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The Parallax of Personalized Medicine: A Critical, Socio-Medical Analysis of the Trajectory of Pharmacogenomics and Genome Wide Association Studies

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The Parallax of Personalized Medicine: A Critical, Socio-Medical Analysis of the Trajectory of Pharmacogenomics and Genome Wide Association Studies

by

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Dedication

As children, my siblings and I always had the sixty-four box of crayons with the sharpener in the back. When I drew my mother, I'd color her in the shade called Burnt Sienna. It reminded me of the gold undertones in her complexion mixed with the color of red beans and rice—like the kind she managed to get in her hair that day we went to see Wanda Rouzan in the park during French Quarter Fest. I was six. We were all dressed alike. We laughed until tears filled our eyes, our stomachs cramped, and we could no longer produce sound. More than thirty years later, when the cancer treatments charred her skin until it peeled and flaked off of her body, I cried at the prescience of a child's color choice.

As a teenager, when I wanted to look like her, I'd put on red lipstick and brightly colored sun dresses—like the kind she always reapplied and wore before bed, respectively. The causality? One day, when she was a teen, there was a fire in her neighborhood. She went outside to join her neighbors and saw *the* boy she liked from school. He laughed at how ridiculous she looked. She vowed never to be caught off-guard again. Twenty years later, that boy… *the* boy became my father. Life is funny that way I suppose.

As an adult, when I want to be her, I put on some hoop earrings and find a quiet place to read a book about history, education, philosophy, or revolution. I analyze the details of them and laugh aloud at the interesting parts…carelessly, freely, knowingly as if the words have just revealed some ironic but timely truth that tickles the part of me captivated by the complexities of the subjective perspective. She said that sometimes their lunacy, lack of consciousness, ethics, or morality triggered a morbid laugh like the caged bird singing. Sometimes in the silence I'd hear her scribbling thoughts on the inside of pages she would not soon read again. I thought perhaps they were for one of us. So, I read them in a quiet place and laugh aloud at the passions of her critiques written in response to an author who would never hear them. I highlight her scratch in bright yellow and respond accordingly. It is the intergenerational destruction of our properties or perhaps the continued dialogues of lives lived in color. I am grateful for that.

I love you, mom, through all space, time, and texts. This one I dedicate to you. Rest in Peace.

Acknowledgements

To all of my friends, family, colleagues, professors, and mentors who guided me, encouraged me, cared for me, and made me laugh when tears were all I could muster, thank you. You know who you are. It was often in the simplest gestures and most sincere acts of kindness that you helped to remind me of who I was capable of being. For that, I am grateful.

To my favorite person in all of the universes—known and unknown. I love you unconditionally, "Moss," through all spaces and times, and for every nanosecond of your existence. You are my son, my life, and my breath. I am absolutely grateful that you came into my life.

To one of my oldest and dearest friends, and to the former love of my life—both of whom passed away during this journey of mine…this dream of mine—it has been in your light, your love, your memory, and the resilience you helped me to develop that I have been able to embrace the awe of life's finitude. ***I nojokhee mithyane eh saad.***

The Parallax of Personalized Medicine: A Critical, Socio-Medical Analysis of the Trajectory of Pharmacogenomics and Genome Wide Association Studies

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Abstract

While neoteric medical technologies in the United States are heralded as fundamental to medical progress, they may simultaneously work to facilitate the victimization of people who do not have access to that progress. For example, the use of race and racialization as molecular and biological concepts in genomic based scientific and medical processes like pharmacogenomics and Genome Wide Association Studies (GWAS) may further perpetuate medical inequity, health disparities, and discrimination. Thus, it is important that we (in the medical community) acknowledge and delegitimize the use of race and racialization in science and medicine in order to help mitigate their potential socio-medical impact. When we, in the medical community, actively work to deconstruct and decentralize the use of race and racialization in science and medicine we may also begin to delegitimize their associated medical and socio-medical health disparities. To this end, my dissertation is a critical analysis of the trajectory of pharmacogenomics and Genome Wide Association Studies—keeping in mind the potential socio-medical affects of their use of race and racialization as molecular and biological concepts. My examination was done through the triangulation of qualitative research with an appraisal of the historical and contemporary medical, socio-medical, and biomedical epistemologies, philosophy, and practices of the scientific, and medical endeavor.

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LIST OF ACRONYMS

ACA	Patient Protection and Affordablity Care Act ["Obamacare"]
ACIP	Advisory Committee on Immunization Practices
ADA	Americans with Disabilities Act
CBO	Congressional Budget Office
CDC	Center for Disease Control
CKD	Chronic Kidney Disease
CRC	Cladistic Race Concept
DNA	Deoxyriboneucleic Acid
DOE	Department of Energy
EEOC	Equal Employment Opportunity Commission
ELSI	Ethical, Legal, and Social Implication [of the human genome project]
ESRD	End Stage Renal Disease
GAO	Government Accountability Office
GWAS	Genome Wide Association Studies
GINA	Genetic Information Nondiscrimination Act
HGP	Human Genome Project
HIPAA	Health Insurance Portability and Accountability Act
H.R. 1628	American Healthcare Act
JCT	Joint Committee on Taxation

NHLBI-CARe National Heart, Lung, and Blood Institute-Candidate-gene Association Resource

NIH National Institute of Health

NTI Narrow Therapeutic Index (drugs)

OMB Office of Management and Budget

OTA Office of Technology Assessment

QALY Quality-Adjusted Life Years

rDNA Recombinant DNA

RNA Riboneucleic Acid

SAKC Seattle Artificial Kidney Center

SNP Single Nucleotide Polymorphism

Chapter I: INTRODUCTION

My interest in the socio-medical effects of pharmacogenomics and genome wide association studies began with the basic premise that medical progress does not affect all people equally. Some of the methodologies and epistemologies of pharmacogenomics and genome wide association studies, for example, use race and racialization as genetic variables within every stage of research, development, and interpretation. In doing this, pharmacogenomics and genome wide association studies reify social ideologies that note race and racialization as molecular and biological concepts. As such, the knowledges that come out of those kinds of genomic processes are poised to not only teach and reinforce pre-existing racial dichotomies but also to legitimize the view that the socio-historical and biologized races of men exist on a continuum of humanness.

These ideas are not an assessment of human variation. Instead, as the progress and promise of genomic medical technologies potentiate a better quality of life for some people, their assumed objectivity will legitimize negative race based and racialized ideologies for other people. It is in the possibility and probability of those instances in which medical inequity, disparity, and discrimination are normalized.

As such, we (in the medical community) must shift the dialogue surrounding personalized medicine and the genomics age of medicine from a promise of progress towards an assessment of those individuals who could be left behind or negatively affected by it. A dialogue of this kind could mitigate the potentially negative socio-

medical impact of molecularized and biologized racial concepts inherent in pharmacogenomics and genome wide association studies.

With this in mind, my dissertation looks at historical and contemporary examples of how the use of race and racialization as molecular and biological concepts have negatively affected poor and minority peoples. Special attention is paid to the ways in which the negative socio-medical impact of these issues were normalized and legitimized. These tasks were accomplished by:

1) examining historical, scientific, and medical ideologies/practices that normalized the use of race and racialization as molecular and biological concepts; and

2) reviewing some of the contemporary socio-medical effects of normalizing and legitimizing race and racialization as molecular and biological concepts within genomic medical technologies like pharmacogenomics and genome wide association studies;

3) using qualitative research to discuss potential socio-medical issues associated with the continued use of race and racialization as molecular and biological concepts

The objectives will be addressed in the following chapters:

Chapter II: Literature Review: In this chapter, historical examples of the use of race and racialization as molecular and biological concepts are explored to show the sustained, normalized, legitimized use of these ideas. Exploring the perpetuation of the use of race and racialization in science and medicine provides a foundation to

hypothesize the trajectory of their use in pharmacogenomics and genome wide association studies. It also helps to show how the normalized and legitimized use of race and racialization as molecular and biological concepts provide a thanatopolitcal foundation in science and medicine.

Chapter III: Theory- Thanatopolitics: Chapter three is a discussion of thanatopolitics—social, political, and economic systems of power that facilitate and perpetuate death. It retraces some of the history of molecularized and biologized racial and racialized dogma as a means of articulating how it has worked to normalize and legitimize medical inequity and facilitate systemic cultural systems of death. This is accomplished by putting Nitzsche's philosophies of great politics and great health in conversation with Michel Foucault's biopower. What emerges and follows is a discussion of the complexities of race (as a socio-historical term and one noted as a characterization of humanity). These ideas fortify the introduction and normalization of racism during the enlightenment. They also shift the relationship between politics and health from sustaining life and making live for the betterment of society to making live and letting die for the betterment of a few members of society over others—the latter concept is referred to by Roberto Esposito as *Thanatopolitics*.

According to Esposito, thanatopolitics privileges "one community, or nation, or group as immune while making another segment of the population outside the *cordon*

sanitaire."[1] For example, the poverty, stratification, and segregation revealed by Hurricane Katrina in 2005, was described by Polish sociologist Zygmunt Bauman as evidence of the selective and exclusive immunity of certain members of society before the catastrophe even occurred thereby allowing New Orleans to be divided into persons who deserved to be saved and those who did not.[2] Chapter four looks at additional historical and contemporary examples of medical and socio-medically applied thanatopolitics.

Chapter IV: Medical and Socio-Medical Affects of Thanatopolitics: This chapter is a critical look Scientific and medical biases associated with the socio-historical ascription of race and racialization as molecular and biological concepts are reviewed to show how they facilitate medical inequity, disparity, discrimination, and a politics of death—a thanatopolitics. More specifically, I argue that the normalized and legitimized use of race and racialization as molecular and biological concepts have perpetuated medical inequity by directly and indirectly affecting the cost of and access to health care and health care related services. Through the lens of genetics and genomics, they have also inadvertently reaffirmed socio-medical stigma and discrimination—thus creating a kind of self-sustaining parallax in which perceived medical progress moves hand-in-hand with thanatopolitics. Chapter five is an exploration and analysis of how health care systems or mechanisms of thanatopolitics are experienced and articulated first hand.

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[1] Roberto Esposito, *Bios: Biopolitics and Philosophy*, translated by Timothy Campbell (Minneapolis, Minnesota: University of Minnesota Press, 2008): 44.

[2] Maximilian Korstanje, "The Beginning of Fear: A Review of Ulrich Beck and Zygmunt Bauman's Works," *Individual and Society* 13, no. 1 (2010).

Chapters V: Methods and Qualitative Data Analysis: This chapter is a look at how study participants experience thanatopolitics in the form of medical inequity, disparity, and discrimination. The significance of this data is examined via the triangulation of its historical relatedness and contemporary relevance. The qualitative data gathered from respondent interviews was then supplemented with an attitudinal survey and request for freelist responses.

Chapter VI: Attitudinal and Freelist Data Analysis is an examination of respondents' perceptions of pharmacogenomics and genome wide association studies relative to the molecularization of race and racialization and its potential for normalizing and legitimizing stigma, medical inequity, and discrimination. This information was gathered using the questionnaire noted in appendix i.

Chapter VII: Conclusion is a synthesis of the issues inherent in the use of race and racialization as molecular and biological concepts within the framework of pharmacogenomics and genome wide association studies. It also examines the potentiality of further systematized medical inequity, socio-medical stigma, and discrimination within the normalized, legitimized, and actualized praxis of pharmacogenomics and genome wide association studies—keeping in mind that those issues are not mutually exclusive. The work of this dissertation begins with a brief look at how the use of race and racialization as molecular and biological concepts is embedded in the Western socialization process, what pharmacogenomics and genome wide

association studies are, and how pharmacogenomics and genome wide association studies have used race based and racialized molecular and biological concepts in their research.

Western Socialization: Understanding the Norms of Opposites

Institutionalized Western philosophical, ideological, and scientific norms regarding race and racialization are the *sine qua non* for contemporary and emerging medical inequities, discriminations, and socio-medical stigmas. Those norms are further galvanized by dialogics of compliance, responsibility, worth and worthiness that exist within the foundations of science and medicine. Genomic medical technologies–like pharmacogenomics and genome wide association studies—are not immune to this framework. By ignoring the presence of scientific ideologies which champion the use of race and racialization as molecular and biological concepts in pharmacogenomics and genome wide association studies, we (in the medical community) become complacent in the normalization and legitimization of medical inequity.

If, however, we (in the medical community) acknowledge that pre-existing social dichotomies of race, wealth, and health are a part of American socialization—and thus the practice of medicine, science, and biomedicine—we can begin to sincerely assess the potentially negative socio-medical impact that these beliefs can have (and have already had) on poor and minority peoples. Thus, it is important that we examine the reality of these problems relative to the potentiality for the further perpetuation and proliferation of medical inequity, socio-medical subjugation, stigma, and discrimination in the age of genomic medicine.

Nonetheless, the process of socialization starts as such: when I was in grade school I was taught that there were things, concepts, and ideas that were distinctly different from each other—opposites. Hot/cold, left/right, up/down, on/off, right/wrong, life/death, rich/poor, healthy/sick, and black/white, for example, were engrained in my psyche and lexicon as being the antithesis of each other. What was never addressed, however, was that these words, concepts, ideas, and labels did not exist in a vacuum. People's lives, political affiliations, socio-economic status, well-being, and race were tied into them.

When I got to college, I learned about anthropologist and ethnologist Claude Lévi-Strauss and linguist Roman Jakobson who postulated that the mechanisms of culture—and language in particular—are developed and perpetuated through structured systems that are universal and composed of binary oppositions—opposites. Lévi-Strauss' theory was referred to as structuralism and Jakobson's structural linguistics. Both concepts asserted that in order to fully comprehend a society you must first understand its use and articulation of opposites, respectively.

Although their ideas did not take into account the effects of historical change on words like Black/White to African American/Caucasian, the basic ideology of opposites within culture and language continue to exist within the framework of Western academic socialization and thus exists as tacit knowledge within society. This, of course, becomes problematic when we apply the basic premises of social and linguistic opposites into

broader social structures, as population-based ascriptions, or as the foundations of our research and the interpretations of that research. In those instances, as characterized by philosopher and psychiatrist Franz Fanon, the plight tied to racial dichotomies "forcefully tosses the Black person into an arid area of non-being from which he has, somehow, to gather together once more the now fractured strands of his being."[3] Hence, Black/White dichotomies move beyond being colors determined by how much light they absorb or project to socio-historical ascriptions of race and racialization applied to populations based on culturally situated, ideologically subjective premises.

The cultural reality and linguistic stability of these words and ideas bleed into the social perceptions that exist between populations of Black and White people. Black and white as opposing ideas and ideals are applied to socio-historical concepts and all of the physical, physiological, cultural, linguistic, and economic attributes ascribed to these two groups become normalized and legitimized through the tacit categorization of opposites.

For example, in the early part of the 19th when the biological sciences were flourishing and Darwin's evolutionary theory was taking hold in society, scientific researchers Josiah Clark Nott and George Gliddon's text *Types of Man* and later the *Indigenous Races of the Earth or New Chapter of Ethnological Inquiry; Including Monographs on Special Departments* noted the Greek male as the apex of man (in health, wealth, and race—the socio-historical construction as well the general reference to

[3] M. Fakhry Davids, *Internal Racism: A Psychoanalytic Approach to Race and Difference* (London, England: Palgrave, 2011): 3.

humanity). Their texts applied the rationale of opposites to the status of minority peoples as existing on the alternate end of a kind of *a priori* gradation of races.[4] Similarly, world renowned psychologist, Carl Gustav Jung (also praised with unifying the human race with the idea of collective consciousness and providing a philosophy that resonates balance and humility), noted his belief in the inferiority of Black people by using the terms *prehistoric human* and *modern Black* as synonyms and stating that Black people and Black consciousness were opposite and less than that of White consciousness.[5] These ideas sit neatly within the foundation and field of psychotherapy thereby informing its culture, belief and practice.

Like Jung, Notts, and Gliddon's work, many of the scientific texts of the 19th and 20th century applied aspects of economist and moral philosopher Adam Smith's principles of rational self-interest and well-being to perceptions of how a rational (and thus wealthy) person looked.[6] The philosophical, ideological, physical, and physiological distinctions they made propagated the idea that poverty was due to irrationality, and thus a lack of humanity. Although this may contemporarily sound like a logical fallacy, it was a sound and socially accepted idea during that time period. The linear, co-dependent concept went as follows: Man is rational. Rationality leads to wealth. Wealth leads to well-being and is evidence of humanity. Thus, the rational man would be wealthy and

[4] Josiah Clark Nott, George Robins Gliddon, and Louis Ferdinand Alfred Maury, Indigenous Races of the Earth or New Chapter of Ethnological Inquiry; Including Monographs on Special Departments (Philadelphia, Pennsylvania: J. B. Lippincott and Company, 1857).

[5] Farhad Dalal, "Jung: A Racist," *British Journal of Psychotherapy* 4, iss. 3, (Mar. 1988): 263-279.

[6] George Mosse, *Toward the Final Solution: A History of European Racism* (New York, New York: Howard Fertig, Inc., 1978).

more human than the poor irrational man. The circular logic of the wealth, rational, and man argument was later supplemented by Darwin's *Origin of Species* misconstrued by biologist, philosopher, and sociologist Herbert Spencer in developing the social and economic version of the theory of the "survival of the fittest"—albeit outside of Darwin's intentionality, perhaps.[7]

Thereafter, Negro people (as the terms Black and African American were not yet in the lexicon) were believed to be poor due to an epidemic pathology of intergenerational ineptness—a culture of poverty— as opposed to systemic stratification and structural violence.[8] The culture of poverty asserted that the lack of socio-economic wealth an individual had was a direct reflection of his or her values and cognitive ability to make monetarily fruitful decisions for one's self and one's family. Thus, poverty—as a value system and a pathology— was believed to be passed down from one generation to the next.

These kinds of ideas became embedded in the cultural and linguistic milieu and helped to normalize systems of experimentation, exploitation, discrimination, medical inequity, and socio-medical stigma that permeated the culture of medicine and the methodologies of science. The supposed logic and rationale of opposites in language, humanity, and wealth were articulated as objective, empirical evidence of the molecular and biological differences of race and racialization. These ideas are lackadaisically

[7] Howard L. Kaye, *The Social Meaning of Modern Biology: From Social Darwinism to Sociobiology* (New Brunswick, New Jersey: Transaction Publishers, 1997 [1986]).
[8] Oscar Lewis "The Culture of Poverty," *American* 215, no. 4 (Oct. 1966): 19-25.

discussed in medical and biomedical research as if they exist above and beyond historical and contemporary epistemologies, praxis, and cultural socialization, but they do not.

Race and Humanity

Sylvia Wynter, attempted to address the issues associated with the normalization and legitimization of socialized ideologies that place the socio-historical ascription of race and a biologized race of man on a continuum in explaining that the overrepresentation of the concept of "man" or the "race of man" (as it was sometimes referenced) emerged out of the late humanist revolution and thus was not indicative of all of humanity.[9] Contrary to how it sounds or the meaning one may apply to it (given its syntax), the *race of man* was a reference to a specific kind of embodiment, one that was not inclusive of all individuals.[10] Instead, the precarious biological characterization of our species, the applicable socio-historical labels tied into those categories, and the added ideals of logic, rationality, normalcy, health, and fitness were made synonymous with the bourgeois, heterosexual, European, male—thus identifying him as the epitome or apex of man, humanity, health, wealth, logic, and rationale—as discussed earlier in this section.[11] These ideas and ideals form the basis of Western ideological, philosophical, and scientific thought and practice.

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[9] Sylvia Wynter, "'No Humans Involved: An Open Letter to My Colleagues," *Forum N.H.I.: Knowledge for the 21st* Century 1, no. 1 (Fall 1994): 42-73.

[10] Ibid.

[11] Sylvia Wynter, "Unsettling the Coloniality of Being/Power/Truth/Freedom: Towards the Human, After Man, Its Overrepresentation—An Argument," *CR: The New Centennial Review* 3, no. 3 (Sep. 2003): 257-337. Doi:10.1353/ncr.2004.0015.

Epitomizing the bourgeois, heterosexual, European man while also molecularizing and biologizing race and racialization triggers thanatopoloitics (a politics of death), social death, and hinders any counter-voice or counter-representation to that narrative formula.[12] Without a counter-voice or equally propagated counter-representation or counternarrative, the ideologies of the majority become normalized and legitimized—as is the case with the use of race and racialization in scientific and medical technologies like pharmacogenomics and genome wide association studies.

Pharmacogenomics and Genome Wide Association Studies

Pharmacogenomics and genome wide association studies examine molecular processes to identify disease variants (or risk of developing specific diseases) and tailor prophylactic or therapeutic pharmaceuticals accordingly. Pharmacogenomics is the study of inter-individual variation of one's inherited and/or acquired drug response relative to his or her DNA and RNA.[13] Pharmacogenomics is somewhat interdisciplinary in that it directly and indirectly engages with cell and molecular biology, epidemiology, informatics, pharmacology and genomics.[14]

The basic premise of pharmacogenomics is to identify genes that affect sensitivity to a particular medicine with the hope of developing more powerful, efficacious, safer

[12] Ibid., 288.
[13] Ibid.
[14] Michael M. Hopkins, Dolores Ibarreta, Sibylle Gaisser, Christien M. Enzing, Jim Ryan, Paul A. Martin, Graham Lewis, Symone Detmar, et. al [+ 7 Coleagues], "Putting Pharmacogenomics into Practice," *Nature Biotechnology* 24, no. 4 (Apr. 2006): 403-410. Doi:10.1038/nbt0406-403.

pharmaceuticals, and vaccines.[15] The primary focus of pharmacogenomics is in the evaluation of polymorphisms that encode for proteins affecting the pathogenesis of disease, proteins affecting pharmacokinetic parameters, and proteins affecting pharmacodynamic parameters.[16] Examining the effects of proteins on pharmacokinetic and/or pharmacodynamic parameters is significant because the relationship between pharmacokinetics and pharmacodynamics affects the possibility of ADRs, the benefits of the medication and/or its appropriate dosing.[17] Noting the relationship between pharmacokinetics and pharmacodynamics is also relevant because ADRs were the fifth leading cause of death in the United States in the late twentieth century and increased incrementally into the twenty-first century—with more than 100,000 people dying due to an ADR as of 2013.[18]

Genome wide association studies are population based genomics research that search for and examine SNPs across the genome to identify their association to disease phenotypes.[19] By recognizing variants associated with complex traits and their affiliation to SNPs, researchers expect to have a better understanding of common, complex

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[15] Ventola, "Pharmacogenomics in Clinical Practice," (2011).

[16] H. Jeroen Derijks, Luc J.J. Derijks, Ingelborg Wilting, and Antoine C. G. Egberts, "Introduction to Pharmacogenetics," *European Journal of Hospital Pharmacy* 13, no. 6 (Jan. 2007): 32-36. Pharmacokinetics is the study of how the body absorbs, distributes and/or metabolizes medications. Pharmacodynamics is the study of the biochemical and physiological effects of a drug on an organism.

[17] Ibid.

[18] Greene Shepherd, Phillip Mohorn, Kristina Yacoub, and Dianne Williams May, "Adverse Drug Reaction Deaths Reported in the United States Vital Statistics, 1999-2006," *The Annals of Pharmacotherapy* 46, no. 2 (Feb. 2012): 169-175. Doi:10.1345/aph.1P592. Also note C. Lee Ventola, "Role of Pharmacogenomic Biomarkers in Predicting and Improving Drug Response: Part 1: The Clinical Significance of Pharmacogenetic Variants," *Pharmacy and Therapeutics* 38, no. 9 (Sep. 2013): 545- 560

[19] Aubrey R. Turner, A. Karim, and Jianfeng Xu, "Utility of Genome-Wide Association Study Findings: Prostate Cancer as a Translational Research Paradigm," *Journal of Internal Medicine* 271, no. 4 (Apr. 2012): 344-352.

diseases.[20] This process is essentially an exploration for causal variants—those which have a direct or indirect effect on disease risk.[21] The basic principle of this process is that common diseases can be attributed to common polymorphisms—the CDCV hypothesis.[22]

Genome wide association studies provide context for pharmacogenomics by doing what Mortsinger-Reif describes as "ruling out contributions by unidentified genes to a drug response phenotype, identifying novel mechanisms, both for drug response and adverse drug reactions, and ensuring that there are no other important contributors before mounting a trial."[23] While pharmacogenomics and genome wide association studies are processes that independently benefit the progress of science and medicine, they are also inextricably linked. For many scientist and clinicians, however, the promise of medical progress is spearheaded by new processes and technologies, like pharmacogenomics and genome wide association studies, that exist under the umbrella of personalized medicine.

Personalized Medicine

Personalized medicine is an approach to medicine in which one's molecular information and processes are used to make preventative, predictive, prophylactic, and/or

[20] Peter M. Visscher, Matthew A. Brown, Mark I. McCarthy and Jian Yang, "Five Years of GWAS Discovery," *The American Journal of Human Genetics* 90, no. 1 (Jan. 2012): 7-24. Doi:10.1016/j.ajhg.2011.11.029.

[21] Ibid.

[22] Ibid.

[23] Alison A. Motsinger-Reif, Eric Jorgenson, Mary V. Relling, Deanna L. Kroetz, Richard Weinshilboum, Nancy J. Cox, and Dan M. Roden, "Genome-Wide Association Studies in Pharmacogenomics: Successes and Lessons," *Pharmacogenetics and Genomics* 23, no. 8 (Aug. 2013): 386.

personalized therapeutic treatments to disease or one's predisposition to disease.[24] The diagnostic and screening practices used in personalized medicine work to identify quantifiable, cellular, biochemical, or molecular characteristics that are indicative of biological pathologic processes and/or pharmacologic responses to therapies. [25] The identified characteristics called biomarkers.

Biomarkers can be used to detect slight changes in biochemical and biological pathways to provide insight into a variety of diseases and/or disease processes.[26] They either note one's predisposition (genetic susceptibility) to a disease, are diagnostic (confirming that one has a disease), are prognostic (forecasting potential disease progression), or predictive (hypothesizing one's response to treatment). Prognostic biomarkers are referred to as biomarkers of disease and predictive biomarkers are sometimes called biomarkers of exposure.[27] Personalized medicine facilitates the use of an apt biomarker toolbox —specifically genomics, transcriptomics, proteomics, and metabolomics—amongst and within the medical and biomedical community.

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[24] Francis S. Collins, *The Language of Life: DNA and the Revolution in Personalized Medicine,* New York, New York: Harper Collins, 2010. Also note S.H. Katsanis, G. Javitt, and K. Hudson, "A Case Study of Personalized Medicine," *Science* 320, no. 5872 (Apr. 2008): 53-54. Doi:10.1126/science.1156604.

[25] Kyle Strimbu and Jorge A. Tavel, "What are Biomarkers?" *Current Opinion on HIV AIDS* 5, no. 6 (Nov. 2010): 463-466. Doi:10.1097/COH.0b013e32833ed177.

[26] Caroline H. Johnson, Julijana Ivanisevic, and Gary Siuzdak, "Metabolomics: Beyond Biomarkers and Towards Mechanisms," *Nature Reviews Molecular Cell Biology* 17 (Mar. 2016): 451-459. Doi:10.1038/nrm.2016.25.

[27] Andreas Ziegler, Armin Koch, Katja Krockenberger, and Anika Großhennig, "Personalized Medicine Using DNA Biomakers: A Review," *Human Genetics* 131, no. 10 (Oct. 2012):1627-1638.

Biological pathways such as gene-regulating pathways (which turn genes on and off), metabolic pathways (which control the body's chemical reactions), and signal transduction pathways (which move a cell's exterior signal to the interior) are all complex processes which are relevant to sustaining the normal functioning of the body. However, for the sake of this paper, the standard biochemical pathway is of the greatest utility in situating pharmacogenomics and genome wide association studies within the framework of personalized medicine.

Generally speaking, the standard biochemical pathway starts with one's genetic information housed within their deoxyribonucleic acid (DNA—composed of four bases) to the transcription of their DNA via ribonucleic acid (RNA) into the development of a protein (protein synthesis).[28] When proteins act as enzymes they catalyze transitional products of metabolic reactions called metabolites. Otherwise, the protein itself may become a kind of metabolite.[29] Unlike DNA, RNA has a degree of plasticity in that things like stress, drug use, excessive alcohol intake, poor dietary habits, and the lack of exercise may directly or indirectly affect the expression of a particular protein. As a result, the development of a protein may be affected by intracellular, extracellular, or environmental factors.[30]

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[28] Wolfram Weckwerth, Kathrin Wenzel, and Oliver Fiehn, "Process for the Integrated Extraction, Identification and Quantification of Metabolites, Proteins, and RNA to Reveal Their Co-Regulation in Biochemical Networks," *Proteomics* 4, no. 1 (Jan. 2004): 78-83. Doi: 10.1002/pmic200200500.

[29] Weckwerth "Process for the Integrated Extraction" (2004).

[30] J. H. Choi and S. Y. Lee, "Secretory and Extracellular Production of Recombinant Proteins Using Escherichia Coli," *Applied Microbiology and Biotechnology* 64, no. 5 (Feb. 2004): 625-635.

Despite the impacts of environmental influences, there is a very small amount of genetic difference (variation) within *homo Sapiens*. In fact, there can be more genetic variation *within* specific human populations than *between* them and humans share approximately 99.9 percent of their genetic make-up.[31] The remaining 0.1 percent of a person's DNA exist sequences that could be unique to him or her. These sequences are called polymorphisms. When an individual's DNA contains a reoccurring, high frequency error it is referred to as a single nucleotide polymorphism (SNP).

SNPs are significant because they are the most common types of genetic variation that exist amongst humans.[32] They can act as surrogate markers or actual markers for genes—if in the coding or regulatory part of the gene—and may actually be the cause of many mutations.[33] SNPs may also affect the structure of a protein, help with detecting one's predisposition to disease, assist with diagnosing diseases, and aid researchers in developing pharmacogenomics for small cohorts of individuals.[34] The use of SNPs in pharmacology and pharmaceutical development allows for the development of targeted therapies using biomarkers to increase the efficacy of pharmaceutical and medical

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[31] Noah A. Rosenberg, Jonathan K. Pritchard, James L. Weber, Howard M. Cann, Kenneth K. Kidd, Lev A. Zhivotovsky and Marcus W. Feldman, "Genetic Structure of Human Populations," *Science* 298, no. 5602 (Dec. 2002): 2381-2385. Also note, D.J. Witherspoon, S. Wooding, A.R. Rogers, E.E. Marchani, W.S. Watkins, M.A. Batzer, and L.B. Jorde, "Genetic Similarities within and Between Human Populations," *Genetics* 176, no. 1 (May 2007): 351-359.

[32] Michael P. Weiner and Thomas J. Hudson, "Introduction to SNP's Discovery of Markers for Disease," *Biotechniques* 32 (Jun. 2002): 4-13.

[33] Ian C. Gray, David A. Campbell, and Nigel K. Spurr, "Single Nucleotide Polymorphisms as Tools in Human Genetics," *Human Molecular Genetics* 9, no. 16 (Oct. 2009): 2403-2408. Doi:10.1093/hmg/9.16.2403.

[34] Ibid.

treatments—thereby reducing (or eliminating) the likelihood of adverse drug reactions (ADRs) and drug-drug interactions.[35]

Unfortunately, however, the scientific structure and methodologies employed in the discovery, analysis, and interpretations associated with aspects of personalized medicine, such as pharmacogenomics and genome wide association studies, have tended to use race and racialization as a means of identifying and demarcating human variation—thereby legitimizing the molecularization and biologization of race and racialization. Thus, a parallax to the benefits of pharmacogenomics and genome wide association studies is that their methodologies use race and racialization as genomic variables. Doing this normalizes medical inequity and disparity by taking a socio-historical construct out of ideology and into something that is physical and physiological. It makes racial ideologies real, molecular, and biological—thus creating a structural, institutionalized violence. Such violences have long existed within scientific and medical inquiry, their application, and continue to hinder the equitable access of medical and scientific progress. Chapter two is a review of the race and racialization as molecular and biological concepts within science and medicine and their imbrication with inequity.

[35] Ventola, "Pharmacogenomics in Clinical Practice," (2011).

Chapter II: LITERATURE REVIEW

This chapter is a review of the perpetuated use of race and racialization as molecular and biological concepts in science and medicine. Historical and contemporary examples of the use of race and racialization as molecular and biological concepts are explored to show how the ideas have been normalized and legitimized through time. Examining these ideas and examples provides a foundation to hypothesize the trajectory of their use in pharmacogenomics and genome wide association studies. Reviewing examples of the use of race and racialization as molecular and biological concepts also helps to show how they have informed thanatopolitcal systems within science and medicine.

As the disciplines of science and medicine have taken a greater interest in physiological and molecular happenings, pre-existing race-based and racialized ideologies have endured in the methodologies, research analysis, and practices. The endurance of such ideologies has provided scientific and medical disciplines with a foundation that champions the use of race and racialization as molecular and biological concepts. This, of course, is problematic as race and racialization are socio-historical ascriptions. Yet, the use of race and racialization as molecular and biological concepts is not new to science and medicine. It has existed for several hundred years.

For example, in the 19th century, Freidrich Nietzsche, spoke of one's physical and psychological health relative to an individual having a master morality or a slave

morality—racialized ideologies.[36] Likewise, Cesare Lombroso's theory of the atavistic proposed that criminality was psychologically innate amongst people with certain physical characteristics.[37] Many of the physical characteristics Lombroso described were common amongst minorities and ethnic Europeans (as people from Southern Europe were called at the time).[38] Thus, the theory of the atavistic was also a theory that used race and racialization as molecular and biological constructs in order to legitimize the ideologies of the time period.

Josiah Clark Nott and George Gliddon also integrated race and racialized ideologies with science and medicine when they suggested that individuals of African Ancestry were the missing link (noting biological evolution) between the Greek male and a *pan troglodyte* (chimpanzee).[39] Such classifications have bled into contemporary depictions of African and African American peoples as being less human, apes, or monkeys. In addition, portraying brown bodies as animalistic legitimized ideologies that attributed disease, sickness, and pestilence to *Otherness*. Many minority groups (such as Jews in the early part of the 20th century) have suffered similar biologized racializations when being referred to as rats infecting, breeding, or taking over particular areas or things.

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[36] Babette Babich and Robert S. Cohen eds., *Nietzsche, Epistemology, and Philosophy of Science: Nietzsche and the Sciences II vol. 204* (Hingham, Massachusetts: Kluwer Academic Publishers and Springer Science and Business Media, 1999)

[37] Cesare Lombroso, *Criminal Man.* Translated by Mary Gibson and Nicole Hahn Rafter (Durham, North Carolina: Duke University Press, 2006).

[38] Ibid.

[39] Josiah Clark Nott, George Robins Gliddon, and Louis Ferdinand Alfred Maury. *Indigenous Races of the Earth or New Chapter of Ethnological Inquiry; Including Monographs on Special Departments*. Philadelphia, Pennsylvania: J. B. Lippincott and Company, 1857.

Like Nott and Gliddon, Edward Long's *History of Jamaica* situated Africans between Europeans and *pongo pygmaeus* (orangutans).[40] Long, Nott, and Gliddon's theories echoed the overarching ideologies of the time: the Great Chain of Being (which essentially created racial hierarchies relative to their perceived closeness to God) and polygenesis (which suggested that different racial and ethnic groups were proof of different species). Making race and racialization evidence of speciation and/or biological evolution also allowed for medical experimentation and socio-medical inequity on the grounds that the victimized individual was not actually a human.

An additional example of the normalized and legitimized use of race and racialization as biological concepts is how Samuel George Morton compiled and organized a collection of skulls by race and species for use in scientific study in the mid-nineteenth century. According to Morton, the size, racial, and species affiliation of the skulls coincided with the intellectual capacity of the individual.[41] People believed to be of African ancestry and other minority peoples were said to have the smallest craniums and thus the lowest intellectual capabilities—a clear use of race and racialization as biological concepts. Morton, a physician, naturalist, anatomy professor, and ethnologist was also a staunch supporter of polygenesis—further noting the molecularization of race

[40] Edward Long, *The History of Jamaica: Or, General Survey of the Ancient and Modern State of that Island, with Reflections on Its Situation, Settlements, Inhabitants, Climate, Products, Commerce, Laws, and Government*, (Cambridge, England: Cambridge University Press, 1774).

[41] Samuel George Morton, *Crania Americana; Or, A Comparative View of the Skulls of Various Aboriginal Nations of North and South America. To which is prefixed an Essay on the Varieties of the Human* Species (London, England: Simpkin, Marshall, and Co.: 1839).

and racialization.[42] Physician and Anthropologist, Paul Broca later used Morton's skull collection as the basis for his scientific and medical understanding of the skull, the brain and to help provide what he believed to be empirical evidence of human speciation (noted by race) and hybridity (caused by the intermixing of races).[43] Broca went on to provide the basis for new instruments in anthropometrics, craniometry, and contemporary understandings of the speech production area of the frontal lobe—also known as Broca's area of the brain. The medical community continues to use the knowledges and interpretations associated with Broca's research to inform our understanding of the brain and the skull. The history of such processes is what has shaped the contemporary use of race and racialization as molecular and biological concepts.

Many contemporary scholars (from a variety of disciplines), have pushed up against the normalization and legitimization of the use of race and racialization as molecular and biological concepts by deconstructing how it is (and has been) influenced by social ideologies (thereby challenging its objectivity), nuancing its foundation, and identifying how it is perpetuated. Deconstructing, nuancing, and identifying how race and racialization are (and have been) situated within science and medicine are important to understanding their scope, perpetuation, and trajectory.

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[42] George M. Fredrickson, *The Black Image in the White Mind: The Debate on African American Character and Destiny, 1817-1914*, (New York, New York: Harper Torchbooks, 1972).

[43] Paul Broca, "On the Phenmenon of Hybridity in the Genus Homo- reprint of Mémoire sur les phénomènes d'hybridité dans le genre human," *Anthropological Society* (1964): 61-63.

For example, according to Jonathan Inda, author of *Racial Prescriptions: Pharmaceuticals, Difference, and the Politics of Life*, pharmacogenomics and biomedical research continue to give value to the use of race and racialization as molecular and biological concepts through the use of patent protections and drug product differentiation.[44] In evaluating trends in patent protections, Inda cites Jonathan Kahn's research on the increasing interest in race-based therapies and the upsurge in race-inflected, gene-related patent approvals, and applications in suggesting that patents in biotechnology and product development molecularize race as a strategy to obtain patent protections and drug approvals. [45] Kahn also states that "patent law both racializes the space of intellectual property, transforming it into a terrain for the re-naturalization of race as some sort of 'objective' biological category, and commodifies race and ethnicity as goods to be patented and subjected to the dictates of market forces."[46] Inda follows up Kahn's perspective by noting the marketing of Travatan (used to reduce intraocular pressure) and Bystolic (a beta blocker) specifically to African Americans— despite the drugs' benefits to other races—as evidence of the pharmaceutical industry's use of race as a molecular and biological concept to facilitate drug product differentiation.[47]

[44] Jonathan Xavier Inda, *Racial Prescriptions: Pharmaceuticals, Difference, and the Politics of Life* (Burlington, Vermont: Ashgate, 2014): 88.

[45] Jonathan Kahn, "Patenting Race," *Nature Biotechnology* 24 (2006):1349. doi:10.1038/nbt1106-1349.

[46] Jonathan Kahn, *Race in a Bottle: The Story of BiDil and Racialized Medicine in a Post-Genomic Age* (New York, New York: Columbia University Press, 2013): 124.

[47] Inda, *Racial Prescriptions,* 2014: 90.

In Inda's example, racialized genetic pharmaceutical patent applications, approvals, and drug product differentiation use social and economic relations to move the ambiguity of race into something more concrete and legitimate. Likewise, the clinical trials, development, and marketing of pharmacogenomics reframe the fallacy of using race and racialization as molecular and biological concepts—thus disregarding its potential socio-medical impact. The interplay of race, genetics, and pharmaceuticals thereby evidences the ways in which socio-historical categories and their concomitant inequities can become exploited and commodified. Disregarding the fallacy and socio-medical impact of race based and racialized concepts in science and medicine, according to African American Studies Professor and author Alexander G. Weheliye, is significant because it shows that "race, racialization, and racial identities [are] ongoing sets of political relations that require, through constant perpetuation via institutions, discourses, practices, desires, infrastructure, technologies, sciences, economies, dreams, and cultural artifacts the barring of nonwhite subjects from the category of human as it is performed in the modern west."[48] Genome wide association studies is similarly constructed.

Like many scientific and medical endeavors, the biological processes and hypotheses relative to genome wide association studies are often depicted and articulated as objective. According to Stephen J. Gould, evolutionary biologist, historian of science, and author of *I Have Landed: The End of a Beginning in Natural History*, because the traditions of science suggest that changes in theory or methodology are driven by

[48] Alexander G. Weheliye, *Habeas Viscus: Racializing Assemblages, Biopolitics, and Black Feminist Theories of the Human* (Durham, North Carolina: Duke University Press, 2014): 3.

observation, scientists tend to be unaware of (or simply chalk up) their biases or assume that they are a part of an observable truth as opposed to a social ideology or social influence.[49] For example, because genome wide association studies scan the genome for SNPs without focusing on biological candidate genes or initial partiality towards specific locations, genes, or variants, they are often characterized as hypothesis free or agnostic forms of research.[50] According to author and professor of medicine Georgios Kitsios, however,

> It remains probably underappreciated that GWAS are dependent on underlying hypothesis despite their 'hypothesis-free' label—which account for important limitations of this approach and could explain why the information derived from GWAS is incomplete. Characterizing these experiments as 'hypothesis-free' or 'agnostic' can be misleading and disregards the fact that the output of any biological experiment is primarily determined by the extent to which the hypothesis tested holds true. Although not explicitly stated, GWAS are based on a priori hypothesis, dictated by the design of genotyping platforms or the analysis methodologies.[51]

Yet, we (in the medical community) continue to overlook the subjectivities inherent in the traditions of science and medicine thereby increasing the risk of further perpetuating pre-existing medical inequities and discrimination. Or, as put by historian of science and humanities professor Daniel J. Kelves, "genetic information remains vulnerable to adverse refraction through the lens of social prejudice, economic interest, or both."[52] Kelves further notes that the historical and contemporary uses of human genetics

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[49] Stephen J. Gould, *I Have Landed: The End of the Beginning of Natural History* (New York, New York: Three Rivers Press, 2003): 360-361.

[50] Georgios Kitsios and Elias Zintzaras, "Genome-Wide Association Studies: 'Hypothesis-Free' or 'Engaged'?" *Translational Research* 154, no. 4 (Oct. 2009): 161-164. PMCID:PMC2971665.

[51] Ibid., 161-162.

[52] Daniel J. Kelves, *In the Name of Eugenics: Genetic and the Uses of Human Heredity* (Cambridge, Massachusetts: Harvard University Press, 2001): X.

were and are affected by social and political contexts. Thus, they are not objective—which would be fine if we (in the medical community) acknowledged the social and socio-medical subjectivities in science and medicine such that a thorough intervention and remedy could be applied.

