this, one can see why, for example, state sponsored eugenics plans would fail to be just in a Rawlsian society. Selecting one's sexual partners free of any state influence must surely be a basic liberty. It is an expression of autonomy. If the state then cannot restrict what pairing of humans may procreate for the sake of creating ideal offspring, then the notion that social structure fully controls what traits and talents emerge from the natural lottery becomes implausible. After all, when it is left to chance, a savant is just as likely to be born in a brothel, as he is a palace. The point is this, while we can assume that members of certain socio-economic classes will often procreate, nothing in nature suggests it is this way exclusively.

---

[10] Rawls, 2001 pp. 54

Rather than argue for the inclusion of health and healthcare as items among Rawls' primary social goods, Daniels extends the principle of equality of opportunity to place obligations on social institutions, such as education and public health legislation, to protect opportunity rather than maximizing aggregate welfare as a utilitarian would. By protecting the functioning of citizens, Daniels argues that healthcare makes a distinct contribution to the protection of equality of opportunity by moving beyond traditional delivery systems and investing in preventative measures such as health education and environmental hygiene initiatives in communities.

Health, as Daniels further contends, is determined to a large extent by cumulative experience.[11] By the time a middle-aged heart attack victim receives acute care, several years of health mismanagement and bodily neglect could occur. Investing in social infrastructure through education early in the lives of citizens could reduce the demand on scare medical resources in the future. Moreover, it might be less of a strain on economic resources. An emphasis on early genetic screening and counseling could also allow individuals to better plan and manage their healthcare needs in a fiscally responsible way and not rely necessarily on the state. Again, consider the case of the diabetic child in the introduction.

In addition to cumulative experience, Daniels' also finds that health is determined in large part by other social factors including literacy, income, and income distribution. Not surprisingly, citizens in wealthier nations tend to live longer than those in impoverished areas. However, it is interesting to note that the proportionate relationship

---

[11] Daniels, 2001

of income and domestic gross product to life expectancy levels off beyond $10,000 GDP per person. Beyond this threshold it appears that further economic advance does not ensure gains in life expectancy.[12]

The need to regulate, or justify income disparities in Daniels' account cannot be overstated. Since there does appear to be a link between income and life expectancy, disparities are likely to lead to disillusionment and erode social cohesion. A drop in political participation by these parties could in turn undermine the ability of political leadership to respond to the needs of a community and further exacerbate existing problems.[13] This makes Rawls' principles guaranteeing basic rights, such as political participation, all the more valuable. Thus, Daniels finds it evident that Rawls' principles of justice imply that we ought to regulate the several social determinants of health.

However, Julian Savulescu objects to Daniels' scheme saying that the promotion of equality of opportunity is not an appropriate goal for healthcare, even if it is appropriate for social justice. This is a direct response to Daniels' assertion that justice turns out to be good for overall population health.[14] Savulescu prefers a consequentialist view for the role of healthcare in society that he calls the Decent Minimum Account. The central idea behind this view is that the goal of just healthcare distribution ought to ensure that the maximum number of people receive a decent minimum of healthcare, where this minimum is considered that which is necessary to promote a minimally decent

---

[12] ibid

[13] Daniels, 2007

[14] Daniels, 2001

life, and not necessarily ensure that everyone has equal access to the opportunity to pursue their rational goals.[15]

It is more plausible according to Savulescu to ensure that everyone receives a decent minimum of some social good, such as education or healthcare, rather than everyone receiving the same amount. Consider education, he offers. If we grant education to all based on fairness, those with modest cognitive skills could receive more educational resources than those that are naturally more talented, leaving this latter group's development stalled. Rather than suffer this consequence, it makes more sense to offer a common decent minimum to all while permitting that others may pursue some level of education beyond this. Savulescu views healthcare in the same light.

He supports his decent minimum account by appealing to a distinction between what he calls *relative* and *non-relative good* states of affairs. A relative good state of affairs is a state of affairs where the value of that state is dependent upon the state of affairs of another individual. For instance, being a certain height can be a relative good state of affairs depending on the height of others in your community. An athlete of a height of greater than six feet, for instance, is in a relative good state of affairs if he is a basketball player and the majority of his opposition is six feet tall or less. By contrast, non-relative good states of affairs are those matters of fact that are good solely in virtue of themselves and do not rely on any comparison to another state of affairs to determine that value. Being educated so that you may better understand yourself and the world around you, as Savulescu testifies, can be said to be non-relatively good. Education

---

[15] Savulescu, 2001

though, is an interesting example. It can be both a relative and non-relative good state of affairs. It is good in itself to be educated for the reasons given above. However, it is also relatively good. On this score, Savulescu cites examples in developing countries where higher education for women correlates with lower birth rates and lower infant mortality rates.

