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The Changing Face of Diabetes:
How Diabetes Came to Be an Issue in African Americans

by

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health struggles humanized the issue of health care for me. My parents, Hua Zhang and James Wang, have been remarkable people who have always wanted the best for me. My mother has been the calm voice of reason, even while juggling her work and her family. I look up to you for all that you do. My father has been incredibly patient whenever I needed help and is my biggest advocate, even when I have doubts about myself. And the smallest person here, but the person who has brought the greatest happiness to me, is my younger brother, Nicky. Thank you for just being you and reminding me what actually is important in life.

Note on Language

I use the terms "black" and "African American" interchangeably. I also will use the term negro if I am trying to preserve the essence of someone's statement or belief.

Introduction

The disproportionate and rising burden of diabetes in racial and ethnic communities in the United States is well documented but not well understood.
-Leandris C. Liburd 2010[1]

Diabetes was the first disease of which I became consciously aware. My grandfather often speaks of his *tang niao bing*, which literally translated from Mandarin Chinese is sugar urine disease. Complications from this disease figures prominently in my life as my grandfather often falls ill from the disease. The complications from diabetes are frightening and insidious, because they can always reappear. While there are so many treatments out there currently, there is still no completely effective way to control the disease.

The summer before I started college, my job at the Health Professionals Follow-Up Study, a longitudinal epidemiological health study, was to prep the diabetes questionnaires for scanning. The questionnaire was a form on which participants were supposed to bubble in their answers with a number 2 pencil. My job was to make sure every bubble was filled in properly, which it often was not. The task was unbelievably tedious, but I learned immensely about the pathology and complications of the disease. Many of the participants had serious issues with their vision, and even more with their mobility. On a particularly hot day the following summer, I was convinced I had developed diabetes because I had been drinking lots of water with no apparent abatement to my thirst. That evening I used the blood

[1] Leandris C. Liburd, ed. *Diabetes and Health Disparities: Community-Based Approaches and Racial and Ethnic Populations* (New York: Springer Publishing Company,2010), 3.

sugar monitor we have for my grandfather, and I found out that I was just being a hypochondriac.

Piqued by my personal interest in the disease and the prominence of the disease in the media and medical research, I began to read more about it. As I read more, I found that the twentieth century was a time of extraordinary change in what we know about the disease. There was remarkable progress in medicine and public health. Epidemiology grew as a science. In developed countries, the widespread use of vaccines and antibiotics largely controlled infectious, communicable diseases. Replacing these diseases as the leading causes of death were the diseases of civilization, such as diabetes.[2] Before the twentieth century, there was little discussion of diabetes at all in the medical literature. Over the course of the twentieth century, rates of diabetes exploded in the world and medical progress allowed greater insight into the pathology and treatment of the disease.[3] What struck me was the vast amount research into diabetes in African Americans. The majority of the research, however, has occurred within the past thirty years.

The study of diabetes

Diabetes mellitus is a much studied disease. Not only is there extensive medical literature on the disease, there are also extensive sociocultural studies of it. Diabetes lends itself to social studies because of its environmental causes. Lifestyle

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[2] Jennie R. Roe and Robert S. Young, eds., *Diabetes as a Disease of Civilization: The Impact of Culture Change on Indigenous Peoples* (Berlin: Mouton de Gruyter,1993).

[3] In this thesis, I do verge into the twenty-first century, because to stop the analysis at 1999 would impose an arbitrary end to continuous trends. Human time does not follow linearly the constraints placed by calendar time, and thus the chronicled history will involve aspects from the nineteenth century as well as the twenty-first century. Marc Bloch disparaged the use of centuries to denote seemingly important periods for historical phenomena, wrote, "In a word, we appear to assign an arbitrarily chosen and strictly pendulum like rhythm to realities to which such regularity is entirely alien." Marc Bloch, *The Historian's Craft*, trans. Peter Putnam (New York: Vintage Books, 1953), 182.

factors such as diet, obesity, and exercise contribute extensively to the development of type 2 diabetes, which accounts for 90 to 95 percent of all cases.

Diabetes mellitus is a disease in which there is a malfunction with the hormone insulin, which regulates the amount of glucose in the blood. Without insulin, blood sugar rises to dangerous levels. There are two main types of diabetes: type 1, or insulin-dependent diabetes formerly known as juvenile diabetes, and type 2, or non-insulin-dependent diabetes formerly known as adult-onset diabetes. In type 1, the body stops producing insulin due to a destruction of the beta cells in the Islets of Langerhans—the part of the pancreas that produces insulin. Injections of insulin are necessary or death will result within in a year or two of diagnosis. The first users of the synthetic insulin were type 1 diabetics, many of whom were bought back from the brink of death. During the 1920s, the newspapers abounded with miraculous cases of gaunt-looking children gaining weight and returning to a hopefully healthy life.[4] There had been no viable treatment for diabetics before. In type 2, the body stops responding to the insulin that is still being produced by the pancreas. Unlike type 1, type 2 is a chronic disease, and its complications, like heart disease or renal failure, often take years to manifest. Many, especially the poor, go years without a diagnosis of their condition, if it all. Type 2 diabetics can treat their condition with lifestyle modifications, oral medication, insulin, bariatric surgery, or a combination of these options. Type 2 is the less noticeable disease, since in 2011, the Centers for Disease

[4] Chris Feudtner, *Bittersweet: Diabetes, Insulin, and the Transformation of Illness*, ed. Allan M. Brandt and Larry R. Churchill, Studies in Social Medicine (Chapel Hill: The University of North Carolina Press, 2003).