Keith Wailoo, historian and professor of public affairs, similarly spoke (in the text *Genetics and the Unsettled Past: The Collision of DNA, Race, and History*) on the significance, potential benefit, and problem of parsing out and evaluating the difference between what is considered genetic evidence and the cultural, political, and historical utility of race and racialization. According to Wailoo et al.,

> . . . genetic science does not exist apart from its context and uses; nor can its claims be fully understood apart from these contexts and uses. What is particularly notable is the way in which genetic ventures . . . are enacting racial projects, in which race (including whiteness, and also to some extent ethnicity) is be reconstituted, and in which notions of race and the past offer both liberating possibilities (for example, a feeling of belonging to the nation, release from false imprisonment, the promise of better health, social healing) and also confinement (for example, racial reification and the biological essentialism of the family and groups).[53]

Without first acknowledging the imbrication of social ideology with medical inequity in scientific and medical practices, there can be no such liberation. Instead, the use of race and racialization as molecular and biological concepts simply continue within the milieu of science and medicine as normalized, legitimized, a priori variables.

[53] Keith Wailoo, Alondra Nelson, and Catherine Lee, eds, *Genetics and the Unsettled Past: The Collison of DNA, Race, and History* (New Brunswick, New Jersey: Rutgers University Press, 2012): 4.

The Molecularization and Biologization of Race and Racialization

The most prevalent a priori hypothesis embedded in genome wide association studies, pharmacogenomics, and other aspects of scientific and medical research is the adherence to operationalizing the use of race and racialization as molecular and biological concepts. Acceptance and integration of molecularized and biologized ideas of race and racialization shape the production, interpretation, and representation of scientific and medical knowledges. Operationalizing and integrating notions of race and racialization as molecular and biological concepts also legitimize, and reify the black/white, unhealthy/healthy, less human/more human dichotomies of the Enlightenment.

As noted by bioethicist Pamela L. Sankar, "the unconscious reliance on such stereotypes by health care practitioners may contribute to racial and ethnic disparities in medical treatment" which also leads to general disparities in health and evidences a broad spectrum of complex, self-perpetuating inequities.[54] Moreover, according to Anne Fausto-Sterling, medical and biomedical practices that reify socio-medical and socio-historical ascriptions are indicative of a constant feedback loop in which the social *produces* the biological.[55] They are not mutually exclusive. They do not exist in a vacuum. As such, molecularized and biologized notions of race and racialization in

[54] Pamela Sankar, Mildred K. Cho, and Joanna Mountain, "Race and Ethnicity in Genetic Research," *American Journal of Medical Genetics* 143A, no. 9 (May 2007): 962. doi: 10.1002/ajmg.a.31575.

[55] Anne Fausto-Sterling, "The Bare Bones of Race," *Social Studies of Science* 38, no. 5 (Oct. 2008): 657-694.

population based genomic research also evidence the codependent interplay between society and science—and thus, again, are inherently subjective.

Yet, moving race and racialization out of the realm of socio-historical construction into a proposedly physiological aspect of an individual makes the ideas and ideals of the molecularization and biologization of race and racialization appear objective, scientific, and therefore rational and logical within the Western ideological construct. For example, Robin O. Andreasen's proposition to identify race and racialization as cladistic[56] not only validated the molecularization and biologization of race and racialization, but also championed them as natural biological classifications—echoing polygenesis.[57] More specifically, Andreasen's Clasdistic Race Concept (CRC) asserted that races be defined as genealogical cladistic subspecies.[58] The genealogical assumptions built into the CRC concept bled race and racialization together with ethnicity and implied that a natural taxonomic hierarchy existed between racial and ethnic groups. As with many of its contemporaries, the CRC's form of racial categorization was perceived as an objective, rational, logical, and scientific articulation of naturally occurring human variation and hierarchy—an issue that continues to be normalized and legitimized within pharmacogenomics and genome wide association studies.

[56] Cladism is a theory which suggest that evolutionary relationships are evidenced by similarly existing characteristics between organisms. These shared characteristics also facilitate the development and/or basis for biological classification.

[57] Robin O. Andreasen, "A New Perspective on the Race Debate," *The British Journal for the Philosophy of Science* 49, no. 2 (Jun. 1998): 199-225.

[58] Zinhle Mncube, "Are Human Races Cladistic Subspecies?" *South African Journal of Philosophy* 34, no. 2 (Jun. 2015): 163-174.

According to sociologist and race theorist Howard Winant, however, the conflation of race and ethnicity in the United States has to do with the structuring of social relations which understand ethnicity as a part of race.[59] They are not perceived as or engaged with as two distinctly different concepts which, for example, are clearly problematized by the categorical examples of American actresses Lupita Nyong'o as a Black/African American/Afro-Mexican and Charlize Theron as a White/African American (born in Africa with American citizenship). Winnat addresses such issues in suggesting that the synonymous use of race and ethnicity is used as a part a broader political agenda to de-politicize race by using ethnicity.[60]

The use of race and ethnicity as synonyms in medical and biomedical research also endorses race and racialization as social, phenotypical, and physiological. This rationale allows for the molecularization of race and the synonymous use of race and ethnicity as markers for human variation and population descriptors for genome wide association studies. Amanda Seyerle's study entitled the "Evidence of Heterogeneity by Race/Ethnicity in Genetic Determinants of QT Interval" is an archetypical example of this.

In Seyerle's article, the authors moved unilaterally from a deeply phenotyped consortia to presumed ancestral affiliations and genotypic causality without parsing out

[59] Howard Winant, "Race, Ethnicity, and Social Science," *Ethnicity and Racial Studies* 38, no. 13 (2015): 2176-2185. Also note Howard Winant, "Response to Andreas Wimmer," *Ethnic and Racial Studies* 38, no. 13 (2015): 2206-2207.

[60] Ibid.

the significant differences and influences that existed between racial and ethnic categorizations.[61] One can deduce then, that Seyerle and her colleagues must have either perceived race and ethnicity to be congruent or did not feel that the distinction was relevant to their analysis and interpretations. Additionally, as with most other medical and biomedical research, Seyerle's study uses European Americans as the standard body (the control) through which other subjects were compared. Perceived homogeneity is implicit in such kinds of categorizations thereby negating the social, socio-medical, genetic, and environmental peculiarities between being ethnically Polish, Caucasian (from the Caucus mountains), Irish, Italian, and German to being racially White or being ethnically Vietnamese, Cambodian, Taiwanese, Chinese, or Japanese, for example, and being classified as racially Asian. In this way, Seyerle's study typifies the kind of scientific and medical research described by Janet K. Shim as having an "over-reliance on race as a seemingly self-evident and etiologically meaningful dimension of difference, and a reluctance to try to ascertain the factors that may account for variable disease incidence and outcomes."[62]

The idea that individuals with shared (or presumably shared) ancestry have genetic variants that are homologous is based on the belief that the common presence of some variants in a particular population may be the result of natural selection— via

[61] Amanda A. Seyerle, Alicia M. Young, Janina M. Jeff, Philip E. Melton, and Neal W. Jorgensen, [+ 16 Authors], "Evidence of Heterogeneity by Race/Ethnicity in Genetic Determinants of QT Interval," *Epidemiology* 25, no. 6 (Nov. 2014): 791.

[62] Janet K. Shim, Katherine Weatherford Darling, Martine D. Lappe, L. Katherine Thomson, Sandra Soo-Jin Lee, Robert A. Hiatt, and Sara L. Ackerman, "Homogeneity and Heterogeneity as Situational Properties Producing—and Moving Beyond?—Race in Post-Genomic Science," *Social Studies Science* 44, no. 4 (Aug. 2014): 580. Doi:10.1177/0306312714531522.

shared environmental exposure or the emergence of a novel variant which has not yet been passed to other populations of people via admixture—and thus are more likely to be group specific.[63] The general idea is that the overrepresentation of specific variants in certain populations evidence etiological differences in the pervasiveness of diseases in one racial group over another.[64] For example, the prevalence of hypertension amongst African Americans in the United States has led many medical and biomedical researchers to hypothesize that it is due to a genetic predisposition or genetic inclination towards sodium retention.[65] The latter hypothesis is described as potentially resulting from a genetic bottle neck occurring during the Transatlantic Slave Trade (a theory known as the Slavery Hypothesis for Hypertension).[66] Some medical and biomedical researchers have also referred to salt sensitivity as heritable while also acknowledging that there is no genetic evidence to call it such.[67] Notions such as these molecularize and biologize race and racialization by feeding into their conflation with genomics.

Nonetheless, the progress of science and medicine continue to compose the map of human diversity by making socio-historical racial ascriptions synonymous with genetic

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[63] Tesfaye B. Mersha and Tilahun Abebe, "Self-Reported Race/Ethnicity in the Age of Genomic Research: It's potential Impact on Understanding Health Disparities," *Human Genetics* 9, no. 1 (Jan. 2015): 1. Doi:10.1186/s40246-014-0023x.

[64] Mersha, "Self-Reported Race/Ethnicity in the Age of Genomic Research," (2015).

[65] Lyla M. Hernandez and Dan G. Blazer eds., *Genes, Behaviors, and the Social Environment* (Washington, DC: The National Academies Press, 2006).

[66] George J. Armelagos, "The Slavery Hypertension Hypothesis- Natural Selection and Scientific Investigation," *Transforming Anthropology* 13, no. 2 (2005): 119-124.

[67] Hugh E. de Warder and G.A. MacGregor, "Sodium and Blood Pressure." *Current Opinion in Cardiology* 17, no. 4 (Jul. 2002): 360-367. Laura P. Svetkey, Sean P. McKeown, and Alexander F. Wilson, "Heritability of Salt Sensitivity in Black Americans," *Hypertension* 28, no. 5 (1996): 854-858. doi:org/10 1161/01.HYP.28.5.854.

variation. This kind of issue is further problematized by some of the ignored limitations of genome wide association studies. For example, genome wide association studies do not note causation, they do not identify complete genes (only their location), they only detect common variants, and SNPs provide a fraction of the epidemiology associated with one's risk.[68] The scientific community has attempted to address these issues by suggesting that admixture research (as opposed to those that blatantly use race) better identifies the reality of human differentiation.[69] However, as noted by sociologist Troy Duster, "admixture research is itself based upon socially constructed categories of race."[70] So, its use in scientific and medical research does not negate the normalized use of race and racialization as molecular and biological concepts. It simply reframes them. Thus, the trajectory and a priori hypothesis of genome wide association studies are linked to the use of race and racialization as molecular and biological concepts as well as the socio-medical effects of those ideas.

In describing the probable socio-medical effects of the use of race and racialization as molecular and biological concepts in genomic processes like pharmacogenomics and genome wide association studies, Michael Yudell, public health professor and researcher of ethics, genomics, and the history of race in biology and public health, simply stated that the "use of biological concepts of race in human genetic

[68] Charles Kooperberg, Michael LeBlanc, James Y. Dai, and Indika Rajapakse, "Structures and Assumptions: Strategies to Harness Gene X Gene, and Gene X Environment Interactions in GWAS," *Statistical Science* 24, no. 4 (Nov. 2009): 472-488.

[69] Troy Duster, "A Post-Genomic Surprise. The Molecular Reinscription of Race in Science, Law, and Medicine," *The British Journal of Sociology* 66, no. 1 (2015): 1-27. doi:10.1111/1468-4446.12118.

[70] Ibid.

research is problematic at best and harmful at worst."[71] The worst case scenario mentioned by Yudell could occur because legitimizing the molecurization and biologization of race and racialization disregards how they potentiate socio-medical and medical inequity. The molecularization and biologization of race and racialization in genome wide association studies is also a nuanced bifold in that the use of race in genomic, population-based research directly and indirectly affects the normalization of information associated with pharmacogenomics.

In addition, minority and underserved peoples are systemically underrepresented in pharmacogenetic research. Thus, while the promise of personalized medicine is essentially a narrative of scientific and medical progress, the relationship between the use of race as a variable in genome wide association studies with the systemic underrepresentation of minority peoples in pharmacogenomic research normalizes inequity in the representation, democratization, and accessibility of that progress narrative. Furthermore, according to Yuddell,

> racial assumptions are not the biological guideposts some believe them to be, as commonly defined racial groups are genetically heterogeneous, and lack clear-cut genetic boundaries. For example, "hemoglobinopathies can be misdiagnosed because of the identification of sickle-cell as a "Black" disease and thalassemia as a "Mediterranean" disease. Likewise, cystic fibrosis is underdiagnosed in populations of people with African ancestry because it is thought of as a "White" disease. Popular misinterpretations of the use of race in genetics also continue to fuel racist beliefs.[72]

[71] Michael Yudell, Dorothy Roberts, Rob DeSallem and Sarah Tishkoff, "Taking Race out of Genetics: Engaging a Century-Long Debate About the Role of Race in Science," *Science* 351, no. 6273 (Feb. 2016): 565. Doi:10.1126/science.aac4951

[72] Ibid., 565.

Hence, inequitable access to scientific and medical progress can be understood as a kind of maleficence as it is a reflection of larger socio-medical, institutionalized mechanisms that work to hinder distributive justice (contrary to the possible intentionality of the researcher or medical professional). Inequity also leads to disparity and may act as an accelerant to death.

Yet, race and racialization continue to be systematically used to stratify data or otherwise typified in the methodologies of large-scale genetic and genomic research.[73] For example, the National Heart, Lung, and Blood Institute (NHLBI) and the Candidate-gene Association Resource (CARe) recently conducted a genome wide association study of 8,090 African Americans in an attempt to correlate disease genotypes with phenotypes by identifying common genetic polymorphisms and risk factors associated with heart disease.[74] The risk factors of interest were heart disease, including high cholesterol, hypertension, and smoking.

The NHLBI-CARe study accounted for possible genetic admixture amongst African Americans and SNP associations, using index SNPs in Caucasian populations as the control against DNA polymorphisms of the African American population. [75] Researchers of the study concluded that there were no "major loci [which] uniquely

[73] Ibid.

[74] Guillaume Lettre, Cameron D. Palmer, Taylor Young, Kenechi G. Ejebe, and Hooman Allayee et. al [+55 authors], "Genome-Wide Association Study of Coronary Heart Disease and Its Risk Factors in 8,090 African Americans: The NHLBI CARe Project," *PLOS Genetics* 7, no.2 (Feb. 2011): e1001300. PMC3037413.

[75] Ibid.

explain the high prevalence of chronic heart disease in African Americans."[76] Problematically, however, the research paradigm for this study framed African Americans and Caucasians as molecular, biological, and socio-historical opposites. As mentioned in the Introduction of this dissertation, the Black/White or African American/Caucasian dichotomy in scientific and medical research is not distinct to the NHLBI-CARe study. Instead its structure is one of the many examples of the social, and socio-historical subjectivities associated with molecularized and biologized notions of race and racialization embedded in Western medicine and the progress of Western medicine.[77]

Contrary to the persisting social, scientific, and medical impulses to conflate the socio-historical concept of race with genomic data, socio-historical racial and racialized ascriptions are not a measure of genetic composition.[78] Race is a linguistically and ideologically fluid construct that is reflective of the political ecology of a particular period in time.[79] For example, during the mass immigration to the United States between 1850 and 1930, individuals from southern Europe were not considered White but rather ethnic Europeans—or now Caucasian (contrary to an individual's ancestral affiliation to or with people of the Caucus mountains).

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[76] Ibid., 1.

[77] Ricardo Ventura Santos, Gláucia Oliveira da Silva, and Sahra Gibbons, "Pharmacogenomics, Human Genetic Diversity and the Incorporation and Rejection of Color/Race in Brazil," *Biosocieties* 10, no. 1 (Mar. 2015): 48-69. Doi:10.1057/biosoc.2014.21.

[78] Jamie Mihoko Doyle, "What Race and Ethnicity Measure in Pharmacologic Research," *Journal of Clinical Pharmacology* 46, no. 4 (Apr. 2006): 401-404. Doi:10.1177/0091270005282633.

[79] Jennifer L. Hochschild, "Racial Reorganization and the United States Census 1850-1930: Mulattoes, Half-Breeds, Mixed Parentage, Hindoos, and the Mexican Race," *Studies in American Political Development* 22, no. 1 (Spr. 2008); 59-96.

Contemporarily, the Caucasian racial ascription is often composed of *inter alia* people of Irish, Italian, French, and/or German descent although they each have distinct cultural, linguistic, and geographical affiliations. Many other groups such as Asians (which may include people who are Taiwanese, Japanese, Chinese, Vietnamese, and/or Indian), African Americans (whom have also been referred to as Black, Negro, and Coloured) and Hispanic people (who were called Spanish until 1970, and then Latinos in 1990's—with many Brazilians also being considered Latinos although they speak Portuguese) have undergone similar transitions in the movement of their socio-historical of their races, its molecularization, biologization, and concomitant racialization.

For many minorities, racial labels—and libels in some instances— have acted as identifiers for persecution, xenophobia, and perceived biological difference. And, while race is a historical, political, and relational conceptualization that is fluid and dynamic, it persists in ordering and shaping the human condition—albeit in a way that has cultural or social causality as opposed to a genetic one.[80] Likewise, racialization, as per Ann Pheonix—professor of psychosocial studies, "emphasizes the social and psychological processes that puts people into racial categories."[81]

Historically, medical inequity has resulted from (and been influenced by) a shift in the political and domestic ecology of any specific culture. War, law, immigration,

[80] Karim Murji and John Solomos Eds. *Racialization: Studies in Theory and Practice* (New York, New York: Oxford University Press, 2005): 8.
[81] Ibid.

invention, segregation/integration, and scientific racism, for example, are all socially peripheral mechanisms that act upon the health outcomes of the people most vulnerable to those systems and during political and domestic ecological shifts. Discrimination, disparity, and stigma, for example, are not inherent in those social and political systems, but have (at one point in time or another) been normalized, rationalized, and legalized within aspects of their praxis. While the acceptance and operationalization of such occurrences may not be the intentionality of scientific and/or medical researchers (or the medical industry in broad strokes), disregarding the potentiality of health inequities and disparities resulting from normalized, racialized, scientific and medical subjectivities does not make them disappear. Instead, it perpetuates an environment through which people are co-opted into believing that everyone has equal access to all of this country's goods and resources. So, if an individual is unable to partake in those resources it is of his or her own fault and disadvantage. This idea is the basis of the American progress narrative. It is also the context through which molecularized and biologized notions of race and racialization reify systems of socio-medical discrimination and disparity (thereby making some people's lives better while letting other people die) and becoming a thanatopolitics—a politics of death.

Chapter III: THEORY-THANATOPOLITICS

While chapter two of this dissertation reviewed the use of race and racialization as molecular and biological concepts in science and medicine in order to hypothesize the possible trajectory of their use in pharmacogenomics and genome wide association studies, this chapter will explore how their use potentiates a politics of death. This is accomplished by putting Nitzsche's philosophies of great politics and great health in conversation with Michel Foucault's biopower, and what Roberto Esposito referred to as the auto-immunitary reaction. What emerges is a discussion of how the normalized use of race and racialization in science and medicine shifts the relationship between politics and health from sustaining life and making live for the betterment of society to making live and letting die for the betterment of a few members of society over others—a process known as *Thanatopolitics*.

Thanatopolitics are social, political, and economic systems of power that facilitate and perpetuate a politics of death. They work in contrast to processes that produce and reinforce life. The life/death dichotomy of thanatopolitics does not necessitate the involvement of a social, political, scientific, or medical entity acting directly upon an individual or group— in the way that a biopolitical agent or apparatus may become directly or indirectly involved in the production of good biological citizens. Instead, thanatopolitics are defined by their disregard of pertinent, life-sustaining mediums needed by individuals or groups within larger society. In this way, thanatopolitics are

systems and mechanisms of power that allow for the death of an individual or group. Thus, they have been most aptly characterized by Roberto Esposito as agents through which health, medical, and socio-medical institutional violences have been rationalized. Because many of the methodologies used and interpretations applied to pharmacogenomics and genome wide association studies molecularize and biologize the socio-historical ascription of race, they also rationalize and reify race and racialization as valid scientific, medical, genetic, and social categories. Historically and contemporarily, thanatopolitics has been the result of such legitimizations, disparities, and discriminations.

Thanatopolitics and Social Death

Because medical inequity, disparity, and structural violence are tied to the production, distribution, and accessibility of healthcare, pharmaceuticals, and healthcare related services, neoteric medical technologies that reinforce medical and socio-medical stratification also increase the probability of one's death. Within the context of pharmacogenomics and genome wide association studies, what is imaginable is the emergence, application, normalization and disregard of systemic social, scientific, and medical inequity. This indifference pushes pharmacogenomics and genome wide association studies beyond the parameters of being new, innovative medical technologies into being furtive agents of thanatopolitical power. The legitimization, biologization, and molecularization of race and racialization through pharmacogenomics and genome wide association studies subsequently nurture varying forms of social and socio-medical

discrimination. The relationship between its genetic and racialized lens also works to reconstitute complex notions of fitness and social worth— with "fit" being indicative of one's general health status as well as a nod to natural selection.

According to John Hope Franklin Book Prize recipient and associate professor Lisa Marie Cacho, the interplay between ascribed and denied worth within institutionalized and popularized power differentials prompt an additional kind of death for poor, marginalized, oppressed and/or minority peoples—a social death.[82] Social death is the social devaluation of an individual or peoples based on socioeconomic, racial, and heteropatriarchal conceptions of worth and worthiness. As the scientific and medical communities continue to use race and racialization as molecular and biological concepts within the framework of their research, interpretations of data, and general production of knowledge, those ideas become the foundation for perceived socio-medical hegemony, normalized thanatopolitical power, and the reification of social death. Molecularization, biologization, and racialization within pharmacogenomics and genome wide association studies will further the application of thanatopolitical power and social death within poor, minority, and/or oppressed communities.

Historically, the actualized interplay between thanatopolitical power and social death have specifically occurred within the framework of racialized medicine or at the behest of broader social systems. According to ethicist and medical writer Harriet A.

[82] Cacho, Lisa Marie. *Social Death: Racialized Rightlessness and the Criminalization of the Unprotected*. New York, New York: New York University Press, 2012.

Washington, the affects of racial biases are what blur the lines between medical research and public health data by perpetuating race-based ideologies and practices in society, medical research, and public health.[83] For example, from the mid 1800's to the latter part of the 20th century, social medicine and public health were often tied to immigration laws. The 1885 image of a wood carving in Harper's Digest entitled "At the Gates: Our Safety Depends upon Official Vigilance" was an archetypical representation of the cultural and medical ecology of the period as well as its associated propaganda.

In the image an angel holding a sword and shield of "cleanliness" stands at the quarantined entrance to the Port of New York City (via Ellis Island) blocking three cloaked, anthropomorphic representations of cholera, small pox, and yellow fever from entering. [84] Noting Ellis Island in the carving was historically and symbolically significant as it was the first Federal Immigration Station in the United States. For more than sixty years it was the point of entry for approximately twelve million immigrants. Thus, the shrouded, anthropomorphized diseases depicted on the wood carving were a representation of the supposed dangers lurking within the genes of immigrant populations. The image depicts what sociologist Zygmunt Bauman describes as the integration of the stranger, the foreign body, and the diseased in modern society—objects of physical, psychological, social, racial, and genetic fear.[85] The legitimized status of the

[83] Harriet A. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (New York, New York: First Anchor Books, 2008).

[84] U.S. National Library of Medicine: National Institute of Health Http://www.nlm.nih.gov/exhibition/visualculture/introduction.html#02

[85] Zygmunt Bauman and Leonidas Donskis, *Moral Blindness* (Cambridge, United Kingdom, Polity Press, 2013). Also note Zygmunt Bauman, "Making and Unmaking Strangers," *Thesis Eleven: Sage Journals* 43, Iss. 1 (Nov. 1995): 1-16. doi:10.1177/072551369504300102.

diseased, foreign, stranger becomes that of a devalued/dehumanized member of society. The product of these ideas is the instigation of thanatopolitical power and the potential social death of racialized peoples.

Fear, dehumanization, social death, and theories of social worth have largely influenced the practice of medicine and have had persisting socio-medical affects within Western society. Friedrich Nietzsche's theories of "great health" and "great politics," for example, typify the ways in which normalized theories of genetic fitness and social worth have informed the Western philosophical, ideological, medical, and socio-medical framework.

Nietzsche's Great Politics and Great Health

Nietzsche explicitly stated in his theories that health was primarily a psychological state of well-being which one sought out and which was a manifestation of one's ability to overcome, resist, and order their inherent disharmony.[86] In his texts *Philosophy in the Tragic Age of the Greeks* and *The Birth of Tragedy* he stated that "the healthy not only respond to, but also seek out challenges to their worldview; suffering for them, is the midwife of creation, crushing those too passive to overcome its challenges while elevating the strong to new levels."[87] So, individuals in great health were considered "dangerously healthy" as they were in perpetual opposition to a state of mind

[86] Babette Babich and Robert S. Cohen eds., *Nietzsche, Epistemology, and Philosophy of Science: Nietzsche and the Sciences II vol. 204* (Hingham, Massachusetts: Kluwer Academic Publishers and Springer Science and Business Media, 1999)

[87] Babich, *Nietzsche, Epistemology, ad Philosophy* (1999): 303.

and/or a person perceived as weak, destitute, and in decay—the unhealthy, abnormal individual.[88]

Nietzsche's theories created a dichotomy between individuals he perceived as taking agency in addressing their disease, sickness, or plight against those he believed to be torpid. His ideas suggested that unhealthy individuals were physically or physiologically sick, and psychologically ill. Otherwise, they too would have worked to alter their state of existence—thus making themselves healthier.

Nietzsche's great politics and great health also blatantly discussed concepts of worth and/or worthiness ascribed to racialized groups. These ideas were echoes of the prevailing medical concepts of the 19th and 20th century which viewed disease and illness in destitute neighborhoods as evidence of intergenerational expressions of genetic inferiority. Thus, Nietzsche's theories were grounded by the normalization of the molecularization and biologization of race and racialization. Social Darwinism and Herbert Spencer's phrase "survival of the fittest" (which mapped evolutionary theory onto social, economic, and political ecologies), evidenced the kinds of thanatopolitical and socio-medical implications of perceived racial and genetic inferiority.

In Nietzsche's theory of great health, he went on to suggest that the condemnation of suffering generated resentment and impeded eminence by blurring the distinction between a "slave morality" (a herd/weak morality characterized as common

[88] Balke, "From a Biopolitical Point of View" (2005).

by way of sympathy and kindness, and which frowned upon strength and independence) and a "master morality" (a noble/strong sensibility characterized as aristocratic by way of self-sufficiency, virtue, and strength).[89] The terms he used in his analysis were not arbitrary. Instead, they worked to reinforce the Black/White, Inhuman/Human, and Unhealthy/Healthy dichotomies already steeped within society. They also created and rationalized a social and socio-medical hierarchy based on one's perceived social, moral, and biological characteristics—legitimizing the molecularization and biologization of race and racialization. Assessment of these attributes continue to bleed into varying aspects of the practice of medicine and the modern context of health care.

For example, in the October 2002 edition of the Journal of Advanced Nursing, John Paley asserted that the ideology of caring and compassion within the nursing profession should have been viewed as a politically unrealistic vice that was evidence of a slave morality.[90] He likened nurses to slaves whom, in a moment of self-deception, convinced themselves that their weaknesses were good thereby debilitating the progress of the profession.[91] Likewise, Francis C. Biley suggested that consumer sovereignty, patient-centered care, and subjectivity in psychiatry and mental health care were evidence of a shifting landscape of medicine from a noble morality to a slave morality—the latter

[89] Friedrich Nietzsche, *On the Genealogy of Morality*, Translated by Maudemarie Clark and Alan J. Swensen (Indianapolis, Indiana: Hackett Publishing Company, Inc., 1998).
[90] John Paley, "Caring as a Slave Morality: Nietzschean Themes in Nursing Ethics," *Journal of Advanced Nursing* 40, no. 1 (Oct. 2002):25-35. Doi: 10.1046/j.1365-2648.2002.02337.x
[91] Ibid.

of which she believed to be detrimental to the practice of medicine and the advancement of society.[92]

Paley and Biley championed stoicism, medical paternalism (and thus a reduction in patient autonomy), and the medical and socio-medical hierarchies that exist in the medical endeavor. Paley and Biley's work also evidenced discourses about the idea that one's capabilities and movement away from a perceived slave morality determined the lens through which health, social, and socio-medical worthiness would be assessed and ascribed. Social and socio-medical hierarchy, and ascribed notions of worth/worthiness are the premises through which unequal access to goods and resources have historically been legally systematized. Thus, social death and the realization of thanatopolitical power are the logical progressions of perceived slave morality and of the inequity and discrimination inherent in Nietzsche's great health.

Similarly, Nietzsche's great politics referred to a process of "taming and breeding" [*Zucht and* Züchtung]. It was geared toward the identification and exclusion of the normal person from the abnormal and the healthy person from the pathological.[93] Individuals were deemed abnormal and rejected based on their ability to contribute to the functioning or general betterment of society.[94] However, the term *contribution* for

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[92] Francis C. Biley, "Nietzsche's Genealogy of Morality and the Changing Boundaries of Medicine, Psychiatry, and Psychiatric and Mental Health," *Journal of Psychiatric and Mental Health Nursing* 17, no. 8 (Oct. 2010): 700-705. Doi: 10.1111/j.1365-2850.2010.01584.x.

[93] Friedrich Balke, "From A Biopolitical Point of View: Nietzsche's Philosophy of Crime," In *Nietzsche and Legal Theory: Half Written Laws*: *Discourses of Law,* Edited by Peter Good Rich and Mariana Valverde (New York: New York: Routledge, 2005): 49-66.

[94] Balke, "From a Biopolitical Point of View" (2005): 53.

Nietzsche (and society during the time) had a dynamic connotation, as it referred to both an individual's physical involvement with the production and stability of society as well as one's genetic input.[95] This kind of systematic, racial molecularization allowed for legal disparity, discrimination, and medical inequity. The categorization and exclusion of individuals based on their perceived normalcy is also indicative of what Bauman referred to as a pole on the moral-immoral axis. It is the movement of social ideas and practices along the axis of morality and immorality that diseased or disease prone parts (people) of the social body are drastically and surgically removed from it—resulting in both a social and physical death.[96] Bauman describes the social surgery used to remove individuals perceived as abnormal from those designated as normal in the following:

> strategems of placing, intentionally or by default, certain acts and/or omitted acts regarding certain categories of humans *outside* [emphasis his] the moral-immoral axis that is, outside the universe of moral obligations and outside the realm of phenomena subject to moral evaluation declare that such acts or inactions, explicitly or implicitly are morally neutral and prevent the choices between them from being subject to ethical judgement. . . [97]

Normalized inequity and hierarchy via the demarcation of normal versus abnormal, healthy versus unhealthy, and master morality versus slave morality, for example, creates what Roberto Esposito refers to as an "auto-immunitary reaction."[98]

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[95] Ibid.
[96] Bauman, *Moral Blindness*, 2013.
[97] Ibid., 46.
[98] Roberto Esposito, *Immunitas: The Protection and Negation of Life* 1st ed. (Cambridge, United Kingdom: Polity Press, 2011).

The Auto-Immunitary Reaction

In the auto-immunitary reaction, poor, minority, and/or marginalized members of society are engaged by wealthier, more elite society members as if they were an immune system trying to get rid of a virus. Society turns on itself in the same way that an autoimmune disease in the body attacks healthy cells—attacks itself. According to Esposito, anger and fear of infiltration (infection) from individuals who are socially, genetically, and physically inferior is what ignites society to turn on itself—thereby causing the social autoimmune reaction. The crux of Esposito's auto-immunitary reaction is the rupture of society's narrative identity and the development, perpetuation, and differentiation of the *Self* from the *Other*—a hierarchy which stratifies groups based on ideas of the "higher" *Self* and the "lower" *Other*.

For example, in a quantitative study done by Dr. Thomas Lemke from the University of Frankfurt and his colleagues from the University of Basel and Helmut Schmidt University, respectively, social *Othering* as a form of genetic discrimination was based on presumed genetic disposition for a particular disease or sickness and the ambiguity of genetic information—regardless of whether the individual was symptomatic.[99] It also directly affected one's interpersonal interactions. Thus, the authors suggested that the concept of discrimination be broadened such that it not only included formalized, systemic prejudices, but also those that one would endure in his or

[99] Thomas Lemke, Katharina Liebsch, Tabea Eissing, Bettina Hoeltje, Ulrike Manz, and Tino Plumecke, "Genetic Discrimination in Germany? Experiences of Othering and Adverse Treatment Due to Risks of Genetic Diseases," *Social World: Journal of Social Research and Practice* 64, no. 3 (Jan. 2013): 269-290.

her everyday engagements. This references an auto-immunitary reaction because the nature of discrimination is the distinction of the *Self* from the *Other*, stratification, and fear of infiltration (infection) by the other. In this case, however, there is simultaneously a fear of physical infiltration (infection) by someone perceived as being lower on the social hierarchy and molecular infiltration (infection) via the introduction of genetic information.

In a similar vein, Shirley Sun, author of *Socio-economics of Personalized Medicine in Asia*, stated that racialization in genetic and genomic research was "demonstrably integral to the social process of "(*Self*-) *Othering*."[100] She further suggested that racialization and the biologization of race in medical and biomedical research fails to acknowledge and problematize the broader effects of using race as a proxy for human variation.[101] Pharmacogenomics and genome wide association studies reassert the kinds of discrimination and othering discussed by Lemke and Sun through the normalized use of race and racialization as molecular and biological concepts. The integration of race and racialization within genomic research also indoctrinates clinicians to the idea that the socio-historical construction of race (and its conjoined ideologies) are legitimate, inherent subscripts to human variation.

[100] Shirley Sun, *Socio-economics of Personalized Medicine in Asia* (New York, New York: Routledge, 2017): 16.
[101] Ibid.

The Auto-Immunitary Reaction and Thanatopolitics

The function of auto-immunitary reactions (as noted by Esposito) is to shift juridical power from ensuring the protection of the entire organism (the collective body of society) to the radical movement of select groups into fortified boundaries—protecting some groups over others while also making some groups live and letting others to die (as noted in biopolitics).[102] Such circumstances lead to the self-designated *higher* life forms protecting themselves from perceived aggression by putting the *lower* life forms to death or allowing them to die— actualizing a kind of law-violence-stratification paradigm via thantopolitical power.[103] Philosopher Jacques Derrida elaborates on this issue in stating that:

> We are here in a space where all self-protection of the unscathed, of the safe and sound, of the sacred (*heilig*, holy) must protect itself against its own protection, its own police, its own power of rejection, in short against its own, which is to say, against its own immunity. It is this terrifying but fatal logic of the auto-immunity of the unscathed that will always have associated science and religion.[104]

Per Derrida, an auto-immunitary reaction is not only evidence of a politics of selection or thanatopolitics but also an integration of science and religion. The integration of science, religion, selection, and death was also embedded in Nietzsche's "great politics."

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[102] Esposito, *Immunitas* (2011).

[103] Vanessa Lemm, "The Biological Threshold of Modern Politics: Nietzsche, Foucault, and the Question of Animal Life," In *Nietzsche, Power, and Politics: Rethinking Nietzsche's Legacy for Political Thought*, ed. Herman W. Siemens and Vasti Rodt (Berlin, Germany: De Gruyer: 2009): 725.

[104] Jacques Derrida, "Faith and Knowledge: The Two Sources of 'Religion' at the Limits of Reason Alone," In *Acts of* Religion, Edited and translated by S. Weber and G. Anidjar (London England: Routledge, 2002): 79-80.

Great politics sought to cultivate humanity through the development and measurement of racial hierarchies based on an individual's (or a population's) perceived future, promise of life, and physiology—eliminating anything or anyone deemed degenerate, unholy, and parasitic.[105] The infrastructure of Nietzsche's great politics and great health—which highlighted the significance of race and racialization as molecular and biological concepts—led many contemporary philosophers to believe that the theories were inherently racist.[106]

The concept of race within Nietzsche's great politics and great health was not only a reference to the socio-historical construction of race but to humanity as a species (e.g. the race of man/homo sapiens). Over time, the different political and physical characteristics of *race,* as a homograph, were mapped on to each other and the notion of the weak, "lower" level individual with a slave morality became synonymous with poor and/or minority peoples. These ideas (and the extent to which they are situated within notions of health) work to form one of the many enduring characterizations of poor and minority peoples—the interlaced socio-historical, molecular, and biological conceptualizations of race and racialization.

Race and Racialization as Molecular and Biological

The fluid use and dynamics of race allowed for the inclusion or exclusion of an individual based on identified humanness, social affiliation, or the presence (or perceived

[105] Lemm, "The Biological Threshold of Modern Politics" (2009): 731.
[106] Balke, "From a Biopolitical Point of View" (2005): 56.

presence) of certain biological characteristics—a biological citizenship.[107] The use of race or racialization in pharmacogenomics and genome wide association studies can not be disentangled from historical and contemporary ascriptions that use race and racialization as indicative of degrees of humanness. While this may not be the intentionality of the researchers or clinicians, molecularized and biologized notions of race and racialization have historically been tethered to infrahumanization—the belief that one's *Self* and applicable ingroup are more human than that of the *Other*.[108] The extent to which one's genetic disease or disorder is visually and/or socially observable further effectuates lay society's and possibly clinicians' perception of one's degree of humanness.

For example, cognitive psychologist Veronica Rodriguez' study on the infrahumanization of individuals with Down Syndrome showed that people attributed more degrees of humanness to individuals with ambiguous faces than those with the phenotypic expression of condition.[109] The individuals with Down Syndrome were also subject to stigma and discrimination related to their condition.[110] Similarly, Giulia Pavon

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[107] Nickolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (Princeton, New Jersey: Princeton University Press, 2006). Also note *Nickolas* Rose and Carlos Novas, "Biological Citizenship," In *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, edited by Aihwa Ong and Stephern J. Collier (Oxford, United Kingdom: Blackwell Publishing, 2007): 3-21.

[108] Jacques-Philippe Leyens, M.P. Paladino, R.T. Rodriguez, J. Vaes, S. Demoulin, A.P. Rodriguez, and R. Gaunt, "The Emotional Side of Prejudice: The Attribution of Secondary Emotions to Ingroups and Outgroups," *Personality and Social Psychology Review* 4, no. 2 (May 2000): 186-197. Also note Nick Haslam, Stephen Loughnan, Yoshihisa, and Paul Bain, "Attributing and Denying Humanness to Others," *European Review of Social Psychology* 19, no. 1 (Jun 2008): 55-85.

[109] Verónica Betancor Rodríguez, Eva Ariño Mateo, Armando Rodríguez-Pérez, and Naira Delgado Rodríguez, "Do They Feel the Same as Us? The Infrahumanization of Individuals with Down Syndrome," *Psicothema* 28, no. 3 (May 2016): 311-317.

[110] Ibid.

and Jeroen Vaes' study on mental health professional's perception of humanness in patients with schizophrenia showed that bio-genetic causes of schizophrenia (as opposed to psycho-environmental causes) were associated with what she described as "the person being perceived in less human terms" in addition to greater favorability for the use of restraints on those individuals.[111] These kinds of perceptions inform the behaviors of society and create structural violences that precipitate thanatopolitics and social death. They also further legitimize hierarchical categorizations and dichotomies of individuals based on their ascribed race, perceived health, and social worth.

Biopolitics and Thanatopolitics

For Michel Foucault, Nietzsche's great health, great politics and the kinds of stratification and discrimination inherent in them represented a turning point in Western philosophical and political thought in that they articulated the relationship between one's biological existence and political existence.[112] Foucault viewed Nietzsche's ideas as a discourse about sovereign control and regulation of a population.[113] It was a kind of homily about a biological life and *belonging* to life itself in that life was "regulated, maximized, and harnessed through governmental policy, free-market global capitalism, juridicization, and medicalization."[114] As with Derrida, Foucault noted that the ideological framework of health is simultaneously a dialogue about selection, science,

[111] Giulia Pavon and Jeroen Vaes, "Bio-genetic vs. Psycho-environmental Conceptions of Schizophrenia and their role in Perceiving Patients in Human Terms," *Psychosis: Psychological, Social, and Integrative Approaches* (May 2017): 1-9. Doi: dx.doi.org/10.1080/17522439.2017.1311359

[112] Michel Foucault, *The History of Sexuality Vol. 1* (New York, New York: Vintage Books, 1990).

[113] Stuart J. Murray, "Thanatopolitics: On the Use of Death for Mobilizing Political Life," *Polygraph* 18, Special Issue (2006): 191-215.

[114] Ibid., 193.

religion, and sovereignty. Foucault went a step further, however, in stating that life (as a biological, social, and political happening) is affected by the capitalist endeavor.

The managed production and distribution of goods and services are the heart of the capitalist endeavor. Unequal access to goods and services (such as health care, pharmaceuticals, and healthcare related services) facilitate medical inequity. So, the actualization of neoteric medical technologies that reinforce (intentionally or unintentionally) medical and socio-medical inequity, stratification, or discrimination fortify income-based health outcomes and assert thanatopolitical power.

For example, using the Future Elderly Model[115] to assess the social trade-offs created by pharmaceutical innovation, economist and Quintiles Chair in Pharmaceutical Development at the University of California Darius Lakadawalla asserts that the high cost of pharmaceutical innovations incentivizes manufactures to do more research to produce more products for future patients while concomitantly reducing the number of people who can currently access the neoteric medical or pharmaceutical technology.[116] The parallax of these kinds of developments is that they hold great promise for people's future access to genomic medicine and/or health care while potentially hindering the

[115] The Future Elderly Model (FEM) is a demographic-economic microsimulation model used to project the future costs, health care expenditures, and health conditions of Medicare eligible individuals over time. Dana Goldman, M. Hurd, P.G. Shekelle, S.J. Newberry, C. W.A. Panis, B. Shang, J. Bhattacharya, G.F. Joyce, and D. Lakdawalla, *Health Status and Medical Treatment of the Future Elderly: Final Report*, RAND Corporation, TR-169-CMS (2004).

[116] National Research Council (US) Committee on National Statistics, "Modeling Medical Technology" in *Improving Health Care Cost Projections for the Medicare Population: Summary of workshop* (Washington, DC: National Academies Press, 2010): 35.

contemporary production of positive biological, social, and socio-medical outcomes in communities that need it the most.

One's biological and social life are also affected by the capitalist endeavor because there is a stark and direct relationship between the perceived worth of an individual, his or her contribution to society, and the extent to which society is willing to invest back into that person in the form of social goods. Access to education and health care, for example, are forms of social investment in individuals that drive health outcomes. If, however, a society chooses not to or fails to make those kinds of resources available to its populace, it is facilitating institutionalized stratification— thereby reducing the actual and proximal development of the individual, limiting his or her income potential, and disregarding the relationship between poverty, education, and health.