The purpose of the distinction is to demonstrate that there are non-relative social goods such as education and healthcare that should be promoted above a decent minimum in virtue of the fact that they are non-relatively good and they appear necessary for a person to have a good life. Social conflicts arise however, when the relative value of such goods, like education or healthcare, is exploited and society permits only the best educated or most healthy to have access to opportunities such as employment. Savulescu's remedy for such injustices is not to ensure only equal amounts of healthcare and education for all. Rather, we should take steps to ensure that opportunities are not distributed according to one's level of education or health state. Goods such as education and healthcare are necessary to promoting a good life, he says, and insofar as these non-relative goods accomplish this, we should ensure a decent minimum of these for as many people as possible. However, this minimum access should be ensured by something like Rawls' first principle. Avoiding discrimination in employment, distribution of income, and the like, because of remaining disparities in health status should be determined by the second principle.

Savulescu appears to imply that it is not a realistic claim that *all* members of society could have access to a supposed decent minimum of care. Given certain economic restraints that may be a reasonable assumption to grant for the sake of argument. However, given this assumption, it becomes necessary to set up laws under Rawls' second principle to ensure that access to opportunities to fulfill one's rational goals and desires are not stymied as a result of diminished health status or education, he says. For Savulescu, healthcare should not be the vanguard of equality of opportunity. That role should be reserved for laws and other social arrangements that rein in discriminatory employment and insurance practices against those who are more likely to get sick.

While this may be as plausible a scheme for healthcare reform as Daniels', Savulescu's claims here do little to convince me that the decent minimum account is necessarily any better than Daniels'. This is owed in part to his failure to address the special moral role of healthcare in a society that I take to be the crux of Daniels' project. Rawls' first principle states that every person in a society is to have access to the same basic set of liberties. While it is erroneous to assume that health, as was defined earlier, is a right or basic liberty, it is not so for autonomy. If the full preservation and exercise of autonomy rests on optimal functioning, then any guarantee of liberty must account for what steps may be taken or resources devoted to maintaining said function so the practice of an enumerated set of liberties is possible. If Rawls' second principle adequately describes the social determinants of population health, then what Savulescu is asserting might be redundant. Laws like GINA fit Rawls' model of justice because they are part of the public health policy that both Daniels and I are advocating here.

In her analysis of GINA, Sherry Colb, a legal scholar and frequent contributor to FindLaw, raises an intriguing notion that lines up nicely with Daniels' application of Rawls and the rise of genomic medicine.[16] Our current relationship to genetic [predisposition] information, she says, may provide the closest thing we have to a veil of ignorance. Though some of our genetic endowment may be evident to us without specific testing, Colb continues, much of it remains a mystery. Colb's assertion is that GINA represents an actualization of Rawls' thought experiment and his theory of justice at work. In a position where no one can be certain of the variations their genetic structure holds and what such variations might produce, it would seem natural that legislators and laymen alike would oppose any genetically based discrimination, which in effect, may level the playing field as Rawls' had envisioned. Efforts to spurn discrimination through laws such as GINA represent the protections Daniels wants for access to opportunity.

But if legislators have committed to protecting its citizens from discrimination based on their genomic profile and stand watch over opportunity in this way, why not also endorse government subsidized genomic analysis as a method of preventative healthcare and education? The cost of tests to determine the susceptibility to manifestation of various cancers, diabetes, and other diseases are far less than their treatments. Information yielded from screening can bolster individual lifestyle and environmental management decisions that can preserve scarce economic and medical resources. These savings could then be channeled into compensation to patient communities that participated in pharmacogenomic research further ensuring their access

---

[16] Colb, 2008

to opportunity is secured. This assertion reduces to a common-sense intuition that if the state is willing to give citizens access to opportunity by protecting those citizens from the lesser-known fates that may affect them, it ought to also give its citizens the chance to know what such fates are—especially if doing so is to the benefit of all.

Clearly there is an aggregate benefit to society as a whole, but the vulnerable communities I am concerned with here, I submit, still stand to benefit the most from my proposal. Both Rawls and Daniels recognize that inequities will exist even if society is arranged on their terms. However, both concur that any such inequities must be to the benefit of the least advantaged. Daniels cautions that one should not think that the only way society has to protect the health of its citizens is through health care. Doing so, he says, could lead one to mistakenly infer that inequalities in health are unjust when access to health care is unequal.[17] But, Daniels has provided compelling evidence that suggests that there are socially controllable factors, so-called social determinants of health, which figure into health status across members of a community. Health, is not simply or solely the product of health care. Thus, any inequities that remain after we have ordered our primary social goods and social institutions according to Rawls' principles are not unjust.[18]

I have proposed above that groups that contribute to the discovery of new pharmacogenomic therapies should receive access to the therapies their specimens led to

---

[17] Daniels, 2008 pp. 22

[18] Daniels, 2008 pp. 82; an example might be a community that views medicine as taboo on cultural or religious grounds. Though they would now have access to the same level of public health education, screening and treatment as the rest of society, they may very well choose not to avail themselves of it on moral grounds.

the creation of. The cost incurred from providing these treatments could be covered in part by the profits generated from the purchase of the treatments by those that have the income to do so and from the healthcare savings generated from preventative measures such as voluntary early screening.