Control estimated that in 2010 about 7.0 million out of the estimated 25.8 million with diabetes, are undiagnosed.[5]

It is widely acknowledged by public health officials and physicians that diabetes is a modern epidemic, with significant morbidity and mortality costs. Since the last two decades of the twentieth century, diabetes in African Americans has been an area of extensive investigation. The incidence of diabetes is rising faster in the African American population than in the white population. Additionally, compared to white Americans, African Americans have worse control over the disease, often due to the lack of proper medical care, and suffer greater morbidity costs. Such research is well-documented. Common themes in this area of study, diabetes in African Americans, are health disparities and the social determinants of disease.

A search on the Pubmed database, a repository for scientific and medical research, using the terms "diabetes," "African American*," "black*," or "negro*" turns up 175,996 articles.[6] Limiting the data of publication from 1900 to 1980, 26,587 appear. In the next two decades (1981 to 1999), over twice the number of articles appear (57,721). In fact, over 85 percent of the articles date from the period since 1980.[7] The question, rising from this, is how the problem of diabetes mellitus became a public health and epidemiological issue in African Americans.

What I discovered in doing my research was that it was very early on in the twentieth century that people refuted the idea that diabetes was rare in African

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[5] Centers for Disease Control and Prevention, U.S. Department of Health and Human Services, National diabetes fact sheet: national estimates and general information on diabetes and prediabetes in the United States, (Atlanta, GA: Centers for Disease Control, 2011).
[6] The search terms were diabetes (for the title) and either African American*, black*, or negro*" (to appear anywhere in the text). The date of the search was April 5, 2012. See pubmed.gov.
[7] The search returned 150,980 articles dating from 1980 to April 5, 2012.

Americans. For instance, using the data of the Metropolitan Life Insurance Company, Louis Dublin, a statistician at the company, found that in 1928 the African American mortality rate of diabetes was rising and *actually exceeding the rates of white Americans* [italics added].[8] In 1947, Herbert H. Marks, another statistician at the Metropolitan Life Insurance Company, he found that the diabetes morality rate in blacks to be "generally as high as or higher than the rates for the white population."[9] He even noted that:

> It is clear, then, that the higher rate among white persons for the country as a whole represents largely the difference between the two populations with respect to geographical distribution. It is generally true that in states where the Negro population is urbanized and has access to abundant medical and health services, the diabetes death rate in non-white populations are high.[10]

There, however, failed to be significant research and attention to this issue until the 1980s. Why?

The answer is not readily apparent in literature about the history of diabetes. Much of the written history on diabetes takes a progressive view of the disease by focusing on the pathological and technological innovations that took place. For instance, Robert Tattersall (2009) in *Diabetes: The Biography* focused on medical changes that occurred in diabetes: the synthesis of insulin, development of oral drugs,

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[8] Louis Dublin, "The Health of the Negro," *Annals of The American Academy of Political and Science*, 140 (1928), 84. The majority of the early data came not from governmental bureaus or public health organizations, but the Metropolitan Life Insurance Agency, which by 1909 insured more Americans than any other company, one out of five Americans. The Metropolitan Life Insurance Agency because of its number of African American policyholders was able to examine African American health and diabetes statistics around the country.

[9] Herbert H. Marks, "Recent Statistics on Diabetes and Diabetics," *The New England Journal of Medicine* 235, no. 9 (1946), 376.

[10] Ibid.

and the direction of pharmaceutical and medical research.[11] Absent from the book, however, is the question of whom benefitted primarily from the medical innovations. The book is about biomedical research. Similarly, Chris Feudtner (2003) in *Bittersweet: Diabetes, Insulin, and the Transformation of Illness* chronicled the transformation that occurred in diabetes with the use of insulin injections, which fundamentally altered the outlook and treatment of diabetes.[12] Similar to Tattersall's book, absent from this book are mentions of diabetes in minorities. The people that figure prominently in the book are Elliot Joslin and white, New Englander patients. These types of histories take a progressive view of the history of a disease, the mishaps of the past culminating the better present state of knowledge.