For example, according to a 2011 study on the Structural Vulnerability and Health of Latino Migrant Laborers in the Unites States, Latino Migrant laborers suffer structural violence in the form of economic exploitation, cultural depreciation, political subordination, persisting legal persecution, and increasingly legitimized U.S. governmental discourses of unworthiness—all of which dramatically increases migrant Laborers' potentiality for poor health out-comes.[117] Their health and well-being are highly correlated to and with their racialization and perceived social worth. The

[117] James Quesada, Laurie K. Hart, and Phillippe Bourgois, "Structural Vulnerability and Health: Latino Migrant Laborers in the Unites States," *Medical Anthropology* 30, no. 4 (Jul. 2011): 339.

application of thanatopolitical power and the potentiality of social death in this instance do not reflect a classical form of sovereign control (a top-down power) that one might see exercised in a monarchy, for example, in which the precepts of life, its regulation, and/or maximization are established in taking life or letting live. Instead, it shows how the dynamics of a society's social, political, and economic ecology work to make a healthy, affluent life for some individuals while passively allowing for the death of others.

The distinction between taking life or *letting live* and making live or *letting die* relative to biopolitics and thanatopolitics is important not only because it situates the concepts as logical correlates, but also because it disarticulates the responsibility of death from the sovereign body. [118] Stuart J. Murray notes the complexity of this concept in stating that:

> We can begin to understand how, under this modern political logic, life itself can become the ultimate apologia for *Rassenhygiene*, compulsory sterilization programs, mercy killings, or state murder, and even genocide. And yet we proclaim very loudly that we have not actually killed anyone, that *their* death has not occurred by my hand, and that according to my idea of responsibility, based on my sovereign reason and autonomy, their death has just happened, a side-effect perhaps…[119]

Murray's statement suggests that modern sovereignty relative to biopolitics would not work to assist individuals in the active resistance of death but would instead engage them with the reality of its irremediable process. This is a clear shift away from the biological, political, and social management of one's life in classical sovereignty (which would accelerate one's death via a beheading or torture).

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[118] Murray, "Thanatopolitics," (2006).
[119] Ibid., 198.

The writings of French anatomist and physiologist Xavier Bichat, however, went a step further in helping society realize that one's biological existence, political existence, and perceived socio-historical attributes evidenced social systems that worked to make live or *let die*. In other words, instead of a sovereign power directly acting upon an individual causing him or her harm, modern sovereignty via thanatopolitical power, ignores the needs of particular groups of people as an indirect means of accelerating their deaths.

Philosophers, such as Foucault, recognized that although the paradox of making live and letting die could first appear as a logical fallacy, the molecularization and biologization of race and racialization divides a population into a continuum— re-instigating and legitimizing the distinction between the *Self* and the *Other* and allowing the indirect killing (letting die) of the *Other* for the supposed protection of society.[120] This racism, as he called it, is different than the kind overtly articulated in Nietzsche's great politics and great health. And yet, it is simply the existence of racism at the intersection of biopolitics that makes it a thanatopolitics—politics of death.[121] Foucault stated that "in the economy of biopower, racism has the function of death according to the principle of the death of others. It is the biological reinforcement of oneself as a member of a race or population, as an element in a unitary and living plurality."[122] And

[120] Lemm, "The Biological Threshold of Modern Politics," (2009).
[121] Ibid.
[122] Michel Foucault, "*Ethics, Subjectivity, and Truth: The Essential Works of Foucault 1954-1984 Vol. 1* (New York, New York: The New Press, 1994): 230.

yet, as he states, "since the population is nothing more than what the state takes care of for its own sake, of course, the state is entitled to slaughter it."[123]

According to Giorgio Agamben, applications of power which recognize and construct (or reconstruct) one's identity through the interplay of one's politically qualified life and bare life did not emerge in the eighteenth century in conjunction with biopolitics, as Foucault suggested. Instead, Agamben proposes that characterizations of the *polis* in antiquity are ripe with thresholds of exclusion and inclusion, bare life [*zoë*] and political life [*bios*] as well as a thin distinction between some forms of violence and justice.[124] The imbrication of these systems is what is and has been fundamental to the genesis of varying forms of Western politics and socio-medical inequity.[125]

For example, in Roxane Richter's book *Medical Outcasts* she characterizes undocumented Zimbabwean woman in South Africa and undocumented Mexican women in the United States as *homo sacers*[126] whose medical and socio-medical plights are directly due to the application of thanatopolitical power in the form of structural violence.[127] In elaborating on those women's experiences, Richter stated that:

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[123] Michel Foucault, "The Political Technology of Individuals," In *Technologies of the Self: A Seminar with Michel Foucault*, edited by Luther H. Martin, Huck Gutman, and Patrick H. Hutton (London, England: Travistock, 1988): 160.

[124] Dean, "Four Theses on the Powers of Life and Death," (2004).

[125] Ibid.

[126] Homo sacer refers to individuals who may be killed but not sacrificed. The *homo sacer* exists outside of juridical-political laws, his or her life is made sacred by authorizing a sovereign killing (one that can not be considered murder), and he or she has been stripped of his or her political existence [*bios*]—thereby reproducing or rather reestablishing the *homo sacer* as purely biological life [*zoë*]. Giorgio Agamben, *Homo Sacer: Soverign Power and Bare Life*, translated by Daniel Heller Roazen (Stanford, California: Stanford University Press, 1998).

[127] Roxane Richter, *Medical Outcasts: Gendered and Institutionalized Xenophobia in Undocumented Migrants Emergency Health Care* (Lanham, Maryland: Lexington Books, 2015): 23.

> Structural violence—in all of its forms—fabricates pronounced and preventable causes of premature death, suffering, needless disabilities, as well as the exacerbation of lower acuity illnesses/diseases into higher acuity illness/disease phases. As we see from this research, the Zimbabwean and Mexican women fall victim to structural violence in that their access to lifesaving emergency medical care is obstructed, discouraged, and flatly denied by some xenophobic medical personnel, political posture, or institutionalized systemic procedure.[128]

Thus, it is not simply their inability to access health care, or pharmaceuticals in South Africa and the United States, respectively, but the relationship between their perceived racialized identities with socio-medical, structural violences that hinders their potentiality for positive health outcomes. Their plight notes an intersection of racialization and biopolitics in which society *lets* them die rather than providing them the necessary tools and resources to *make* them live (or better facilitate their ability to live). This is the application of thanatopolitics based on the molecularization and biologization of race and racialization.

According to Agamben, situations such as that of the undocumented Zimbabwean and Mexican women are archetypical of the conflation of governmentality, politics, and biotechnology— which causes biopolitics to veer into thanatopolitics.[129] Martin Heidegger concurred but further suggested that the causal shift of biopolitics to thanatopolitics occurred because some technologies change the way that one is able to *be* in the world.[130] Neoteric medical technologies which potentiate medical and socio-

[128] Ibid.
[129] Stefan Herbrechter, *Posthumanism: A Critical Analysis* (New York, New York: Bloomsbury, 2013): 208-211.
[130] Ibid.

medical inequity have historically shown themselves as altering how individuals are able to *be* in the world and whether people's health outcomes would allow them to *be* for very long.

For example, since the completion of the Human Genome Project, how we (as a species) are able to be in the world has changed. We have a new-found potential to alter aspects of our genetic make-up, diagnose and treat disease on a molecular level, and potentially tailor pharmaceuticals to particular groups of people. What has not changed, however, is the general ideological foundation of Western society and Western medicine. We continue to be victims of—and perhaps victimized by—auto-immunitary reactions instigated by historically situated dichotomies of the Self /Other, black/white, healthy/unhealthy and worthy/unworthy.

The molecularization and biologization of race and racialization in pharmacogenomics and genome wide association studies sits at the cross roads of the progress of science and medicine and medical and socio-medical inequities legitimized by the kinds of fore noted dichotomies being embedded in and ignored by the culture of medicine—such as the ideals of Nichezsche's great politics and great health. His ideas and the biopolitics of life, death, race and racialization are normalized. So, we engage with them with a sense of benign routine. Yet, neoteric medical technologies like pharmacogenomics and genome wide association studies represent medical progress and the potential for greater health for *some* people. For others, the socio-historical ascription

of race and racialization has been molecularized and biologized—the result of which may push them to bare life and otherwise instigate thanatopolitics.

Chapter IV: MEDICAL AND SOCIO-MEDICAL AFFECTS OF THANATOPOLITICS

"*The power of the gene reflects the appeal of scientific explanations that reinforce and legitimate existing social categories*."[131]

As mentioned in chapters two and three of this dissertation, thanatopolitics are social, political, and economic systems of power that facilitate and perpetuate death. They privilege the lives of one community over others and do not require direct engagement. Instead, thanatopolitics may simply disregard what people need to have healthy, long lives. With this in mind, this chapter will move from the theoretical structure and influences of thanatopolitics into examples of how they are (and have been) actualized. This will be accomplished by examining how particular groups of people are victimized by the progress of science and medicine and reviewing how that has presented a host of medical and socio-medical issues. The assemblage of those two things (examining the victimization of progress and reviewing its medical and socio-medical affects) provides a depiction of the affects of thanatopolitics. Forthcoming historical and contemporary examples of medical inequity also speak to the longevity of this framework. All of these matters evidence how scientific and medical systems normalize and legitimize medical inequity by reifying the use of race and racialization as molecular and biological—as opposed to acknowledging its socio-historical ascription**.**

[131] Jennifer Terry and Jacqueline L. Urla, eds., *Deviant Bodies: Critical Perspectives on Difference in Science and Popular Culture* (Bloomington, Indiana: Indiana University Press, 1993): 388.

Contrary to the advent and normalization of rapidly advancing, complex medical technologies, medical disparity, inequity, and discrimination have endured. This is due in part to the persistently increasing costs of health care and health care related services. It is also partially due to the general lack of access to quality health care amongst poor and minority peoples. These issues are exacerbated by the intermingling of micro and macro level aggressions, stigmas, and medical discourses that reinforce a framework of thanatopolitics and infrahumanization—the belief that one's own community is more human than someone else's or that the outgroup is not human at all—within science and medicine.[132] The broader effects of infrahumanization in medical research and practice are a socio-medical ecology that fosters institutionalized medical inequity. Moreover, the use of race and racialization as molecular and biological concepts have hindered the development and sustainability of positive health outcomes for many poor and minority populations. The use of race in genome wide association studies, for example, disregards the influence of one's socio-political and natural environment on the phenotypic expression of his or her complex traits, mutations that may directly or indirectly affect the phenotypic expression of a genotype, or the possible discordance between one's shared common ancestry, and how one self-identifies. Additionally, using race as a proxy for homozygosity lends itself to the possibility and probability of reinforcing stereotypes, stigma, and discrimination associated with perceived health, behavioral, and/or cognitive

[132] Omar Sultan Haque and Adam Waytz, "Dehumanization in Medicine: Causes, Solutions, and Functions," *Perspectives on Psychological Science* 7, no. 2 (2012): 176-186. Also note Jacques-Phillippe Leyens, "Humanity Forever in Medical Dehumanization," in *Humanness and Dehumanization* eds. Paul G. Bain, Jeroen Vaes, Jacques Phillippe Leyens (New York, New York: Routledge, 2014), 176.

issues via genetic essentialism. More specifically, racializing genetic attributes for various medical conditions lends itself to the possible production of naturalistic fallicies which suggest that specific diseases or sicknesses are immutable, homogenous, and natural.[133] For example, the 1995 book by Richard Herrnstein and Charles Murray entitled *The Bell Curve* molecularized and biologized race and invoked genetic essentialism by arguing that particular races of people were inherently smarter than others.

Race and Racialization in the Medical Endeavor

Herrnstein and Murray's theories were effective in revitalizing public interest and solidarity in the supposed inherent intellectual differences between socio-historically ascribed and biologized races. Since then, race has continued to be considered a relevant (and perhaps primary) factor in scientific and medical epistemology, research, pedagogy, and practice. The continued use of race in physician and student rounds presentations as well as race-based analysis in clinical research is evidence of the idea that racial categorization is perceived as inherently germane in science and medicine.[134] As noted throughout this dissertation, such normalized and legitimized use helps to perpetuate medical inequity, disparity, and discrimination through the accepted categorization and racialization of people.

[133] Ilan Dar-Nimrod and Steven J. Heine, "Genetic Essentialism: On Deceptive Determinism of DNA," *Psychological Bulletin- American Psychological Association* 137, no. 5 (Sep. 2011): 800.

[134] Mariam O. Fofana, "The Spectre of Race in American Medicine," *Medical Humanities* 39, no. 2 (Dec. 2013): 137-141. Doi:10.1136/medhum-2013-010374.

For example, the introduction and FDA approval of BiDil was a poignant display of this issue because it not only was the first race-based pharmaceutical approved by the FDA, but also because there was no scientific evidence to indicate that it would *not* work (or would work differently) on other races of people— as the clinical trials only included self-identified African Americans.[135] In fact, the only genetic information associated with BiDil was a warning that patients who were fast acetylators of hydralazine would have lower exposure to the active drug—an issue that had nothing to do with race.[136] Nonetheless, BiDil was fast-tracked as an orphan drug specifically targeted to African Americans—reifying the molecularization of race and legitimizing the idea that African Americans and Caucasians were genetically different groups.[137] Molecularizing race in this way worked to solidify the tacit Western idea of a Black/White dichotomy. As described by culture of medicine professor David S. Jones:

> The logic of BiDil depended on an implicit assumption that blacks and whites were different, and that this difference—at least as it related to heart failure pathophysiology and treatment—was rooted in genetics. The superior efficacy of BiDil in blacks versus whites seemed to validate both the basic assumptions of pharmacogenomics and the widespread faith that race could be used as a proxy for human genetic variation.[138]

University of Pennsylvania Law Professor Dorothy E. Roberts went a step further in stating that:

> In the past, the FDA has had no problem generalizing clinical trials involving white people to approve drugs for everyone. That is because it believes that white

[135] Brody, "BiDil: Assessing a Race-Based Pharmaceutical," (2006).
[136] David S. Jones, "The Prospects of Personalized Medicine," in *Genetic Explanation: Sense and Nonsense*, Sheldon Krimsky and Jeremy Gruber Eds. (Cambridge, Massachusetts: Harvard University Press, 2013): 147-170.
[137] Ibid.
[138] Ibid.: 164.

> bodies function like human bodies. However, with BiDil, a clinical trial involving all African Americans could only serve as proof of how the drug works in blacks. By approving BiDil only for use in black patients, the FDA emphasized the supposed distinctive, and substandard quality of black bodies. It sent a message that black people can not represent all of humanity as well as white people can.[139]

Professor Jones and professor Robert's statements are further problematized by the histographies of medicine which depict the use of minority and poor peoples' bodies to explore the human physiology, anatomy, and the general human condition. In most of those cases, the pursuit of medical progress took the form of experimentation and/or exploitation. And thus, the progress of science and medicine of the time went hand-in-hand with the victimization of poor and/or minority people. This is the root and application of thanatopolitics.

For example, for more than thirty years, experiments such as the Total-Body Irradiation (TBI) experiment, the plutonium injection experiment, the Holmesburg prison pharmaceutical experiments, and the zirconium injection experiment (in addition to the Tuskegee experiment and many others) were conducted on hundreds of minorities and poor people and were sponsored by the U.S. Government—in conjunction with Universities like Johns Hopkins and Vanderbilt.[140] Likewise, the imbricated history of robbing graves in Negro Burial Grounds/African American cemeteries and anatomy

[139] Dorothy E. Roberts, "What's Wrong with Race-Based Medicine?: Genes, Drugs, and Health Disparities," *Minnesota Journal of Lal, Science, and Technology* 12, no. 1 (2011): 3.

[140] U.S. President's Advisor Committee, *The Human Radiation Experiments* (New York, New York: Oxford University Press, 1996): 512.

instruction in U.S. Medical Schools,[141] the erased history of James Marion Sim's (the "Father of Gynecology") experimental gynecological surgeries on unanesthetized enslaved black women,[142] and the theft and pervasive reproduction of Henrietta Lack's cancer cells[143] all speak to the exploitative use of minority and poor peoples for medical, biomedical, and pharmaceutical research. There is no evidence (that I am aware of) in history in which the bodies of poor and/or minority peoples were used in nonexperimental, nonexploitative medical or biomedical research as the standard body (compared to other groups of people) for the purposes of a therapeutic treatment that all races of people would have equal access to. Instead, minority and poor peoples have only been considered representative of the race of man during times of scientific and/or medical experimentation, exploitation, and exploration. Such circumstances clearly adhere to the tacit thanatopolitical framework which makes certain groups live while allowing others to die. They are the effects of thanatopolitics as played out by science and medicine.

In instances other than experimentation, exploitation, and exploration the bodies of poor and/or minority peoples are considered representative of social and genetic variance—a variance that can not be applied to other groups. This idea of racial categories (specifically relative to majority versus minority racial and racialized

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[141] James M. Davidson, "Resurrection Men" in Dallas: The Illegal Use of Black Bodies as Medical Cadavers (1900-1907)," *International Journal of Historical Archaeology* 11, no. 3 (Sept. 2007): 193-220.

[142] Sara Spettel and Mark Donald White, "The Portrayal of James Marion Sims' Controversial Surgical Legacy," *Journal of Urology* 185, no. 6 (Jun. 2011): 2424-2427. Doi:10.1016/j.juro.2011.01.077.

[143] Marlon Rachquel Moore, "Opposed to the Being of Henrietta: Bioslavery, Pop Culture, and the Third Life of HeLa Cells," *Medical Humanities* 43, no. 1 (Mar. 2017): 55-61. Doi:10.1136/medhum-2016-011072.

dichotomies) as proxy for genetic and genomic human variation continues to permeate many aspects of contemporary medical and biomedical research. As such, the history of BiDil (relative to production, clinical trials, and marketing, for example) continues to be relevant more than a decade later.

According to law professor Johnathan Kahn, "the role of the federal, legal and regulatory system in producing BiDil as an ethnic drug is especially important because it lends the imprimatur of the state to the use of race as a biological category."[144] The approval of BiDil also implied that the health disparities experienced by minority and poor peoples had a specific pathophysiological or genetic/genomic etiology as opposed to ones invoked by structural violence and social inequity.[145] Molecularizing and biologizing race and racialization in these ways takes the onus off of social systems and mechanisms of power which work to facilitate thanatopolitics and reframes it as an issue of self-surveillance. Thus, BiDil, as a new pharmaceutical advancement, simultaneously represented the potential to customize medicine to potentially increase its efficacy (noting the progress of science and medicine) while also legitimized pre-existing racial dichotomies by molecularizing and biologizing race and racialization (the socio-medical affects of that progress). Therein lies a parallax.

[144] Jonathan Kahn, "How a Drug Becomes "Ethnic": Law, Commerce, and the Production of Racial Categories in Medicine," *Yale Journal Health Policy Law Ethics* 4, no. 1 (Winter 2004): 33. Also note Brody, "BiDil: Assessing a Race-Based Pharmaceutical," (2006).

[145] Roberts, "What's Wrong with Race-Based Medicine?" (2011).

Addressing the Parallax

National and international researchers associated with the Human Genome Project (HGP) foresaw the potentiality of a race, genomics, and medical inequity nexus butting up against the progress of the project and thusly developed —in conjunction with the National Institute of Health (NIH) and the Department of Energy (DOE)— a working group to analyze and facilitate a dialogue about the potential Ethical, Legal, and Social Implications (ELSI) of genomic research.[146] Their study lasted for approximately eight years with the crux of its assessment being the need for protective legislation to address possible employment and insurance discriminations.[147] The potential for employment and insurance discrimination are socio-medical effects using race and racialization as molecular and biological concepts and legitimizing those ideas by situating them into genomic research. In grasping that possibility, that report, in addition to collaborative work on discrimination based on genetic predisposition with the United States Equal Employment Opportunity Commission (EEOC) in association with the Americans with Disabilities Act (ADA), provided the foundation for the Genetic Information Non-Discrimination Act (GINA) of 2008. GINA was designed to *protect* individuals. However, the protection GINA provides is against the socio-medical effects of progress, e.g. inequity, disparity, and discrimination caused by the introduction of a new medical

[146] Trip, *Economic Impact of the Human Genome Project Report* (2011).

[147] Karen M. Meagher and Lisa M. Lee, "Integrating Public Health and Deliberative Bioethics: Lessons from the Human Genome Project Ethical, Legal, and Social Implications Program," *Public Health Reports* 131, no. 1 (Jan. 2016): 44-51.

technology into a social system rife with ideologies that have normalized thanatopolitics via structural violence and stratification). A closer look at GINA and how it is situated in the parallax of scientific and medical progress follows.

Genetic Information Nondiscrimination Act (H.R. 493) *Public Law 110-223 110th Congress*

The Genetic Information Nondiscrimination Act (GINA) is a United States Federal Law that was developed to supplement the Health Insurance Portability and Accountability Act (HIPAA) in providing the minimum standard of protection for individuals relative to their genetic information.[148] Its basic tenets prohibit employer discrimination against applicants and employees based on their genetic information. Prohibited actions include the refusal of employment, firing, promotion, requiring applicants and employees to undergo genetic testing, or the collection of genetic data[149]. However, as outlined in GINA, "genetic information may be obtained from an employee with written authorization when he or she is enrolled in a wellness program, when the employer conducts genetic monitoring, or when family history is provided under the Family Medical Leave Act."[150]

Also, in an interestingly aversive maneuver, as of July 18, 2016, employers can offer monetary incentives (up to 30 percent of the total cost of coverage) or other forms

[148] F. Randy Vogenberg, Carol Isaacson Barash and Michael Pursel," Personalized Medicine Part 2: Ethical, Legal, and Regulatory Issues," *Journal of Pharmacy and Therapeutics* 35, no. 11 (Nov. 2010): 624-642.

[149] Vogenberg, "Personalized Medicine: Part 2" (2010). GINA Title II, sections 201-213.

[150] Sheryl Erwin, "Legal Update: Living with the Genetic Information Nondiscrimination Act," *Genetic Medicine* 10, no. 12, (Dec. 2008): 872. Doi:10.1097/GIM.0b013e31818ca4e7.

of goods, commodities, and services (or penalties) to an employee or his or her spouse who provides voluntary information about his or her *own* past and current health status and genetic risk— regardless of whether or not the wellness program is a group plan.[151] An employee's child (biological or otherwise) may also be offered participation in a company wellness program in exchange for current and past health information and their genetic information. However, effective January 1, 2017, the EEOC bars companies from offering incentives to the child of an employee—as it increases the likelihood of his or her participation as well as an employer's ability to make predictions about the health and/or genetic information of the parent. [152]

In addition to prohibiting employment discrimination, GINA also forbids medical insurance companies from requesting genetic testing of people who apply for their services.[153] The revised provision of section 105 of Title I (insurance) clarifies genetic information as health information—thereby making it covered by the HIPAA Privacy Rule—and includes security protections which bar "group health plans, health insurance issuers, and issuers of Medicare supplemental policies from using or disclosing genetic information for underwriting purposes."[154] That is to say then, that one of the protections

[151] United States (U.S.) Equal Employment Opportunity Commission (EEOC), "Regulations Under the Americans With Disabilities Act; Genetic Information Non-discrimination Act. Final Rule 29 CFR Parts 1630 and 1635," *Federal Register* 81, no. 95 (May 2016): 31125-31143. RIN:0945-AA03.

[152] Final Rule 29 CFR Part 1635, Equal Employment Opportunity Commission: Genetic Information Nondiscrimination Act *Federal Register* 81, no. 95 (May 2016): 31147. RIN 3046-AB02. In this case, the biological relationship one has to his or her child is inconsequential because an employer may make predictions about the health of an employee without knowing his or her biological relationship to the child.

[153] Vogenberg, "Personalized Medicine: Part 2" (2010). GINA Title I, SECTIONS 101-106.

[154] United States Department of Health and Human Services, "Modification to the HIPPA Privacy, Security, Enforcement, and Breach Notification Rules Under the Health Information Technology for Economic and Critical Health Act and the Genetic Information Nondiscrimination Act (GINA): Other

provided by GINA is against companies that may choose to decrease one's accessibility to health or healthcare related services by increasing the insurance costs of those services. It is essentially the potential for medical inequity caused by the imbrication of thanatopolitics and scientific and medical progress. GINA is an attempt to pre-emptively address the socio-medical affects of progress by providing individuals with increased genetic and/or genomic privacy.

Many states in the United States have also taken to introducing laws to try to safeguard the genetic rights of their populace without hindering the progress of genomic medicine. However, according to the October 18th, 1997 edition of the New York Times, the development of state laws to prevent discrimination, regulate genetic testing, and the development of a genetic underclass were with agitation and concern that such laws could potentially hinder biomedical research by limiting researchers' ability to conduct clinical trials and force them to navigate and/or negotiate the idea of one's genetic information as his or her personal property—thus limiting the potential use of a respondent's genetic material in future research.[155] The overarching argument of the first

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Modifications to the HIPAA Rules. Final Rule 45CFR Parts 160-164," *Federal Register* 78, no. 17 (Jan. 2013): 5568. RIN: 0945-AA03. The "HIPAA Privacy Rule, 45 CFR Part 160 and subparts A and E of Part 164, requires covered entities to have safeguards in place to ensure the privacy of protected health information, sets forth the circumstances under which covered entities may use or disclose an individual's protected health information, and gives individual's rights with respect to the protected health information, including rights to examine and obtain a copy of their health records and to request corrections." Pg. 5567 "The HIPAA Security Rule, 45 CFR Part 160 and Subparts A and C of Part 164, applies only to protected health information in electronic form and requires covered entities to implement certain administrative, physical, and technical safeguards to protect this electronic information." Pg. 5567.

[155] Robert Pear, "States Pass Laws to Regulate Uses of Genetic Testing," *The New York Times* Oct. 18, 1997. http://www.nytimes.com/1997/us/states-pass-laws-to-regulate-uses-of-genetic-testing.html. Also note Jacquelyn Ann K. Kegley, "Challenges to Informed Consent: New Developments in Biomedical Research and Healthcare May Mark the End of the Traditional Concept of Informed Consent," *European Molecular Biology Organization* 5, no. 9 (Sept. 2004): 832-836. PMCID:PMC1299146.

two issues has largely been addressed by GINA. The latter of the issues, that of informed consent and the usage of respondent genetic information for future usage, continues to be fraught.

For example, according to a 2015 article by Dara Hallinan and Michael Friedewald of the Leibniz Institute of Information Infrastructure entitled *Life Science, Society, and Policy*, one of the potential problems of having open informed consent (which would allow researchers to use a respondent's genetic information for their current research and future research), biobanking, and the potentiality of these concepts is that the formal information required for informed consent as set forth by data protection regulations may be difficult to articulate for yet unknown research. More specifically, Hallinan and Friedewald question whether a researcher would be able to explicitly state the purpose, recipient, data collected, or third country transfers of a study he or she has not yet devised or if these requirements would simply need to be reworded or eliminated.[156] The solution to this conundrum remains unclear—thereby requiring states and individual researchers to navigate the contemporary terrain of scientific and medical research with future discriminations and probable regulations in mind.

The American Civil Liberties Union notes that there are more than sixty pending bills, introduced by nineteen states, that address genetic discrimination in employment

[156] Dara Hallinan and Michael Friedwald, "Open Consent, Biobanking, and Data Protection Law: Can Open Consent be "Informed' Under the Forthcoming Data Protection Regulation?" *Life Sciences, Society, and Policy* 11, no. 1 (Jan. 2015): 1-36. Doi:10.1186/s40504-014-0020-9.

and/or (health) insurance sectors.[157] There are also approximately twenty-four states with already enacted laws against employment or insurance related genetic testing or that provide legal safe-guards to protect people against genetic discrimination.[158] Many of the participating states, however, do not currently have bills or laws that cover all three of the most potential forms of discrimination outlined by the HGP committee: genetic testing, health insurance, and employment.[159] Thus, they are limited in covering some of the socio-medical affects of genetic and genomic related research as outlined by the HGP. For example, Arizona law protects against genetic discrimination in disability insurance and health insurance but does not protect individuals from genetic discrimination at their place of employment.[160] Only four states (including Arizona) provide laws to protect individuals against genetic discrimination relative to their life insurance.[161]

This is problematic as GINA does not cover many of the insurance types, such as long-term care, life, or disability insurances, which are pivotal to poor and middle-income people with chronic conditions (genetic or otherwise).[162] GINA also does not cover any open-access or private access databases. These are either not safeguarded or protected by private institutions. Individuals with a diagnosis or symptoms of disease without genetic predisposition are also not covered by GINA (as noted by the National

[157] American Civil Liberties Union, "Summary of Laws Regarding Genetic Discrimination," https://www.aclu.org/other/summary-laws-regarding-genetic-discrimination.
[158] Ibid.
[159] Ibid.
[160] Ibid.
[161] Ibid.
[162] Ibid.

Human Genome Research Institute).[163] Moreover, because the monetary, negative sanctions applied to insurance companies who violate GINA pale in comparison to the possible, prolonged health care costs associated with a genetic disease, insurers may have little impetus to comply.[164] As noted throughout this dissertation, thanatopolitics are defined by their disregard of pertinent, life-sustaining mediums needed by individuals or groups within larger society. They are systems and mechanisms of power that *allow* for the death of an individual or group. Thus, the inaccessibility of long-term care insurance, disability insurance, and/or life insurance amongst poor people with chronic conditions (genomic or otherwise) and the lack of GINA enforcement act as thanatopolitics because they decrease an individual's potential to obtain adequate care—thereby increasing their potential for negative health outcomes or death.

Lack of stringent or effective enforcement of GINA is further agitated by its use of Title VII of the Civil Right Act of 1964 which puts the burden of proving that genetic discrimination has occurred on the victim.[165] Also, it is well-documented that the psychological, physical, and monetary costs and time commitment required to successfully bring about a Title VII complaint is quite cumbersome.[166] According to

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[163] "Genetic Information Nondiscrimination Act of 2008," National Human Genome Research Institute, http://www.genome.gov/10002328.

[164] Erwin, "Legal Update," (2008).

[165] Ibid. Also note 42 United States Congress §§ 2000e to 200e-17 (2000), amended by Civil Rights Act of 1991, 42 United States Congress § 1981a (2000) Title VII which prohibits employment discrimination on the basis of race, color, religion, sex, or national origin. 42. U.S.C. § 2000e-2 (2000). Also note the Age Discrimination in Employment Act (ADEA), 29 United States Congress §§ 621-634 (2000) which prohibits employment discrimination on the basis of age) and the Americans with Disabilities Act (ADA), 42 United States Congress §§ 12101-12117 (2000) (ADA) which prohibits employment discrimination on the basis of disability).

[166] Ibid., 873.

California Western School of Law assistant professor Jessica Fink, the failing of this kind of antidiscrimination practice is that it does not address the effects of subtle biases (or micro aggressions) on employment, health discriminations, or disparities.[167] It also does not address the potential development and exacerbation of group bias— referred to as litigation-induced group bias—brought about by discrimination lawsuits.[168] Fink states that:

> The defendant in a Title VII case—already primed to resent the plaintiff because of the stigma, stress, and expense of the suit—psychologically will have a ready target for his or her ire, viewing the plaintiff not as a victim of workplace mistreatment, but rather as an agitator intent on causing trouble.[169]

Also, litigation-induced bias, according to social cognition researcher Linda Hamilton Krieger, creates a them vs. us, ingroup vs. outgroup, or Self/Other dichotomy through the delineation of anti-discrimination lawsuits and the ways in which attorneys approach the representation of their clients.[170] Fink suggests that social categorizations created by antidiscrimination litigation facilitates the perception that the *Other* (individuals in the outgroup) are more homogenous (physically, physiologically, and socially) than one's ingroup thus they represent what she describes as "a unified, undifferentiated mass of 'lesser' antagonistic' beings."[171] Reference to these issues is not intended to diminish the significance and positive effects of antidiscrimination legislation

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[167] Jessica Fink, "Unintended Consequences: How Anti-discrimination Litigation Increases Group Bias in Employer-Defendants," *New Mexico Law Review* 38, no. 333 (Spr. 2008): 333-372.
[168] Ibid., 335.
[169] Ibid., 341.
[170] Ibid.
[171] Ibid., 342.

but rather to draw attention to some of the non-monetary, socio-medical costs of such litigation. With some of these potentially compounding problems in mind, lawyers such as Ifeoma Ajunwa propose that GINA be strengthened by adding a disparate impact cause of action such that it is in keeping with other antidiscrimination laws set by the Supreme Court.[172] Ajunwa further suggests that the academic and medical communities take notice of the potentiality of genetic testing to sometimes result in medical disparity and inequity.

Medical Disparity and Inequity

For example, For more than ten years, targeted genetic testing has been used to identify five primary, pathogenic genetic variants which contribute to the development of hypertrophic cardiomyopathy (HCM).[173] According to the National Heart, Lung, and Blood Institute (NHLBI) Exome Sequencing Project (ESP) data set, all of the primary pathogenic variants associated with an increased risk of HCM occurred at significantly higher rates amongst African Americans.[174] However, the application of a clinical classification algorithm being used by the Laboratory for Molecular Medicine, Partners HealthCare Personalized Medicine later identified the previously suggested prevalence of HCM genetic variants in African Americans as the result of a lack of diversity in clinical trials and that the mutations are benign. Nonetheless, the misclassification of benign

[172] Ifeoma Ajunwa, "Genetic Data and Civil Rights," *Harvard Civil Rights—Civil Liberties Law Review (CR-CL)* 51, no. 1 (Winter 2016): 75-114.

[173] Arjun K. Manrai, Birgit H. Funke, Heidi L. Rehm and Morten S. Olesen et. al [+ 5 authors], "Genetic Misdiagnosis and the Potential for Health Disparities," *New England Journal of Medicine* 375 (Aug. 2016): 655-665.

[174] Ibid.

genetic variants as pathogenic led to racialized disparities due to the persisting misdiagnosis and risk predictions of HCM amongst African Americans.[175] Moreover, the inaccessibility and insecurity of genetic testing and genetic information increases the likelihood of genetic discrimination—an issue Ajunwa feels should not require proof of intent.[176] Thus, while the basic tenets of GINA have attempted to protect people from some of the socio-medical injustices that may arise from the acquisition, interpretation, use**,** and democratization of genomic information, it fails to account for aspects of genomic medicine that may propagate pre-existing race-based social issues, ideologies, or thanatopolitics. Such issues are manifested in the contemporary use of race and racialization in pharmacogenomics and genome wide association studies. The next section of this chapter looks at the potential of those issues in more depth.

Medical Inequity and Pharmaceuticals

The use of genomically based pharmaceuticals (pharmacogenomics) brings with it a set of social challenges that have yet to be addressed or have otherwise been ignored prior to the development of its infrastructure and impending normalization.[177] Yet, contemporary issues associated with medical and pharmaceutical costs and access forecast some of the ways that pharmacogenomics may further exacerbate medical inequity and thanatopolitics. For example, according to medical anthropologist Morris W. Foster, "by heightening the social significance of differential drug responses and

[175] Ibid.
[176] Ajunwa, "Genetic Data and Civil Rights," (2016).
[177] Kathinka Evers, "Personalized Medicine in Psychiatry: Ethical Challenges and Opportunities," *Dialogues in Clinical Neuroscience* 11, no. 4 (Dec. 2009): 427-434.

access, pharmacogenomics may contribute to the ways in which health disparities are reified as (as well as perceptions of differences between) people with differing social identities."[178] Likewise, the use of the socio-historical ascription of race and racialized concepts as proxies in genome wide association studies will legitimize social stigma while simultaneously furthering institutionalized medical inequity.

With these issues in mind, the next section of this chapter will discuss the interplay between stigma, access, discrimination, and the costs of pharmaceuticals as means of further projecting the socio-medical trajectories of pharmacogenomics and genome wide association studies. In order to provide more context to these issues, I will first explore some of the history of pharmaceuticals, the pharmaceutical industry, and their progression towards "big Pharma" and pharmacogenomics.

In the earlier part of the nineteenth century, pharmaceuticals were mostly a kind of hodgepodge of diluted opiates.[179] Substances like heroin, cocaine, morphine, and diluted alcohol served as the main ingredients in many drugs by manufacturers like Eli Lilly, Merck, and Bayer.[180] Needless to say, the efficacy and safety of these drugs were questionable at best and ultimately resulted in a massive amount of deaths and deformities.

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[178] Morris W. Foster, "Pharmacogenomics and the Social Construction of Identity," In *Pharmacogenomics: Social Ethical, and Clinical Dimensions*, edited by Mark A. Rothstein (Hoboken, New Jersey: John Wiley and Sons, Inc, 2003): 251.

[179] Sonia Shah, *The Body Hunters: Testing New Drugs on the World's Poorest Patients* (New York, New York: New York Press, 2006).

[180] Ibid.

In 1906 The Food and Drug Act was enacted. It required drug makers to list ingredients on the product label and regulated the drugs' distribution.[181] Four years prior, the Biologics Control Act was also passed. This Act, however, was designed to regulate biological products used on the American populace and was in response to the death of thirteen children whom had been accidently given diphtheria antitoxin by the St. Louis Board of Health (and died of tetanus) when receiving a vaccine for diphtheria made from the blood serum of a horse infected with tetanus—clearly a situation in which people were negatively affected by scientific and medical progress.[182] During the court case brought about by two of the grieving families, the presiding judge stated that it was not the duty of the Board of Health to protect public health and that although it was exercising the sovereign power of and for the State, the State could not be sued for its officer's negligence.[183] The situation was one of thanatopolitics as well as one of the first major medical disasters in the United States. As such, the court's response to such a tragedy led to what the *Journal of the American Medical Association* referred to as the "Unjustifiable Distrust of Diphtheria Antitoxin"—an issue resulting from the lack of purity standards applied to the development and distribution of vaccines.[184]

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[181] Ibid. Note that in 1911, in U.S. vs. Johnson, the United States Governments ruled that the Food and Drugs Act did not prohibit false claims of therapeutic efficacy only equivocal ingredients and/or the identity of the drug. This ruling was amended by the Sherley Amendment in 1912 which prohibited false therapeutic claims. Deaths associated with Mrs. Winslow's Soothing Syrup for colicky babies (which was laced with morphine) was the motivation behind this change.

[182] J. W. MacDonald editor, "The Saint Louis Tragedy," *The Medical Dial: A Monthly Record of Medicine and Surgery* 3, no. 12 (Dec. 1901): 301.

[183] James Hendrie Lloyd ed., "Editorial Comment: The Medio-Legal Aspect of the St. Louis Tetanus Cases," *The Philadelphia Medical Journal* 9, no. 15 (Apr. 1902): 632.

[184] Ross E. DeHovitz, "The 1901 St. Louis Incident: The First Modern Medical Disaster," *Pediatrics* 133, no. 6 (Jun. 2014): 964-965. Doi:10.1542/peds.2013-2817.

Distrust in medicines and vaccines was further amplified by the Elixir Tragedy of 1937 in which S.E. Massengill's use of diethylene glycol (normally used as antifreeze) to dissolve sulfanilamide (known as elixir sulfanilamide)—a drug used to treat streptococcal infections— ultimately caused the deaths of more than one hundred people in fifteen states.[185] In 1938, Congress passed the Food, Drug and Cosmetic Act—the current basis and authority for FDA regulations—which required drug makers to test the toxicity levels of their products.[186] Thereafter, sulfanilamide (the pill form) was replaced by penicillin.

Over the next few years, Penicillin continued to usher in a period of hope, promise, and improved public health.[187] Unlike its predecessors, Penicillin was both safe and effective against a variety of sicknesses and diseases including Tuberculosis and Syphilis.[188] As a result, Penicillin helped to shift the public perception of medicines from that of snake oils to social goods—thus providing the impetus for an almost 500 percent increase in the NIH's budget between 1945 and 1970.[189] The efficacy and profitability of Penicillin also shepherded a biotech revolution and the commercialization of academic research via the Bayh-Dole Act of 1980.[190] Soon after the initiation of the Bayh-Dole

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[185] Ibid.

[186] Carol Bellentine, "Taste of Raspberries, Taste of Death: The 1937 Elixir Sulfanilamide Incident," *U.S. Food and Drug Administration Consumer Magazine* (Silver Springs, Maryland: Food and Drug Administration, 1981).

[187] Philip J. Hilts, *Protecting America's Health: The FDA, Business, and One Hundred Years of Regulation* (Chapel Hill, North Carolina: University of Carolina Press, 2003): 104.

[188] B. Lee Ligon, "Penicillin: Its Discovery and Early Development," *Seminars in Pediatric Infectious Diseases* 15, no. 1 (Jan 2004): 52-57.

[189] Shah, *The Body Hunters*, (2006).

[190] Ibid. Also note that the Bayh-Dole Act allowed universities to patent their findings and commercialize them.

Act there was a 65 percent increase in the number of drug applications submitted to the FDA and triple the amount of prescription drug sales compared to previous years.[191]

As pharmaceutical development and consumption continued to flood American Society there was a decrease in the rate of communicable disease and a considerable increase in the lifespan of the American populace.[192] The reduced need for therapeutic drugs to treat communicable diseases caused decreased profits for the pharmaceutical industry, and triggered many drug manufactures to begin developing over-the-counter drugs used to alter one's appearance and/or physical or mental capabilities. [193] Lifestyle drugs, as they are called, were specifically designed to enhance one's quality of life (regardless of whether the individual had a medical or health related need) and thus could be taken by healthy people.[194] Lifestyle drugs (also sometimes referred to as cosmetic or discretionary drugs) existed on the periphery of medical and social definitions of health and thus could be subjectively applied to an innumerable amount of circumstances for a prolonged period of time.[195]

In 1984 Congress passed legislation which would give drug manufacturers five years of patent protection— equating to monopolies on drugs now considered

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[191] Ibid. Also note that the thalidomide incident of 1970 had little effect on the increasing costs and profits associated with the production and consumption of pharmaceuticals in the United States specifically.

[192] Shah, *The Body Hunters*, (2006).

[193] S. Z. Rahman, V. Gupta, Anupama Sukhlecha, and Y. Khhunte, "Lifestyle Drugs: Concept and Impact on Society," *Indian Journal of Pharmaceutical Science* 72, no. 4 (Jul.-Aug. 2010): 409-413.

[194] Shah, *The Body Hunters*, (2006).

[195] Elizabeth Siegal Watkins, "How the Pill Became a Lifestyle Drug: The Pharmaceutical Industry and Birth Control in the United States Since 1960," *American Journal of Public Health* 102, no. 8 (Aug. 2012): 1462-1472.

"blockbusters" and which could potentially afford them a billion dollars in sales or more per year.[196] The shift from disease or sickness centered pharmaceuticals to lifestyle drugs complimented by drug company monopolies provided the foundation for the development of a politically influential cohort of pharmaceutical companies often referred to as "big Pharma".[197] The introduction of pharmacogenomics, however, is projected to alter the balance of power associated with the production and distribution of pharmaceuticals thereby changing the interplay between big Pharma, the life sciences, the consumer, and the provider, within the larger political arena.[198] This will further problematize issues of health care and pharmaceutical costs and access.