At first glance, this may seem like an attempt at shoehorning a welfare program into Rawls' scheme that should not belong. However I do not believe Rawls and Daniels' schemes and my proposal are at all in tension. First, when one considers the moral significance of health in society as Daniels sees it, that it protects access to opportunity by maintaining function, it does not appear that we can allow these subject populations to provide the necessary genetic data to derive treatments without some form of compensation. To do otherwise would be blatant exploitation that would widen the gulf of disparity in overall population health. One segment of society is getting progressively healthier, in a sense, while another is certainly not. In no way is this inequity to the benefit of the most disadvantaged in this scenario. Second, not subsidizing the cost of treatment could actually constitute a prima facie violation of non-malficience as not treating them with the best available treatment, which may also become the standard of care, leaves only sub-standard treatment, if any at all.

Daniels would certainly view access to opportunity as a basic liberty accounted for by Rawls' first principle. And, to that effect, such access must be equally available to all. Granted, no one is saying the subject population cannot have the treatment, only that they cannot have it if they cannot pay for it. However, if access to pharmacogenomic therapies is available to one party at the expense of another with no reciprocity aimed at maintaining equality of opportunity then social policy, which as we have seen can be determinant of health, has failed. My proposal, I believe meets that challenge in a manner consistent with both Rawls and Daniels' framework.

Conclusions

Genomic medicine has given us a new light in which to consider the conditions that affect health, which as Daniels holds, have a direct impact on the ability of citizens to function and thus pursue opportunities in an effort to find a place in society. The obligation to protect these opportunities falls to the people's political leadership, which can be accomplished in Daniels' view by seeing to an equal distribution of the social determinants of health. This equal distribution is achieved by investing, not exclusively in access to delivery systems, but in educational and other preventative measures.

Clearly though, reforming delivery systems must be some part of the solution. As I have suggested, if the new approach to medicine is going to focus on how inherited genetic variation determines disease, and the search for efficacious treatments rests on communities contributing to the solution, there must be some recourse made available to them. That is, their right to access to opportunity must also be preserved. By committing to early warning through screening and encouraging preventative health management for all citizens, the costs that would have been otherwise incurred by treating them in the future could be used to compensate individuals and communities that participated in research from which new treatments emerged that they would not have been able to purchase themselves. As medicine begins to look within for answers to the etiology of disease, political leaders should contemplate Daniels' approach and seriously consider that accepting the obligation to ensure access to opportunity for its citizens also entails providing the opportunity to prevent knowable harms.

Work Cited

Colb, Sherry *"What's So Special About Genetic Discrimination? Congress Passes a Revealing Bill."* from www.findlaw.com, originally accessed May 30, 2008. (http://writ.news.findlaw.com/colb/20080514.html)

Daniels, Norman *Just Health Care*. Cambridge University Press. New York, 1985

Daniels, Norman *"Justice, Health and Healthcare"* in *American Journal of Bioethics* (2001) pp. 2—16

Daniels, Norman *Just Health* Cambridge University Press. New York, 2008

Hudson, Kathy L., Holohan, M.K., Collins, Francis S. *"Keeping Pace with the Times—The Genetic Nondiscrimination Act of 2008"* in *New England Journal of Medicine* Vol. 358, No. 25 (2008) p. 2661—2663

Irwin, Terrance., Fine, Gail *Aristotle: Selections.* Hackett Press. Indiana, 1995

Peterson-Iyer, Kathleen *"Pharmacogenomics, Ethics and Public Policy"* in *Kennedy Institute of Ethics Journal* Vol. 18, No. 1 (2008) p. 35—56

Rawls, John *A Theory of Justice—Revised Edition*. Harvard University Press. Massachusetts, 1999

Sansom, William "Study: Genetic Variation Raises HIV Risk in People of African Descent" from www.uthscsa.edu originally access July 24, 2008 (http://www.uthscsa.edu/hscnews/)

Savulescu, Julian *"Justice and Healthcare: The Right to a Decent Minimum, Not Equality of Opportunity"* in *American Journal of Bioethics* (2001) pp. 17—19