Most of the literature on health disparities and about diabetes focuses on the present state of affairs. Works that take this approach include *Health Issues in the Black Community* (2009) and *Diabetes and Health Disparities: Community-Based Approaches* (2010) which both provide an outlook of the current issues diabetes in African Americans.[13] The works, however, try to make sense of the contemporary etiologic factors of diabetes, not the history of the examination of those factors. The historical investigation of the study of diabetes in African Americans is often limited to citing the 1985 Heckler Report as a turning point. In the 1985 *Report of the Secretary's Task Force on Black & Minority Health*, commonly referred to as the Heckler Report, the US Department of Health and Human Services with the Secretary of Health and Human Services, Margaret Heckler, examined the status of minority health and found dismal

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[11] Robert Tattersall, *Diabetes: The Biography* (Oxford: Oxford University Press, 2009).
[12] Feudtner, *Bittersweet: Diabetes, Insulin, and the Transformation of Illness*.
[13] Ronald L. Braithwaite, Sandra E. Taylor, and Henrie M. Treadwell, eds., *Health Issues in the Black Community*, 3rd Edition ed. (San Francisco: Jossey-Bass,2009); Liburd, ed. *Diabetes and Health Disparities: Community-Based Approaches and Racial and Ethnic Populations*.

health disparities between white and black Americans.[14] Epidemiological and medical studies on diabetes often occur as discrete examination with little work to tie the works together.

To aid in my study, the work of Arleen Tuchman, Harry Marks, and Sarah Igo has been useful, because in their work, they all ask the question of what the categories mean in medical or social measuring.[15] I draw heavily from the approach of Arleen Tuchman (2011) who touched on the transientness of racial focuses in medicine. She examined the focus on Jewish Americans in the diabetes literature, which mostly disappeared by the mid-twentieth century.

A study in agnotology

How in the 1980s African Americans came to suddenly be a widely studied group in diabetes research is a study in agnotology. Londa Schiebinger defined agnotology as the study that "traces the cultural policies of ignorance [and] takes the measure of our ignorance, and analyzes why some knowledges are suppressed, lost, ignored, or abandoned, while others are embraced."[16] Alison Wylie wrote that there

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[14] Margaret M. Heckler, U.S. Department of Health and Human Services, Report of the Secretary's Task Force on Black & Minority Health, (Washington D.C.: Government Printing Office, 1985). For an example of a source that cites the importance of the Heckler see: Vanessa Northington Gamble and Deborah Stone, "U.S. Policy on Health Inequities: The Interplay of Politics and Research," *Journal of Health Politics, Policy and Law* 31, no. 1 (2006). Sandra L. Gadson, "Health Equality: The New Civil Rights Frontier," *Journal of the National Medical Association* 9, no. 3 (2006); Howard K. Koh, Garth Graham, and Sherry A. Glied, "Reducing Racial and Ethnic Disparities: The Action Plan From The Department of Health and Human Services," *Health Affairs* 30, no. 10 (2011).

[15] Arleen Marcia Tuchman, "Diabetes and Race: A Historical Perspective," *American Journal of Public Health* 101, no. 1 (2011); Harry M. Marks, "Epidemiologists Explain Pellagra: Gender, Race, and Political Economy in the Work of Edgar Sydenstricker," *The Journal of the History of Medicine and Allied Sciences* 58, no. 1 (2003); Sarah E. Igo, *The Averaged American: Surveys, Citizens, and the Making of a Mass Public* (Cambridge: Harvard University Press, 2007).

[16] Londa Schiebinger, "West Indian Abortifacients and the Making of Ignorance," in *How Well Do Facts Travel?: The Dissemination of Reliable Knowledge*, ed. Peter Howlett and Mary S. Morgan

are "sociopolitical, economic, and cultural impediments to research" resulting in the persistence of ignorance.[17] It was not the case that in the 1980s that diabetes suddenly spiked in African Americans. Since the early twentieth century, researchers noted that diabetes rates were rising in African Americans and even sometimes surpassing rates in whites.[18] The purpose of this thesis is not, however, to analyze real increases in the rates of diabetes in African Americans over time. Such a study would also be extraordinarily difficult due to the changing standards of diagnoses over time. The purpose of this thesis is to trace the evolution of understandings of African American health and diabetes in the twentieth century. The reasons for why this knowledge was not taken up in the broader discussion on diabetes has to do with the structures and policies of public health and epidemiology and the cultural beliefs about diabetes and race.

To answer the question of how diabetes in African Americans became a widely studied issue, I examined the contextual scaffolding of the American structures of medicine, public health, epidemiology, and race that allowed the facts of diabetes in African Americans to proliferate or to be forgotten in the medical literature. David Boyd Haycock used the term "contextual scaffolding" to refer to the "kinds of support that enable a fact to be established and become sufficiently stable to travel well."[19]

(Cambridge: Cambridge University Press, 2010), 152. Londa Schiebinger argued: "Ignorance is often not merely the absence of knowledge but an outcome of cultural struggle."

[17] Alison Wylie, "Mapping Ignorance in Archaeology: The Advantages of Historical Hindsight," in *How Well Do Facts Travel?: The Dissemination of Reliable Knowledge*, ed. Peter Howlett and Mary S. Morgan (Cambridge: Cambridge University Press, 2010), 184.

[18] Louis I. Dublin, "The Health of the Negro," *Annals of the American Academy of Political and Social Science* 140(1928); Herbert H. Marks, "Recent Statistics on Diabetes and Diabetics," *The Medical Clinics of North America* 31, no. 2 (1947).