Economic Costs and Access

According to Laviero Mancinelli et al., as with previous pharmaceutical discoveries, pharmacogenomics will usher in "novel approaches in drug discovery, an individualized application of drug therapy, and new insights into disease prevention."[199] However, much of its fanfare disregards questions of cost, access, profitability, and its relationship to blockbuster drugs.[200] Instead, what is often expressed in both scientific and non-scientific literature is the idea that medicines created and used for a particular genomic make-up or for a racially categorized group will be very effective and reduce the

[196] Shah, *The Body Hunters*, (2006).
[197] Ibid.
[198] Joseph Ferrara, "Personalized Medicine: Challenging Pharmaceutical and Diagnostic Company Business Models," *McGill Journal of Medicine* 10, no. 1 (Jan. 2007): 59-61.
[199] Laviero Mancinelli, Maureen Cronin, and Wolfgang Sadee, "Pharmacogenomics: The Promise of Personalized Medicine," *The American Journal of the American Association of Pharmaceutical Scientists* 2, no. 1 (Mar. 2000): 29. Doi:10.1208/ps020104.
[200] Raiiv Saini, Santosh Saini, and R.S. Sugandha, "Pharmacogenomics: The Future of Medicine," *Journal of Advanced Pharmaceutical Technology and Research* 1, no. 4 (Oct. 2010): 423-424.

presence of Adverse Drug Reactions (ADRs)—thus making the medicines safer and more effective.[201]

However, because the probability of increasing financial capital is the undercurrent of production in a market economy—such as what we have in the United States—issues of costs and profitability will likely be two of the primary factors determining the viability of pharmacogenomics.[202] As per the leading researcher and professor at the Department of Public Health and Caring Sciences, Center for Research Ethics and Bioethics, Kathinka Evers, "the need for pharmaceutical companies to recoup their investments is an economic reality that can clash with the interest of health care, and it is not self-evident that the latter's concerns will outweigh the former."[203] One may assume that this is problematized by the fact that pharmacogenomics will be targeted to smaller, more specialized, niche markets and thus could potentially be less profitable.[204] However, a shift in the production of blockbuster drugs to niche or orphan pharmaceuticals will likely be more lucrative than was previously anticipated.

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[201] Evers, "Personalized Medicine," (2009).

[202] William B. Wong, Josh J. Carlson, Rahber Thariani and David L. Veenstra, "Cost Effectiveness of Pharmacogenomics: A Critical and Systemic Review," *PharmacoEconomics* 28, no. 11 (Nov. 2010): 1001-1013. Also note: John Borchardt, "The Business of Pharmacogenomics," *Modern Drug Discovery* 4, no. 7 (Jul. 2001): 35-39. Also note: Marika Plöthner, Dana Ribbentrop, Jan-Phillip Hartman, and Martin Frank, "Cost-Effectiveness of Pharmacogenomic and Pharmacogenetic Therapies: A Systematic Review of the Approved Active Substances for Personalized Medicine in Germany," *Advances in Therapy* 33, no. 9 (Jul. 2016): 1461-1480. [Although the latter of the two sources references another country, the information and analysis is still very relevant and applicable to U.S. based pharmacogenomic endeavors].

[203] Evers, "Personalized Medicine," (2009): 231.

[204] Ann K. Daly, "Genome Wide Association Studies in Pharmacogenomics," *Nature Review Genetics* 11 (Apr. 2010): 241-246.

Relative to the manufacture and distribution of pharmacogenomics, drugs that were previously pulled off of the market due to high toxicity, poor results, or those that were rejected in the last stage of clinical trials may be reevaluated by the FDA's Center for Drug Evaluation and Research (CDER).[205] Niche pharmaceuticals may also be customized without having to resubmit evidence of the drug's safety, quality, or efficacy relative to its intended use.[206] Instead, manufacturers would only have to prove that their drug has a surrogate endpoint—a biomarker which substitutes or acts as a validated correlate for an effective clinical endpoint used to predict the efficacy or clinical benefit of a therapy.[207]

Sonia Shah describes the pharmaceutical loophole created by the use of surrogate endpoints in stating that:

> instead of having to prove that a new cardiovascular drug reduced mortality from heart disease, for instance, drug companies could simply show that the drug reduced cholesterol levels. Or, rather than show that a new cancer or AIDS drug extended patient's lives, they could prove instead that the drug shrank tumors or increased white blood cell levels.[208]

Keeping in mind the need to prove a surrogate endpoint, such as what Shah describes, affords many pharmaceutical companies the opportunity to recover revenue

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[205] C.E. Reeder and Michael Dickson, "Economic Implications of Pharmacogenomics," In *Pharmacogenomics: Social Ethical, and Clinical Dimensions*, edited by Mark A. Rothstein (Hoboken, New Jersey John Wiley and Sons, Inc, 2003): 229-250.

[206] Ibid.

[207] Russell Katz, "Biomarkers and Surrogate Markers: An FDA Perspective," *Journal of the American Society for Experimental NeuroTherapeutics (NeuroRX)* 1, no. 2 (Apr. 2004): 189. Doi:10.1602/neurorx.1.2.189. Also note Tsung Yu, Yea-Jen Hsu, Kevin M. Fain, Cynthia M. Boyd, Janet T. Holbrook, and Millo A. Puhan, "Use of Surrogate Outcomes in US FDA Drug Approvals, 2003-2013: A Survey," *BMJ Open* 5: e007960 (Oct. 2015):1-10. Doi:10.1136/bmjopen-2015-007960.

[208] Sonia Shah, "The Body Hunters," (2006): 46.

lost from discontinued drugs by rebranding them as niche drugs. Pharmaceuticals like Cerivastatin (used to lower cholesterol and prevent cardiovascular disease), Cisapride (used to increase motility in the upper gastrointestinal tract), Trolitazone (an antidiabetic and anti-inflammatory drug) and Alosdtron (used to treat severe irritable bowel syndrome (IBS), for example, are anticipated to be re-evaluated, relabeled and remarketed using the fore mentioned kind of process.[209]

A look at current assemblages and distributions of aggregate pharmaceutical data (such as what is produced and sold by the Intercontinental Marketing Services (IMS),[210] and anonymized genomic information with medical data (as is distributed via multinational biopharmaceutical companies such as AMGen[211] and WuXi Pharma Tech of China), allows one to anticipate the probability that pharmaceutical companies will continue to use genetic and genomic data to predict the prevalence of specific diseases and sicknesses in particular domestic populations—such that lifestyle, therapeutic, and/or

[209] Reeder, "Economic Implications of Pharmacogenomics," (2003).

[210] IMS is one of the largest bioinformatics companies in the United States. Their primary function is to provide pharmaceutical companies with physician prescribing data and trends, and electronic prescription records from pharmacies or major physician organizations such as the American Medical Association. With this information, organizations like PhRMA are able to target sales information to specific doctors and to forecast the use (or market for the increased use of) specific drugs. Robert Steinbrook, "For Sale: Physicians' Prescribing Data," *New England Journal of Medicine* 345, no. 26 (June 2006): 2745-2747. Doi:10.1056/NEJMp068125.

[211] AMGen, formerly known as Applied Molecular Genetics Inc, is a United States based company which purchased and later sold part of deCODE genetics to WUXi Pharma Tech in 2015. deCODE genetics was a biopharmaceutical company out of Iceland which attempted to identify disease related genes using population-based studies and patient medical records. Its practices were considered to have ethical issues related to privacy and consent. The company filed for bankruptcy and was eventually purchased by the California company AMGen. AMGen broke the company up, continues to operate aspects of it, and sold a piece of it back to WUXI Pharma Tech. David E. Winickoff, "Genome and Nation: Iceland's Health Sector Database and Its Legacy," *Innovations: Technology, Governance, Globalization* 1 no, 2 (Feb. 2006): 80-105.

prophylactic pharmaceuticals can be tailored to them.[212] As predictive analytics is also tied to both physician practices and the probability of patient response, using genomic information to note disease risk may increase the use of prophylactic pharmaceuticals and/or prophylactic surgeries—thus increasing pharmaceutical and medical industry profits.

Additionally, as the human life expectancy increases, older individuals will increasingly make up greater percentages of the population—making the prevalence of chronic illnesses and neurodegenerative diseases more likely. Senior patients also tend to take pharmaceutical cocktails to address multiple, co-existing health problems contrary to one's physician or health care team's ability to discern the effectiveness of each individual pill.[213] Pharmaceutical companies may also be able to anticipate the needs of an aging population by building databases of genetic profiles. For example, late-onset diseases such as Alzheimer's, Parkinson's, and some cancers could be identified by drug or insurance companies via genetic testing/screening such that medications could be developed for people they *anticipate* having particular diseases upon old age—thus developing drugs for consumers' current and future use. The use of genetic profiles to predict pharmaceutical need may also facilitate the development of drugs for lifelong use such as Adderall and Ritalin.

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[212] Jianqing Fan and Han Liu, "Statistical Analysis of Big Data on Pharmacogenomics," *Advanced Drug Delivery Reviews* 65, no. 7 (Jun. 2013): 987-1000. Doi:10.1016/j.addt.2013.04.008.

[213] Alan K. Maynard, Book Review "Reasonable RX: Solving the Drug Price Crisis," *New England Journal of Medicine* 359, no. 8 (Aug. 2008): 875-876. Doi:10.1056/NEJMbkrev0804720.

Additionally, advances in pharmacogenomics will allow for the sub-division of disease populations based on differing genetic sequences—thus creating smaller patient populations, orphan drugs, and greater profitability potential—keeping in mind the increased costs often equates to decreased accessibility. Unequal access is medical inequity.[214] As the reduction of a patient population and the production of orphan drugs may seem antithetical to increasing pharmaceutical sales, I will take a few moments to discuss the ways in which the Orphan Drug Act increases the probable profitability of pharmacogenomics

Orphan Drug Act (P.L. 97-414)

In 1983 the United States' Congress enacted orphan drug legislation which would give all pharmaceutical drug companies federal funding to perform clinical trials, a tax credit of 50 percent to cover clinical testing costs, a drug application fee waiver, priority review from the Federal Drug Administration *and* product exclusivity on orphan drugs for seven years—thus affording drug companies the ability to essentially price gouge their medications (to small groups).[215] These benefits were designed to incentivize private industries such that they would have an interest in the development of pharmaceuticals for a small patient pool—defined as fewer than 200,000 people. However, the combination of these incentives with the consistently increasing trend in

[214] Richard Y. Cheung, Jillian Clare Kohler, and Patricia Illingworth, "Orphan Drug Policies: Implications for the United States, Canada, and Developing Countries," *Health Law Journal* 12 (Feb 2004): 183-200.

[215] Aaron S. Kesselheim, "Innovation and the Orphan Drug Act, 1983-2009: Regulatory and Clinical Characteristics of Approved Orphan Drugs," In. *Rare Diseases and Orphan Products: Accelerating Research and Development*, Edited by M. J. Fields and T.F. Boat (Washington, D.C.: National Academies Press, 2010).

prescription drug use in the United States, and the onset of more tailored medical therapies have fostered a pharmaceutical ecology in which some drug manufacturers are submitting drug applications for orphan drugs (to acquire orphan drug benefits and protections) to the Food and Drug Administration (FDA) but upon approval, the drugs are used off-label.[216] Other companies exploit loopholes in the Orphan Drug Act to support and develop profitable, multi-use drugs—each aspect of which would hold orphan drug status—a process referred to as salami slicing.[217] Practices such as these have left many patients at the mercy of the pharmaceutical industry. One of the most relevant examples of a drug that was not technically an orphan drug but that had successfully navigated the loopholes and ambiguities in the Orphan Drug Act (such that it could be afforded many of the economic, market, and manufacturing incentives) was the Epipen.

In August of 2016, the cost of Epipen, an epinephrine auto-injector used to treat people experiencing anaphylaxis (a severe allergic reaction) increased five times and over 400 percent since 2009. The cost increase amounted to approximately $249 for two pens to $615.58.[218] To put this in perspective, in 2004 just under 2.5 million Epipens were prescribed in the United States, with an average of 5.71 pens distributed per 1000

[216] Michael G. Daniel, Timothy.M. Pawlik, Amanda.N. Fader, Nestor.F. Esnola, and Martin.A. Makary, "The Orphan Drug Act: Restoring the Mission to Rare Diseases," *American Journal of Clinical Oncology: Cancer Clinical Trials* 38, no. 2 (Apr. 2016): 210. Doi:10.1097/COC.0000000000000251.

[217] Matthew Herder, "Orphan Drug Incentives in the Pharmacogenomic Context: Policy Responses in the USA and Canada," *Journal of Law and the Biosciences Peer Commentary* 3, no. 1 (Jan. 2016): 158-166.

[218] Chris Woodyard and Mary Jo Layton, "Massive Price Increase on Epi-pens Raise Alarm," *USA Today Money/Business and Ashbury Park N.J. Press* (McLean, Virginia) August 25, 2016.

people.[219] Since then, the number of patients using Epipens increased by 67 percent. In addition, forty-seven states now strongly encourage or require schools to carry Epipens and the U.S. Food and Drug Administration allows the drug to be marketed to people at-risk as opposed to those with a history of life-threatening allergic reactions—thus massively expanding their possible consumer population.[220] This, of course, translated into massive profits for Mylan Specialty, L.P. who manufacturers Epipen.[221]

Similarly, the "Genzyme Corporation's development of Ceredase and Cerazyme to treat Gaucher's disease costs approximately $170,000 a year and Biogen Idec Inc.'s drug Tecfidera—used to treat multiple sclerosis—costs an estimated $54,900 a year."[222] Likewise, 92 percent of FDA approved cancer drugs cost more than $100,000 a year in 2012.[223] Cycloserie (seromycin)—used to treat tuberculosis and urinary tract infections—also increased from approximately $500 to $10,800 per one month supply of 250 mg

[219] Carlos.A. Carmargo Jr., Sunday Clark, Michael S. Kaplan, Phillip Lieberman, and R.A. Wood, "Regional Differences in Epi-pen Prescriptions in the United States: The Potential Role of Vitamin D," *Journal of Allergy and Clinical Immunology* 120, no. 1 (Jul. 2007): 131-136. Doi:10.1016/j.jaci.2007.03.049.

[220] Cynthia Koons and Robert Langreth, "How Marketing Turned the EpiPen into a Billion-Dollar Business," *Bloomberg/Businessweek*. September 23, 2015. Www.bloomberg.com/news/articles/2015-09-23/how-marketing-turned-the-epipen-into-a billion-dollar-business.

[221] Ibid.

[222] Stan Finklestein and Peter Temin, *Reasonable Rx: Solving the Drug Price Crisis* (Upper Saddle River, New Jersey: Financial Times Press, 2008): 1-20, Also in Imanni K. Sheppard, "Addressing Inequity in Personalized Medicine: A Preemptive Approach in the Practice of Medicine." Paper Presented at the American Medical Association's ChangeMedEd Conference entitled: Cultivating a Community of Innovation (Oct. 2015). www.eventscribe.com/2015/ChangeMedEd/assets/pdf214851.pdf.

[223] Camille Abboud, Ellin Berman, Adam Cohen, Jorge Cortes, and Daniel DeAngelo et. al [+114 Collaborators], "The Price of Drugs for Chronic Myeloid Leukemia (CML) is a Reflection of the Unstable Prices of Cancer Drugs: From the Perspective of a Large Group of CML Experts," *Blood* 121, no. 22 (May 2013): 4439-4442. Doi:10.0082/blood-2013-03-490003.

capsules.[224] Soliris (a treatment for the blood disorder paroxysmal nocturnal hemoglobinuria (PNH) costs upwards of $440,000 a year; Solvaldi (sofosbuvir)—a medication used with other antivirals to treat chronic hepatitis C genotype 1, 2,3, or 4—costs approximately $84,000 per course of treatment and Daraprim (pyrimethamine)—an antiparasitic medication often used to treat AIDS patients, people undergoing chemotherapy, transplant recipients and to help prevent malaria—increased in price by 5,500 percent overnight from $13.50 to $750 per pill.[225] This level of inflation is projected to increase by more than 50 percent in 2017 and currently accounts for approximately 27 percent of the United States' total pharmaceutical expenditure—although the number of people who require such medications only represent 1 percent of the patient population.[226] Nonetheless, those individuals may experience severe difficulties accessing the necessary medications due to massive cost increases. Wealthy individuals or people with really good health insurance would be able to purchase the necessary treatments but poor people would be forced to cope with the resulting medical inequity.

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[224] Adam R. Houston, Reed F. Beall and Amir Attaran, "Upstream Solutions for Price-Gouging on Critical Generic Medicines," *Journal of Pharmaceutical Policy and Practice* 9, no. 15 (May 2016): 15-18. Doi:10.1186/s40545-016-0064-8.

[225] Genevieve.M. Halpenny, "High Drug Prices Hurt Everyone," *ACS Medicinal Chemistry Letters* 7, no. 6 (May 2016): 544-546. Doi:10.1021/acsmedchemlett.6b00139. Also note Michael McCarthy, "Drug's 5000% Price Increase Puts Spotlight on Soaring US Drug Costs," *BMJ* 351 (Sep. 2015): h5114. Doi:10.1136/bmj.h5114.

[226] Stephen Barlas, "Are Specialty Drug Prices Destroying Insurers and Hurting Consumers?: A Number of Efforts are Under Way to Reduce Price Pressure," *Pharmacy and Therapeutics* 39, no. 8 (Aug. 2014): 563-566.

Over the past three years, the costs of the top ten medications in the United States have increased by an average of approximately 44 percent—with companies like Valeant increasing the cost of more than twenty of their most popular pharmaceuticals by 200 percent to 800 percent.[227] This means that drugs like Isuprel (used to treat an irregular heartbeat) that used to cost $215.46 per one-millimeter valve now costs $1,246.62 for the same quantity. Yet, the "median household income in the United States is approximately $51,000 with an average poverty threshold for a family of four being roughly $23,834".[228] Also, although the costs of health care and health care related services (such as pharmaceuticals) may be partially covered by an individual's state or private insurance, one of the many consequences of pharmaceutical inflation and price gouging is a paralleled increase in health insurance premiums, prescription abandonment[229], and decreased medical compliance—specifically for the middle class.[230] Directly or indirectly denying people access to what they need to survive is a thanatopolitical action.

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[227] Caroline Humer, "Exclusive: Makers Took Big Price Increases on Widely Used U.S. Drugs," *Reuters Health*. April 5th 2016. www.reuters.com/article/idUSKCN0X10TH. Also in in Imanni K. Sheppard, "Addressing Inequity in Personalized Medicine: A Preemptive Approach in the Practice of Medicine." Paper Presented at the American Medical Association's ChangeMedEd Conference entitled: Cultivating a Community of Innovation (Oct. 2015). www.eventscribe.com/2015/ChangeMedEd/assets/pdf214851.pdf.

[228] United States Census Bureau, Report Release Number: CB14-169, *Income, Poverty and Health Insurance Coverage in the United States: 2013*, (Washington, DC: United States Department of Labor and Statistics, 2013). in Imanni K. Sheppard, "Addressing Inequity in Personalized Medicine: A Preemptive Approach in the Practice of Medicine." Paper Presented at the American Medical Association's ChangeMedEd Conference entitled: Cultivating a Community of Innovation (Oct. 2015). www.eventscribe.com/2015/ChangeMedEd/assets/pdf214851.pdf.

[229] Prescription abandonment occurs when a patient has a prescription for a drug but never takes possession of it. Patrick Gleason, Catherine I. Starner, Brent W. Gunderson, Jeremy A. Shafer, and H. Scott Sarran, "Association of Prescription Abandonment with Cost Share for High-Cost Specialty Pharmacy Medications," *Journal of Managed Care Pharmacy* 15, Iss. 8 (Oct. 2009): 648-658.

[230] Barlas, "Are Speciality Drug Prices Destroying Insurers or Hurting Consumers?" (2014). Also note Pengxiang Li, J. Sandford Schwartz, and Jalps A. Doshi, "Impact of Cost Sharing on Therapeutic Substitution: The Story of Statins in 2006," *Journal of the American Heart Association* 5, no. 11 (Nov. 2016): pii:e003377. Doi:10.1161/JAHA.116.003377.

Nonetheless, approximately 22 percent of drug expenditures were attributed to higher drug costs, 42 percent were due to increases in the volume of prescriptions, and 33 percent were attributed to utilization shifts toward novel, higher priced pharmaceuticals.[231] Economists project that as pharmacogenomics become the norm, the U.S. population continues to grow, and prescription volume increases, pharmacogenomics will contribute to the total national expenditure for medicine.[232]

This is problematized by the fact that the GINI index score in the United States "has increased 4.9 percent (at 0.476 in 2013)—noting an increasing gap in income inequality in the United States".[233] In other words, as the cost of pharmaceuticals continues to increase, many American families will be unlikely able to cover the costs of their prescriptions. Additionally, as noted by Michael Herder:

> unless a rare disease patient has a rare form of cancer and belongs to a high socioeconomic status class, the US approach to orphan drugs seems unlikely to improve that patient's lot. While the new orphan drug regulations promise to limit industry gaming of the boundaries of rare disease, which is important given the recent progress in genomics and epigenomics, they do not respond to this prior, more fundamental problem.[234]

Herder goes on to state that the decreased cost of research and development, the fast-tracking of regulatory reviews, and Orphan Drug market protections have helped to facilitate their development as some of the most expensive and profitable

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[231] Reeder, "Economic Implications of Pharmacogenomics," (2003).
[232] Ibid., 237.
[233] Ibid. Also in Imanni K. Sheppard, "Addressing Inequity in Personalized Medicine: A Preemptive Approach in the Practice of Medicine." Paper Presented at the American Medical Association's ChangeMedEd Conference entitled: Cultivating a Community of Innovation (Oct. 2015). www.eventscribe.com/2015/ChangeMedEd/assets/pdf214851.pdf.
[234] Herder, "Orphan Drug Incentives in the Pharmacogenomic Context," (2016): 166.

pharmaceuticals in the world.[235] John Castellani, the President and CEO of Pharmaceutical Research and Manufacturers of America (PhRMA), however, stated that "it is penny-wise and pound-foolish to focus solely on the price of a new medicine while completely ignoring the value it provides to patients and the health care system broadly."[236]

Here, I am reminded of the reality that the actualization of thanatopolitics in the form of *making* live and *letting* die is indicated within the medical encounter through the use of individual or collective blame and/or responsibilitization. Self-surveillance, medical compliance, and physical prophylactic measures (such as exercising or healthy eating) are believed by society to be indicative of one's ascribed social worth or great health—as Nietzsche put it. What is evidenced was described by Rachel Shields and her colleagues as "the withholding of medical care for people deemed unrecoverable and burdensome to the efficiency of the health care system; and in the concept of heroism through the sacrifice of one's life or body integrity".[237] Like GINA, Obamacare was supposed to help to mitigate or otherwise protect people from the medical (or socio-medical) effects of thanatopolitics.

[235] Matthew Herder, "What is the Purpose of the Orphan Drug Act?" *Public Library of Science (PLOS)* 14, 1 (Jan. 2017): e1002191. Doi.1371/journal.pmed.1002191. PMCID: PMC5207521.

[236] Barlas, "Are Specialty Drug Prices Destroying Insurers and Hurting Consumers? (2014): 564.

[237] Rachel Shields, Joshua I. Newman, and Christopher McLeod, "Life in Three Deaths: Thanatopolitical Biopoiesis and Militaristic Nationalism," *SAGE* vol. 14, no. 5 (Jul. 2014): 428.

Obamacare

Unfortunately, while the Patient Protection and Affordable Care Act (ACA)—also known as Obamacare or the Affordable Care Act—afforded millions of low income and minority peoples with access to health care and health care related services, it was of limited assistance to many individuals. Yes, since the adoption of the Affordable Care Act the rate of uninsured people nineteen years of age and older has dropped by 11percent and more than one million previously uninsured people now have insurance.[238] However, in order to gain allies and increase the monetary and political backing of the Affordable Care Act, the U.S. government met in 2009 with the heads of the Pharmaceutical Research and Manufacturers (PhRMA)—an organization that represents the United States' leading pharmacological research and biotech companies—to work out an agreement that could be mutually beneficial.[239]

During that meeting, the following provisions were agreed upon: in exchange for $80 billion to $150 billion dollars contributed in the form of fees, rebates, and discounts, $150 million dollars in advertising support of the Affordable Care Act, and another $33

[238] Miriam Reisman, "The Affordable Care Act, Five Years Later: Policies, Progress, and Politics," *Pharmacies and Therapeutics* 40, no. 9 (Sept. 2015): 575-600. The Affordable Care Act is composed of the Patient Protection and Affordable Care Act Public Law 111-148, and the Health Care and Education Reconciliation Act, Public Law 111-152. Final Rule 29 CFR Part 1635, Equal Employment Opportunity Commission: Genetic Information Nondiscrimination Act *Federal Register* 81, no. 95 (May. 2016): RIN 3046-AB02.

[239] Christopher-Paul Milne and Kenneth I. Kaitin, "Impact of the New US Health-Care Reform Legislation on the Pharmaceutical Industry: Who Are the Real Winners?" *Journal of Clinical Pharmacology and Therapeutics* 88, no. 5 (Nov. 2010): 589-592. Doi: 10.1038/clpt.2010.167. Note that issues associated with the Health Care and Education Reconciliation Act (HCERA) were not included in discussions between the White House, the Senate Finance Committee and PhRMA because HCERA is an amendment to the ACA and thusly occurred seven days after it had been passed.

million dollars used to close the donut hole[240] created by Medicaid part D, there would be an absence of governmental input in the price of pharmaceuticals, there would be no re-importation of drugs (particularly from Canada where the cost of medicine is considerably cheaper), and there would not be anything put into place in the Affordable Care Act that would address pharmaceutical pricing.[241] Several loopholes were established, such as the provision that prescription drug coverage must be included in new insurance plans, that all prescriptions do not have to be covered by those plans, that new insurance plans can limit their approval to only cover generic drugs.[242] However, many medications have no generic alternatives. Also, generic drug manufacturers are only required to prove that their product can reach 10 percent above or below the same maximum drug concentration (Cmax) levels of the brand name and that the generic version has the same pharmacokinetic parameters of the area below the plasma concentration-time curve.[243] This is referred to as bioequivalence—a concept that supposes that two drugs will have the same or about the same level of biological performance in a living organism (*in vivo*).[244]

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[240] The "donut hole" refers to a monetary gap that occurs in senior citizen health care benefits. Each person's benefits allotted them $2800 in care. Once that amount was reached, he or she would need to cover the entire costs of their medical benefits until they reached $6400 at which point they would be eligible for full medical coverage again.

[241] Milne and Kaitin, "Impact of the New US Health-Care-Reform Legislation," (2010).

[242] Reisman, "The Affordable Care Act" (2015).

[243] Barbara M. Davit, Patrick E. Nwakama, Gary J. Buehler, Dale P. Conner, Sam H. Haidar, Devvrat T. Patel, Yongsheng Yang, Lawrence X. Yu, and Janet Woodcock, "Comparing Generic and Innovator Drugs: A Review of 12 Years of Bioequivalence Data from the United States Food and Drug Administration," *Annals of Pharmacotherapy* 43, no. 10 (Oct. 2009): 1583-1597. Doi:10.1345/aph.1M141. in Imanni K. Sheppard, "Addressing Inequity in Personalized Medicine: A Preemptive Approach in the Practice of Medicine." Paper Presented at the American Medical Association's ChangeMedEd Conference entitled: Cultivating a Community of Innovation (Oct. 2015). www.eventscribe.com/2015/ChangeMedEd/assets/pdf214851.pdf.

[244] Ibid.

Generic Drugs and Affordable, Equitable Access

The manufacturers of generic drugs do not have to prove that their medication is safe or that it will achieve the same results as the brand name pharmaceutical.[245] Safety and efficacy are expected (or rather anticipated) because of the bioequivalence between the generic drug and its blockbuster counterpart—an equivalence noted by data averages for each study population.[246] Fortunately, most people do not experience side effects associated with small changes in the chemical composition of generic drugs.[247]

Patients on Narrow Therapeutic Index drugs (NTIs), however, may not have access to generic equivalents of their medications as slight changes in the chemical composition of their medications have the potential to cause harm.[248] As the brand name drug may not be covered by their medical insurance company, those individuals may have to cover the cost of those pharmaceuticals or additional medical monitoring associated with the use of a generic substitutions where applicable.[249] Also note that regulations associated with the bioequivalence of generic drugs only apply to small molecule drugs—organic compounds with low molecular weight which allow them to easily enter cells.[250] While pharmacogenomics may positively affect the development

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[245] Ibid.

[246] Atholl Johnston, "Equivalence and Interchangeability of Narrow Therapeutic Index Drugs in Organ Transplantation," *European Journal of Hospital Pharmacy, Science, and Practice* 20, no. 5 (Oct. 2013): 302-307. Doi:10.1136/ejhpharm-2012-000258.

[247] Davit, "A Review of Bioequivalence," (2009).

[248] Johnston, "Equivalence and Interchangeability" (2013).

[249] Ibid.

[250] E. Lacaná, S. Amur, P. Mummanneni, H. Zhao, and Felix W. Frueh, "The Emerging Role of Pharmacogenomics in Biologics," *Clinical Pharmacology & Therapeutics* 82, no. 4 (Aug. 2007): 466-471. Doi:10.1038/sj.clpt.6100334.

and application of NTIs, single gene and gene-to-gene interactions and/or variations between people decrease the probability of generic equivalency.[251] In addition, states and individual insurance companies can construct their benefits plans at their discretion, setting their own costs, and using their own formularies.[252] Thus, individuals with chronic conditions can be negatively affected by the varied cost of their medications relative to different benefits plans.[253]

The cost of health care and healthcare related services could be further problematized by impending legislation intended to minimize patient access to equitable medical insurance (and related services) specifically to low income individuals and the elderly. For example, in May of 2017, the House of Representative voted in favor of the American Health Care Act (H.R. 1628). In this bill, individuals nearing sixty-five years of age may be charged five times or more for their insurance compared to their younger counterparts.[254] Elder individuals may also have their Medicaid insurance eliminated by 2020.[255] H.R. 1628 also gives states the ability to charge more for individuals with pre-existing conditions and does not require insurers to cover at least 60 percent of the cost of medical benefits.[256]

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[251] Ibid.
[252] Reisman, "The Affordable Care Act" (2015).
[253] Ibid., 577.
[254] Congressional Budget Office (CBO), Report *H.R. 1628 American Health Care Act of 2017* (Washington, D.C.: CBO, May 24, 2017).
[255] Ibid.
[256] Ibid.

Additionally, the Congressional Budget Office (CBO) and the Staff of the Joint Committee on Taxation (JCT) project that over the next ten years, the structure of H.R. 1628 will cause "approximately 23 million people younger than sixty-five" to become uninsured—with 13 million people losing their medical insurance by the end of 2018 and an additional 2 million people becoming uninsured every year after that.[257] The report makes no mention of approximately how many people will become underinsured as a result of H.R. 1628.

Also of note, as of July 19, 2017, H.R. 1628 has had an amendment in the nature of a substitute [LYN17479] attached to it and has effectively been retitled the "Obamacare Repeal Reconciliation Act of 2017." As its title suggests, its primary purpose is to repeal a majority of the provisions of the Patient Protection and Affordable Care Act. These changes would shift the CBO's and JCT's original estimated number of uninsured peoples from 13 million to 17 million by the end of 2018.[258] That number will increase to 27 million by 2020, and upwards of 32 million uninsured people by the year 2026—less than ten years away.[259] The CBO and JCT further projected that the average premiums for individual policies would double by the year 2026 and stated that at least 75 percent of the U.S. population would likely reside in areas void of an insurer participating in the nongroup market during the same ten-year period.[260] These kinds of

[257] Ibid, 40.
[258] Congressional Budget Office (CBO), Report *H.R. 1628 Obamacare Repeal Reconciliation Act of 2017- LYN17479* (Washington, D.C.: CBO, July 19, 2017).
[259] Ibid, 19.
[260] Ibid.

statistics are significant because the speak to the ways in which political and economic systems will directly and indirectly affect negative health outcomes for millions of people.

The potential loss of insurance, the increase in the cost of insurance premiums, and the reduction of medical coverage form a panopticon of potentiated medical inequity. They are a thanatopolitics and the individuals most likely to be negatively affected by these medical inequities and disparities are poor and elderly peoples. The actualization of medical inequity and systemic stratification become increasing problematic as pharmacogenomics takes center stage in the therapeutic and prophylactic treatment of disease and sickness.

Provided that the CBO and JCT's projections are correct, the unbridled cost of niche pharmaceuticals, such as pharmacogenomics, will be out of reach for individuals who do not have insurance or can not afford to pay out-of-pocket expenses or pay-as-you-go medical procedures. Likewise, those individuals whom are underinsured and those individuals whom are essentially being weaned off of their insurance (as they become senior members of society) will have limited (or no access) to genomic based healthcare initiatives or the adjoining pharmacogenomics. H.R.1628, is thusly reflective of political and economic systems that help to facilitate and perpetuate the kinds of negative health outcomes and increased mortality that are characteristic of poor and elderly peoples. To this end, it is a thanatopolitics. Contrary to the possible intentions of biomedical researchers or medical professionals, the health care enterprise is situated

within larger political and economic systems—systems that shape the socio-medical experiences and quality-of-life of the entire populace.

New genomic technologies, like pharmacogenomics for example, are subject to the development of a segmented market in which a small amount of each product produced will be created to accommodate smaller, highly specified consumer groups.[261] However, "history has shown us that the small groups for whom neoteric medical technologies will be accessible are unlikely to reflect larger society— domestically or internationally".[262] Instead, it is more likely that the small groups for whom more specialized drugs would be available will be those individuals that can afford them, those whom are deemed worthy, or those perceived to have a virtuous or moral character. Thus costs, access, and perceived social worth become the variables through which one moves closer to or farther away from the medical and socio-medical effects of thanatopolics.

Social Worth, Costs, and Access

For example, in 2004 a company called Chiron (which is housed in the United Kingdom) announced that Britain's Medicines and Healthcare products' Regulatory Agency (MHRA) in Liverpool temporary suspended its license due to possible bacterial contamination.[263] As such, Chiron (which produces approximately half of the United

[261] Reeder "Economic Implications of Pharmacogenomics," (2003).

[262] Imanni K. Sheppard, "Addressing Inequity in Personalized Medicine: A Preemptive Approach in the Practice of Medicine." Paper Presented at the American Medical Association's ChangeMedEd Conference entitled: Cultivating a Community of Innovation (Oct. 2015). www.eventscribe.com/2015/ChangeMedEd/assets/pdf214851.pdf.

[263] Helen Pearson, "Flu Vaccine Shortage Looms: Contamination Problems Halve US Stock of Shots," *Nature* Published Online (Oct. 6, 2004). Doi:10.1038/news041004-8.

States' supply of flu vaccine and which acts as one of the three major manufactures of the flu vaccine to the United States) would be unable to produce or distribute flu vaccines to the United States.[264] This caused an unexpected shortage of the flu vaccine—whereas 98 million people [85 million considered as high risk, 6 million people who came into household contact with children, and 7 million healthcare workers] needed the vaccine (estimated five months early at 188 million) but only 48-50 million doses would be available from other manufactures.[265] In response, the Center for Disease Control (CDC) appointed a panel of bioethicists to address the need for a "fair allocation" of the vaccines.[266] The bioethics committee ultimately stated that in order to manage the possible influenza pandemic, individuals who were "essential to the provision of health care, public safety, and the functioning of key aspects of society should receive priority in distribution of vaccine, antivirals, and other scarce resources."[267] Unfortunately, the committee's determination failed to acknowledge social ideologies embedded in the concepts of having valued/'key' and non-valued members of society.[268] With these issues in mind, a secondary ethics subcommittee stated that:

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[264] Ibid. Also note the United States Government Accountability Office, *Influenza Vaccine: Shortages in 2004-2005 Season Underscore Need for Better Preparation*, Report GAO-05-984 to the Congressional Committee (Washington, D.C.: GAO, 2005).

[265] Robert S. Olick, "Ethics in Public Health: Rationing the Flu Vaccine," *Journal of Public Health Management Practice* 11, no. 4 (2005): 373-374. *Also* note: United States Government Accountability Office, *Flu Vaccine: Recent Supply Shortages Underscore Ongoing Challenges*, Testimony GAO-05-177T of Janet Heinrich Before the Subcommittee on Health and the Subcommittee on Oversight and Investigation, Committee on Energy and Commerce, House of Representatives (Washington, D.C.: GAO, 2004).

[266] Albert R. Jonsen, *Bioethics Beyond the Headlines: Who Lives? Who Dies? Who Decides?* (Lanham, Maryland: Rowman and Littlefield Publishers, 2005).

[267] Kathy Kinlaw and Robert Levine, "Ethical Guidelines in Pandemic Influenza," in *Report Recommendations of the Ethics Subcommittee of the Advisory Committee of the Director* (Washington, DC: Center for Disease Control and Prevention, 2007): 3.

[268] Ibid.

> These questions are set in important historical and social contexts involving individuals' ability to attain essential positions given societal barriers and obstacles. Discussion of these questions, while very important in ordinary times, takes on a lower priority when confronted with the urgent demands of preserving society.[269]

Such a decision was an articulation of utilitarian ethics over egalitarian ethics as one's ability to access the vaccine and other scarce resources would be determined by his or her perceived social utility and social worth. Hence, during the pandemic, individuals 50-64 years of age and older and those with a high risk of influenza related morbidity and mortality would be negatively impacted by the influenza vaccine shortage—as per the CDC and their panel of medical and public health experts—known as the Advisory Committee on Immunization Practices (ACIP)— tiered prioritization system.[270]

Similarly, in 2009 the H1N1 influenza pandemic (often referred to as "swine flu") emerged as a global, public health threat. Like the previous outbreak of the H5N1 (avian) influenza in 2004, researchers anticipated needing at least two doses of the vaccine to ensure maximum efficacy in society and there was persisting concern about the U.S.'s ability to produce and distribute a sufficient amount of the product before the current strain of influenza mutated.[271] To address the possibility of a vaccine shortage, the CDC again consulted the ACIP to recommend the best way to allocate swine flu

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[269] Ibid.

[270] Leila C. Kahwati, John R. Elter, Kristy A. Straits-Tröster, Linda S. Kinsinger, and Victoria J. Davey, "The Impact of the 2004-2005 Influenza Vaccine Shortage in the Veterans Health Administration," *Journal of General Internal Medicine* 22, no. 8 (Aug. 2007): 1132-1138. Doi: 10.1007/s11606-007-0249-6. PMCID: PMC2305749.

[271] Benjamin E. Berkman, "Incorporating Explicit Ethical Reasoning into Pandemic Influenza Policies," *Journal of Contemporary Health Law Policy* 26, no. 1 (Fall 2009): 1-19.

vaccines throughout the U.S. and other parts of the world if possible.[272] Thus, a plan was developed to distribute the vaccine globally. This, however, had less to do with distributive justice and more to do with what the Deputy Director of Bioethics Core and the National Human Genome Research Institute, Benjamin E. Berkman, referred to as a fear that "unfettered transmission of the disease could cause it to mutate, becoming much more virulent and possibly rendering existing medical countermeasures ineffective. This mutated strain could then pose a direct threat to formerly vaccine protected countries."[273] As such, the swine flu pandemic caused the facilitation of an unprecedented, collaborative global health response.[274]

Relative to the vaccine's distribution in the United States, however, the ACIP decided that the goal of distribution should be to minimize morbidity and mortality by prioritizing individuals based on the severity, risk, and frequency of their illness, and to preserve the normal functioning of society by prioritizing people who can help others—e.g. individuals with social worth and social utility.[275] While these determinations were laudable, they too lacked a general consideration of how to minimize peripheral concerns such as equity, justice, discrimination, and disparity.[276] Thus, as with the previous influenza outbreak, only individuals whose jobs or current health statuses were

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[272] Centers for Disease Control, "Use of Influenza A (H1N1) 2009 Monovalent Vaccine: Recommendations of the Advisory Committee on Immunization Practices (ACIP)," *Morbidity and Mortality Weekly Report* 58, no. RR-10 (Aug. 2009): 1-12.

[273] Berkman, "Incorporating Explicit Ethical Reasoning," (2009): 8.

[274] Atika Abelin, Tony Colegate, Stephen Gardner, Norbert Hehme, and Abraham Palache, "Lessons from Pandemic Influenza A (H1N1): The Research-Based Vaccine Industry's Perspective," *Vaccine* 29, no. 6 (Feb. 2011): 1135-1138. Doi:10.1016j.vaccine2010.11.042 .

[275] Berkman, "Incorporating Explicit Ethical Reasoning," (2009).

[276] Ibid., 6.

determined to be pivotal to the functioning of society was to have access to the vaccine—with no contingency plan in place to assist those individuals who did not qualify or whom would be indirectly affected by the sickness.

Complicated issues of access and distributive justice are not new, however. They have persisted through time despite the advent of many medical technologies. For example, in 1960 Wayne Quinton designed a Teflon shunt for Belding Scribner that allowed patients with chronic renal failure to be treated using repeated, long-term hemodialysis.[277] Quinton and Scribner's hemodialysis treatments increased patients' quality of life and decreased their mortality. As such, the demand for this new method of dialysis far outweighed treatment accessibility.[278] Problems associated with supply and demand of treatment and treatment accessibility were compounded by its $10,000 per patient per year costs—a price insurance companies were reluctant to pay (especially in the 1960's).[279] By 1962, the Seattle Artificial Kidney Center (SAKC) was established but was limited in its spatial and monetary capabilities to care for its increasing number of patients.[280] The Admissions and Policy Committee was developed to address the issues related to hemodialysis accessibility and costs by deciding which patients would be selected for treatment.[281]

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[277] Christopher R. Blagg, "The Early History of Chronic Renal Failure in the United States: A View from Seattle," *American Journal of Kidney Disease* 49, no. 3 (Mar. 2007): 482-496.

[278] Jeanne Lenzer, "Belding Scribner: The Inventor of Shunt Dialysis," *BMJ* 327 (Jul. 2003): 167.

[279] Jonsen, *Bioethics Beyond the Headlines* (2005): 144. Note that Shana Alexander's article states that the cost of dialysis treatment was approximately $15,000 per patient per year.

[280] Blagg, "The Early History of Chronic Renal Failure in the United States, 2007.

[281] Ibid.

Although the admissibility criteria for treatment included things like emotional maturity, compliance, and having a low protein/low sodium diet, one's age (no one younger than twenty-five or older than forty-five were admitted), income, net worth, educational background, nature of occupation, and performance potentiality was also pertinent factors of eligibility.[282] Likewise, as the introduction of long-term hemodialysis treatment as a neoteric medical technology occurred prior to the Civil Rights Movement (which worked to desegregate hospitals and other health care centers like the SAKC) and Title VI of the Civil Rights Act (which prohibited federally funded programs to discriminate) it would have been unnecessary to articulate race as criteria for eligibility because African Americans and other minority peoples would not have had access to the treatment because they would not have had access to the hospital itself.[283] As such, the majority of patients selected for hemodialysis by the Admissions and Policy committee were wealthy Caucasian men. This coincided with what researchers at the Seattle Civil Rights and Labor History Project referred to as Seattle's long history of de facto segregation. As with many such narratives of medical progress, the normalization of medical inequity, medical disparity, and discrimination are obscured or otherwise absent.

What *was* articulated as the primary criterion for treatment was the prospective patient's social worth—as indicated by his or her assumed contribution to society. In

[282] Shana Alexander, "They Decide Who Lives, Who Dies: Medical Miracle and a Moral Burden of a Small Committee," *Life Magazine* (November 9, 1962): 102-128 (non-sequential in magazine).

[283] Neil J. Salkind Editor, *Encyclopedia of Human Development* (Thousand Oaks, California: SAGE Publications, 2006): 821. Also note Cara A. Fauci, "Racism and Health Care in America: Legal Responses to Racial Disparities in the Allocation of Kidneys," *Boston College Third World Law Journal* 21, Iss. 1, Article 3 (Jan. 2001): 35-68.

describing the medical ecology of the time, Dr. Will Ross, a senior Fellow at the Center for Health Policy and a Dean at the Washington University School of Medicine, stated that "those individuals deemed highly valuable to society would receive dialysis, ostensible to facilitate their physical rehabilitation and return to their jobs, families, and civic duties. Social worth, however, turned out to be just as subjective as it sounds and bioethicists immediately condemned the practice as highly discriminatory and derided the committee as a 'God panel."[284] Accessibility, then, would later be determined by one's ability to afford the life-saving treatment along with one's perceived social utility—or what Michel Foucault refers to as the status of one's biological citizenship.[285] The discernment of the committee was often criticized, such as what was noted by an article in UCLA's Law Review 1968 which stated that the practice was evidence of "the bourgeoisie sparing the bourgeoisie, [and] ruling out the creative, non-conformists who rub the bourgeois the wrong way but who historically have contributed so much in the making of America. The Pacific Northwest in no place for Henry David Thoreau with bad kidneys."[286] Belding's medical technology helped to revolutionize health and healthcare for a very select group of people. This occurred because the medical technology was situated within a scientific and medical framework that was (and continues to be) informed by social ideologies that perpetuated medical inequity and

[284] Will Ross, "God Panels and the History of Hemodialysis in America: A Cautionary Tale," *American Medical Association Journal of Ethics: Virtual Mentor* 14, no. 11 (Nov. 2012): 890-896.

[285] Beth Greenhough, "Biopolitics and Biological Citizenship," *The Wiley Blackwell Encyclopedia of Health, Illness, Behavior, and Society*, (Feb. 2014): 145-148. Doi:10.1002/9781118410868.ebehibs152, Feb.2014.

[286] David Sanders and Jesse Dukeminier, Jr., "Medical Advance and Legal Lag: Hemodialysis and Kidney Transplantation," *UCLA Law Review* 15 (1968): 377.

thanatopolitics. Like neoteric genomic technologies, the advent of long-term hemodialysis was a parallax in that it ushered in the potential for better health outcomes while disregarding how discriminations relative to the treatment would further push medical inequity.

Following Title VI of the Civil Rights Act and the development of Medicare, poor and minority peoples gained access to dialysis treatment facilities, but the quality of care individuals received and the standards of the dialysis facilities were minimal at best.[287] Also, positively contributing to society and having bad kidneys are not enough to qualify for a kidney transplant—so that dialysis treatment is no longer needed. Contemporarily, racial and economic discriminations and disparities plague minority and poor patients. African Americans with chronic kidney disease (CKD) and end-stage renal disease (ESRD) continue to have significantly lower referral rates for peritoneal dialysis, are less likely to have a fistula placed, are less likely to reach target hemoglobin levels, are less likely to get adequate dialysis doses, are less likely to be referred for invasive cardiovascular procedures (when applicable to their disease), and are underrepresented in referrals for kidney transplants—even as the number of African American dialysis patients far exceeds that of any other group.[288]

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[287] Belding H. Scribner, "Dialysis Therapy in the United States: A Historical Perspective," *Home Hemodialysis International* 3, Iss. 1 (Jan. 1999): 9-12.

[288] Lauren M. Kucirka, Morgan E. Grams, Justin Lessler, Erin Carlyle Hall, Nathan James, Allan B, Massie, Robert A. Montgomery, and Dorry L. Segev, "Age and Racial Disparities in Dialysis Survival," *Journal of the American Medical Association* 306, no. 6 (Aug. 2011): 620-626. Doi: 10.100/jama.2011.1127. Also note Donal N. Reddan, Lydia Anne Szczech, Preston S. Klassen, and William F. Owen Jr., "Racial Inequity in America's ESRD Program," *Seminars in Dialysis* 13, Iss. 6 (Dec. 2000): 399-403.

Many of these discriminations and disparities are normalized and legitimized by the idea that African Americans have a dialysis survival advantage relative to other races. However, this concept (like many molecularized and biologized racial ideas) fails to note that higher survival rates in African American dialysis patients only apply individuals over fifty years of age who have insurance and regular access to medical care—as opposed to genetic reasons.[289] Younger patients with ESRD have a mortality rate approximately twice that of their counterparts and their risk of death dramatically increases when accessibility to kidney transplants is accounted for.[290] African Americans with CKD also die at a higher rate than any other group. Thus, the idea of a survival advantage amongst African American dialysis patients is a continuation of molecularized and biologized race and racialized ideas that are normalized and legitimized within the broader scientific and medical endeavor. These ideas have persisted throughout varying aspects of the progress of medicine and medical education.[291]

Additionally, the interplay between the eligibility criteria for dialysis treatment in the 1960's and the actualization of cherry picking patients for kidney transplants (regardless of the rationale behind it) results in a series of systems which actively make wealthy, non-minority individuals live while letting racialized *Others* die. This issue is the nature of thanatopolitics and tthe idea of social worth or good biological citizenship

[289] Ibid.
[290] Ibid.
[291] Kelly M. Hoffman, Sophie Trawalter, Jordan R. Axt, and M. Norman Oliver, "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs About Biological Differences Between Blacks and Whites," *Proceedings of the National Academy of Sciences* 113, no. 6, (Apr. 2016): 4296-4301.

(as noted within the context of gaining dialysis treatment) is an echo of Nietzsche's ideas of great politics and great health.

The limited accessibility and availability of the left-ventricle assist device (LVAD) in the 1990's was resolved by calculating an individual's quality of adjusted life years (QALYs)—a mathematical equation which measures the perceived utility of an individual multiplied by the number of years he or she is a vital member of society.[292] Again, being a good biological citizen was the most significant determinant to accessibility—a vivid reflection of Nietzsche's judgment criteria relative to the rejection of abnormal phenomena. Unfortunately, QALYs, as a measure of one's quality of life and the cost-effectiveness of certain medical treatments, do not account for social variables that directly or indirectly affect health outcomes and they tend to discriminate against elderly members of society.[293] QALY assessments also shape concepts of what constitutes the normal, healthy person—as the process requires the standardization of perceived normalcy and health—thus potentially legitimizing discrimination and stigma. Researchers at Indiana University had the following to say about the influence of stigma:

> while stigma is seen as cross culturally ubiquitous, cultural and historical forces shape norms. The national context provides an overarching ideology by categorizing stigmatized groups and providing clues to appropriate responses toward them. The larger context embeds normative expectations in and through economic development, social organization, and cultural systems because each reflects access to social power.[294]

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[292] Michel Schlander, "Measures of Efficiency in Healthcare: QALMs about QALYs?" *Journal of Evidence and Equity in Healthcare* 104, no. 3 (Apr. 2010): 214-226.

[293] Caroline Carlisle, Tom Mason, Caroline Watkins and Elizabeth Whitehead eds., *Stigma and Social Exclusion in Healthcare* (New York, New York: Routledge, 2001).

[294] Jack K. Martin, Annie Lang, and Sigrun Olafsdottir, "Rethinking Theoretical Approaches to Stigma: A Framework Integrating Normative Illness on Stigma (FINIS)," *Social Sciences and Medicine* 67, no. 3 (Aug. 2008): 436-437.

According to philosopher Michael Lockwood, the more detailed and explicit use of subjective, qualitative criteria to discern priority of access to health care and health care related services, the greater the potentiality of confirming the prejudices of those individuals or systems that use the eligibility criteria as a standard of practice.[295] The historical and contemporary narrative of medicine and medical education as well as the continued use of race and racialization as molecular and biological concepts have shown his hypothesis to be true. It follows that some of the most stark socio-medical effects of thanatopolitics are stigma and discrimination. The next section of this paper is an exploration race, stigma, and discrimination relative to the parallax of pharmacogenomics and genome wide association studies.

Race, Stigma, and Discrimination

As noted throughout this dissertation, genome wide association studies are linked to the development of pharmacogenomics. However, genotyping and phenotyping errors, difficulty noting environmental exposures which modify trait expression, and undetected or unaccounted population affiliations via shared common ancestral heritage problematize the clinical validity and utility of genome wide association studies as well as the ways in which they define, interpret, and articulate population structures.[296]

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[295] Lennart Nordenfelt Editor, *Concepts and Measurement of Quality of Life in Health Care* (Dordrecht, The Netherlands: Kluwer Academic Publishers, 1994; Heidelberg, Germany: Springer Science and Business Media, 2013): 143.

[296] Daan J.A. Crommelin, Robert D. Sindelar, and Bernd Meibohm Eds., *Pharmaceutical Biotechnology: Fundamentals and Applications* (New York, New York: Springer Science+ Business Media, 2013). Also note Aubrey R. Turner, A. Karim Kader, and Jianfeng Xu, "Utility of Genome-Wide

Moreover, the use of race and racialization as molecular and biological concepts in genome wide association studies suffuses genomic research with issues of socio-historical ascription without acknowledging the effects (or potential effects) of these subjectivities on the production of scientific and medical knowledge. The use of race and racialization as molecular and biological concepts in genome wide association studies also lends itself to reifying presumed correlations of particular diseases (or sicknesses) with specific racial groups. This is problematic because it increases the probability of medical and socio-medical discrimination, as well as the stigmatization of that group.

The molecularization and biologization of race and racialization of disease and sickness also provide the foundation for socio-medical and institutionalized *Othering*. GINA does not protect poor and minority peoples from the molecularization and biologization of race because the onset and application of those ideologies occur at the base level of scientific inquiry and methodology as opposed to being initiated upon one's social engagement—e.g. via insurance or employment discrimination. Thus, although the normalized and legitimized discrimination and stigmatization of certain populations are already deeply embedded in the epistemologies and practices of contemporary scientific and medical endeavors, it is reasonable to hypothesize that the introduction of additional alienating premises—such as the reified alignment of race and genetics in genome wide association studies—will negatively impact an already strained social fabric.

Association Study Findings: Prostate Cancer as a Translational Research Paradigm," *Journal of Internal Medicine* 271, no. 4 (Apr. 2012): 344-352. Doi:10.1111/j.1365-2796.2012.02522.x.

Before elaborating on that any further, however, I will first briefly discuss what stigma is and how it is defined. This will provide greater context for discussing the socio-medical affects of molecularized and biologized race and racialization relative to stigma, pharmacogenomics, and genome wide association studies. Following this discussion, I will review examples of how medical stigma, discrimination, and inequity have been normalized relative to the socio-medical encounter.

Stigma

In a 2008 article published in the journal of Society, Science, and Medicine, stigma was defined as "a mark separating individuals from one another based on a socially conferred judgment that some persons or groups are tainted and 'less than.' It often leads to negative beliefs. . . and a desire to avoid or exclude persons who hold stigmatized statuses."[297] Additionally, according to sociologist Erving Goffman, stigma comes in one of three forms: 1) physical abomination such as a deformity, 2) social deviance or social pathology, and/or 3) tribal stigma—ascribed labels shared by one's ingroup/community.[298] Each of the fore noted characteristics work simultaneously to fabricate the social identity of the stigmatized individuals while also establishing physical, psychological, and tribal norms within society—leading to institutionalized discrimination.[299]

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[297] Martin, "Rethinking Theoretical Approaches to Stigma, (2008): 431-432.

[298] Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (New York, New York: Prentice Hall, 1963): 4.

[299] Author Kleinman and Rachel Hall-Clifford, "Stigma: A Social, Cultural, and Moral Process," *Journal of Epidemiology and Community Health* 63, no. 6 (Jun. 2009): 418-419.

The ascription of these statuses occurs on both the macro and micro level. For example, when governmental bodies rationalize and legitimize stigmatizing and/or discriminatory practices within society, what emerges is what Indiana University researchers on the influence of stigma described as "stigma embedded in a larger cultural context that shapes the extent to which stereotyping exists, the nature of social cleavages that define others, and the way that different groups accept, reject, or modify dominant cultural beliefs."[300] This is a macro effect of stigma.

Micro level effects, however, occur within interpersonal engagements that determine (via social perception and evaluation) the value, and social differentiation of the target of discriminatory practices.[301] The greater the differentiation between the targeted person and the person perceived as normal, the more severe the problem and/or sickness is believed to be—thus increasing the level of stigma acted upon the targeted individual.[302] Using the organic analogy (a functionalist concept) that equated society to a biological organism may help to better contextualize how these small interactions become a larger part of the social, political, and medical ecology.

For example, according to the organic analogy, micro level events (interpersonal engagements) work together like the organs of the body to create a functioning whole (society). Each system within the body works to maintain the functioning of the other systems. So, small stigmatizing interactions become the mechanisms through which the

[300] Martin, "Rethinking Theoretical Approaches to Stigma," (2008).
[301] Ibid.
[302] Ibid.

larger systems are supported (and defined)—the whole as the sum of its parts. These small interactions become the foundation for society's larger ideological framework. And thus, it is the interplay between micro and macro level stigmatizing events or systems that make-up the basic ideological and behavioral norms of society.

Historically, the social and philosophical understanding of the organic analogy went hand and hand with the popularization of Social Darwinism and the slogan "survival of the fittest." Relating the organic analogy with Social Darwinism reiterated the biologization of social hierarchies, inequity, and racism legitimized during the Enlightenment. Social Darwinism also delineated between the perceived normal, healthy, fit, biological citizen, and others who should be (and were) stigmatized and discriminated against on the basis of their perceived deficiencies—facilitating a link between illness, stigma, and the notion of individual *and* collective biological and social fitness.

Thus, the social stigmatization and discrimination of peoples based on their perceived biological deficiencies is not a new concept. Instead, the origin of the word *stigma* and its social application are Greek. They used the "term *stigma* to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal, or a traitor—a blemished person, ritually polluted, to be avoided, especially in public places."[303] The Greek cultural understanding and application of

[303] Goffman, *Stigma* (1963): 1.

stigma is important to the possible trajectory of pharmacogenomics and genome wide association studies because the ideas and ideals of Greek philosophy and society are often heralded as the basis of Western philosophical and medical thought, epistemology, and practice. Moreover, in evaluating the history of medicine, Christos F. Kleisiaris et al. noted that "Hippocrates set the stepping stones for the foundations of medicine, developing medical terms and definitions, protocols and guidelines for the classification of diseases which are considered the gold standard for the diagnosis, management and prevention of diseases."[304] As many scientific, mathematic, and artistic disciplines in Western society have been influenced by Greek culture and knowledge, it is plausible that the basic tenents of the Greek conceptualization of stigma continue to permeate into historical and contemporary medical practices. Also, since the nineteenth century, there has been a stark and persisting association between stigma (like other social determinants of health) and its direct and indirect effects on health inequities.[305] Thus, it should be of no surprise that stigma and discrimination have continued to influence many aspects of our micro and macro level, health-related interactions.

For example, in 1971 Richard Nixon issued an executive order requiring all African Americans to participate in mandatory testing for sickle cell anemia—although there was no cure for the disease, no definitive treatment at the time, no means of prenatal

[304] Christos F. Kleisiaris, Chrisanthos Sfakianakis, and Ioanna V. Papathanasiou "Health Care Practices in Ancient Greece The Hippocratic Ideal," *Journal of Medical Ethics and History of Medicine* 7 (Mar. 2014): 4.

[305] Mark L. Hatzenbuehler, Jo. C. Phelan, Bruce G. Link, "Stigma as a Fundamental Cause of Population Health Inequalities," *American Journal of Public Health* 103, no. 5 (May 2013): 813-821.

diagnosis, and other nationalities of people were affected by it.[306] In May of 1972, Nixon stated that the disease is especially pernicious because it strikes only blacks and no one else."[307] After Nixon's address more than two hundred fifty federally-assisted programs emerged throughout the United States and genetic screenings for sickle cell was compulsory for African Americans.[308] Consequently, two types of stigmas developed: one associated with those individuals whom were diagnosed with the disease and another—a courtesy stigma—attributed to *all* African Americans due to public misinformation and the assumed shared ancestry of the stigmatized group.[309] An additional biological label and social libel also emerged: the *carrier* status. Being ascribed as a carrier meant that all African Americans, regardless of their actual health, could be categorized as unfit and thus abnormal within the larger socio-medical context.

For example, an article in *Pediatrics* stated that:

> Sickle-cell trait carriers were found to weigh less, have smaller upper arm circumference, lesser skinfold thickness, and showed less mature skeletal age, differing significantly from normal children. Sickle-cell carriers tend to score lower on four of five intellectual measures, scoring one fifth to one third of a standard deviation lower than normal children.[310]

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[306] K. G. Fulda and Kristine Lykens, "Ethical Issues in Predictive Genetic testing: A Public Health Perspective," *Journal of Medical Ethics* 32, no. 3 (Mar. 2006): 143-147. Doi:10.1136/jme.2004.010272.

[307] Richard M. Nixon, *Public Papers of the Presidents of the United States: Richard M. Nixon* 1972 (Washington, DC: Best Books, 1972): 597.

[308] Daniel J. Kelves, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (Berkeley, California: University of California Press, 1985): 278.

[309] Regina H. Kenen and Robert M. Schmidt, "Stigmatization of Carrier Status: Social Implications of Heterozygote Genetic Screening Programs," *American Journal of Public Health* 68, no. 11 (Nov. 1978): 1116-1120.

[310] Michael K. McCormack, Sandra Scarr-Salapatek, Herbert Polesky, William Thompson, Soloman H. Katz and William B. Baker, "A Comparison of the Physical and Intellectual Development of Black Children With and Without Sickle-Cell Trait," *Pediatrics* 56, no. 6 (Dec 1975): 1021.

Such designations re-articulated many of the molecularized and biologized racial ideologies of the nineteenth century. Because science was deemed to be more sophisticated, however, those beliefs were accepted as theory (without question) or were further legitimized through supposedly objective empirical data. Because of the kinds of fore noted studies, the implementation of federally mandated sickle-cell testing, and the auto-immunitary reaction (as defined by Roberto Esposito) of the general populace, sickle cell became as a racialized disease with abomination and tribal stigmas attached to it. Moreover, having a carrier status (or possible carrier status) afforded many sociocultural entities and institutions a legitimate basis through which discriminatory practices could be applied—resulting in the social death of many African Americans.[311] Concurrently, scientific journals continued to publish research and debates on the supposed correlation between African American cognitive and medical heredity. The crux of the researchers' arguments was that African Americans have sociogenic brain damage that worked in conjunction with the presence of sickle cell anemia resulting in inherently low IQ's.[312] These issues were the socio-medical affects of introducing race based scientific and medical endeavors into a society where pre-existing thanatopolitical systems were already feeding off of racial dichotomies and race based social ideologies. So, the socio-medical effects of sickle-cell testing (and their applicable technologies) was

[311] Kenen "Stigmatization of Carrier Status" (1978).

[312] Drexel A. Peterson Jr., "The Effects of sickle-Cell Disease on Black IQ and Educational Accomplishment: Support for Montagu and 'Sociogenic Brain Damage," *American Anthropologist* New Series 76, no. 1 (Mar. 1974): 39-42.

the normalization and legitimization of sickle-cell as a molecular, biological, racialized disease.

In an attempt to mitigate some of the broad sweeping impact of mandatory sickle cell testing on the African American community, Nixon signed the National Sickle Cell Anemia Control Act in the latter part of 1972 making sickle cell testing voluntary.[313] But, the damage had already been done. The molecularization and biologization of race and racialization as well as reiterations of the supposed correlation and causation between race and intellect continue to be legitimized, normalized, and democratized in a variety of Western academic disciplines.

Molecularizing and Biologizing Race and Racialization

For example, Richard Herrnstein and Charles Murry's book *The Bell Curve: Intelligence and Class Structure in American Life* (published in 1994) argued that race and intellect were correlates determined by one's genetic and environmental influences.[314] Likewise, Nicholas Wade's book entitled *"A Troublesome Inheritance: Genes, Race, and Human History*" identified races as diverging in a manner similar to subspecies and claimed that the bio-genetic makeup of Europeans (Jewish people in particular) account for their superior intellect and advanced human achievement.[315]

[313] Kenen "Stigmatization of Carrier Status" (1978).
[314] Richard J. Herrnstein and Charles Murry, *Bell Curve: Intelligence and Class Structure in American Life* (New York, New York: Free Press Paperbacks, 1994).
[315] Nicholas Wade, *A Troublesome Inheritance: Genes, Race, and Human History* (New York, New York: The Penguin Press 2014).

Other genetic diseases such as Tay-Sachs, carried religious and racialized stigmas in addition to the burden of ethics relative to one's reproductive responsibility. Unlike sickle-cell, there were very few federal testing facilities or programs (none of which were mandatory) used to identify people with Tay-Sachs or carriers of it. Instead, upon the medical and scientific community suggesting that the Ashkenazi Jews of Eastern European descent were genetically unique—because the disease occurred primarily amongst their group—testing began to be privately funded and organized by and within the Jewish community itself.[316] Also, the designation of genetic uniqueness shaped the ways in which research involving Ashkenazi Jews was contextualized and articulated as well as how society perceived them.[317] While this may not have resulted in the kinds of stigma and discrimination that acted upon the African American community relative to sickle cell, the noted prevalence of the disease within their community directly and indirectly altered the medical and marriage practices of the Ashkenazic Jews.

For example, members of their community were to undergo anonymous screening for heterozygous (carrier) status of the disease (with the results affecting whom they would be allowed to marry).[318] Testing included an amniocentesis and/or selective abortion if the fetus tested positive for the disease. The idea was to ensure the positive

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[316] Richard M. Goodman, *Genetic Disorders Among the Jewish People* (Baltimore, Maryland: Johns Hopkins University Press, 1979).

[317] Sherry I. Brandt-Rauf, Victoria H. Raveis, Nathan F. Drummond, Jill A. Conte, and Sheila M. Rothman, "Ashkenazi Jews and Breast Cancer: The Consequences of Linking Ethnicity to Genetic Disease," *American Journal of Public Health* 96, no. 11 (Nov. 2006): 1979-1988. Doi:10.2105/AJPH.2005.083014.

[318] Paul J. Edelson, "The Tay-Sachs Disease Screening Program in the U.S. as a Model for the Control of Genetic Disease: An Historical View," *Health Matrix: The Journal of Law-Medicine* 7, no. 1 (Winter 1997): 125-133.

biological citizenship of a couple while also preventing them from having to give birth to a defective child.[319] Thus, stigma based on carrier status came from within the Jewish community and directly impacted people's social and reproductive behaviors. These practices were effective in decreasing the prevalence of Tay-Sachs disease amongst Ashkenazi Jews. Yet, the social and reproductive changes that occurred within the Ashkenazi Jewish community also raised questions regarding their willingness to participate in programs used to identify race based genetic defects leading to the abortion of Jewish pregnancies, given similar Nazi atrocities in WWII.[320]. Note, again how the ambiguity of race as a socio-historical ascription, a reference to one's humanity (as in the race of man), and in this case, the imbrication of one's religion, culture, and heritage (as a Jewish race) is characteristic of the molecularization and biologization of that race.

Ultimately, however, the combination of Ashkenazi Jews's self-imposed isolation, prophylactic practices, and the presence of a genetic disorder led to a variety of stigmatizing depictions of them as a community of the ill—a concept which endured from the late 19th century through about the middle of the 20th century.[321] Through this, Jewish people were further racialized, marginalized, stigmatized, and discriminated against because of Tay-Sachs disease and the discourses surrounding it.[322]

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[319] Kenen "Stigmatization of Carrier Status" (1978): 1118.

[320] Paul J. Edelson, "The Tay-Sachs Disease Screening Program in the U.S." (1997): 130.

[321] Sander Gilman, *Jewish Frontiers: Essays on Bodies, Histories, and Identities* (New York, New York: Palgrave Macmillian, 2003).

[322] Shelley Reuter, "The Genuine Jewish Type: Racial Ideology and Anti-Immigrationism in Early Medical Writing about Tay-Sachs Disease," *The Canadian Journal of Sociology* 31, no. 3 (Summer 2006): 291-323. Doi:10.1353/cjs.2006.0061.

According to Susan Sontag, the relationships between disease, stigma, and discrimination have persisted since at least the Middle Ages. Diseases like leprosy, cancer, tuberculosis, and syphilis were not only perceived as physical abominations but also as evidence of one's poor moral aptitude and/or damnation by God—ideas reverberated in Nichezsche's great politics and great health.[323] The idea that one' s health is a reflection of his or her morality or damnation is also a kind of salvation-oriented, political power or pastoral power in which the molecularization and biologization of one's race and racialized existence is totalized by society. As per Michel Foucault, the individual's existence becomes compartmentalized into separate, isolated, individual subjects.[324] To this end, afflicted individuals were often ostracized from society, denied goods and resources, and ascribed labels which prevented them from fully integrating into their communities.[325] The resulting nexus of inequity, stigma, discrimination, and marginalization is social death.

As discussed earlier in this dissertation, the socio-medical affects of a social death relative to sickness and disease (or perceived sickness and disease) are a kind of institutionalized, sometimes intergenerational panoptican of medical disparity and discrimination. Because medical inequity, discrimination, and social death are products of societal happenings, they also tend to emerge from the normalization and

[323] Susan Sontag, "Disease as Political Metaphor," *The New York Review of Books* 25, no. 2 (Feb. 1978): 29-33.
[324] Michel Foucault, *Ethics, Subjectivity, and Truth: The Essential Works of Foucault, 1954-1984. Vol. I* (New York, New York: The New Press, 1994): 325.
[325] Sontag, "Disease as Political Metaphor," (1978).

legitimization of *Othering*. As the scientific and medical community continue to use molecularized and biologized notions of race within the framework of their research, interpretations of data, and general production of knowledge, those ideas become the foundation for perceived socio-medical hegemony, normalized thanatopolitical power, and the reification of social death.

The wielding of thanatopolitical power was predicated on supposition, fear, anger and death and whose *doxa* addressed what Rachel Shields et. al referred to as a "*you* who is not one," but rather "a *you* whose oneness is spoken in the name of the many."[326] In other words, the sick or diseased individual was no longer seen as just one person, but rather a representative piece of a larger, homogenous whole—such as what occurred with sickle cell and Tay-Sachs diseases. The overlap of these auto-immunitary reactions with the totalization of entire groups of people further bifurcates the *Self* and the *Other* into those whose deaths are rendered publicly grievable and those whose deaths are not—again resulting in the normalization and legitimation of micro and macro-level events without acknowledging their broader socio-medical implications.[327]

Many sicknesses and diseases such as HIV/AIDS, obesity, and type-2 diabetes, for example, contemporarily carry with them a tag of stigma, discrimination, and molecularized and/or biologized concepts of race, sexual preference, or a perceived lack of personal responsibility or self-surveillance. Negative social and medical stigmas

[326] Rachel Shields et. al, "Life in Three Deaths" (2014): 433.
[327] Judith Butler, *Precarious Life: The Powers of Mourning and Violence* (London, England: Verso, 2004).

associated with one's assumed responsibility for a sickness or disease undermines socio-medical attempts to emphasize the social determinants of those diseases or sicknesses.[328] Likewise, antagonistic perceptions of individual responsibility relative to the acquisition or progression of a specific disease or sickness may reduce compassion for the sick individual's plight. The resulting desensitization and institutionalized stigma is a possible repercussion of the hidden curricular, or other forms of socialization in science and medicine, in particular.

Additionally, micro-level, racialized stigma and discrimination experienced by some Hispanic people, for example, may act as barriers to medical equity. For example, an article in the August 2016 edition of the Journal of the American Society on Aging noted that while Hispanic peoples may have a higher prevalence of Type-2 diabetes than non-Hispanic whites, acculturation, adaptation, assimilation, social barriers, limitations in communication, and hindrances to medical compliance may also be significant factors contributing to the rate of Type-2 diabetes in Hispanic communities.[329]

Evidence for this hypothesis is found in the earlier part of the 19th century in which diabetes was called *Iudenkrankheit* (or the Jewish disease) in European medical journals because Jewish people were believed to have what physician J. G. Wilson

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[328] Jeff Niederdeppe, Sungjong Roh, and Michael A. Shapiro, "Acknowledging Individual Responsibility While Emphasizing Social Determinants in Narratives to Promote Obesity-Reducing Public Policy: A Randomized Experiment," *PLOS* 10, no. 2 (Feb. 2015): e0117565. Doi: 10.1371/journal.pone.0117565. PMCID: PMC4338108.

[329] Willy Marcos Valencia, Lisset Oropesa-Gonzales, Christie-Michele Hogue, and Hermes Jose Florez, "Diabetes in Older Hispanic/Latino Americans," *Journal of the American Society on Aging: Generations* (Winter 2014): 1-19. http://www.asaging.org/blog/diabetes-older-hispaniclatino-americans-understanding-who-greatest-risk

described as "some hereditary defect" that increased their susceptibility to the disease.[330] As some Jewish people immigrated to the United States, the molecularization and biologization of their race continued to be legitimized as they were often socio-medically characterized as inherently diabetic and genetically defective.

According to physician Willian Osler, it was the "neurotic temperament" of Jewish people that made them more prone to developing diabetes.[331] Medical anecdotes such as these continued to gain steam through the medical community throughout the 20th century but virtually disappeared from medical literature after WWII.[332] As per Dr. Arleen Marcia Tuchman, a specialist in the history of science and medicine, "diabetes was conceptualized as a Jewish disease not necessarily because its prevalence was high amongst this population, but because medicine, science, and culture reinforced each other, helping to construct narratives that made sense at the time."[333] Thus, again, normalizing the molecularization and biologization of race and racialization within the frame work of supposed genetics, medicine, and science.

Analyzing, understanding, and discussing molecularized and biologized encounters of race and disease (such type-2 diabetes relative to Jewish and Hispanic peoples) are paramount to our ability to mitigate the socio-medical impact of stigma and discrimination on specific populations. More specifically, as noted in Mark

[330] Arleen Marcia Tuchman, "Diabetes and Race: A Historical Perspective," *American Journal of Public Health* 101, no. 1 (Jan. 2011): 25.
[331] Ibid., 25.
[332] Ibid.
[333] Ibid., 24.

Hatzenhuler's analysis of stigma, "because of its pervasiveness, its disruption of multiple life domains (e.g. resources, social relationships, and coping behaviors), and its corrosive impact on the health of populations, stigma should be considered alongside the other major organizing concepts for research on social determinants of population health."[334]

The use of race and racialization in genomic, medical, and biomedical research—particularly pharmacogenomics and genome wide association studies—problematizes, normalizes, and legitimizes the race-disease dynamic. Nonetheless, the ideology and practice of using race and racialization as molecular and biological concepts continue to be the standard in scientific and medical research. Molecularization, biologization, and racialization within pharmacogenomics and genome wide association studies may thusly further the application of thanatopolitical power and social death by adding to the normalization and legitimization of medical inequity, disparity, and discrimination. It is a circular, self-perpetuating process. Thus, failing to preemptively address the potential socio-medical affects of the continued use of race and racialization as molecular and biological concepts further actualizes thanatopolitics.

I wondered then, how members of the general populace were understanding and/or engaging with these processes, how their contemporary phenomenologies were indicative of the foundations of Western philosophical thought, and how their perspectives could help to forecast the potential trajectories of future racialized research. The following two chapters explore these questions.

[334] Hatzenbuehler, "Stigma as a Fundamental Cause of Population Health Inequalities," (2013): 813.

Chapter V: Methods and Qualitative Data Analysis

This dissertation uses a mixed-methodology to review how people have been affected by the use of race and racialization as molecular and biological concepts. This study also explored respondent perceptions of race and racialization in science and medicine to hypothesize how applicable medical and scientific practices may be perceived and/or engaged with in the future.

All data was put into dialogue with their historical underpinnings in order to triangulate the information and depict the extent to which race and racialized ideologies have persisted in science and medicine through time. This process is important to inferring how the trajectory of pharmacogenomic and genome wide association studies will be (and are) influenced by historical and contemporary, socialized ideologies.

Historical and Contemporary Data Comparative

The findings of this study were drawn from descriptive library research on historical and contemporary ideologies, epistemologies, and practices using primary and secondary source materials. Pertinent data was then situated within the context of medical inequity to better inform the relationship between the historical ideological framework of medicine and its present-day practices. Historically applicable research findings also acted as a basis through which the use of race and racialization as molecular and biological concepts could be compared to contemporary genomic processes such as pharmacogenomics and genome wide association studies.

Qualitative Analysis

Text based research was supplemented with a two-part, qualitative research protocol. Data for this part of the methodological framework was gathered using open-ended interviews followed by a questionnaire and freelist prompts. Participants were asked to describe some of their experiences accessing or trying to access health care or pharmaceuticals specifically in the United States. Each interview was conducted prior to the questionnaire such that it could act as a mnemonic trigger for their survey and freelist responses. The purpose of this line of questioning was to obtain a phenomenography of research participant's access to healthcare and medications, where applicable.[335] Qualitative data was also anatomized following informed consent and respondents were given pseudonyms associated with the crux of their narratives. Data was then transferred to an encrypted, external hard drive.

Interviews

Interviews lasted one hour to one hour and fifteen minutes each and were digitally recorded. Respondent narratives were then transcribed verbatim, cross tabulated, and analyzed using atlas.ti qualitative data analysis software and a language tonal analyzer. Qualitative data analysis software was used to examine themes present in respondent

[335] The purpose of a phenomenography is to analyze and generally get a sense of how people conceptualize, apprehend, and otherwise experience aspects of the world around them. It looks at the experiences of one individual and notes how and/or in what ways that individual's experiences are important. A phenomenological research design, however, tries to understand the extent to which one's narrative is relative or evidence of a larger phenomenon. In this way, it essentially becomes a case study of an event or happening as opposed to a singularity. Note Alan Barnard, Heather McCosker, and Rod Gerber, "Phenomenography: A Qualitative Research Approach for Exploring Understanding in Health Care," *Qualitative Health Research* 9, no. 2 (Mar. 1999): 212-226.

narratives. The qualitative tonal analyzer assessed the occurrence of anger, disgust, fear, joy, and sadness present in the participant responses. It also examined the analytical, tentative and confidence level of the data (based on its linguistic style). Note, however, that the tonal analyzer evaluated each emotion categorically as opposed to comparatively.

Respondents

Participants for this study were recruited from the Houston and Galveston metropolitan areas through convenience sampling and snow-balling. The target population sample for this study were adults of any sex, gender, or race who wanted to discuss their experiences accessing or trying to access health care and/or health care related services. Because the attitudinal survey and freelist design sought to extract the salience and normalization of ideas in society, respondents did not need to be members of the scientific or medical community to participate in this study.

Unfortunately, several people did not feel that they qualified for participation in the study. They assumed, even after repeated conversations, that senior citizens, people with chronic medical conditions, or individuals whom had experienced a trauma (physical, psychological, physiological or otherwise) were the most valid respondents for research on one's medical experiences. This issue was revealed by way of repeated conversations had with individuals who noted interest in my research but whom did not perceive himself or herself as qualifying for participation due to a lack of one of the fore noted exclusionary reasons.

A few individuals tended to refer me to someone they perceived as better fitting my criteria. For the interested but self-perceived unqualified individual, however, they had only been to see a doctor a few times (and for "minor" reasons) in their lives and thus their experiences were not relevant. As such, several individuals referred me to people who had more frequent physician-patient interactions due to chronic or reoccurring diseases or illnesses. Thus, of the twenty people recruited for this study, four people self-excluded. Sixteen people felt that their narratives were apposite and thus continued participation in the study.[336]

Questionnaire/Freelist

After being interviewed, respondents were asked to complete a thirty question survey composed of basic sociodemographic inquiry (such as age, sex, gender, occupation, and race), and a request for attitudinal responses associated with the cost of medicine, race and medicine, and the subjectivity of science.[337] The end of the survey was a five prompt freelist used to note cultural domain—bringing the total number of questions and prompts on the survey to thirty-five.[338] The attitudinal portion of the questionnaire was a pre-coded, 5-point, Likert scale with matrix formatting—using the

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[336] Judith Green and Nicki Thorogood, *Qualitative Methods for Health Research*, 2nd ed. (Thousand Oaks, California: SAGE, 2009 [2004]). Also note Greg Guest, Arwen Bunce, and Laura Johnson, "How Many Interviews are Enough? An Experiment with Data Saturation and Variability," *Field Methods* 18, no. 1 (Feb. 2006): 59-82.

[337] Floyd J. Fowler, *Survey Research Methods*, 4th ed. (Thousand Oaks, California: Sage Publications, 2008).

[338] Susan C. Weller and Antone Kimball Romney, *Systematic Data Collection: Qualitative Research Mekthods Series 10* (Newbury Park, California: Sage, 1988). Cultural domain may be defined as "an organized set of words, concepts, or sentences, all on the same level of contrast that jointly refer to a single conceptual sphere." 9

agree to strongly disagree continuum. This format allowed for increased readability and simplified analytic processing.[339]

The sociodemographic data retrieved from the questionnaire was grouped and tabulated based on number of occurrences. Because of the small sample size and the general structure of the Likert scale, mass statistical analysis could not be applied.[340] Instead, participant responses were tallied and a data summary was conducted using median, or mode as indicators of participant attitudes towards specific phenomena queried on the form.

The freelist assessment was based on the frequency of words within a thematic grouping. For example, the number of times the word "history" was written relative to genetics, or race and medicine provided a general measure of salience within the study population. Grouping respondent's freelist answers thematically also allowed me to identify and analyze the ambiguous ways in which "history," for example, was used relative to health-related topics.[341]

Relationships that exists between data sets as well as emerging themes, reoccurring statements, and/or conceptual insights are noted throughout this chapter and chapter six. The imbrication of historical and contemporary data with this study's

[339] W. Lawrence Neuman, *Basics of Social Research: Qualitative and Quantitative Approaches* (Boston, Massachusetts: Pearson Education, Allyn and Bacon, 2007).

[340] Ann Bowling, *Research Methods in Health: Investigating Health and Health Services*, 2nd ed. (Berkshire, UK: Open University Press, 1997).

qualitative data are further assessed to note the probability that future scientific and medical knowledges, research, practices, and medical technologies will have characteristics situated within the normalized use of race and racialization as molecular and biological concepts.

The next section of this dissertation reviews respondent's sociodemographic characteristics. Participant's sociodemographic information is followed by snippets of their interviews discussing some of the medical and socio-medical affects of race and racialization as molecular and biological concepts in science and medicine. Several themes emerged from those narratives including issues of discrimination based on race, citizenship, sexuality, socioeconomic status, and cost related health care inaccessibility. The chronology and linguistic style the narratives were also important as they revealed aspects of respondents' perceived quality of life and emotionality. As such, the narrative snippets are followed by a closer look at the significance of their chronology and style.

Qualitative Data Analysis and Results

Sociodemography

The sociodemographic section of this study's questionnaire did not include *a priori* categories for race or gender. Instead, respondents were asked to self-identify by answering the questions "What is your race" and "What is your gender," respectively. By eliminating the option for respondents to choose pre-selected characterizations, I was able to obtain a more accurate representation of how my research population perceived

themselves.[342] This is significant because the concept of race is what John H. Fujimura describes as a "sociohistorical construct that is relational, processual, and dynamic, changing over time and local[ity]."[343] Its construction, history, and utility (specifically in genomic research) have thusly been problematized throughout the course of this paper. And, the gender construct has become more fluid.

Race

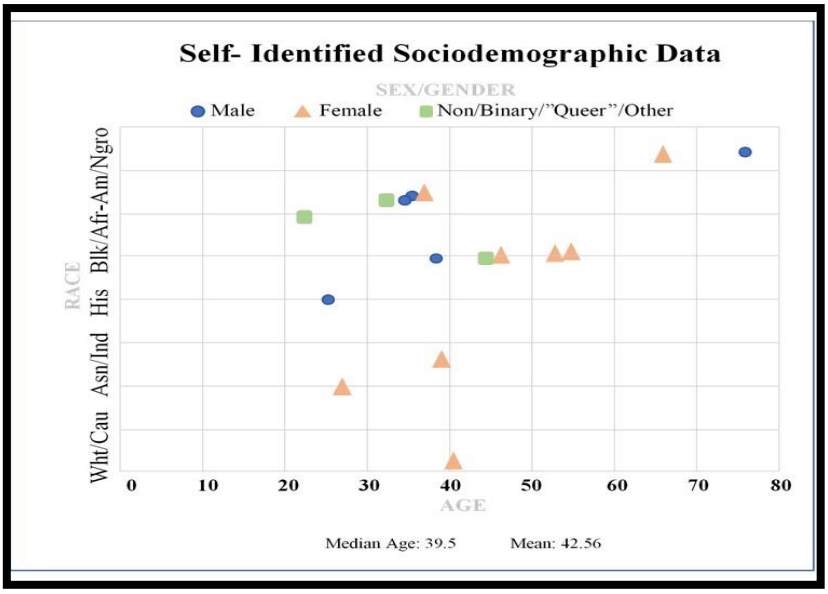
The historical complexity and ambiguity of race—and more recently gender— are noted throughout this paper and are further evidenced by the interplay between respondents' age and self-identified racial categorizations (see table 1). For example, table three shows that five individuals, whose ages ranged from 23 to 37 years old, identified as African American. Five people between 39 and 55 years of age identified as Black and two individuals whose ages were 67 and 78 years of age identified as Negro.

[342] Sana Loue, *Assessing Race, Ethnicity and Gender in Health* (New York, New York: Springer Science & Business Media, 2006)

[343] Joan H. Fujimura, Ramya Rajagoplan, Pilar N. Ossorio, and Kjell A. Dolsum, "Race and Ancestry: Operationalizing Populations in Human Genetic Variation Studies," In *What's the Use of Race: Modern Governance and the Biology of Difference*, edited by David S. Jones and Ian Whitmarsh, Cambridge, Massachusetts: MIT Press, 2010:169.

Also, a 40-year-old respondent from India noted that she was unsure of whether to put her race as Indian or Asian. She stated that she does not usually experience confusion in that regard as her decision is typically based on the options available on the form she is completing— thus reiterating the existence of variance in socio-historical racial ascriptions for the same group. Likewise, one participant identified himself as both Mexican and Hispanic while another participant classified herself as both White and Caucasian. These distinctions are significant relative to the inherent problems of using race in genome wide association studies and for the development and marketing of race-based pharmaceuticals, for example.[344]

Table 1: Respondent Self-Identified Sociodemographic Data.