[19] David Boyd Haycock, "The Facts of Life and Death: A Case of Exception Longevity," in *How Well Do Facts Travel?: The Dissemination of Reliable Knowledge*, ed. Peter Howlett and Mary S. Morgan

Undergirding the notion of contextual scaffolding is the idea that facts travel, and some facts travel well and become part of the conversation, say about diabetes, while others languish in the background and fail to stimulate further research.[20] Facts travel fruitfully when these bits of knowledge find new uses and users and form new definitional contrasts.[21] For instance in 1942, Julian Herman Lewis, the first African American to earn a PhD in medicine, argued: "Whatever the previous rates have been it is now true that there is not a very significant difference between Negroes and Caucasian in the occurrence of diabetes."[22] But this "fact" and facts like this, that showed that diabetes existed in African Americans in ever-increasing rates, that appeared throughout the early and mid-twentieth century did not travel fruitfully. It took the Heckler Report, which was "the first comprehensive US government account of the health disparities affecting racial and ethnic minorities in the United States,"[23] to alert the country on disparities between black and white health, such as the mortality and morbidity gap in diabetes. To understand this change, it is necessary to examine the historical contextual scaffolding of medicine and public health, epidemiology, and perceptions of diabetes and race in diabetes research to answer the question of how diabetes in African Americans became an issue.

(Cambridge: Cambridge University Press, 2010), 404. Haycock used the term "contextual scaffolding" to examine how facts about longetivity spread and seventeenth century England.

[20] See Mary S. Morgan, "Travelling Facts," in *How Well Do Facts Travel?: The Dissemination of Reliable Knowledge*, ed. Peter Howlett and Mary S. Morgan (Cambridge: Cambridge University Press, 2010).

[21] Ibid., 18.

[22] Julian Herman Lewis, *The Biology of the Negro* (Chicago: The University of Chicago Press, 1942), 282.

[23] Koh, Graham, and Glied, "Reducing Racial and Ethnic Disparities: The Action Plan From The Department of Health and Human Services," 1822.

This project is organized into three chapters, each of which examines one area of the intersecting narratives.

Chapter 1 deals with the history of medicine and public health. For much of the twentieth century, not only did public health and medicine not study African Americans, but also chronic diseases. The fledging field of public health in 1900 was primarily concerned with infectious diseases. Medical investigation also concentrated on the biomedical aspects of a disease. As these paradigms began to change, the state began to take responsibility for the health care of minorities in the latter half of the century.

Chapter 2 discusses practices of epidemiology. At the turn of twentieth century, epidemiologists primarily studied infectious diseases, not chronic diseases. There was an epidemiologic shift around mid-century, because as medicine largely conquered infectious diseases, chronic diseases became a bigger concern. With this new paradigm of epidemiologic study, the variables that mattered in study also changed. Epidemiologists increasingly considered variables like race.

Chapter 3 examines the cultural connotations of diabetes and race. While the first two chapters primarily focuses on practices of medicine and epidemiology, the third chapter focuses on how perceptions of the characteristics of diabetes as a disease of the rich and fat as well as beliefs about race influenced how physicians studied diabetes.

Certain issues are outside the scope of this thesis. The biggest is that I do not analyze the difference of African Americans women versus men. The experience of black men and black women throughout history have been extraordinary different. Additionally, the African American female rate of disease is separate and different

from the African American male rate of disease. In many respects, African American women have been dually subjugated by their race and their gender. African American women have been historically even more absent from the medical literature. An adequate examination of this issue is another topic in itself.

This is a study intended to defamiliarize a familiar disease. It goes beyond reductionists answers of "it was not counted" or even "racism" in explaining how over the twentieth century researchers went from largely ignoring diabetes in African Americans to considering it a major public health issue. The approach I have taken is one that traces the broader history of approaches to African American health and diabetes over the twentieth century to explain the issue. For the production of knowledge in African Americans and the subsequent acceptance and internalization of those facts in medicine and epidemiology, there need to be favorable conditions in the public health, epidemiology, and perceptions of the diabetic. The change of these factors built the foundations for the acceptance in 1980s that diabetes in African Americans was a public health problem. The focus of the late twentieth century of African Americans and diabetes was not purely a function that the disease was an issue in that group. The picture presented of diabetes may reflect the actual distribution of the disease, but it also reflects the assumptions of how to study a disease.

Chapter 1: Diabetes & Public Health

Simply by selecting a particular issue for investigation, public-health professionals reveal the aspects of society that are important and amenable to beneficial change.
-John McKinlay & Lisa Marceau 2000[1]

Some have noted that there are two ways of looking at a disease. One is in terms of its symptoms and causal factors. Erwin H. Ackerknecht argued in 1982: "Our evidence tells us that disease forms have remained essentially the same throughout the millions of years."[2] In this model, human intervention does not change disease. This is what Henry Sigerist, the famed historian of medicine, termed the facts of a disease to be "no more than the sum total of abnormal reactions of the organism or its parts to abnormal stimuli."[3] Another way to look at disease is to go beyond its biochemical aspects and to include the influences of culture and society. Robert Hudson argued: "diseases are not immutable entities but dynamic social constructions that have biographies of their own."[4] Charles E. Rosenberg wrote: "In some ways disease does not exist until we have agreed that it does, by perceiving, naming, and responding to it." This is a particularly useful way of considering diseases, because how physicians and the medical community have perceived diabetes is influenced by what the medical community deems relevant categories of analysis.[5]

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[1] John McKinlay and Lisa Marceau, "US Public Health and the 21st Century: Diabetes Mellitus," *The Lancet* 356(2000): 760.
[2] Erwin H. Ackerknecht, *A Short History of Medicine*, Revised ed. (Baltimore: The Johns Hopkins University Press, 1982), 3.
[3] J.N. Hays, *The Burdens of Disease: Epidemics and Human Response in Western History* (New Brunswick: Rutgers University Press, 1998), 3.
[4] Ibid., 4.
[5] Charles E. Rosenberg, "Introduction Framing Disease: Illness, Society, and History," in *Framing Disease: Studies in Cultural History*, ed. Charles E. Rosenberg and Janet Golden, *Health and Medicine*

The social life of diabetes mellitus has taken twists and turns. The diabetes literature of the early twentieth century did not describe diabetes as a major disease among African Americans. The prevalence of the disease increased throughout the century, and by mid-century, statisticians, particularly those at the Metropolitan Life Insurance Company, were noting that the diabetes mortality rates between whites and blacks were about equal.[6] It was not until the end of the twentieth century that diabetes among blacks became a major health policy concern. By the early years of the twenty-first century, researchers no longer ignored diabetes as a health policy concern for African Americans. This chapter is about how public health transformed so that the study of diabetes in African Americans could have been possible.

In 2011, the Centers for Disease Control estimated that there were 18.8 million people diagnosed with the disease and another 7.0 million undiagnosed, or 8.3 percent of the total population. The estimate is that 18.7 percent or 4.9 million non-Hispanic blacks, age twenty or older have the disease, whereas, 15.8 million or 10.2 percent of all non-Hispanic whites have diabetes.[7] Researchers at the Centers for Disease Control (CDC), using data from the National Health Interview Surveys, found that in 2000, the estimated lifetime risk of developing diabetes was higher for both non-Hispanic black men and women than for non-Hispanic white men (26.7

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in American Society (New Brunswick, New Jersey: Rutgers University Press, 1992), xiii. His conclusion was that a disease does not exist in the social consciousness until it is named.

[6] For examples see: Marks, "Recent Statistics on Diabetes and Diabetics."; Louis I. Dublin, "The Problem of Negro Health as Revealed by Vital Statistics," *The Journal of Negro Education* 18, no. 3 (1949).

[7] Centers for Disease Control and Prevention, "National diabetes fact sheet: national estimates and general information on diabetes and prediabetes in the United States."

percent) and women (31.2 percent).[8] There is extensive medical literature on the contemporary health disparities for different racial groups. The 2000 US Census found that the average American lifespan was 77.8 years, but the average African American lifespan was 73.1 years.[9] Such differences speak to more systemic lifestyle factors than just chronic illness, but attention to the health disparities has become part of the national public health agenda.

It has only been within the past thirty years that studying diabetes mellitus specifically in African Americans has been a significant public policy and medical issue.[10] The 1980s and 1990s were decades of change in medical research. For instance, the Heckler Report in 1985 was the first comprehensive examination into minority health. For most of the century, however, public health research was not conducive for the study of chronic diseases, even less so for the study of African American health issues. The purpose of this chapter is to trace the evolution of the field of public health—its growth as an institution and its changing focuses—to explain how it became fruitful for the production of facts like diabetes. Over the twentieth century, the health of citizens became increasingly a matter of state, making it an issue of public health. But for most of the twentieth century, public health was a fledging field, and medical and public health research concentrated on the biomedical

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[8] K.M. Venkat Narayan et al., "Lifetime Risk for Diabete Mellitus in the United States," *JAMA: the Journal of the American Medical Association* 290, no. 14 (2003).

[9] Georges C. Benjamin, "Foreword," in *Health Issues in the Black Community* ed. Ronald L. Braithwaite, Sandra E. Taylor, and Henrie M. Treadwell (San Francisco: Jossey-Bass, 2009).

[10] While the fields of medicine and public health are highly dependent on each other, they are different fields. Findings by public health officials about diseases did not necessary translate to medicine and vice versa. Allan M. Brandt argued that pubic health is often thought of as focusing upstream, preventing disease through ameliorating the social and environmental conditions, and medicine is often thought of as focusing downstream, once the disease has already taken shape and must be treated. See Allan M. Brandt and Martha Gardner, "Antagonism and Accommodation: Interpreting the Relationship Between Public Health and Medicine in the United States During the 20th Century," *American Journal of Public Health* 90, no. 5 (2000).

aspects of disease, especially infectious diseases. The original function of the U.S. Public Health Service, established in 1912, was to prevent the transmission of communicable diseases and gather information on those diseases.[11] By mid-century, the use of vaccines and antibiotics controlled most of these infectious disease, leading to rise of chronic diseases as the major causes of death. The biomedical paradigm, which focuses on the biochemical and molecular basis of disease, was an effective way to study infectious diseases. It contributed to the theme of technological process in medicine that dominated much of the century. Allan Brandt and Martha Gardner, wrote there was "a particularly American fascination with scientific and technical remedies for complex social problems as an approach to reform."[12] In the latter half of the century, however, the critique was that this model of understanding disease was too mechanistic and reductive, ignoring the important social dimension of disease.[13] African American health also became increasingly a matter of state, creating top-down changes in medical research and public health.