[344] Mersha "Self-reported Race/Ethnicity in the Age of Genomic Research," *Human* Genomics (2015).

Age

There were no respondents 38 years of age or between 55 and 67 years old. Thus, there is no data for that age cohort. Respondents average age was 42.56 years old. This cohort is firmly situated in Generation X and thus would perhaps lend itself to a statistical skew in quantitative research. However, as this study has a phenomenological research design, the use of this group allows for a richer—and perhaps more complex—examination of the doctor-patient interaction because participant experiences span from the time of medical paternalism to the expansion of medical professionalism and patient autonomy, to what has become (or is becoming) something more genomic, technological, commoditized, and commercialized.[345]

Gender

As previously noted, did not offer participants *a priori* gender categories. Gender identification, gender dysphoria (or gender incongruence) and the idea of characterizing one's self as non-binary[346] has become more mainstream, and more socially and medically complex than previous generations.[347] These cultural and gender

[345] Charles S. Bryan, "Medical Professionalism Meets Generation X: A Perfect Storm?" *Texas Heart Institute* 38, no. 5 (Nov. 2011): 465-470.

[346] Individuals who are non-binary do not perceive themselves as being either male or female. Instead, they identify as a-gender, intergender, transgender, lesbian, gay, or bisexual for example. Note Christina. Richards, Walter Pierre Bouman, Leighton Seal, Meg John Baker, Timo O. Nieder, and Guy T'Sjoen, "Non-Binary or GenderQueer Genders," *International Review of Psychiatry* 28, no. 1 (Jan. 2016): 95-102. Doi: 10.3109/09540261.2015.1106446.

[347] Sam Winter, Milton Diamond, Jamison Green, Dan Karasic, Terry Reed, Stephen Whittle, and Keven Wylie, "Transgender People: Health and the Margins of Society," *Lancet* 23, no. 388 (Jul. 2016): 390-400. Also note Heather Dean Glessner, Erin VandenLangenberg, Patricia McCarthy Veach, and Bonnie S. LeRoy, "Are Genetic Counselors and GLBT Patients 'on the same page'? An Investigation of Attitudes, Practices, and Genetic Counseling Experiences," *Journal of Genetic Counseling* 21, no. 2 (Apr. 2012): 326-336.

shifts must be taken into account when attempting to better grasp and ultimately depict one's study population.

Amongst the study population, five individuals identified themselves as male. Eight participants self-identified as female. One person self-identified as non-binary and another person identified as queer—both preferred masculine pronouns when asked. Another respondent simply wrote in the words "not significant." These characterizations are relevant to the study of personalized medicine and its trajectory because the past few years have been met with an increase in the number of people who experience (or whom can openly discuss their experiences of) gender dysphoria. This may reveal and/or develop an upsurge in the number of people whose social and physical identities are incongruent with their genetic (genomic) material. According to Carlo Trombetta et al., "there has been a large increase in referrals to gender identity services for children and adolescents in Western countries. This is probably due to an increase in social awareness or better recognition of the conditions in these countries."[348] It is also significant to note contemporary conceptualizations of gender because its interplay with race may directly or indirectly negatively affect one's health outcome.[349] There are also limited scholarly

[348] Carlo Trombetta, Michele Bertolotto and Gioanni Liguori eds., *Management of Gender Dysphoria: A Multidisciplinary Approach* (New York, New York: Springer, 2015):62

[349] Vickie M. Mays, Susan D. Cochran, and Namdi W. Barnes, "Race, Race-Based Discrimination, and Health Outcomes Among African Americans, "*Annual Review of Psychology* 58 (Jan. 2007): 201-225. Doi:10.1146annurev.psych.57.102904.190212. Also note Leonard E. Egede, "Race, Ethnicity, Culture, and Disparities in Health Car," *Journal of General Internal Medicine* 21, no. 6 (June 2006): 667-669. Doi:10.1111/j.155-1497.2006.0512.x.

dialogues and/or literature examining the ethical and social role, responsibilities, or limitations of genomic medicine and health care in those instances.[350]

Occupation

Respondent occupations were categorized *a posteriori* into one of four categories: blue collar (jobs that require manual labor), white collar (professional, managerial, administrative, office work) pink collar (jobs in the service industry such as waiters, bartenders or chefs) and academia (jobs in post-secondary education).[351] Within this study population, two people had blue collar jobs— both were ex-military. Eight people had white collar jobs (including two pharmacists, a health information services officer, and a secretary), seven people were in academia (including two academic advisors, one adjunct and four graduate students) and two individuals held pink collar jobs (one was a cake decorator and the other was a chef). The total number of individuals listed here is greater than sixteen because two participants had more than one job. There was no significant difference in respondent attitudinal responses relative to his or her occupation.

Qualitative Analysis

Many of the issues noted in respondent interviews echo the kinds of discriminations and disparities observed in the historical and contemporary literature. More specifically, experiences of discrimination based on race, citizenship,

[350] Anthony G. Fenech and Godfrey Grech, "Pharmacogenomics and Personalized Medicine: Does Gender Have a Role?" *Journal of the Malta College of Pharmacy Practice*, 20 (Summer 2014): 7-10.

[351] Subhashis Basu, G. Ratcliffe and M. Green, "Health and Pink-Collar Work," *Occupational Medicine* 65, no. 7 (Oct. 2015): 529-534. Doi:10.1093/occmed/kqv103.

socioeconomic status/perceived socioeconomic status, and sexuality were the four most reoccurring themes voiced within participants' narratives. Concerns about the current and future costs of pharmaceuticals and health care were also prevalent within respondents' interviews. Likewise, the chronology, linguistic representation, and tone of most of the narratives indicated apprehensions about personal agency as well as fear, disgust, anger, and tentativeness regarding health care accessibility. The following paragraphs are snippets of interviews discussing the fore noted themes related to access and discrimination, cost and accessibility, comparative chronology, and tonal analysis. These issues are important because they are a critical look at some of the broader medical and socio-medical effects of race and racialization in science and medicine.

Access and Discrimination

According to Kelly H. Hoffman et al, "individuals with at least some medical training hold and may use false beliefs about biological differences between blacks and whites to inform medical judgments, which may contribute to racial disparities…"[352] Such beliefs stem from normalized and legitimized ideologies of the molecularization and biologization of race and racialization that have persisted through history. Socialized ideas of the kind of Black/White dichotomies discussed in the Introduction of this dissertation also inform medical students' perceptions—and thus their treatments—of African American and White people. For example, in a recent study published in the

[352] Kelly M. Hoffman, Sophie Trawalter, Jordan R. Axt, and M. Norman Oliver, "Racial Bias in Pain Assessment, and False Beliefs About Biological Differences Between Blacks and Whites," *Proceedings from the National Academy of Sciences* 113, no.16 (Apr. 2016): 4296. Doi:10.1073/pnas.156047113.

Proceeding of the National Academy of Sciences, some of the racially biologized ideas existing amongst medical professionals included beliefs that the nerve endings of African Americans were less sensitive than their White counterparts; the notion that the blood of African Americans coagulated more slowly than Whites; that White people had larger brains than African Americans (and thus greater inherent intellect); that the skin of African Americans was thicker than their White counterparts; that African Americans were more fertile than White people; that African Americans had more efficient respiratory systems than Whites; and that African Americans had stronger immune systems than Whites.[353]

As noted throughout this dissertation, race and racialization are socio-historical constructs. Racial labels change through time as does the racialized characteristics applied to them. Thus, the use of race and racialization as molecular and biological concepts in science and medicine fails to acknowledge their ambiguity and disregards the social ideologies that have legitimized their perpetuation.

For example, respondent K.N. discussed in her interview for this dissertation the extent to which her ascribed race fails to reflect the complexity of her ethnic heritage. The following snippet of her narrative also speaks to the extent to which race and racialization work to reinforce broader social dynamics including hierarchy and stigma. Her narrative, then, paints a picture of the ways that race and racialization are ascribed,

[353] Hoffman, "Racial Bias in Pain Assessment," (2016): 4296-4301.

operationalized, and internalized by the individual receiving the label as well as the society giving it. The excerpt of her narrative is as follows:

> My mother is a Desi from Tamil in India. So, she has a fairly dark brown complexion. She left India with my father who is part Indian—feather not dot—Guatemalan, and Papua New Guinean, basically. I don't know if you've seen those folks but everybody's brown. So, I'm brown. We are basically the same color. I think that's why my mother liked him. He didn't look down on her because she was brown—like most people in India STILL do—and he didn't have that crazy British, colonialist mentality that many Indian people have. As far as I know, my ancestors were never slaves. Which is not like it's a big deal but everywhere I go and on everything I fill out regardless of what kind of form it is or if I fill it out or someone who doesn't know my story (pauses) I'm Black or African American to them and perhaps even to myself. They look at me and my brown skin, and muscular body, and almond shaped eyes and *they* decide that I am a Black person. They decide that I am African American. I used to sort of verbally fight the issue, but you start to feel isolated and sometimes pompous, disrespectful, or ridiculous for always having to tell your story and explain your heritage. It's a fine line because I live the life of a Black woman with all the ridicule, the oppression, the supposition about my lifestyle or sexual habits, or proximal development. (pauses) I live it because of that assumption which is fine because it is my reality but also not fine because it is not my truth. It is like a (pauses) like a complicated projection of a body that exists outside of a person as a person, like outside of a person's body and their psyche, if you will. Who am I then if I'm not a Black person when my skin, my biggest organ apparently, and society say otherwise? You see what I'm saying? . . . someone told me one day when she was taking my medical history "Duh, your Black." I didn't laugh with her then, I just said in a mumbled tone that I was Asian. I've even had doctors try to tell me about how Black people's bodies do this different or handle that differently without ever actually speaking with me about my actual, individual body and what's going on with *it*. It's just frustrating. So, I let people choose who I am on any given day. No wait, I don't let them choose, they choose of their own free will because the rest of society or the world or whatever tells them that they can.

K.N.'s narrative speaks to what Emmanuel Levinas referred to as "totalization." Totalization is a kind of violence acted upon someone—the *Other*—by denying him or

her autonomy.[354] It is the predetermination of an individual based on a judgment of their race, socioeconomic status, and/or sexual orientation. Through totalization, one pre-creates a perception and characterization of an individual that he or she is unable to escape. If the social majority's perception of that individual or group of people is cut off from the minority group's subjective reality, the labeled person will exist primarily within the confines of the majority group's perceived/totalized identities. [355] The creation and perpetuation of totalized identities are legitimized when used in science and medicine because those fields are often perceived as existing outside of the subjectivities of society—so the bias becomes viewed as an objective truth.

K. N.'s narrative snippet is also informative because it exemplifies what Franz Fanon problematized as the complex psychic and social dimensions associated with internalizing totalizing, subjugated identities while simultaneously contesting them.[356] In other words, K.N. is both living in and contesting an identity impressed upon her. Sociologist and group psychoanalyst Farhad Dalal described circumstances such as K.N.'s as the "structure of the psyche and the structures of society reflecting and reinforcing each other" in that the racial and racialized categories K.N. was put in shapes

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[354] Emmanuel Levinas, *Totality and Infinity: An Essay on Exteriority*, translated by Alphonse Lingis (Pittsburgh, Pennsylvania: Duquesne University Press, 1969).

[355] Hans-Georg Gadamer, *Truth and Method* 2nd ed., translated by Joel Weinsheimer and Donal G. Marshall (New York, New York: Continuum Publishing Group, 1989). The blending or fusion of horizons is Gadamer's metaphor referring to the process through which our present understanding of a situation or person, for example, is expanded beyond our point of view or line of sight (literally and figuratively). Thus enables one to learn something new and valuable from the new perspective. Also note Jeff Clark, "Philosophy, Understanding and the Consultation: A Fusion of Horizons," *British Journal of General Practice* 58, no, 546 (Jan. 2008): 58-60. Doi:10.3399/bigp08X263929.

[356] Ibid.

her engagement with society as well as her perception of herself *within* society.[357] Finally, K.N.'s narrative snippet speaks to the ways in which race and racialization are social constructs. Additionally, the social ascription and biologization of race are shown as dissonance between one's racial and ethnic identities.

To this end, K. N.'s narrative is recognition of the scientific, medical, and social distortion between self-identified, assigned, and assumed racial categorization.[358] It also notes the disconnect between the socio-historical constructions of race and racialization, and the increasing complexity and heterogeneity of people's ancestry. Most importantly, K.N.'s narrative excerpt speaks to why and how race is not genetically encoded and thus is an inappropriate proxy for genomic research—specifically pharmacogenomics and genome wide association studies. We, in the medical community, must use such examples to question the utility and validity of molecularizing race in processes like pharmacogenomics and genome wide association studies. Without acknowledging the inherent problems of using race and racialization as molecular and biological concepts, the scientific and medical community risks further legitimizing the kind of race-based biases embedded in medical inequity.

These assumptions are culturally malignant in that they not only influence physician prescribing tendencies but also the general doctor-patient engagement as a

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[357] Ibid., 7-8.

[358] Timothy R. Rebbeck and Pamela Sankar, "Ethnicity, Ancestry, and Race in Molecular Epidemiology Research," *Cancer Epidemiology, Biomarkers and Prevention* 14 (Nov. 2005): 2467. Doi:10.1158/1055-9965.EPI-05-0649

whole. As genomic medicines and medical practices like pharmacogenomics and genome wide association studies become embedded in the fabric of health care, the kinds of racially biologized concepts referenced in the preceding paragraph will be further mapped on to and into the epistemologies, interpretations, and process of the scientific and medical endeavor. As with many other such instances that have occurred through time, those ideologies will be normalized, legitimized, socialized and heralded as objective within scientific and medical communities. According to Gorgio Agamben and Zygmat Bauman "to the conscious understanding of agents, such as researchers, medical doctors, or lawyers, these phenomena will appear more as blind zones and un-intended consequences than as intended action."[359] Nonetheless, to those individuals who are directly and indirectly affected by racial and racialized molecular and biological supposition, the individual intentionality of the researcher or physician is surpassed by institutionalized thanatopolitical medical systems that facilitate and perpetuate inequity.

One of the most pervasive examples of this is the overrepresentation of minority peoples in the inadequate treatment for acute and chronic pain management. According to a recent study published in the *Journal of Clinical Orthopedics and Related Research*, for example, the undertreatment of pain for minority populations is largely due to physicians who are unaware of their own cultural beliefs, subjectivities, and/or stereotypes regarding minority peoples, pain management, and the use of narcotic

[359] Bauman and Donskis, *Moral Blindness*, (2013): 178.

analgesics.[360] Persisting stereotypes feed the kinds of medical inequities discussed by many of the respondents of this study.

For example, according to respondent C.C., stereotypes regarding the African American threshold for pain and/or the abuse of controlled substances (such as pain medications) precipitate disparities in pain management between racial groups. During her interview, she provided the following perspective:

> I have actually had to correct one of my Techs who (pauses) ok, so there is an issue with people abusing pain medications, or narcotics or sedatives, oxycodone or whatever and an issue of people selling those things on the street. So, the Tech was just turning people away and wouldn't fill their prescriptions for those kinds of things. So, I was noticing that if it was a Black person that she would just turn them away but she would fill those prescriptions for people of other races. She would just turn the Black people away. But, when you can look at their profile you can see how often they get it filled. Now there is this thing out here where you can log into it and (pauses) say if I pull up your name I can see all of the controlled substances that you've gotten filled at different pharmacies. People would get away with filling out a prescription at one retail pharmacy and they don't know that the person also just got one filled at another retail pharmacy because they don't have access to each other's systems. The person may even have gotten them filled the same day—two different doctors with two different prescriptions. So with this new system, it will get rid of that issue. I can go in and see that someone just got one filled two days ago. Another way is to look for trends. Are they doctor shopping? Are they on all these different kinds of controls? So, there are a lot of different red flags.
>
> So, I said "um, what's the problem with that?" She didn't really have a good reason. So, I said "before they leave let me see the prescription. Let me be the judge of what happens here." So, she was being like the gatekeeper whereas I would be the person that needs to decide and I needed to see if there was an issue or if there was something that made me think that there was a problem. So, I was just realizing that if it was a Black person that she was more likely to treat them like they were a drug abuser or whatever and thus their prescription didn't need to be filled.

[360] Jana Mossey, "Defining Racial and Ethnic Disparities in Pain Management," *Clinical Orthopedics and Related Research* 469, no. 7 (Jul. 2011): 1859.

> It was her personal bias. This was a Hispanic young lady and I already knew that she has certain biases toward people because she would outwardly say things that were very critical without knowing that she's saying things that were very critical or inappropriate. So, based on my observations I realized that she didn't even know that she was feeling those things necessarily. So, I just basically took away her ability to make that judgment—I took away her ability to make that decision.

Again, preconceived notions of race and racialized behaviors (such stereotypes regarding the abuse of controlled substances) work as primary agents prohibiting an individual's access to medical goods and resources—thereby potentiating thanatopolitics. Such issues, in addition to those of cost and access were repeatedly articulated in respondent narratives. Respondents healthcare phenomenologies also depicted a lack of confidence in the health care system, decreased feelings of agency, decreased quality of care, decreased continuity of care, anger, and fear. These experiences and feelings are significant to understanding the broader medical and socio-medical affects of a shifting health care systems on poor and minority peoples.

For example, respondent U.A. spoke of the relationship between medical inequity, his ethnicity, and his perceived citizenship status. In synthesizing those three issues, he was ultimately discussing structural violence based on racialized system. According to J.A. Powell, Williams Chair in Civil Rights and Civil Liberties at the Moritz College of Law at Ohio State University, the kind of system U.A. speaks of is one in which "macrolevel systems, social forces, institutions, ideologies, and processes interact with one another to generate and reinforce inequities among racial and ethnic groups."[361] As

[361] Gee, Gilbert C. and Chandra L. Ford, "Structural Racism and Health Inequities," *Du Bois Review* 8, no. 1 (Apr. 2011): 117. (115-132). Also note Powell, J.A., "Structural Racism: Building Upon Insights of John Calmore," *Berkeley Law Review* 86, no. 791 (2007): 791-816.

noted in U.A.'s narrative snippet, the socio-medical affects of race and racialization are immediately recognizable in the medical encounter.

U.A. discusses some of the effects of these issues on negative health outcomes in the following excerpt of his interview:

> The reason I feel like it is more prevalent here in the United States is because a lot of Hispanic people are immigrants (pauses) illegal immigrants and going to the doctor is scary because they feel like they are going to get turned in to immigration and get deported and everything or that they [the hospitals] are not going to accept them because they are illegal or that they won't be treated well because they *are* illegal or because they're fat, or because they're Hispanic [emphasis his]. Being Mexican *and* an immigrant (pauses) even if you have your green card or you were born here, people treat you like shit, like you're stupid or like you work for them or should work for them [emphasis his]. So, when you're sick on top of all of that, people just like (pauses) especially like doctors and nurses and stuff (pauses) they treat you like you have done something wrong; like you're a burden and they could be doing something else or helping a real person. And I think *that* is a big part of the reason why so many people are sick [emphasis his]. On the one hand they don't want to lose touch with their cultural heritage so they will continue eating the food etcetera but then they also have that fear of like going to get a check up to make sure everything is ok or to see if maybe I need to change up my diet or something or I need a little bit more exercise and getting deported or being treated like, like an immigrant or a fatty or like, like (pauses) like you're not a child of God or something. . . . But, I do think that the combination of the cultural but also that very real fear of being deported or humiliated or talked down to or whatever is why there are so many Hispanics with those kinds of diseases and nobody really talks about that part of it.
>
> I maybe should also mention that I have another family member who was from Mexico, my cousin. He recently passed away due to cancer. So, and (pauses) he was twenty-six and I think that right there (pauses) that he died because he like didn't really understand how cancer works and because he didn't want to be deported or deal with all the crazy shit I mentioned. So, he died.

In that snippet, respondent U.A. speaks of a group who are reluctant to seek medical care because they fear deportation but also because they fear stigma and discrimination by medical professionals—so much so that his cousin chose not to seek medical care for cancer. Thus, U.A.'s perception of the collective health outcomes of Hispanic peoples in the United States is tied to their engagement with a medical system they perceive as facilitating medical inequity on the basis of ethnicity and perceived citizenship. The article "Life in Three Deaths: Thanatopolitical Biopoiesis and Militaristic Nationalism," attempted to address the complexity of health and citizenship in a racialized medical system in stating that:

> In many obvious ways, the category of citizenship has been subjected to shifts in biological science and biotechnology, fields that directly attempt to understand and control life processes, including the coming into being of ongoing racist, eugenic, and genetic projects that actively aim to demarcate the healthy, competent, and desirable citizen.[362]

By simply using the word "ongoing", the fore noted quote articulates the history and trajectory of race and racialized scientific and medical endeavors. Meanwhile, individuals like U.A. and his cousin exist in a kind of liminality between the threshold of biopolitics, geopolitical boarders, and the need for biological citizenship—as their health outcomes are tied to their ethnicity, citizenship, and perceived citizenship.[363] Also, their fears of deportation are not unfounded.

[362] Ibid., 428.
[363] Rachel Shields et al., "Life in Three Deaths" (2014): 425-437.

When an individual is deported by a hospital, as opposed to the federal government, it is referred to as medical repatriation. There is no regulation. There are no limitations or statues in United States Law and patients can be repatriated without consent.[364] However, medical repatriation is not considered "patient dumping"—refusing or referring patients who are unable to pay for care to another facility—because Emergency Medical Treatment and Active Labor Act (EMTALA) requires that all individuals (illegal immigrants or not) be medically stabilized before release. Once the individual is stabilized, however, he or she can be deported—medically repatriated.

Processes like medical repatriation facilitate fear and medical inequity. They increase the potential of negative health outcomes and/or death by normalizing the behaviors of racialized systems. To this end, the experience of fear and medical inequity are the socio-medical and medical affects of the thanatopolitical system that is medical repatriation.

For some respondents, like G.S.80, discrimination and medical inequity were not facilitated by perceived, race, citizenship, or cost. Instead, his experience with disease-related stigma, discrimination, and desensitization defined his perception of health care and ascribed him the status of social deviant. A snippet of his narrative is as follows:

> I was working here at this job and when I got hired they said pick a doctor off of the approved list and I picked a doctor. I came to work one day and I couldn't see. My eyes were burning and I could *not* see [emphasis his]. So, I called this

[364] Michael J. Young, M. Phil, and Lisa Soleymani Lehmann, "Undocumented Injustice? medical Repatriation and the Ends of Health Care," *New England Journal of Medicine* vol. 370., no. 7 (Feb 2014): 669-673. Doi. 10.1056/NEJMhle1311198

> doctor on the list and some receptionist on the phone or somebody answered the phone and I said "I need to see somebody because my eyes are burning." And, the receptionist person said "Are you gay? You sound like one of those gay men? Do you know what kind of doctor this is?" and I was like "No." And then she responded by saying that "This is a *regular* doctor [emphasis his]. He does not see AIDS patients. I assume you are HIV positive. Are you HIV positive?" I was like "No, I'm not! I just assumed that the doctor saw people who were gay or whatever. But, I don't have HIV or AIDS!" Then she went on to say that I needed to understand that *that* doctor only saw *regular, normal people* [emphasis his] who were not HIV positive, that he only saw normal patients and not patients that went against God and society and that there was nothing he could do for me [emphasis his]. See, I've been gay since the 80's when people hated you and would rather spit or piss on you than stand next to you let alone parade with you down the street. They feared you. When AIDS came out no one knew what it was or how it was contracted just that gay folks had it. So, they blamed you. They hated you. Even after that Italian model (pauses) Gia died of AIDS people still blamed us—all of us. They despised you—doctors, nurses, people on the street, everybody. They didn't care to know you or help you or care for you. They hated us (pauses) called us abominations to our faces. Can you imagine? So anyway, I couldn't get the help I needed and my eyes continued to burn from that day until they stopped burning on their own. And I don't think I've ever been or even tried to go to the doctor since then and (pauses) because of (pauses) because of that experience. I was trying to get help and I could not get the help that I needed. (pauses) I tend to try to be pretty healthy and generally take care of myself.
>
> Now, you can say that you are gay or sick or whatever and don't have to worry about being fired or physically harmed, but (pauses) I just can't bring myself to do it. You had to live in secret then and I guess a part of me still feels like that—like I need to live in secret. And, she broke my trust so that's that.

The kinds of medical avoidance that G.S.80 talks about is indicative of the kinds of broader socio-medical ideologies that saturate society and have evidenced the normalized subjectivities historically and contemporarily inherent in the institution of medicine. Granted, all health care professionals or members of lay society do not contemporarily believe that gay men are deviant or diseased, but there was a time when disenfranchised, already marginalized members of the gay community were further

stigmatized and discriminated against because of their perceived affiliation with an ominous epidemic—gay-related immune deficiency (GRID), as it was originally called.[365] Because AIDS was a degenerative disease that was contagious, readily apparent, and perceived as being the fault or responsibility of the person infected, the stigma and discrimination of people with AIDS (PWAs), people suspected of having AIDS, and the general hysteria associated with the disease were all magnified.[366] According to Gregory Herek, the "lack of accurate information about its transmission, and a willingness to support draconian public policies that would restrict civil liberties in the name of fighting it" changed the kind of discrimination and stigma experienced by AIDS patients and gay individuals from a series of micro occurrences to a systemic, macro-level event—thus changing their socio-medical identities and facilitating a clear thanatopolitics.[367]

While discourses on the medical, and social implications of race, racism, and discrimination in general continue to be intellectualized amongst a variety of medical and academic disciplines, its impact has yet to effectively penetrate the epistemologies and praxis of the medical and biomedical industries.[368] This is perhaps due to the centuries of scientific racism that worked to legitimize inequity. However, we can not begin to

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[365] Gregory M. Herek and Eric K. Glunt, "An Epidemic of Stigma: Public Reactions to AIDS," *American Psychologist* 43, no. 11 (Nov. 1988): 886-891. Doi:org/10.1037/0003-066x.43.11.886.

[366] Gregory M. Herek, "AIDS and Stigma," *American Behavioral Scientist* 42, no. 7 (Apr. 1999): 1106-1116. Doi/abs/10.1177/0002764299042007004.

[367] Ibid., 1106.

[368] Mays, "Race, Race-Based Discrimination, and Health Outcomes Among African Americans," (2008). Also note O. Kenrik Duru, Nina T. Harawa, Dulce Kermah, and Keith C. Norris, "Allostatic Load Burden and Racial Disparities in Mortality," *Journal of the National Medical Association* 104, no. 1 (Jan. 2012): 89-95.

discuss the acute and chronic effects of the molecularization and biologization of race and racialization in science and medicine if we are unable to first acknowledge that they exist. Instead, we (members of the academic, medical, and scientific community) have reified biological reductionism and genetic essentialism and used their bases as the most relevant and meaningful proxies for medical and social scientific research and practice. Moreover, according to Foster and Sharp, "the difference in power and privilege between researchers and socially defined populations lacking in significant economic and political resources may affect the ability of the latter to conceptualize and negotiate the conditions for research participation and to take effective action on any subsequent concerns about sample misuse or adverse interpretations of genetic findings."[369] This disenfranchises racialized bodies relative to their use as research subjects and relative to the interpretations and democratization of the applicable data. It also further victimizes them within the framework of medical progress. These basic premises and issues relative to the molecularization and biologization of race and racialization within genomic medicine and genomic scientific/medical endeavors is further evaluated in the following attitudinal analysis of respondent perceptions.

Cost and Access

Within respondent narratives, cost and access were discussed as dynamic concerns reflecting such issues as the price of pharmaceuticals and private insurance, the amount of time (relative to cost-benefit) one spends searching for a physician that will

[369] Morris W. Foster and Richard R. Sharp, "Race, Ethnicity, and Genomics: Social Classifications as Proxies of Biological Heterogeneity," *Genome Research* 12 (Sep. 2016): 844-850.

take government subsidized insurance, one's ability to directly and immediately access health care, and issues of care continuity.[370] Self-medicating was also a recurring theme within respondent narratives relative to cost—albeit with much less frequency. As previously noted, the cost of pharmacogenomics is unlikely to be less than that of contemporary blockbuster pharmaceuticals. Thus, if one's inability to access and/or afford current forms of medications is an indicator of his or her ability to afford future pharmaceuticals, it can be inferred that many individuals may be left with prescriptions for pharmacogenomics that he or she can not afford.

The Affordable Care Act and the Department of Health and Human Services' Disparities Action Plan were designed to help quell the issue of health care affordability by increasing health care coverage for low and moderate income families and vulnerable populations. The Affordable Care Act and the Disparities Action Plan was also supposed to increase country-wide disease prevention and public health initiatives to further address problems associated with health care costs and accessibility.[371] Unfortunately, while laudable, these programs only scratched the surface of the complex and interrelated structural barriers that facilitate and perpetuate intergenerational health disparities,

[370] In an attempt to maintain thematic integrity, the metaphorical use of the term "cost" was not reassigned under a different category. Instead, when and/or if a respondent used the term relative to a cost-benefit analysis, it remained as a part of the broader conceptualization of the term.

[371] Petry Ubri and Samantha Artiga, "Disparities in Health and Health Care: Five Key Questions and Answers," *The Henry J. Kaiser Family Foundation Executive Summary Issue Brief no. 8396* (Washington, DC, Kaiser Family Foundation: Dec. 2012).

discrimination, and general poor quality of care—even when controlling for cost, access, and insurance.[372]

Intergenerational medical inequity and disparity continue to plague minorities, the marginalized, and the otherwise impecunious people of the United States—with no evidence of meaningful or lasting structural and societal changes on the horizon. Hence, contrary to the clinical proficiency said to be inherent in pharmacogenomics and genome wide association studies, we can begin to assert that the proliferation of niche markets relative to genomic medicine and health care, for example, will further amplify medical inequity and disparity for poor and minority peoples. As previously noted, this process will also likely increase feelings of agentic deficiency amongst those individuals most directly affected unaffordable health care and/or health care related services.[373]

The plight of M.P. is an elaboration of such an issue. She stated in the following excerpt of her narrative that:

> I am completely for Obamacare. I think everyone should have access to health care. So, it's frustrating to kind of run into all of these road blocks and it's interesting too because I have had doctors make the appointment and they take that kind of health insurance but then they'll call back about a day or so later like "Is this a Marketplace plan?" Then, they say that they can see me but I would have to pay out of pocket. So, yeah. They can see you but it will be about four or five hundred dollars. I started like calling (pauses) because my insurance sent me a list of approved providers. So this is actually going off of their website's list in my area that take that insurance but then, again, when you go down the list it's

[372] B. Mitchell Peck and Meredith Denny, "Disparities in the Conduct of the Medical Encounter: The Effects of Physician and Patient Race and Gender," *SAGE* 2, no. 3 (Sep. 2012): 1-14. Doi:10.1177/2158244012459193. Also note Rachel L. Johnson, Debra Roter, Neil R. Powe, and Lisa A. Cooper, "Patient Race/Ethnicity and Quality of Patient-Physician Communication During Medical Visits," *American Journal of Public Health* 94., no. 12 (Dec. 2004): 2084-2090.

[373] Bruce Quinn and Foley Hoag, *The Future of Coverage and Payment for Personalized Medicine Diagnostics* (Washington, DC: Personalized Medicine Coalition, 2015).

> something different. I found (pauses) I think it was like the seventh or eighth person who would finally see me and I had to wait *a month* [emphasis hers] I think before they had an available time slot. And, they were actually very sympathetic and were saying that like "we're very booked because a lot of people have this problem." So, I self-medicate. It can get to a point where (pauses). You know, I am relatively healthy. So, I haven't (pauses) it hasn't gotten to a point where I needed to see a doctor in a short amount of time. So, luckily it hasn't really gotten to the point where I have to really try to figure it out. But like, if you get the flu or a cold I don't go to the doctor I just self-treat it with some Theraflu or something unfortunately. But, it is scary knowing that you don't really have that resource that you need if something did get bad. It's like you have the illusion of having it because a part of actually having it is being able to access it. It is almost like it is kind of like a mask to avoid the tax penalty. So, it's like you have insurance so you avoid the tax issue but you don't have any of the benefits from it.

The tax penalty she is referring to is also called the *individual mandate* and is associated with the Affordable Care Act. This mandate views an individual's lack of health care insurance as a kind of inactive citizenship (similar to not filing one's taxes, failing to report to military duty, or not registering for selective duty) and carries a monetary, negative sanction referred to as the individual shared responsibility payment—the tax or penalty.[374] In 2016, the penalty for being uninsured was just under seven hundred dollars for an adult and just under three hundred-fifty dollars for a child—which amounts to approximately 2.5 percent of an individual's household income above the filing threshold depending on the person's filing status[375]

[374] Jeffrey J. Lee, Deena Kelly, and Matthew D. McHugh, "Health Reform and the Constitutionality of the Individual Mandate," *Policy, Politics and Nursing Practice* 12, no. 4 (Nov. 2011): 236-244. Doi:10.1177/1527154411432645.

[375] U.S. Centers for Medicare and Medicaid Services, "If You Don't Have Health Insurance How Much You'll Pay," *U.S. Federal Government*. Healthcare.gov/fees/fee-for-the-not-being-covered/. Accessed September 22, 2016.

Individuals who would have been unlikely to have health insurance in the past (for whatever reason) are required to obtain it now or be penalized. However, as noted by M.P., having insurance does not necessarily equate to being able to access health related services in any meaningful way or timely manner. In these instances, the individual mandate acts as a negative, biopolitical sanction applied to the American populace in the name of public health.[376]

M.P.'s narrative is thereby a depiction of biopolitics and a reiteration of the ways in which poorer health outcomes are facilitated by persisting inaccessibility to health care or health care related services. Yes, she technically has health insurance but if one has to wait a month or more to be seen by a physician it is not illogical for to assert that she does not *actually* have entrée to that benefit. Also, given that most viral and bacterial infections may only last about two weeks, by the time she is likely able to get in to see her doctor her sickness may have already subsided.

Such a situation is analogous to that of someone who owns a car but can only drive it once every month or two. Eventually, that person may begin to feel that the car is not actually his or her property. Occasional access to the car would also have no major impact on his or her daily transportation needs, his or her ability to access locations beyond the vicinity of public transportation, and could potentially compound costs relative to the need for vehicle maintenance *and* bus, Uber or taxi services. Similarly,

[376] Paul Rabinow and Nikolas Rose, "Biopower Today," *BioSocieties* 1, no. 2 (Jun. 2006): 195-217. DOI: 10.1017/S1745855206040014.

according to respondent M.P., having governmental health coverage provides a miniscule amount of assurance and does not account for the costs of self-medicating versus that of risking the individual mandate tax.[377]

Respondent W.Y.'s health care phenomenology was also fraught with systemic health care accessibility issues, disparities, and discriminations. For her, however, the decreased ability to access regular doctor's appointments for therapeutic treatment of her chronic illness and prophylactic treatment of other more acute sicknesses, caused her symptoms to worsen over time. W.Y.'s difficulty accessing healthcare also negatively affected her continuity of care. During our interview she stated that:

> Unfortunately, I don't have health care coverage (pauses) per se. So, I have been left, basically, to navigate the Harris County Health System (long pause). In 2013 I had some health issues and ended up with pneumonia and was unable to get rid of it and ended up with a lung mass. So, I was going to [name omitted] hospital and they basically (pauses) after I returned a few times (pauses) urged me to get care under the Harris Health System because I didn't have private insurance. Eventually, I was fortunate enough to find out that I didn't have lung cancer or breast cancer, because I was tested for both. and that my lung (pauses) the lung mass was granulated so it would just basically dissolve over time. Eventually though, I ended up with (pauses) my home had mold in it which I suspected but I ended up having some more serious health concerns from the mold. And so *that* [emphasis hers] issue dealing with that with the Harris County Health System was well (pauses) different because I was not an immediate concern and so care was, at that point, so-so at best. I would say it was average at best. One of the problems I had was that there was no continuity of care. So, when I would receive or rather go to my appointments I would see one resident at this place on this day and I would see somebody different the next visit. So, the continuity of care and with the health issues I was having (pauses) I was having lung problems (pauses) so the care just was not adequate.

[377] R. J. Muise and D. Yerushalmi, "Wearing the Crown of Solomon? Chief Justice Roberts and the Affordable Care Act "Tax," *Journal of Health Politics, Policy and Law* 38, no. 2 (Apr. 2013): 291-298. Doi:10.1215/03616878-1966279.

> I'm forty-six years old (pauses) almost forty-six years old so I feel like I know my body and I know when something's not right and so, you know, being that I don't have a long history of care with this certain provider, they pretty much don't know you and know your body. It's like when I go in and I have a complaint or a concern it really was sometimes kind of brushed off. I would go in there and I would tell them "this is what's happening" and that it was the same way that I felt when I had pneumonia. I'd say, "My body feels exactly the same during that time that I had the lung mass." But, you know, they still just kinda did what they wanted to do. At one point I feel like I am having, well, I know that I am having, some memory loss right now and I have had a terrible time trying to convince them that I need to see a neurologist and then right now, see, I am waiting since when (pauses) I want to say December but it may have been October to see a rheumatologist for a diagnosis. I have some positive Lupus tests and I have some arthritis that has started but all they do is basically give me pain meds and say well we think that it is possible that you may have this but it is also possible that you don't and until you see a neurologist (pauses) I mean until to see the rheumatologist we won't have a definite diagnosis. But, I won't see (pauses) I can't see a rheumatologist until July which is about six months out. So, I am still waiting to see a rheumatologist.

According to respondent W.Y., when she needed immediate, emergency care she was able to get it. She went to the emergency room. She received all applicable testing, medications, and follow-up appointments. However, when her lung condition went from acute to chronic the immediacy and continuity of her care shifted dramatically. At the time of our interview she had already waited four months to see a rheumatologist and would need to wait another six months before being able to get in for an appointment. That is almost a year of waiting for a doctor's appointment. Meanwhile, over the counter ibuprofen and steroids have been suggested as a means of dealing with her pain. This matter further problematizes her plight in that some of the adverse effects of uncontrolled pain include the loss of physical strength, immune system impairment, and increased susceptibility to disease— issues which could potentially irritate her preexisting

conditions while simultaneously increasing her susceptibility to other diseases and/or sicknesses.[378] Additionally, although she pays very little for her health insurance, the costs for her prescriptions were double that of retail pharmacies. To an individual who earns less than 150 percent of the federal poverty level of $21,983 a year for two people, the differences in pharmaceutical costs could be astronomical.[379]

Additionally, narratives such as W.Y.'s outline the relationship between one's socioeconomic status and the inability to access consistent care or otherwise afford health care related services. They also evidence the reality that access to care and care continuity are not mutually exclusive. Instead, they bleed into each other and reveal how one's poor health becomes a consequence of his or her level of poverty (or perhaps a lack of private insurance).[380]

For example, in the interview with respondent B.D., she describes her experiences trying to afford medication and the effects of those circumstances on her health and quality of life as an attempt to navigate the complexities of being black and impoverished. She also discussed how cost and the embeddedness of race and racialization in medical engagements informed her continuity of care and interpersonal treatment in a teaching hospital.

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[378] Ronald Wyatt, "Pain and Ethnicity," *American Medical Association Journal of Ethics* 15, no. 5 (May 2013): 449.

[379] Note that her income approximation was obtained via the eligibility standard outlined on the website for Health and Human Services Assistant Secretary for Planning and Evaluation (HHS ASPE) located at http://aspe.hhs.gov/poverty/14poverty.cfm.

[380] Gay Becker and Edwina Newsom, "Socioeconomic Status and Dissatisfaction with Health Care Among Chronically Ill African Americans," *American Journal of Public Health* 93, no. 5 (May 2003): 742-748. PMCID:PMC1447830.

B.D. elaborated on her perspective by discussing some of the details and difficulties she experienced while trying to access her medications. She explained how the limited access to medications and/or medical supplies, their lack of affordability, and her decreased quality of life were indicative of a general lack of continuity in her medical care. The following except is a snippet of that discussion:

> . . . the worst experience I have ever had was with trying to get medication because I only went to that doctor one time and they were asking me about my diabetes and they asked me how I treat it. They were like "is it shots?" and I was like "no, it's a pump" and of course with the pump it is considered medical supplies which goes into the whole pharmaceuticals issue and whether or not you would have to pay half or eighty-twenty and all of that fun stuff. . . . Anyway, I went [to this clinic] and the guy told me that they would not give me a prescription for insulin. Yeah, and so I was like what the fuck? I need insulin to live. Right! So, either you can give me a prescription or I can go to the hospital because I don't have any more insulin. And then I was told that the reason I could not get a prescription for insulin is because I have an insulin pump and that was not something that the resident seeing me this time was familiar with. So, then I was like ok, I can just go back to taking shots and you can just give me a prescription for insulin and the syringes. Then she says, "well, no, because I know that you are on the pump I can't do that." I was like lady this doctor just told me that she would not prescribe my insulin for me. That's crazy! I mean, imagine someone telling you that I am just not going to give you the medicine that you need to live. Now, the cost of the insulin was a completely different issue because like, I was taking about (pauses) at that time I was taking (pauses) it was about $108 per bottle and I want to say that I was taking about three bottles a month and so, yeah, it got a little bit costly. So, you get to the point where you're like well, am I going to eat? What can I eat that is not going to take too much insulin? . . . I do have one medication that is really like a blood pressure medication and its function is really to just guard my kidneys. And that one I just started (pauses) like it's a daily pill and I just started spreading it out. I was like, well, as long as it's still kinda' in my system it is still doing something. You know, you just kinda' become your own doctor in that aspect because you have to be realistic. If I take it daily it's going to run out really quickly. So, I am going to take it maybe every other day or maybe every third day just to keep it in my system.

I am disinclined to consider her particular situation the effects of medical negligence or maleficence. Instead, I would assume that the Resident in question was simply adhering to a medical or clinical code that would not allow him or her to write a prescription for a pharmaceutical and medical device that he or she was not familiar with. As such, B.D.'s resulting circumstances evidence an additional aspect of the imbrication of medicine and society in which impoverished people without a continuity of care may also have a more difficult time accessing health care and/or health care related services. An inability or decreased ability to access certain kinds health care or health care related services due to one's economic or socio-economic standing is one of the many ways in which thanatopolitics becomes institutionalized and thereby normalized in society.

B.D.'s childhood and adult experiences with the medical community (whom she described as having difficulty reconciling the that she is an African American female with Type-1 diabetes as opposed to Type-2 diabetes) also made her ability to access pharmaceuticals and consistent health more difficult. In her interview for this dissertation, she stated that medical professionals frequently assume that because she is an African American she does not fully understand which type of diabetes she has (and thus her diagnosis is a mischaracterization). She also stated that they generally do not fully review her medical file or history before making that assumption and they become fatalistic relative to her potential survival rate and risks upon diagnosis confirmation. B.D. went on to share that she is rarely asked about her *actual* condition, her ability to comply with the demands of her disease, or her quality of life before being told that she

simply needs to exercise to address the upper body obesity characteristic of her assumed race and chronic disease.