Public health in the early twentieth century

The state's responsibility for the health of its citizen is a relatively recent development, with roots in the nineteenth century.[14] It was only in the 1930s that the U.S. began experimenting with methods of financing health care, which included

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[11] Nancy Krieger and Elizabeth Fee, "Measuring Social Inequalities in Health in the United States: A Historical Review, 1900-1950," *International Journal of Health Services* 26, no. 3 (1996): 394.
[12] Brandt and Gardner, "Antagonism and Accommodation: Interpreting the Relationship Between Public Health and Medicine in the United States During the 20th Century."
[13] David Cantor, "The Diseased Body," in *Medicine in the Twentieth Century*, ed. Roger Cooter and John Pickstone (Amsterdam: Harwood Academic Publishers, 2000), 358. George L. Engel, "The Need for a New Medical Model: A Challenge for Biomedicine," *Science* 196, no. 4286 (1977).
[14] In the Western world, European countries developed systems for the care of its citizens before the US did. See Dorothy Porter, *Health, Civilization and the State: A history of public health from ancient to modern times* (London: Routledge, 1999).

private insurance and governmental insurance. It was also in the 1930s that the U.S. adopted its first form of national social welfare, Social Security (1935). In the 1940s, under the Hill-Burton Act, the federal government began giving out loans for hospitals seeking to build new facilities. In the 1960s, the vast expansion of federal power included the creation of Medicare and Medicaid. In the 1990s, President Bill Clinton attempted, but failed, to establish a system of national, universal health care coverage. Michael Foucault's theory of bio-power in which the state becomes concerned with the techniques and management of populations and people is especially relevant in the twentieth century. The body in the twentieth century is a political entity. That being said, for most of the twentieth century, the U.S. paid more attention to the health of white Americans.

Efforts to measure and control disease, including diabetes, are part of the purview of public health. Modern public health boards are concerned with chronic diseases like diabetes. For instance, in 2005 the New York City Department of Health and Mental Hygiene, in an effort to control the epidemic of diabetes, which in 2003 caused about twenty thousand hospitalizations in the city, implemented a system in which there was an electronic, laboratory-based reporting of blood sugar (the hemoglobin A1C test results, which provides an average of one's blood sugar for a two to three month period) to the Department of Health and Mental Hygiene.[15] Advocacy efforts to reduce diabetes and educate African Americans about diabetes are also a modern example of public health works. For instance, between 1993 and 1995, researchers at Columbia University and the Albert Einstein College of

[15] Amy L. Fairchild and Ava Alkon, "Back to the Future? Diabetes, HIV, and the Boundaries of Public Health," *Journal of Health Politics, Policy and Law* 32, no. 4 (2007).

Medicine designed an intervention to increase the number of African Americans with diabetes mellitus that gets annual dilated ophthalmic examinations.[16] These eye examinations help identify and treat diabetes-related eye diseases, which can lead to blindness. Such attention to chronic diseases and health disparities was not characteristic of much of twentieth century medicine.

The history of public health in America began in the nineteenth century. At the beginning of the nineteenth century, the U.S. was still a primarily agrarian and rural country. The first efforts to organize public health began on the nineteenth century East Coast in response to outbreaks of infectious diseases like yellow fever, plague, and cholera. For example, in 1805 the New York City Board of Health formed to deal with epidemic diseases like cholera. The board would only meet in times of emergency and was not a permanent bureaucracy.[17] The Civil War (1861 to 1865) was a turning point for public health. The sanitary programs used in the war to control diseases like dysentery, the bloody flux, and typhoid in the soldiers were models that cities and states later adopted.[18] Cities and states in the North were the first to establish boards of health. The South, ravaged by the war, established boards later on in the 1870s and 1880s. These boards were largely concerned with controlling with communicable diseases. For instance, the New York City Health Department inspected meats and milk and public drainage. The Louisiana Board of Health was supposed to function as a quarantine authority for diseases like yellow

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[16] Charles E. Basch et al., "The Effect of Health Education on the Rate of Ophthalmic Examinations Among African Americans With Diabetes Mellitus," *The American Journal of Public Health* 89, no. 12 (1999).
[17] Porter, *Health, Civilization and the State: A history of public health from ancient to modern times*, 148.
[18] Ibid., 150.

fever. However, characteristic of the boards in the North and South was that they had little power and there was poor funding. Their function was largely licensing physicians, not direct public health intervention.[19] Even the American Public Health Association, formed in 1872, was a goodwill organization, not a professional group. Public health became more institutionalized in the Progressive Era.