The fore noted excerpt is not only a telling example of the plight of some low-income individuals but it is also a microcosm of contemporary healthcare systems. These systems or mechanisms of care force patients to compartmentalize their healthcare needs—as opposed to engaging with them holistically— by seeking medical professionals in different areas of specialization for different symptoms and different therapeutic or prophylactic care plans. One might assume that the cohesion of the services would be performed by the Primary Care Physician(PCP). However, as B.D. indirectly pointed out, many clinics are staffed with medical students doing their residency. For one reason or another, upon completion of their residencies, Residents tend to depart from that location. This leaves many of the clinic's patient without consistent PCPs—an issue which negatively affects the quality of life and continuity of care for clinic patients. In B.D.'s case, the discontinuity of her care and the lack of a PCP essentially eliminated her ability to access the pharmaceuticals and applicable medical supplies that she needs to live.

For example, upon being denied insulin because of the medical Resident's lack of familiarity with her method of treatment, B.D. contacted a counselor at the clinic to discuss her options. Her description of the encounter with the clinic's counselor was as follows:

> So, I called this lady to tell her like this is what just happened. She told me to come by and when I got there she was like googling stuff and telling me stuff like maybe if I just tried to exercise more and I was like that is type-2 diabetes. I walked in and she's telling me about Type-2 diabetes stuff even after I told her on the phone and while I was standing there that I had Type-1 diabetes, that I needed insulin not exercise to live, and that I needed her to actually look at the history record thing I completed online for verification or insight. I kept trying to tell her that, that was type-2 diabetes stuff. That was not my issue. That was not going to solve my issue or help me when I run out of insulin. I was like lady this doctor just told me that she would not prescribe my insulin for me. That's crazy! But, she continued to tell me about all of the things I could do to make myself healthier without ever addressing what I could do to get the insulin I needed or looking at me in my face.

B.D.'s narrative speaks to some of the broader, more complex issues associated with race and racialization being used and perceived as molecular and biological concepts in medicine. More specifically, her narrative exemplifies the kinds of difficulties individuals face when racially biologized and molecularized characterizations of diseases and sickness are not in tuned with the expectations of health care professionals or the medical community. As we move into the age of genomic medicine—particularly pharmacogenomics and genome wide association studies—the socio-medical actualization of these methodologies act as potential hindrances to receiving health care for people who do not fit the normalized and legitimized profile of a particular disease. Thus, the potential issues minority peoples face are further nuanced by the perceived discordance between the race and racialization of certain diseases and the potential discontinuity of care experienced by poor people.

According to Becker and Newson's article on the interplay of one's socioeconomic status and dissatisfaction of care, "low socioeconomic status has potentially deadly consequences for several reasons: its associations with other determinants of health status, its relationship to health insurance or the absence thereof, and the constraints on care at sites serving people who have low incomes."[381] Consequently, the burden of illness is defined by the tautological, inextricable link between poverty and poor health—an issue that Western society has known about for decades and that does not seem to be changing in the foreseeable future.

As such, I hypothesize that it is the preexisting, structural disadvantages associated with poverty and the perpetuation of medical inequity and disparity that will inform how pharmacogenomics and genome wide association studies will impact lower income and minority peoples. As noted in chapter four, contemporary issues of cost and access act as predictors of some of the potential problems that can occur with the normalization of high cost, genomically based pharmaceuticals, and the use of race and racialization in genomic research—particularly genome wide association studies.

Comparative Chronology

Many of the participants' narratives obtained for this study had similar properties. Not only were they all self-reflective—a necessary component for most qualitative interviews—but they were also comparative appraisals of the study participant's

[381] Ibid.

perceived social expectations and personal agency. Likewise, the chronology of each respondent's narrative was a comparative (either comparing that present situation with that of the past or vice versa) that began in a time when the individual experienced the least amount of direct agency or when he or she relied heavily on proxy agency or via one's parents and one's parents' applicable insurance. This occurred contrary to the age of the research participant.

According to Albert Bandura's agentic perspective of social cognitive theory, human agency is characterized by self-reflectiveness which distinguishes between one's ability to have and apply direct personal agency, rely on a kind of proxy agency (agency via the help of other people), or rely on collective agency which is actualized by socially coordinative and interdependent means.[382] Within the context of the qualitative data obtained for this study, an individual's ability to either obtain and use private insurance, obtain and use governmental insurance or that of a proxy's (such as a parent or guardian), or one's need to seek health care via a community health facility or clinic, for example, was discussed in the respondent's narrative chronology by first articulating a period in time in which the individual seemed to lack direct personal agency. This chronological structure represented a time when they had what Bandura described as a reduced "capacity to exercise control over the nature and quality of their own lives"—hence the

[382] Albert Bandura, "Social Cognitive Theory: An Agentic Perspective," *Annual Review of Psychology* 52 (Feb. 2001): 1-26. Doi:10.1146/annurev.psych.52.1.1.

need to begin each narrative from a point in which he or she had (or has) the least amount of agency.[383]

Simply put, respondents were comparing their past and present experiences based on how they perceived their ability to take care of themselves relative to the standards, expectations and/or norms of American society. This could be better understood by asking oneself at what age or in what period of life are you responsible for yourself and your own well-being? The answers you may come up with are a part of a larger social and cognitive process. Such answers were communicated by respondents via the structure and content of the initial chronological structure (*fabula),* and the specific elements and re-presentation of their narratives (*sjuzet*). For example, respondent M.P. began her narrative by stating that:[384]

> Well, recently it hasn't been so good with the (pauses) I am on the Marketplace. It's Obamacare and I am actually finding it really difficult to find a doctor to see me when they find out that I have the discounted or subsidized plan. So, currently, I do not have a Primary Care Provider. I have only recently found a gynecologist who would take my insurance after calling about seven or eight different offices. So, it's not going super well lately and I have only recently become interested in (pauses) I have been keeping up with my health. I turned twenty-seven in September and so now I'm like I'm getting older and I have to start taking care of myself because mommy and daddy aren't going to be like "go to the doctor" anymore. So, I have to take care of myself and find the resources myself and it is proving difficult.

M. P. began her narrative by articulating her contemporary inability to access health care using governmental assistance (Obamacare) and relates it to her perception of

[383] Ibid.

[384] Note that times of respondent silence or sentence discontinuity during the recounting of his or her story is textually recorded as a "pause."

what she feels she *should* be capable of— given her age and degree of autonomy. For example, she stated that she was 27 years old, that she was getting older, and that she should be able to take care of herself. Her need to use a kind of proxy agency— previously through her parents but currently through the use of governmental insurance— was not in tuned with the kind of agency she believed she should be able to exercise.[385] Given her health care situation, however, she lacked the agency to do that. Thus, as noted via a tonal analysis of her narrative, the retelling of her experiences indicated high levels of anger, sadness, fear, tentativeness, and conscientiousness at 63 percent, 43 percent, 26 percent as well as 10 percent and 23 percent, respectively.[386]

Similarly, respondent V.A., began her narrative by stating the following:

> When my parents came over (pauses) and I don't remember what earlier forms of health care were like but I always went to the doctor every year. I always went to the dentist. I don't remember having an ID but I am pretty sure that my dad had some form of health insurance like maybe a gold card. Then one day he was like "Go to the doctor! Go to the dentist before it runs out. Go to the eye doctor!" because we had like optometry care too. And, I didn't (pauses) I don't know why (pauses) I guess I was busy with school and then things started going (pauses) not downhill but going typical I guess. Like I had teeth problems and then eye problems and then I think that the first time that it finally sunk in that we didn't have insurance was right before we got Obamacare it was I think I had to get my eye examined and I had to pay out-of-pocket and it really hurt having to pay for like your own glasses and paying for the check-up and the eye drops or whatever. You realize that other people didn't have what you have or had and you didn't take advantage of it. So, for me at this point, I am just paying everything out of pocket and I haven't been to the doctor in a while and like the dentist either. Like, I had a really bad fever two weeks ago and I think that maybe one of my teeth was falling out and I have to think about like saving up money and not going out and doing all of this stuff that I have been so accustomed to. Like, I need to save up and go

[385] Note that the percentages listed total more than 100 percent because they are thematically characterized (as referenced in the methods section of this paper) and analyzed relative to the prevalence of a specific them (such as anger, fear or sadness) within an overarching category such as "emotion."

[386] As previously noted, the three categories examined are emotion, language style and social tendency.

> to the dentist. I might just have to pull the tooth out. So, yeah, that's where I am right now. I am just having to think long term about my health and just eating better and all of that.

V. A.'s narrative is also a comparative of her previous health and health acquisition status with her current experiences. According to a tonal analysis, the syntax and prosody of her narrative depict high levels of anger, fear, and tentativeness, at 74 percent, 43 percent, and 94 percent, respectively. Like M.P., the interaction between V. A.'s narratives' *fabula* and *sjuhet* with her linguistic structure and tone are indicative of her perceived quality of life and agency via self-reflection. More specifically, V.A. perceived herself as having a quality of life that negatively compared to her previous health care related experiences. It was perhaps these elements of her narrative that facilitated the production anger, fear and tentativeness identified in her narrative retelling.

Another respondent, B.D., noted a similarly structured, comparative phenomenology as well as a transition from proxy agency to a reduction in her ability to take care of herself. She stated that:

> I was living with my mom and I was under her insurance and back in the day, I guess maybe I didn't know enough, but insurance was great. It was not a problem to go to the doctor and it was not a problem to get medication. But, as I got older I would say that it all stayed that way through about college when I left home and got my own job. I was fortunate enough to get a job that had insurance. So, I was actually able to go to the doctor when I needed it and I could go and get medication (pauses). Then I started a new job and I just noticed that maybe insurance was free before then and now they wanted to charge me for it. I am not really sure how that went. Then suddenly, you start to be more aware of everything. You are wondering like how much co-pays are and just wanting to know the cost of everything, my medications, and strips and everything just suddenly became this huge burden.

Like many of the other study participants, B.D.'s story was laced with fear (57 percent), sadness (45 percent), and tentativeness (86 percent). She also acknowledged a generally decreased ability to take care of herself relative to the cost and accessibility of health care and health care related services. Narrative snippets such as M.P.'s, B.D., and V.A. not only speak to some of the economic and health related hardships faced by some impoverished peoples, but also how that positionality affects one's self-perception and well-being, and his or her intrapersonal and interpersonal engagement. These are socio-medical affects that have stemmed from one's difficulty accessing health care and/or health care related services.

Medical inequity is facilitated by the unequal accessibility and/or affordability of health care and health care related services. Disparity is normalized through thanatopolitical systems which favor the wealthy. Thus, the kinds of narrative descriptions noted by M.P., V.A., and B.D. are significant because they provide context for understanding and forecasting the interplay between medical inequity and disparity relative to the trajectory of pharmacogenomics and genome wide association studies by describing some of the contemporary hindrances individuals experience relative to health care accessibility.

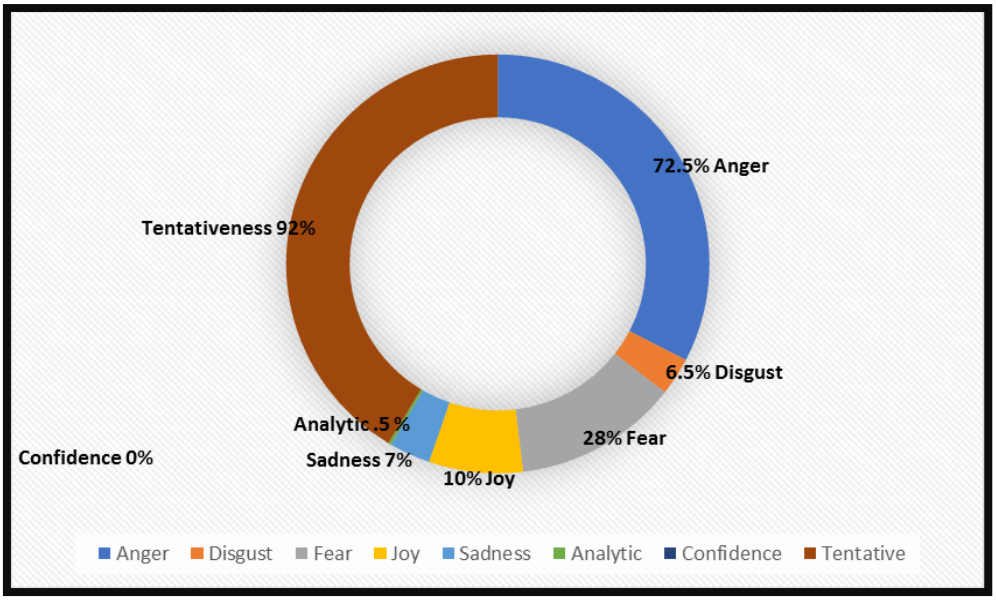
As discussed in chapter four of this dissertation, the economic and social costs of accessing genomic medicine and genomic related health care services will likely exist outside of the practical accessibility of many people (like M.P., V.A., and B.D.). As

orphan drugs, many pharmacogenomics will likely echo the astronomical costs of similar niche drugs without governmental pressure or interference. Furthermore, contemporary health care trends are not leaning towards greater accessibility and affordability for poor peoples. So, the inequitable access of health care and health care related services facilitated by genomics research will likely be more disparate than it is now.

Tonal Analysis

An aggregate tonal analysis of the interviews showed that 72.5 percent of participants expressed anger within their narrative retelling. An additional 28 percent of respondents were fearful. Disgust and sadness were equally indicated in approximately 6.5 percent of the experiences articulated by participants, and 10 percent of participant narratives indicated feelings of joy. The most prevalent aspect of the interviews, however, was the feeling of tentativeness, at 92 percent. What is most telling, however, is that none of the participant narrative experiences indicated feelings of confidence (see table 2). Note that these percentages total more than 100 percent because they are analyzed by the software as independent variables.

Table 2: Aggregate Tonal Analysis of Participant Interviews



Creating a dialogue between respondent narrative *fabula* and *sjuzet* with the fore noted aggregate tonal analysis, allowed for the critical analysis and nuance of participants' phenomenology. Many of their subjective realities were underlined by a lack of confidence in their ability to access health care and/or pharmaceuticals. This sense was compounded by feelings of tentativeness and fear—the latter of which to a much lesser degree. A further analysis of respondent interviews indicated that their feelings were likely in response to the intersection of increasing or unstable health care costs with an inability (or decreased ability) to *actually* access care or applicable medications. Discrimination (based on race and/or insurance type held) was a peripheral issue that also affected the timorous sensibility of respondent narratives.

Chapter VI: Attitudinal and Freelist Data Results

As noted in the preface and introduction of this dissertation, to better triangulate the significance and embedded nature of this data with the normalization and legitimization of molecularized and biologized race and racialization, all information gathered was assessed and textualized relative to their historical underpinnings. Noting the contemporary and historical relationship between ideas and concepts of race and racialization within the epistemologies and ideologies of science and medicine works to identify how they have become a part of the Western medicine socialization process. It is within that process that the molecularization and biologization of race and racialization are legitimized and perpetuated in future medical and biomedical endeavors—thus facilitating the trajectory of pharmacogenomics and genome wide association studies. The results, analysis, and historical significance of the attitudinal and freelist data are thusly explored and noted below.

Attitudinal Data

An attitudinal survey is exactly what it sounds like: an assessment of respondent attitudes or perceptions of a word, idea, or concept. It is analyzed via a likeart scale that ranges from strongly disagree to agree. Such an analysis is a significant way to gauge the contemporary pulse of a cohort and hypothesize about the potential or perceived health and socio-medical impacts of the words, ideas, and concepts provided to study participants as prompts. As the scope of this dissertation is in noting the trajectory of pharmacogenomics and genome wide association studies relative to their role in the

molecularization and biologization of race, racialization, and medical inequity, the following attitudinal statements and analysis are grounded by variables which note the potentiation and perpetuation of the normalization and legitimization of race, racialization, and medical inequity. The attitudinal analysis consisted of thirty statements grouped into the following themes: 1) the subjectivity of science, 2) race and medicine, and 3) the cost and access (see appendix).

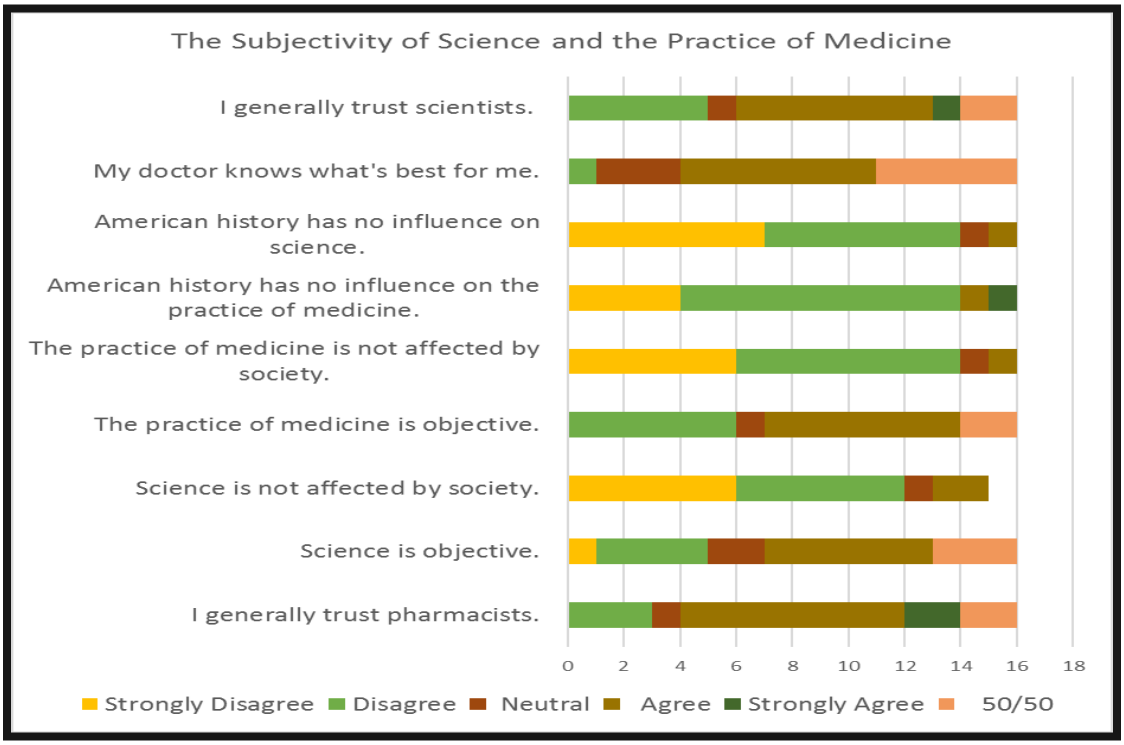
Subjectivity of Science

Seventy-five percent of respondents disagreed or strongly disagreed with the idea that **science was not affected by society**. Another 87.5 percent of participants disagreed or strongly disagreed with the idea that **the practice of medicine was not affected by society**, and that **American history has no influence on the practice of medicine** or **science** in general (these were a total of three separate prompts that generated the same percentages). These statistics note the presence of a conflict between the 68.8 percent of respondents who agreed that **science was objective** and the majority of participants who felt that **science and the practice of medicine were affected by society, history, *and* were objective**. The other 31.2 percent of respondents were ambivalent to the objectivity of science and the practice of medicine. Ambivalence was recorded as a 50/50 attitudinal designation on the survey. One person chose not to answer.

Also, 56.25 percent percent of respondents of this study generally **trusted physicians**, and another 62.5 percent of respondents **trusted their pharmacists**. However, only 43.5 percent of people thought that their **doctors knew what was best for**

them—with 31.2 percent of respondents noting ambivalence. Although these figures indicate that respondents generally trust their physicians and believe that they have their better interest in mind, a considerable amount of study participants felt otherwise (at 43.75 percent and 56 percent, respectively) (see table 3).

Table 3: Attitudinal Responses Regarding the Subjectivity of Science and the Practice of Medicine



This issue could be due to the conflict between one's desire to trust the scientific and/or medical system while also being cognizant of its indiscretions (particularly against poor and minority peoples). Likewise, an individual may want to believe that his or her physician or health care worker is objective but may have experienced micro-aggressions that indicated a differing, subjective reality—one embedded in race, racialization, and culture. This discordance notes a complexity and conflict within the doctor patient

encounter. It can be difficult to reconcile that someone would be embedded in a culture but not be influenced or affected by it in the same way that someone may simultaneously trust his or her physician but not feel that that individual actually knows what is best for him or her).

Respondent answers may initially seem confounding, however, participant attitudinal responses evidence a collective consciousness of Western society which is founded on the principle that science and medicine are rational, logical, reasonable, objective, and empirically based.[387] This ideological framework further asserts that the primary methodology of scientific and medical endeavors, the scientific method, and thus the acquisition of scientific knowledge exists outside of the agency of the researcher. A scientist or a physician, for example, is allegedly not shaped by the ideologies and subjectivities of any kind of social or institutional apparatus. As such, the scientific and medical community tends not to acknowledge how its history, knowledge, and practice have been affected by racialized concepts. Such denials prevent medical practitioners from being more sincerely informed and more aptly prepared to practice as socialized humans as opposed to idealized versions of the Self. Further discussion of the influence of society on science and medicine follows.

Historical Significance

According to Lorraine Datson and Peter Louis Galison, the philosophies of science and medicine are rooted in the idea that individuals seeking scientific knowledges

[387] Paul Feyerabend, *Science in a Free Society* (London, England: New Left Books, 1978).

are able to "suppress some aspect of the self—thus countering subjectivity and dissembling the knower from his or her knowledge."[388] Hence, the knower (the self) becomes simply a vessel of knowledge—an unveiler or discoverer of information as opposed to a producer of it.[389] As such, one may perceive the concepts of science and medicine as being affected by society and American history without necessarily associating that belief to and with the practice of medicine or broader scientific endeavors. Dialogics in this regard champion the notion that science and medicine are objective—not tainted by religion, ideology or other mechanisms manifested by and filtered through culture. However, this conceptualization contradicts social psychology as well as the history of both science and medicine. In fact, the tradition of natural law, which is often heralded as the foundation of medical ethics, comes out of the Christian and Judeo-Christian doctrines and Roman Stoicism.[390] Leonardo da Vinci's "Vitruvian Man"—which is a depiction of idealized, divine proportionality is also a relevant symbol of religio-scientific, ignored subjectivities.[391] Likewise, Edward Topsell's "Lamia"—a chimera said to be found in the bible—was referenced and illustrated in two scientific texts from the seventeenth century entitled *The History of Four-footed Beast* and the

[388] Lorraine Datson and Peter Louis Galison, *Objectivity (*Cambridge, Massachusetts: Zone Books, 2010):19

[389] Ibid.

[390] Johanna Geyer-Kordesch, "Natural Law and Medical Ethics in the 18th Century," in *The Codification of Medical Morality: Historical and Philosophical Studies of the Formalizations of Medical Morality in the 18th and 19th Centuries* Vol. 1, eds. Robert Baker, Dorothy Porter and Roy Porter (Dordrecht, Germany: Kluwer [Springer], 1993): 123-139.

[391] A. Richard Turner, *Inventing Leonardo* (New York, New York: Alfred A. Knopf Publishing, Inc., 1993): 210.

Historie of Serpents.[392] Similarly, Jacob Bondt's "Orangutan"—which was an anthropomorphized, saytr-esq creation—appeared in the *Historae Naturlis and Medicar Indiae Orientalis* (a scientific text from the 17th century).[393] Yet, discourses on the objectivity of science and medicine disregard the extent to which social religion, for example, influenced the epistemology, praxis, textual, and visual representations of many aspects of science and medicine.

As per Stephen J. Gould, relevance, logic, and normality are inherently subjective within scientific and medical endeavors.[394] He further suggests that the idea of knowledge existing outside of the sphere of interpersonal and intrapersonal influence is unrealistic, unattainable, and antithetical to the human condition.[395] As with many of his philosophical contemporaries, Gould believed that science was an imaginative, cultural, social phenomenon composed of facts based on intuition, and influenced by culture.[396] Thus, the scientific endeavor should be understood as moving from inflexible, absolute truths to a fungibility that allow for fluid supposition.[397] Science and medicine are not static practices and representations of an unattainable tabula rasa. They are dynamic reflections of cultural happenings. Gould asserts that:

> Science may differ from other intellectual activity in its focus upon the construction and operation of natural objects. But, scientists are not robotic inducing machines. . . scientists are human beings, immersed in culture, and

[392] Allen G. Debus, *Man and Nature in the Renaissance* (New York, New York: Cambridge University Press, 1978): 26.
[393] Ibid.
[394] Stephen Jay Gould, *The Mismeasure of Man* (New York, New York: W.W. Norton and Company, 1996.
[395] Ibid.
[396] Ibid.
[397] Ibid.

> struggling with all of the curious tools of inference that minds permit. . . Objective minds do not exist outside of culture, so we must make the best of our ineluctable embedding.[398]

Philosophers Charles Taylor and Michael Foucault concur with Gould and note that people's behaviors tend to be congruent with and integrated into the social milieu because we are all cultural and political subjects nestled within a broader paradigm of power.[399]

Pierre Bourdieu goes a few steps further in stating that the universe is situated within a structural duality or two-fold social genesis in which one's objective and subjective realities exist in a dialectical relationship.[400] This relationship causes an oscillation between one's experiences of objectivity in the first order and objectivity of the second order. Objectivity in the first order is essentially a reference to the production, demand, and distribution of material resources and other sources of monetary and cultural capital.[401] Objectivity in the second order refers to one's cognitive physical, and symbolic templates through which he or she is able to engage with and classify the practical activities of social agents.[402] The latter of these two concepts is sometimes referred to as *habitus* and is representative of the subjective reality of the individual.

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[398] Stephen J. Gould, *Time's Arrow, Time's Cycle* (Cambridge, Massachusetts: Harvard University Press, 1987): 7.

[399] Charles Taylor, "The Dialogical Self," in *The Interpretive Turn: Philosophy, Science, and* Culture, edited by David Hiley, et. al (Ithica, New York: Cornell University Press, 1991), 304-314. Also note Arthur W. Frank and Theresa Jones, "Bioethics and the Later Foucault," *Journal of Medical Humanities* 24, no. ¾ (Winter 2003): 179-186.

[400] Pierre Bourdieu, "Social Space and Symbolic Power," *Sociological Theory* 7, no. 1 (Spring 1989): 14-25.

[401] Pierre Bourdieu, Loic J.D. Wacquant, *An Invitation to Reflexive Sociology* (Chicago, Illinois: University of Chicago Press, 1992).

[402] Ibid.

Habitus is also indicative of the extent to which one's enculturation and social embeddedness have shaped his or her perception.

The historical use of anthropometrics, physiognomies, and skin complexion as variables in determining perceived sickness or deviance within the practice of medicine and medical endeavors (as well as other broader socio-medical happenings) are evidence of habitus and medical socialization. They also further constitute the interplay between the socio-historical construction of race and the race of man—as a logical and rational individual. For example, the molecularization and biologization of race and racialization was starkly evident in Cesare Lombroso's theory of the atavistic which suggested that one could identify socio-pathological individuals by the presence of particular physical characteristics.[403] In keeping with the social, medical, and racial climate of the time, the physical characteristics believed to signify socio-pathology were akin to anyone who was not an Western European. Thus, relative to habitus, all individuals (historically and contemporarily) simultaneously exist as a part of first order and second order constructions of his or her material and intangible environment. He or she is also a fixture in other people's truths or perception of truths—as is the inherent nature of racialization.[404] The excerpt of respondent B.D.'s narrative discussed in chapter four is a stark example of how contemporary habitus and medical socialization can be thanatopolitical.

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[403] Charles A. Ellwood, "Lombroso's Theory of Crime," *Journal of Criminal Law and Criminology* 2, no. 5 (Jan. 1912): 716-723.

[404] Walter Glannon, *Brain, Body, and Mind: Neuroethics with a Human Face* (New York, New York: Oxford University Press, 2013).

Other examples of the dialectical relationship between one's engagement with first order and second order objectivities—as described by Bourdieu—can be seen in the concept of phrenology— a pseudoscientific study which used skull size and shape as indicators of one's character and mental capacity.[405] Likewise, negative eugenics (which sought to rid society of traits perceived by the bourgeois as being undesirable) successfully normalized and legitimized the molecularization and bioogization of race and racialization.[406] Also, as referenced in the introduction of this text, Josiah Notts, George Robbins, Louis Ferdinand, and Alfred Murry's *Indigenous Races of the Earth* depicted a Negro as the missing link between a pan troglodyte (chimp) and the apex of man (a Greek man).[407]

These examples are an infinitesimal fraction of the number of scientific concepts and texts that were influenced by Western social ideologies that normalized and legitimized race and racialization as well as those that have blatantly shaped the development of future scientific and medical endeavors. One of the broader issues of this is the need to acknowledge that any and all work produced by humans—whether mechanical, mathematical, scientific, medical, or social, for example, do not exist in a vacuum and thus should be understood within their subjective realities. As such, in evaluating the use, analysis, and applicable interpretations of processes such as

[405] Donald Simpson, "Phrenology and the Neurosciences: Contributions of F.J. Gall and J.G. Spurtzheim," *ANZ Journal of Surgery* 75, no. 6 (Jun. 2005): 475-482. Doi:10.111/j.445-219.2005.03426.x

[406] Daniel J. Kelves, "Eugenics and Human Rights," *BMJ* 319, no. 7207 (Aug. 1999): 435-438. PMCID:PMC1127045.

[407] Notts, Gliddon et. al, *Indigenous Races of the Earth or New Chapter of Ethnological Inquiry,* 1857.

pharmacogenomics and genome wide association studies, one must also acknowledge that the science of medicine has been, continues to be, and will likely be affected by the history, culture, and racialized systems embedded in Western society. Thus, neoteric medical technologies like pharmacogenomics and genome wide association studies, which normalize and legitimize the use of race (as a socio-historical ascription) will also further molecularize and biologize race and racialization. In the next section, respondent's contemporary perceptions of the imbrications of race, medicine, and genetics was evaluated to discern one's potential future perceptions of the concepts. An analysis of study participants' attitudinal responses follows.

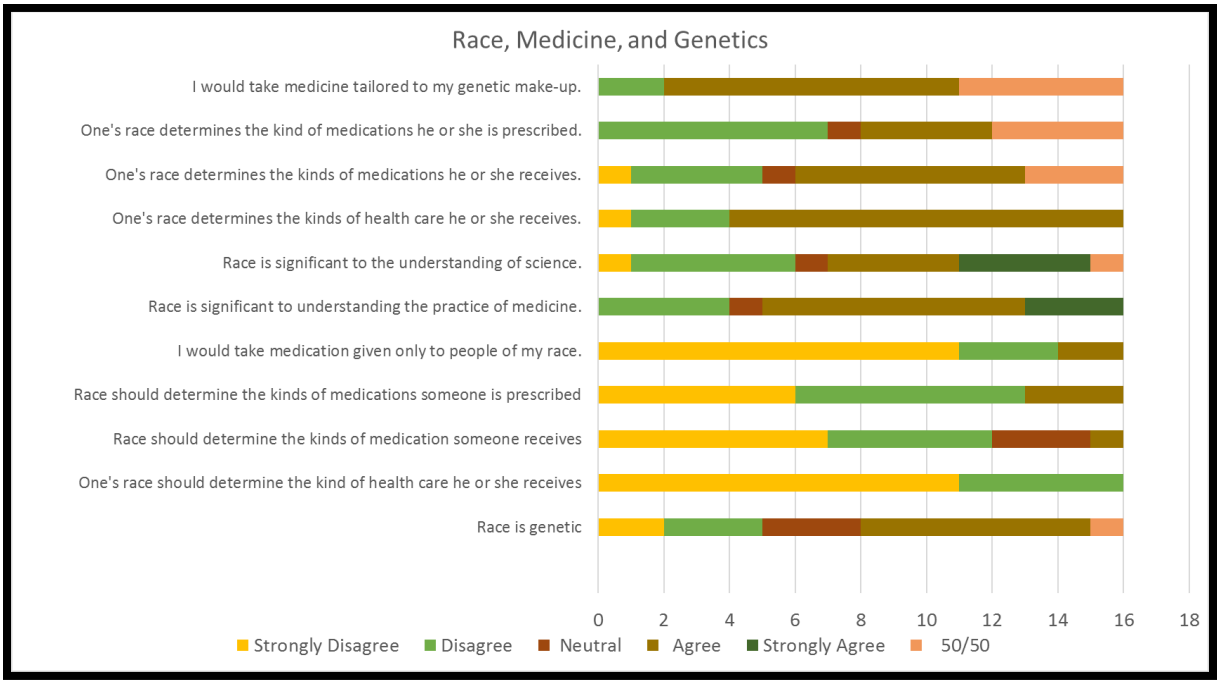
Race, Medicine, and Genetics

Participant attitudinal responses in this section of the survey iterated respondents' apprehensions and experiences relative to the intersection of race, the practice of medicine, and genetics. Sixty-nine percent of study participants agreed with the statement that **race was genetic** and 56 percent of participants strongly agreed that they **would take medications tailored to their genetic make-up**. However, 87.5 percent of study participants indicated that they would **not take medication given only to people of their race**. The idea then, is that respondent would be more likely to take pharmaceuticals tailored for their genetic make-up and/or socio-historically ascribed race only if those same medications were also made available to people of other races.

Also, all study participants either disagreed or strongly disagreed with the idea that **one's race *should determine* the kind of health care he or she receives**. Seventy-five percent participants disagreed or strongly disagreed with the idea that **one's race *should determine* the kind of medications he or she *receives***. Eighty-eight percent of participants strongly disagreed or disagreed with the idea that **one's race *should determine* the kinds of medications he or she is *prescribed***. Yet, 68.75 percent of respondents agreed or strongly agreed **that race is significant to understanding the practice of medicine** and 50 percent of people agreed **that it is important to the understanding of science**.

However, 75 percent of study participants agreed that **one's race *does determine* the kinds of health care he or she receives**. Forty-three percent of participants agreed that **one's race determines the kinds of medications he or she receives** but 68.75 percent of respondents strongly disagreed with (or were ambiguous to) the notion that **one's race determined the kind of medications he or she is *prescribed***. (see table 4). What is implied in participant responses then, is that race (while relevant to aspects of science and the practice of medicine) should work to inform health care. It should not determine it—but it does.

Table 4: Respondent Attitudinal Responses Regarding Race, Medicine, and Genetics.



Respondent perceptions of race determining the kinds of health care and medications he or she receives as well as the kind of medications he or she is prescribed is in tuned with a plethora of medical literature which outlines the racial and ethnic disparities that exist in the management of pain. Jana Mossey's article and the interview snippet of respondent C.C. in chapter six also explore the phenomenology of race, racialization, and pain management. Study participant's attitudinal responses are also an echo of another aspect of the Western ideological and philosophical framework: the social and scientific conflation of race, disease, and genetics.

Historical Significance

One of the most influential periods of perpetuated, race based ideas of health and disease was the Age of Enlightenment (also known as the Age of Reason, and simply The Enlightenment). The Enlightenment existed from approximately the mid-17th century to approximately the mid-18th century in Europe. Because this era brought about the authority of reason, aesthetics, ethics, and the notion of the rational subject to the forefront of society, it is often credited with the development of the modern world, political and economic liberalism, and science in general (as it currently exists).[408] The Enlightenment also cultivated the ideas of political theorists like Thomas Hobbes, Denis Diderot, Immanuel Kant, John Locke, François-Marie Arouet (whose pen name was Voltaire), and Jean-Jacques Rousseau—individuals whose work continues to be instrumental in the economic, philosophical, ideological, and material development of Western society.[409]

However, the Age of Enlightenment was also fundamental in creating an infrastructure of racialization and racialized thinking. Terms like race, savagery, colonialism, imperialism, and civilization (and thus the idea of the civilized being, and unilineal evolutionism) along with notions of inferiority, and the exclusivity of humanness (who qualified as human and what constituted the race of man) were all

[408] Louis Dupré, *The Enlightenment and the Intellectual Foundations of Modern Culture* (New Haven, Connecticut: Yale University Press, 2004).
[409] Ibid. Ibid.

refined, normalized, legitimized, and defended during The Enlightenment.[410]. The molecularization and biologization of race and racialization also took form during this period.

For example, George-Louis Leclerc, Comte de Buffon (a French naturalist and biologist credited in scientific history as the father of all thought in natural history and biological evolution) believed in the degradation theory. The degradation theory is the idea that all races of man degraded from the White male due to environmental factors. Such a scientific conclusion was significant as Buffon was one of the first people to examine the relationship between geography, geological time, and the distribution of species— now referred to as Buffon's law—the basis of biogeography.[411]

Circa 1749, Buffon used his concepts of biogeography to construct a taxonomy of human beings which he published in the *Varities of the Human* Species. In his text he stated that although all humans were a part of the same species, people of dark complexions were a primordial type of human that had undergone degeneration due to their tropical locations, diet and cultures.[412] He went on to state that the weak, vitiated savages [American Indians and people of dark skin] lacked the capacity to improve upon

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[410] Emmanuel Chukwundi Eze ed., *Race and the Enlightenment: A Reader* (Hoboken, New Jersey: Wiley-Blackwell, 1997).

[411] Brian K. Hall, *Evolutionary Developmental Biology* (New York, New York: Springer Science and Business Media, 1992)

[412] Georgina M. Montgomery and Mark A. Largent eds., *A Companion to the History of American Science* (Hoboken, New Jersey: Wiley- Blackwell, 2015). It is important to note that "culture" during this time period was typically in reference to European societies deemed civil and thus, the behaviors/traditions/taboos, cosmology, and symbology of peoples ascribed as primitive or savage were not understood or articulated as actually being cultural but instinctual. Note traditional ethnographies for this delineation.

themselves and thus Europeans would need to dominate and subdue nature in order to avoid degeneration.[413] His concern over the possible degeneration of Europeans was (and is) framed as an issue of public health. Thus, it typified what Foucault referred to as biopower by suggesting that there be a direct government intervention to avoid racial and social collapse—with *race* being both the race of man and the socio-historical ascription.[414]

The idea of one ascribed race being unable to improve their social position as well as the monogenic idea that some groups of people degenerated from one race also provided the foundation for the *racial hygiene* movement of the 19th and 20th centuries, social Darwinism—propagating such catch phrases as Herbert Spencer's "survival of the fittest" and the idea of unilineal evolutionism. Buffon's science also influenced Francis Galton's use of pedigree analysis—a symbolic assessment of proposed phenotypic data originally used for the study of plants and animals—to infer the genetic constitution of individuals.[415] The fore noted examples are archetypical of the extent to which the molecularization and biologization of race and racialization was (and is) embedded into purportedly objective medical and scientific practices and interpretations.

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[413] Marvin Harris, *The Rise of Anthropological Theory: A History of Theories of Culture* (Lanham, Maryland: Altimira Pres-Rowman & Littlefield, 2001).

[414] Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the 21st Century* (Princeton, New Jersey: Princeton University Press: 2007).

[415] Nicholas W. Gilham, "Evolution by Jumps: Francis Galton and William Bateson and the Mechanism of Evolutionary Change," *Genetics* 159, no. 4 (Dec. 2001): 1383-1392. PMCID: PMC1461897.

Moreover, because Buffon's outline of human and subhuman species directly influenced that of Carolus Linnaeus and Johann Friedrich Blumenbach, Buffon's work continues to be significant to understanding the historical and contemporary conflation of race, genetics, and diseases. Linnaeus published the racial categorization of humans in his book *Systemae Naturae* in 1758 and Blumenbach published a similar racial categorization in 1779.[416] Linnaeus is also credited with introducing the concept of binomial nomenclature (a two-part, formal, Latin system used for naming species—such as Homo Sapien). Using this system, humans could be sub-divided into categories such as night and day, thinking and unthinking, or via one of his six groups: *Americanus rubescus* (American red), *Europaeus albus* (Europeans white), *Asiaticus luridus* (Asians yellow), *Afer niger* (Africans black), *Monstrosus* (referring to disabled individuals) and *ferus* (referring to "wild" children).[417] Linnaeus' taxonomy was a scientific nod to Aristotle's *Scala Naturae* (ladder of life also referred to as the Great Chain of Being) which depicted all life as existing within a strict hierarchical structure ordained by God.

The Great Chain of Being suggested that the basic characteristics of humanity included existence, life, will, reason, and logic. Contrarily, animalistic characteristics were void of logic and reason. As such, anyone not perceived as having either logic or reason would exist somewhere between human and animal.[418] This system existed for

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[416] Ernst Mayr, *The Growth of Biological Thought: Diversity, Evolution, and Inheritance* (Cambridge, Massachusetts: Harvard University Press, 2003). It is noted here as "proposed" phenotypic data because he surmised phenotype based on his assumptions of one's genotype.

[417] Ibid. Also note Jonathan Marks, "Long Shadow of Linnaeus's Human Taxonomy," *Nature* 447, no. 3 (May 2007): 28. Doi:10.1038/447028a.

[418] Mayr, *The Growth of Biological Thought*, (2003).

more than two thousand years before being revamped by Linnaeus. According to scientific historian Libet Koerner, "Linnaeus wavered between seeing nature as a paradise for man's rational use and seeing man as a weak and contemptible thing; no better than a monkey." As discussed in the Introduction of this dissertation, the idea of the irrational man being no better than a monkey was later procured by Josiah Clark Nott and George Gliddon in their 1854 text *Types of Mankind* which depicted a Negro as the missing link between the apex of mankind (the Greek male) and a pan troglodyte (chimp). The ethnological zoos—where people like Congolese, Mbuti pygmy Ota Benga were exhibited—of the nineteenth and twentieth centuries were also normalized, legitimized, biologized, and racialized scientific endeavors.[419] All of those systems and mechanisms of science and medicine meshed together historical and contemporary conceptions of the molecularization and biologization of race and racialization.

As previously noted, the categorization of the human species was also elaborated on by Johann Friedrich Blumenbach. Blumenbach suggested that the different physical and behavioral characteristics of homo sapiens allotted for the natural creation of five races of man: Caucasion (white), Mongolian (yellow), Malayan (brown), Ethiopian (black), and American (red).[420] The methods used to conclude the forementioned racial distinctions introduced inter alia anthropometrics, physiognomies, and craniology as seemingly objective, viable, verifiable, and relevant means of evaluating human

[419] Bruce R. Dain, *Hideous Monster of the Mind*: *American Race Theory in the Early Republic* (Cambridge, Massachusetts: Harvard University Press, 2002). Also note Josiah Nott and George Gliddon, *Types of Mankind* (Philadephia, Pennsylvania: Lipponcott, Grambo, and Co., 1854).
[420] Mayr, *The Growth of Biological Thought*, (2003).

variation. The use of these biometric approaches ultimately pushed up against Gregor Mendel's genetic approach to studying difference and largely displaced it in many scientific and social scientific disciplines.[421] Varying forms of biometrics also gave credence to the scientific racism of the 19th and 20th centuries and continues to be used in contemporary medical, biomedical and scientific endeavors.[422]

For example, some members of the medical and scientific community suggest that substantial variations in allele variant frequency and phenotype frequency across the five racial subpopulations map onto continental ancestry and have different phenotypic expressions relative to health and disease.[423] So, noting these differences are significant to the identification of certain diseases and/or sicknesses as well as for devising specific health plans. For author and physician Sally Satel, for example, recognizing these differences is both morally and medically justifiable when addressing one's health or disease because they allow physicians to provide the most applicable standard of care. She stated that:

> In practicing medicine, I am not colorblind. I always take note of my patient's "race." So do many of my colleagues. We do it because certain diseases and treatment responses cluster by ethnicity. Recognizing these patterns can help us diagnose disease more efficiently and prescribe medications more effectively. When it comes to practicing medicine, stereotyping often works."[424]

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[421] Michael R. Speicher, Stylianos E. Antonarakis, Arno G. Motulsky eds., *Vogel and Motulsky's Human Genetics: Problems and Approaches 4th Ed.* (Heidelberg, Germany: Springer, 2010).

[422] Simon During *Cultural Studies: A Critical Introduction* (New York, New York: Routledge Press, 2005).

[423] Fine, Michael J., Said A. Ibrahim, and Stephen B. Thomas, "The Role of Race and Genetics in Health Disparities Research," *American Journal of Public Health* 95, no. 12 (2005): 2125

[424] Sandra Soo-Jin Lee*, "Racializing Drug Design: Implications of Pharmacogenomics for Health Disparities," American Journal of Public Health* vol. 95, no. 12 (Dec. 2005): 2135.

However, contrasting voices in the scientific community stated that:

> the public health implications of ancestral clustering of genes is controversial and that race at the ancestral level has not been proven useful in terms of predicting individual's diagnoses or individual's responses to drugs or causes of disease…[furthermore] it is impossible for race to provide the sensitivity and specificity needed to characterize DNA sequence variation for the purpose of guiding preventative or therapeutic medicine.[425]

Unfortunately, however, while both of the forenoted quotes (and affiliated groups) have subjective, perspectival relevance, neither of them adequately addresses what H. Jack Grier describes as "the major determinants of population health status and primary explanations of disparities among population groups [which] lie in the social, physical, and economic environments, [and] are determined by the larger society's norms, values, social stratification systems and political economy."[426] Intergenerational health inequities are facilitated and perpetuated by the tandem play of disparity and discrimination. Thus, while race and racism are not biologically based, how society engages with them may have very real, biological effects—thus they are not genetic but linked socio-medically.

According to medical anthropologist Clarence C. Gravlee, if we ignore the intergenerational, socio-medical affects of the molecularization and biologization of race and racialization we "blind ourselves to the biological consequences of race and racism

[425] Ibid., 2126.

[426] H. Jack Griger, "Racial and Ethnic Disparities in Diagnosis and Treatment: A Review of the Evidence and Consideration of Causes," in *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, edited by B.D. Smedley, A.Y. Stith, and A. R. Nelson (Washington, DC: National Academic Press, 2003): 418.

leaving ourselves without a constructive framework to explain biological differences between racially defined groups" thereby perpetuating genetic determinism.[427] Gravlee goes on to state that:

> The toxic effects of exposure to racism in one's own lifetime include a higher risk of hypertension, diabetes, stroke, and other conditions. These conditions, in turn, affect the health of the next generation, because they alter the quality of the fetal and early postnatal environment. The immediate consequence of this intergenerational effect is a higher risk of adverse birth outcomes, but there is also a lingering effect into adulthood, as adult chronic diseases like heart disease and diabetes can be traced in part to prenatal and early life conditions. Thus, the cycle begins again.[428]

Thus, again, it is social and socio-medical mechanisms which facilitate disease differentiation in these instances, not racialized genetics. The historical, contemporary, social, and scientific conflation of race, genetics, and disease is thus a complex issue. It directly and indirectly affects the ideology of medical education, how doctors practice medicine and perceive their patients, how patient's medical and behavioral constitution is interpreted, as well as the kinds of medical care and/or the standard of care an individual has access to. The introduction and normalization of genomic medicine and processes such as pharmacogenomics and genome wide association which overtly integrate race, genetics, and medicine, will not be immune to the history of that imbrication. Instead, they are more likely to reify the molecularization and biologization of race and racialization while also acting as hindrances to one's ability to access care at all. In the

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[427] Clarence C. Gravlee, "Race, Biology, and Culture: Rethinking the Connections," In *Anthropology of Race: Genes, Biology, and Culture*, edited by J. Hartigan (Santa Fe, New Mexico: SAR Press, 2013): 34.

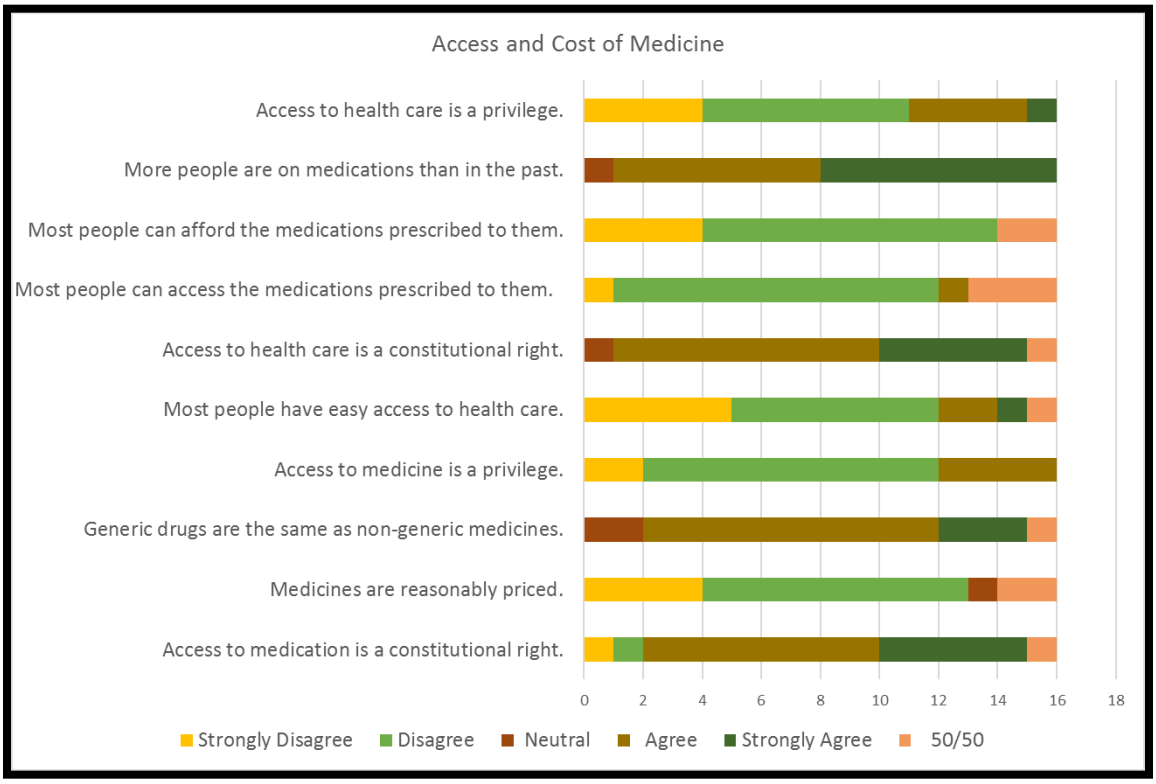
[428] Clarence C. Gravlee, "How Race Becomes Biology: Embodiment of Social Inequity," *American Journal of Physical Anthropology* 139, no. 1 (May 2009): 52. Doi:10.1002/ajpa.20983.

following paragraph, respondents indicated their perceptions of their ability to access medicine and its concomitant costs.

Access and Cost of Medicine

More than 81 percent of study participants agreed or strongly agreed that **people in American society do not have easy access to health care**. **Access to medications and health care were noted by participants to be constitutional rights**, at 81.25 percent and 87.50 percent, respectively. However, 75 percent of respondents agreed or strongly agreed that **access to *medications* should be considered a privilege**. Greater than 68 percent of respondents believed that **access to *health care* should be considered privileges** (see Table 5).

Table 5: Attitudinal Responses Regarding Access & Cost of Healthcare/Healthcare Related Services



This section of the survey also examined participants' perceptions of the amount of people on medications compared to previous periods in time. Ninety-four percent of respondents strongly agreed that **a greater number of people are on pharmaceuticals than in the past**. Eight-one percent of people also agreed that **medications are reasonably priced**—keeping in mind that the idea of what is reasonable is subjective. Yet, 87.50 percent of respondents agreed that **most people can *not* afford the medications prescribed to them** or that **they can *not* access the medications prescribed to them** (75 percent). So, the general perception is that people are being

prescribed more medications than in the past and that they should be able to afford them (as they are indicated as being reasonably priced) but people can not afford them and can not access them. Affordability, however, is subjective. As such, the issue of affordability and access as noted by respondents is ultimately a reflection of his or her perception of his or her financial and health care viability. The tonal analysis in chapter six notes a similar kind of salience relative to respondent health care affordability and accessibility. The salience of respondent responses are also identified and nuanced in the next section (freelist) of this document. As with the attitudinal data, freelist results and analysis are triangulated to and with their historical significance.

Freelist

A freelist is a tool used in qualitative inquiry and analysis designed to help determine (or hypothesize about) the prominence and cohesion of an idea or concept within a particular group. Importance (or potential importance) is extracted and analyzed through the use of domain prompts. The prompts are usually a word or phrase provided to study participants whom are then asked to respond by giving the researcher the first word or words that come to mind. In order to get an idea of what comes to mind when study participants hear or read some of the basic premises of pharmacogenomics and genome wide association studies, as well as some of the potential, broader socio-medical issues discussed in chapters two and four of this dissertation, respondents were given the following domain prompts: 1) medicine, 2) science, 3) race and medicine, 4) health, 5) genetics, and 6) genetic medicine. Freelist domains are in bold italics before the

section discussing its results. Table eight provides a brief look at participant responses. An analysis of those responses relative to the introduction of genomic based pharmaceuticals (and/or medical processes), the historical significance, and the molecularization and biologization of race and racialization follows.

Table 6: Responses to Freelist Prompts

FREELIST PROMPTS	**RESPONSES** (duplicates are noted once on this chart)
Medicine	doctor, physician, health, cost, meds (or medicine), Western, cure, and effective
Science	logical, real, nature, natural, and normal
Race and Medicine	history, experimentation, inequity, inequality, discrimination, Tuskegee, understudied subjects, bullshit, and how one group is impacted by medicine versus another group
Health	exercise daily, watch your weight, eat healthy, eat right, lose weight, work out, don't be fat, get up, living better, cardio, take care of our bodies, and food portions
Genetics	DNA, RNA, genes, history, culture, ancestors, strength, Tuskegee, and hair
Genetic Medicine	medicine, manipulation, Tuskegee, history, cancer, don't know

Medicine

When given the prompt medicine, the most salient participant responses were doctor, physician, health, cost, meds (or medicine), Western, cure, and effective (see table 8). These words evidence the idea that respondents understand the term medicine holistically. Thus, the term itself is indicative of many different aspects of the health care system including *medicine* as a pharmaceutical as well as *medicine* as a practice or process. The spectrum of answers also implies that there is a fluidity or perhaps a conceptual obscurity relative to the way that respondents understand and discuss medicine. This could potentially hinder communication during the doctor patient encounter. For example, a physician may think of *medicine* as a kind of knowable, objective truth that can be explained through research. A patient, on the other hand, may think of *medicine* in terms of a cost-cure dynamic. A brief discussion during the doctor-patient engagement could help each party come to a consensus of understanding and expectation. Unfortunately, the time allotted for doctor-patient interaction continues to dwindle, making the potential for such a dialogue nil.

The *medicine* prompt responses also revealed that participants did not distinguish between the institution of medicine, its general elements (such as cost, prescriptions, or visitation) and the practitioner of medicine, the doctor. This is interesting because it, too, lends itself to the idea that the doctor is both medicine and the practice of medicine. Accordingly, physicians play both a symbolic and a material role in the facilitation and

delivery of health care.[429] Other professions such as teaching or garbage collecting, for example, do not similarly absorb the laborer into the process or production of that labor. Being perceived as the symbolic, material, and practitioner of one's job is also relevant to contemporary dialogues of identity formation amongst medical students and practicing physicians who seek to understand why it is operationally impossible and implausible for them to separate their personal and professional lives.[430]

It is illogical for the medical community to require (unspoken or otherwise) its members to fully embody their disciplines but not assume or acknowledge that medical practitioners would also be simultaneously embedded in the cultural systems, mechanisms, and ideologies most applicable to their day to day lives/non-medical interpersonal engagements. Medicine as a practice and a symbolic concept exists within— and is a product of—cultural systems. It is not a mutually exclusive element of them. Thus, scientific and medical technologies produced by individuals within those systems will also be affected by its ideas and ideals. As discussed throughout the attitudinal section of this chapter, here is no *tabula rasa*.

[429] Keven Real, Rachel Bramson, and Marshall Scott Poole, "The Symbolic and Material Nature of Physician Identity: Implications for Physician-Patient Communication," *Health Communication* 24, no. 7 (Oct. 2009): 575-587. Doi:10.1080/10410230903242184.

[430] Matthew DeCamp, Thomas W. Koenig, and Margaret S. Chisolm, "Social Media and Physicians' Online Identity Crisis," *JAMA* 310, no. 6 (Aug. 2013): 581-582. Doi:10.1001/jama.2013.8238.

Science

When prompted by the word science, the words logical, real, nature, natural, and normal were repeatedly listed by participants. The word theory was also listed albeit less frequently. These words are a reverberation of the collective consciousness of Western society in that they identify science as something that is revelatory of pre-existing, natural or rational facts as opposed to being generative of new ones.[431] This notion has existed since antiquity when philosophers such as Pythagoras, Thales, and Anaximander insisted that natural phenomena were an "orderly arrangement that was beautiful"—a cosmos.[432] For them, the ordered nature of the universe allowed it to be knowable and explained through research, argument and evidence.[433] As such, science and all scientific endeavors therein would be unbiased (only revealing the natural world as opposed to causing it or being affected by it).

Hence, science and medicine were depicted as existing outside of the agency of the researcher or physician. He or she was simply the knower of knowledge that was unveiled to the world. From this perspective, scientists (and others involved in varying aspects of the scientific and medical endeavors) have not been perceived by society as products of culture nor are they the producers of it. Since antiquity, they have been seen as individuals who simply reveal what is real, logical, and natural. They are depicted as

[431] Paul Feyerrabend, *Science in a Free Society* (London, England: New Left Book, 1978).
[432] Lynn Hunt, Thomas R. Martin, Barbara H. Rosenwein, Bonnie G. Smith, and R. Po-chia Hsia, *The Making of the West Combined Volume: People and Cultures vol. I to 1740* (New York, New York: Bedford/St. Martin's Publishing, 2012): 70.
[433] Ibid.

neutral and objective. This issue, however, disconnects the human element and influence from the scientific endeavor and practice of medicine.

Historical Significance

The fore noted descriptors of *science* are also interesting because the intersection of logic, rationality, realism, and nature were key factors in the integration, development, and application of Carlous Linnaeaus's taxonomies into science and social society.[434] Those four elements, Linnaeus's work, and Johann Fredrich Blumenbach's treatise on racial classifications (discussed earlier in this chapter) as degeneration acted in dialogue with each other to characterize the process through which social organization and social hierarchies were mapped onto the biologized self.[435] Ultimately, the progression of these processes led to a paradigm shift in the conception of what it meant to be human.

For example, in the sixteenth century, to be human was to be a spiritual being. In the seventeenth and eighteenth centuries it was being rational and from the nineteenth century onward, one's human-ness was and is typically in reference to his or her as a biological being. During each of these time periods, the biological being (the self) was an examination of the extent to which an individual was perceived as a rational, logical, and thus natural man—in both gender and species. Additionally, the particulars of one's social reality—be it poverty, sickness, or a lack of education —was perceived to be

[434] Ibid.
[435] Stephen Jay Gould, "The Geometer of Race," *Discover* 15, no.11 (Nov. 1994): 64-70.

evoked by biology.[436] These issues were applied using principles from texts such as Adam Smith's *Wealth of Nations* which suggested that rationality and logic had aesthetic and economic identifiers—because a rational and logical person would also be wealthy.[437] However, wealth had a very specific rendering in that it did not include mobile wealth—an unstable kind of prosperity associated with the merchant class. Instead, wealth (in this regard) was only indicative of the affluence of the gentry—individuals who owned land and similar kinds of stable economic fortune. These distinctions propagated the idea that poverty was due to irrationality, and thus a lack of humanity (in that *man* was a reference to the "race of man" as opposed to one's socio-historical or gendered identity). The linear, co-dependent logic of this idea was as follows: Man is rational. Rationality leads to wealth. Wealth leads to well-being. Thus, a lack of well-being was considered evidence of one's lack of rationality, wealth, and humanness—an echo of Nietzsche's great health and great politics. A similar framework was used to discern deservedness/qualification at the onset of dialysis machine (discussed in chapter four).

It is also important to note that people of African ancestry were not considered men during this time period and thus were not considered to be rational, logical, thinking individuals—thereby explaining their social, economic, and medical plight. Evaluation of their social condition disregarded the thanatopolitical systems and mechanisms of

[436] Richard C. Lewontin, *Biology as Ideology: The Doctrine of DNA* (New York: Harper Perennial, 1991).

[437] George Mosse, *Toward the Final Solution: A History of European Racism* (New York, New York: Howard Fertig, Inc., 1978).

culture. And thus, the idea of describing *science* as something that is logical, natural, and rational, for example continues to disregard the racialized subjectivities inherent in thoese ideas. Yet, they are not new to the collective consciousness of Western society. Medical inequity perpetuated on the bases of such rhetoric has also been well established within the contemporary epistemologies and praxis of scientific and medical communities. The continued normalization and legitimization of the molecularization and biologization of race and racialization are evidence of these ideologies.

Race and Medicine

Respondents were asked to list the first few words that came to mind upon hearing the phrase *race and medicine*. The most salient words listed in this section were history, experimentation, inequity, inequality, discrimination, Tuskegee, understudied subjects, bullshit and the phrase: how one group is impacted by medicine versus another group. This list is particularly interesting because they are thematically grounded by a perceived negative relationship between race and medicine while also referencing an awareness of the historical and contemporary imbrication of the two concepts. More specifically, respondents lists speak to the ways in which black bodies have been acted upon in the name of the medical progress narrative. Their responses also note the affects of race and racialization on negative health outcomes. Yet, as referenced in respondent attitudinal responses, many participants felt that the socio-historical ascription of race was significant to the understanding of medicine and science, at 68.75 percent and 50 percent respectively. This dynamic is not bewildering in that it simply asks that race be

examined holistically as something that is ascribed by, situated within, and engaged with relative to society and socio-medical systems which potentiate medical inequity, disparity, and perhaps thanatopolitics.

Such a request is in opposition to the idea of race being perceived as a stagnant truth with inherent, biological and/or genetically pre-determined health outcomes—the direction in which neoteric medical technologies such as pharmacogenomics and genome wide association studies are headed. Addressing the distinction between race in science and medicine and racialized science and medicine, however, would require intense, broad sweeping changes to contemporary social ideologies that directly and indirectly affect medicine as a symbolic and material process.

Health

Following the prompt on race and medicine, study participants were asked to list the first few things that came to mind upon reading the word *health*. The responses for this prompt all had to do with self-surveillance. Words and phrases like exercise daily, watch your weight, eat healthy, eat right, lose weight, work out, don't be fat, and get up dominated participant responses. None of the words or statements listed had to do with external forces or issues (such as food desserts, food swamps, poverty, inequality, or inequity) that could negatively affect someone's health. There was a stark lack of factors relating to the social determinants of health and health disparities in participant responses. Respondent freelist for the health prompt reflected health care discourses in

the United States that are often embedded in the idea of responsibilitization—a concept which ultimately leads to issues of fault and/or blame.

According to sociologist and social theorist Nikolas Rose, responsibilitization relative to genomic data and specifically personalized medicine is problematic because it obliges the medical consumer to take on the role and expectations of the physician (thereby accepting the consequences of their future health status) contrary to one's actual skill set and/or capabilities.[438] He goes on to state that although responsibilitization in health care is a positive shift from medical paternalism to something more patient centered and autonomous, it requires a patient to constantly and successfully balance varying forms of self-surveillance with being a good and productive biological citizen—via health screening, diet, exercise, genetic testing and the like.[439] Rose asserts that the depth of such responsibility will be multiplied relative to personalized medicine thus causing people to respond in the following ways:

> they may feel guilt, or may be regarded by others as in some way guilty, if they are unable or unwilling to do that—culpable for their own future illness and those of their family, even if in reality there was little that they could do to prevent these—as, for example in most cases of degenerative disease or cancer. The other side of being persuaded that you have the power and responsibility to take control of your own health is inescapably a feeling of failure of, despite all, you fall ill. They are placed in the uncomfortable position of having responsibility for an uncertain future, with limited ability to alter outcomes.[440]

Philosopher and bioethicist Dan W. Brock goes a step further and suggests that using one's genomic information to increase the predictive capacity of disease screening

[438] Nikolas Rose, "Personalized Medicine: Promise, Problems and Perils of a New Paradigm for Healthcare," *Procedia—Social and Behavioral Sciences* 77, no. 22 (Apr. 2013): 341-352.
[439] Rose, "Personalized Medicine," (2013).
[440] Ibid., 349-350.

and pharmaceutical efficiency changes one's perceptions of his or her individual health—contrary to whether they actually feel ill or are asymptomatic.[441] According to Brock, the discrepancy between being labeled ill or diseased (by one's physician and perhaps society) without actually feeling or seeing oneself in the diseased state "will undermine their sense of themselves as healthy, well-functioning individuals and will have serious adverse effects both on their conceptions of themselves and on the quality of their lives."[442]

Dialogics of self-surveillance and responsibilitization, however, fail to acknowledge the increasing potentiality of physician liability relative to the normalization of pharmacogenomics. More specifically, the promise of personalized medicine and the touted efficacy of noting heterogeneity of therapeutic effect are housed in the possibility of "increased clinician liability if a patient does not respond as indicated or if he or she is denied access to a specific medication due to an unforeseeable adverse drug reaction (ADR), or due to the presence (or absence) of a particular genetic variant.[443] To elaborate, most blockbuster pharmaceuticals are designed to be metabolized by the enzymes in the cytochrome P450 (CYP450) system which handles biotranformation—

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[441] Dan Brock, "The Human Genome Project and Human Identity," in *Genes and Human Self Knowledge: Historical and Philosophical Reflections,* edited by Robert F. Weir, Susan C. Lawrence, Evan Fales (eds.) (Iowa City, Iowa: University of Iowa Press, 1994).

[442] Ibid., 29.

[443] F. Randy Vogenberg, Carol Isaacson Barash and Michael Pursel, "Personalized Medicine Part 1: Evolution and Development into Theranostics," *Pharmacy and Therapeutics* 35, no. 10 (Oct. 2010): 560-576. PMC2957753, Also in Imanni K. Sheppard, "Addressing Inequity in Personalized Medicine: A Preemptive Approach in the Practice of Medicine." Paper Presented at the American Medical Association's ChangeMedEd Conference entitled: Cultivating a Community of Innovation (Oct. 2015). www.eventscribe.com/2015/ChangeMedEd/assets/pdf214851.pdf.

basically the absorption and excretion of drugs."[444] Pharmacodiagnostics is essentially a vehicle to personalized medicine and the use of metabalomics to identify heterogeneity of therapeutic effect and ultimately reduce (or eliminate) ADR's.[445] The combination of these processes are designed to achieve what F. Randy Vogenberg et. al describe in *Pharmacy and Therapeutics* as "optimal medical outcomes in the management of disease or a patient's predisposition to disease. As such, personalized medicine promises to bring about a new standard of healthcare; one with the potential to accelerate clinical trials, achieve better health outcomes and satisfy patients."[446] "Liability, then, happens when patients are not satisfied, when they had an ADR, or when some other miscellaneous enzyme at a different loci negatively affected their ability to metabolize a medication in the manner intended or expected by doctors and researchers".[447]At that point, the responsibility to manage their health care could potentially shift from the individual consumer/patient to the physician/medical industry which essentially guaranteed the efficacy of their product. This, of course, is problematic. It also speaks to loopholes of respnsibilitization in health care and the ambiguity of health.

Genetics

About half of the lists acquired from this prompt were related to the physiology of the human body. Some people wrote out "deoxyribonucleic acid" (DNA). Other people

[444] Ibid. Also in Sheppard, "Addressing Inequity in Personalized Medicine: (Oct. 2015). www.eventscribe.com/2015/ChangeMedEd/assets/pdf214851.pdf.
[445] Ibid. Also in Sheppard, "Addressing Inequity in Personalized Medicine: (Oct. 2015). www.eventscribe.com/2015/ChangeMedEd/assets/pdf214851.pdf.
[446] Ibid., 562. Also in Sheppard, "Addressing Inequity in Personalized Medicine: (Oct. 2015). www.eventscribe.com/2015/ChangeMedEd/assets/pdf214851.pdf.
[447] Ibid.

listed the bases of DNA and a few respondents listed the bases of RNA. The word "genes" was also listed. However, history, culture, ancestors, strength, Tuskegee, and hair were the most repeated and salient words noted. This is significant because it suggests that while many of the study participants have a general idea of the science associated with genetics and specifically DNA, the word *genetics* brings to mind the biology of genetics as well as some of its broader social underpinnings. Words like Tuskegee, culture, and hair, allude to this understanding. As such, any lay discussion of genetics should perhaps be inclusive of the relationship between a biological understanding of genetics and the socio-medical history of genetics and genetics research.

Historical Significance

Acknowledging the relationship between a biological understanding of genetics, its socio-medical history, and its practice is significant for two reasons: 1) such discourses will inform the epistemologies and practice of neoteric, genomic (and genetic) medical technologies like pharmacogenomics and genome wide association studies and 2) the hermeneutics of genetics has historically been directly and indirectly affected by culture—specifically its ideologies and its socialization processes. For example, in the early part of the 19th and 20th centuries, the narrative of genetics was entwined with public health discourses aimed at defending the race of man through the identification (and in some cases the elimination) of socially undesirable characteristics. The normalization and legitimization of thanatopolitical social systems and mechanisms that

worked to eliminate hereditary defectives are the most pertinent examples of this relationship.

For example, the bourgeoisie attempt to control society's gene pool is readily apparent in the forty-five year long forced sterilization practices of almost 8,000 individuals in states like North Carolina—practices that disproportionately targeted poor, minority peoples. Throughout the United States, more than 60,000 individuals underwent forced sterilization disguised as public health.[448] Such thanatopolitical practices occurred longer than the Tuskegee experiments and affected more people. Yet, because they were normalized and legitimized processes that molecularized and biologized race and racialization, they have remained a silent happening in the medical community; one that is vividly tragic to those individuals forced to undergo the procedure in the not so distant past.

Likewise, in the landmark case of Buck vs. Bell in 1927 (and the appeal Buck vs. Priddy[449]) Carrie Buck was said to be a feeble-minded imbecile by the U.S Supreme Court. She was seventeen. As an imbecile, should was considered a hereditary defective and was subjected to compulsory sterilization. Many state sponsored sterilization programs tended to assert their authority and encroach on the reproductive rights and

[448] Alexandra Minna Stern, *Eugenic Nation: Faults and Frontiers of Better Breeding in Modern America* (Oakland, California: University of California Press, 2016): 271.

[449] Albert Priddy was the Superintendent of the Virginia Colony for the Epileptic and Feebleminded in Lynchburg, Virginia. Many women who worked outside of the home or whom were not perceived as normal were considered epileptic, hysterical, mentally-ill, defective, and/or feeble-minded and subsequently institutionalized and/or sterilized.

freedoms of people in prisons and mental institutions because those individuals were perceived as being genetically tainted and otherwise lacking in degrees of humanness.

Sterilization practices and corresponding laws based their concerns on research from people like Richard Dogdale who made-up a family called the "Juke's"[450] and Henry H. Goddard's study of the fictive "Kallikak" family which outlined the supposed hereditary nature of socio-pathological behavior, social deviance, and racial degeneration.[451] In both cases, undesirable behavioral and psychological traits were believed to have been passed from one generation to the next—thus noting their heritability and potentiality to corrupt the perceived racial purity of the middle class.

The coerced use of the Norplant contraceptive device in the 1990's was similarly an attempt to ameliorate the presence of perceived, socially defective, or deviant genes from society.[452] Likewise, the mandatory Sickle Cell testing of the 1970's (which forced African Americans school aged children and young adults to undergo diagnostic, and carrier genetic testing) was an attempt to identify genetically diseased individuals for the sake of public curiosity articulated as public health concerns, as no curative therapies existed at the time. This resulted in a host of ethical issues including the District of Columbia's mandatory sickle cell testing (which referred to sickle cell disease and sickle cell trait as communicable), or New York State's law which required only African

[450] Richard Louis Dogdale, *"The Jukes": A Study in Crime, Pauperism, Disease and Heredity: Also Further Studies of Criminals* (New York, New York: The Snickerbocker Press, 1877).
[451] Henry H. Goddard, *The Kallikak Family: A Study in the Hereditary of Feeblemindedness* (New York, New York: McMillian, 1912).
[452] Fulda, "Ethical Issues in Predictive Genetic Testing: (2006).

Americans to be tested prior to being allowed marriage licenses.[453] Those situations were representative of the local government's involvement in determining and regulating the genetic criterion for procreation in African American communities.[454] Moreover, it has become commonplace for historical and contemporary interpretations, applications, and narratives of genetics (and genomics) to be filtered through that kind of socio-medical, juridical lens. As noted throughout this text, the use of race and racialization in pharmacogenomics and genome wide association studies, in particular, make them active agents in the perpetuation of the perceived legitimacy of the molecularization and biologization of race and racialization. They, like many other neoteric medical technologies before them, become purveyors of subjective, racialized ideologies vehemently propagated as objective truths. However, although the socio-historical ascription of race and the race of man are often collapsed into culturally derived ideals of the biological and molecular self, they are not the same. They are also not genetic and thus can not and should not be used as standardized, legitimized variables within genomic medicine or genomic research.

Genetic Medicine

In response to the prompt *genetic medicine*, ten participants wrote that they did not know what it meant. The remaining people listed the words race and medicine,

[453] Howard Markel, "Scientific Advances and Social Risks: Historical Perspectives of Genetic Screening Programs for Sickle Cell Disease, Tay-Sachs Disease, Neural Tube," in *Promoting Safe and Effective Genetic Testing in the United States. Final Report of the Task Force on Genetic Screening.* Washington, DC: NIH-DOE Working Group on Ethical, Legal, and Social Implications of Human Genome Research, 1997.

[454] U.S. Congress Office of Technology Assessment, *Biology, Medicine, and the Bill of Rights—Special Report, OTA-CIT-371* (Washington, DC: U.S. Government Printing Office, 1988): 69.

manipulation, Tuskegee, history, and cancer. One person chose not to answer. This list of words does not acknowledge genetic medicine as a process informed by one's molecular information. They do, however, imply a sense of trepidation or caution to and with the concept itself. Respondents apprehension regarding genetic medicine is deduced by the presence of the words "Tuskegee," and "manipulation." Tuskegee is a reference to forty-years worth of experimentation on African American males without their knowledge or consent and the word "manipulation" typically does not have a positive connotation.

According to the United States Congress' former Office of Technology Assessment (OTA)[455] people tend to become or desire to become more knowledgeable about scientific information and general technologies when they have a personal motivation, risk, or when that science or technology is depicted as controversial by mass media.[456] Based on my data, however, it is unclear whether increased knowledge of genetic medicine will also increase one's level of comfort with the idea and practice of it.

[455] The Office of Technology Assessment (OTA) was a governmental agency whose sole purpose was to provide Congress with objective information (if possible) on the physical, social, economic, biological, and political effects of new technologies. The organization existed from 1972-1995, and was discontinued by Newt Gingrich (then Republican Speaker of the House) via budgetary cuts. Since then, some of the OTA's work has been reallocated to the Government Accountability Office (GAO) but no agency parallel to the OTA has been established. Michael Rodemeyer, Daniel Sarewitz, and James Wilsdon, *The Future of Technology* Assessment (Washington, DC: Foresight and Governance Project Woodrow Wilson International Center for Scholars: 2005). Also note: Celia Wexler, "Bring Back The Office of Technology Assessment," *The New York Times.* Updated May 28, 2015. http://www.nytimes.com/roomfordebate/2015/05/28/scientists-curbing-the-ethical-use-of-science/bring-back-the-office-of-technology-assessment.

[456] Larry Thomas, "Communicating Genetics: Journalists' Role in Helping the Public Understand Genetics," in *Genes and Human Self Knowledge: Historical and Philosophical Reflections*, Robert F. Weir, Susan C. Lawrence, Evan Fales eds. (Iowa City, Iowa: University of Iowa Press, 1994).

Noting the Recurrence of the Word "History" in Participant Responses

One of the only words mentioned relative to several different freelist prompts was *history*. Unlike *Tuskegee*, which was also mentioned in several sections, *history* seems to have a more fluid conceptualization. For example, in the section prompted by the phrase *race and medicine*, history was a reference to events in the history of medicine that specifically reflected on the ways that the practice of medicine acted upon racialized bodies. This conclusion is based on the relationship of the word *history* with the assemblage of words present in that category: bias, inequity, discrimination, unfair, Tuskegee and experimentation, for example. The *history* listed in response to the *genetics* prompt, however, seems to have more to do with inheritance than partiality or prejudice. Words like genetics, genes, and ancestors reaffirm my assertion in this regard. Finally, in the *health* prompt, *history* was a reference to one's individual medical history and/or the ways in which one's individual behavior affects his or health. I note behavioral history as a possibility because all of the words and phrases noted in response to the prompt had to do with the intersections of one's comportment with his/her health determination. Exercise, living better, cardio, healthy eating, taking care of our bodies, and food portions were some of the words noted.

The fluidity and salience of *history* relative to freelist prompts implies that respondents are cognizant of the inflections and influences of one's individual, collective, and social histories on their health and well-being. For respondents, issues of medical inequity, inheritance, and personal responsibility flow through each of the fore noted

prompts. These concepts also formulate pieces of the social determinants of health and health disparity. They are relevant to holistically understanding the particulars and peculiarities of negative health outcomes. In pharmacogenomics and genome wide association studies, for example, it is the history of the normalization and legitimization of the molecularization and biologization of race and racialization that inform its knowledges, practices, and interpretations. It is that foundation that also potentiates negative health outcomes for poor and minority peoples.

Chapter VII: Conclusion

Yes, pharmacogenomics has the potential to make medicines more efficacious with less side effects. Yes, genome wide association studies can revolutionize genetic screening and may assist researchers and physicians with detecting and/or predicting the presence of certain diseases. But, how do the knowledges, methodologies, and applicable data interpretations of these technologies play out beyond the medical or scientific endeavor? The conceptual application of scientific modelling applied to historical and socio-medical contexts suggests that the regularization of neoteric medical technologies (such as pharmacogenomics and genome wide association studies) which utilize socio-historical, racial ascription in tandem with the genetic categorization will further instigate cultural behaviors that are stigmatizing or discriminatory. Moreover, (as discussed throughout this paper) the use of race in genetic and genomic research legitimizes its molecularization, biologization, and racialization—all of which inform how genome wide association studies and pharmacogenomics will be researched, analyzed, interpreted, actualized, their information democratized, their premises taught, and their knowledges utilized. This framework moves beyond the sphere of medical and biomedical research and into a socio-medical ideology that normalizes thanatopolitical systems and medical inequity.

As said by Stuart Murray, "the cruel myth, of course, is that there is equal access for all, that the market's terms are independent and fair. Neoliberalism must utterly

disavow the often-criminal infrastructural inequalities it relies upon and perpetuates."[457] But, the chances of such a repudiation are unlikely to occur. Instead, a holistic evaluation of the potential socio-medical affects of the molecularization and biologization of race and racialization relative to genomic medicine is disregarded and the progress of medicine is engaged with as if it were a cultural vacuum. This, of course, is problematic and otherwise off-kilter with the historical and contemporary affects of racialized neoteric medical technologies in Western society. I discuss these circumstances and some of their broader socio-medical affects throughout chapters four, five, and six of this dissertation.

For example, when asked about the interplay between race, genetics/genomics, and medicine, participants of this study wondered about the social implications of having such starkly defining aspects of the Self— their genomic information—available to individuals (such as employers or physicians) whom may not have their best interests in mind (even after being informed if GINA). Fear, anger, and tentativeness riddled respondent recollections and their narratives spoke of anxiety related to potential and contemporary forms of sigma, discrimination, and medical inequity. Those issues are likely to be exacerbated by impending cost increases, limited access, and the ambiguity of racialized genomic based health care and pharmaceuticals.

[457] Stuart J. Murray, "Thanatopolitics: On the Use of Death for Mobilizing Political Life," *Polygraph* 18, Special Issue (2006): 213.

Also, historical atrocities and cultural distrust in the distributive justice of science and the institution of medicine gave respondents pause when confronted with the probable integration of genomic based health care/medicine into their repertoire of available health care options. Those apprehensions were amplified by socio-medical histographies and contemporary examples of racialization and scientific subjectivities that defined and essentialized individuals based on their perceived or actual medical status. The Genetic Information Non-discrimination Act, anti-discrimination laws associated with the Americans with Disabilities Act, and Title VII of the Civil Rights Act each work to help quell the kinds of concerns noted by respondents of this study.

Unfortunately, history has shown that even with legislation, poor and minority peoples tend to be situated on the negative end of medical progress—especially that which had racial and/or racialized underpinnings. Poor and minority peoples have also often become *homo sacer* through the facilitation of neoteric medical technologies and ideologies that normalized and legitimized inequity. As suggested by Stuart J. Murray and Giorgio Agamben:

> Through burgeoning governmental and medical technologies, the individual's life now counts first as a biological member of the state's population, one biopolitical entity among a mass of others or, as Foucault sums up, 'man-as-species.' Effectively, the individual is displaced and becomes regularized by technology in which bodies are replaced by general biological processes. And here, finally, *Other* is 'allowed' to die in order to promote the sacred health and well-being of the population—us against them—those whose death is merely an unfortunate

> side-effect, quickly forgotten, disavowed: 'death of the bad race, of the inferior race (or the degenerate, or the abnormal).[458]

The ideas noted by Murray and Agamben are a dialogue of racialized ideologies that have been normalized and legitimized within the spheres of science and medicine. They evidence the broader socio-medical and systemic thanatopolitical affects of the Self/Other dichotomy relative to the molecularization and biologization of race and racialization. These issues are omnipresent in scientific and medical epistemologies and praxis and show no signs of de-racializing. Instead, and contrary to the dire need for there to be a stark demarcation between genomics and race, the trajectory of medical progress (in the form of pharmacogenomics and genome wide association studies) is one in which the plight of poor and minority peoples will continue to be an ignored consequence of the illusion of scientific and medical objectivity. Such problems will continue to be paraded before society as utilitarianism when they are really just medical inequity in the *Emperor's New Clothes*, daring the world to say otherwise.

[458] Murray, "*Thanatopolitics,"* (2006): 198. Also note: Giorgio Agamben, *Homo Sacer: Sovereign Power and Bare Life*, translated by Daniel Heller-Roazen, (Stanford, California: Stanford University Press, 1998).

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Appendix i: Survey and Freelist Prompts

SURVEY:

Please rate how strongly you agree or disagree with the following statements by bubbling in the corresponding ovals	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
American history has no influence on the practice of medicine	○	○	○	○	○
One's race should determine the kind of health care he or she receives	○	○	○	○	○
Access to medication is a right	○	○	○	○	○
The practice of medicine is objective	○	○	○	○	○
Most people have easy access to health care	○	○	○	○	○
One's race determines the kind of health care he or she receives	○	○	○	○	○
I would take medication given only to people of my race	○	○	○	○	○
Generic medications are the same as non-generic medication	○	○	○	○	○
One's race determines the kind of medications he or she receives	○	○	○	○	○
Most people can afford the medications prescribed to them	○	○	○	○	○

Medications are reasonably priced	○	○	○	○	○
One’s should determine the kinds of medications he or she is prescribed	○	○	○	○	○
I generally trust scientists	○	○	○	○	○
Race is genetic	○	○	○	○	○
I generally trust pharmacists	○	○	○	○	○
American history has no influence on science	○	○	○	○	○
One's race determines the kind of medications he or she is prescribed	○	○	○	○	○
Access to health care is a constitutional right	○	○	○	○	○
The practice of medicine is not affected by society	○	○	○	○	○
Race is significant to the understanding of science	○	○	○	○	○
Generic medications are as effective as non-generic medications	○	○	○	○	○
My doctor knows what is best for me	○	○	○	○	○
Access to healthcare is a privilege	○	○	○	○	○
Race is significant to the understanding of the practice of medicine	○	○	○	○	○

Science is not affected by society					
Access to medication is a privilege	○	○	○	○	○
Most people can access the medications prescribed to them	○	○	○	○	○
Science is objective	○	○	○	○	○
More people are on medications than in the past.	○	○	○	○	○
Race should determine the kind of medication someone receives	○	○	○	○	○

Please read each question and write the first word, words or phrase that you think of

What comes to mind when you think of the word *medicine*?	_____
What comes to mind when you think of the word *science*?	_____
What comes to mind when you think of the phrase *race and medicine*?	_____
What comes to mind when you think of the word *health*?	_____
What comes to mind when you think of the word *genetics*?	_____

What comes to mind when you think of the term *genetic medicine*?	_____ _

Thematic groupings of survey statements:

Subjectivity of Science and the Practice of Medicine:
I generally trust pharmacists.
Science is objective.
Science is affected by society.
The practice of medicine is objective.
The practice of medicine is not affected by society.
American history has no influence on the practice of medicine.
American history has no influence on science.
I generally trust medical practitioners.
I generally trust scientists.

Race, Science, and the Practice of Medicine:

Race is genetic.
One's race should determine the kind of health care he or she receives.
Race should determine the kind of medication someone receives.
Race should determine the kinds of medications someone is prescribed.
I would take medication given only to people of my race.
Race is significant to the understanding of the practice of medicine.
Race is significant to the understanding of science.
One's race determines the kind of health care he or she receives.
One's race determines the kind of medications he or she receives.
One's race determines the kind of medications he or she is prescribed.

Cost of Healthcare and Pharmaceuticals:

Access to medication is a constitutional right.
Medicines are reasonably priced.
Generic drugs are the same as non-generic medicines.
Access to medicine is a privilege.
Most people have easy access to health care.
Access to health care is a constitutional right.
Most people can access the medications prescribed to them.
Generic drugs are as effective as non-generic drugs.

Most people can afford the medications prescribed to them.
More people are on medications than in the past.
Access to health care is a privilege.