In the end of the nineteenth century and first two decades of the twentieth century, Progressives fought for social change. They saw disease as a form of moral failing. Public health became increasingly intertwined with social reforms. Part of the Progressives' reforms was that techniques of scientific management became part of public policy. Reformers like William Welch, the founder of the Johns Hopkins School of Medicine and Public Health, argued that sanitary improvement was the best way to improve the condition of the poor.[20] The Progressives' effort to reduce rates of tuberculosis in Baltimore was one such example of this.[21] While the Progressives made health part of public policy, diseases like diabetes were not on their agenda, because they were communicable, infectious diseases. The exclusion of diabetes and other chronic diseases was part of a larger medical trend in which the ethos of bacteriology and germ theory, which largely applied to communicable diseases, reigned.[22] This medical trend was biomedicine.

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[19] Ibid., 155.
[20] Elizabeth Fee, "Public Health and the State: The United States," in *The History of Public Health and the Modern State*, ed. Dorothy Porter, *The Wellcome Institute Series in the History of Medicine* (Amsterdam Edition Rodopi B.V. , 1994), 235.
[21] Samuel Kelton Roberts Jr., *Infectious Fear: Politics, Diseases, and the Health Effects of Segregation* (Chapel Hill: University of North Carolina Press, 2009).
[22] Fee, "Public Health and the State: The United States."

Biomedicine in the twentieth century

Biomedicine in the twentieth century dictated the direction of much medical research. Even the historiography of diabetes reflect this—most of what was written was about the medical discoveries of the disease. Characteristic of this paradigm was not looking at the socioeconomic factors of disease. The biomedical paradigm has a heavy emphasis on science, measurements, and statistics. It focused on the germ theory and bacteriology in research and practice at the expense of what Allan Brandt and Martha Gardner called the "wider range of social, behavioral, and environmental forces in the maintenance of health and the production of disease."[23] Referring to biomedicine and its impact on research, Lisa Berkman and Lester Breslow wrote: "It appeared that the future of health progress lay in differentiating diseases, discovering their specific causes (principally microorganisms), and then preventing these agents from being carried by vectors to human hosts."[24] While biomedicine was a paradigm of research for medicine, public health "became increasingly accommodationist to the authority of biomedicine."[25] The emphasis on biomedicine was on the biochemical pathogens and pathologies of disease, not disease on a population-level.

Scientists working in late nineteenth and early twentieth century made astounding discoveries in medicine. For instance, in 1883, Robert Koch identified the exact pathogen for cholera, the *Vibrio cholerae* bacterium. In 1890, Koch published his guidelines for finding and isolating the bacteria that caused illness, now known as

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[23] Allan M. Brandt and Martha Gardner, ""The Golden Age of Medicine?"," in *Medicine in the Twentieth Century*, ed. Roger Cooper and John Pickstone (Amsterdam, The Netherlands: Harwood Academic Publishers, 2000), 711.
[24] Lisa F. Berkman and Lester Breslow, *Health and Ways of Living: The Alameda County Study* (New York: Oxford University Press, 1983), 5.
[25] Brandt and Gardner, "Antagonism and Accommodation: Interpreting the Relationship Between Public Health and Medicine in the United States During the 20th Century," 711.

Koch's postulates. The postulates were originally: 1) finding the microorganism present in all sick organisms, but in not healthy organisms; 2) isolating the microorganism in a culture; 3) introducing the culture to a healthy organism, which should cause disease, and 4) recovering the microorganism from the diseased organism and comparing it to the original pathogen.[26] Such an approach seemed to provide the answer to curing many of the diseases that plagued humanity.

Not only was the biomedicine approach successful in the lab, American physicians embraced biomedicine as a way to buffer the strength of their profession. In 1900, American medicine was barely professionalized. There was not a central accreditation standard, and medical schools differed widely in their standards. In 1910, Abraham Flexner issued the Flexner Report, which sought to reform medical education. It called for a stricter science background. With the newly professionalized and science-based medical professions, the highly scientific way of approaching medicine, the biomedical paradigm, took root.

The implication of the biomedical paradigm for diabetes was that the direction of medical research about the disease focused a lot on the pathological aspects of the disease. The initial extraction and purification of bovine insulin in 1921 and the subsequent forms of insulin therapy received extensive attention. In the early days of insulin, the drug produced significant and deadly complications from the drug, which ironically included severe hypoglycemia for a disease characterized by hyperglycemia. At the laboratory bench, physicians concentrated on refining insulin

[26] Koch later dropped the first postulate, because there can be asymptomatic carriers of a disease, who have the pathogen but are not sick.

and its method of delivery and developing synthetic insulin to replace bovine insulin. The journal *Diabetes*, which started in 1952, mostly published articles on the biochemical processes of the disease. Stories like the miraculous recovery of Elizabeth Hughes—the daughter of Charles Evan Hughes, who, in 1916, lost the presidential election to Woodrow Wilson—dominated the discourse in the popular media. Elizabeth, a type 1 diabetic, was fourteen and not quite fifty pounds when she first received insulin.[27] There was widespread enthusiasm in society that the answers for diabetes could be found in the laboratory.

Pharmaceutical companies also invested heavily in developing drugs to treat diabetes. In doing so, they directed much of the research to the biological risk factors of diseases that could be treated with medications.[28] Through their marketing efforts and creating a market for their products, they altered the way the disease was treated and what was considered a risk factor.[29] In the 1950s, tolbutamide, under the brand name Orinase, was the first successful oral hypoglycemic drug for type 2 diabetes, whose treatment had only been insulin therapy. A 1957 article in the *New York Times* noted that people hailed tolbutamide as "potentially the greatest find in diabetes research in the last thirty-six years," namely, since the discovery of insulin in 1921. The use of Orinase faded in the 1970s, as cases of cardiovascular complications from the drug began surfacing. Replacing Orinase was a whole arsenal of other drugs,

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[27] Thea Cooper and Arthur Ainsberg, *Breakthrough: Elizabeth Hughes, the Disovery of Insuilin, and the Making of a Medical Miracle* (New York: St. Martin's Press, 2010).
[28] Jeremy A. Greene, *Prescribing by Numbers: Drugs and the Definition of Disease* (Baltimore: The Johns Hopkins University Press, 2007).
[29] Ibid., 1.

which included metaformin, which is still used today.[30] The historiography of diabetes tends to focus on the biotechnical changed in diabetes and those consequent impacts.[31]

There were exceptions to this biomedical approach. Due to the nature of diabetes as a non-infectious disease, physicians researching diabetes did not place the same emphasis on pathogens. Elliott Joslin's guidelines for taking care of diabetes patients, espoused in the many editions of *A Diabetes Manual for the Mutual Use of Doctor and Patient*, was one that involved strict diet control and regular visits to the physician. Joslin (1869-1962) was America's foremost diabetes specialist at that time. He founded the Joslin Clinic in Boston, Massachusetts, which was the epicenter of diabetes research in the twentieth century. Among much of its impact on the care for diabetic patients included a system of regular check-ups and maintenance for diabetic patients and information about how to reduce complications from diabetic pregnancies.[32] Joslin even gave out badges and medals to the patients who demonstrated good control over their diabetes and had few diabetes-related complications.[33] But the most prominent research occurred at the laboratory bench, purifying insulin and developing oral medications.[34]

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[30] Avandia, a thiazolindinedione, sold by GlaxoSmithKline, was one the best-selling diabetes drugs in the 2000s, but was pulled from the shelves in many countries in 2011 because of the risks of cardiovascular complications.
[31] Tattersall, *Diabetes: The Biography*; Feudtner, *Bittersweet: Diabetes, Insulin, and the Transformation of Illness*; Greene, *Prescribing by Numbers: Drugs and the Definition of Disease*.
[32] Feudtner, *Bittersweet: Diabetes, Insulin, and the Transformation of Illness*.
[33] Ibid. Elliott P. Joslin, *Diabetic Manual for the Patient*, Tenth ed. (Philadelphia: Lea & Febinger, 1959), 23. In the 1959 edition of the manual, Joslin describes the Life Expectancy Medal he gave to Amelia Peabody. He gave the Life Expectancy Model to diabetes were living longer than the average life expectancy of the time. There is an image of the medal on page 210 of 1959 edition.
[34] Tattersall, *Diabetes: The Biography*.

Another example of an exception to biomedicine was the work of Joseph Goldberger and Edgar Sydenstricker on pellagra. Their work identified not a pathogen as the cause of disease, but a nutritional deficiency of niacin. Yet their studies in working-class mill communities in the South, while groundbreaking in their approach of looking at the social determinants of disease, were still excluded African Americans from research.

A lack of niacin, Vitamin B3, causes pellagra, but social factors that lead to the nutritional deficiencies are the root causes.[35] Symptoms include skin lesions, insomnia, weakness, diarrhea, dermatitis, and dementia. Pellagra can also cause death.[36] It was especially prevalent in the South, where at least 100,000 people died from it between 1900 and 1940. The medical community, in the new age of germ theory, thought an infectious agent caused pellagra. The official Pellagra Commission of the U.S. Public Health Service stated that pellagra was "a specific infectious disease communicated from person to person by means at present unknown."[37] In 1914, the commission appointed Joseph Goldberger to lead the investigation. Goldberger, born in Hungary, was an epidemiologist who had worked at the Port of New York City, inspecting immigrants, and had researched various infectious diseases for the U.S. Public Health Service. Edgar Sydenstricker, who later worked on the National Health Survey, worked with Goldberger in studying the cause of pellagra. Goldberger suspected

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[35] Sources of niacin include meats with tryptophan, leafy vegetables, sweet potatoes, carrots, nuts, and yeast. The diets of those communities with high rates of pellagra were corn-based and corn has indigestible niacin.

[36] For these four symptoms, dermatitis, diarrhea, dementia, and death, pellagra is sometimes known as the disease of the four D's. Alfredo Morabia, "Part I: Epidemiology: An epistemological perspective," in *A History of Epidemiologic Methods and Concepts*, ed. Alfredo Morabia (Basel, Switzerland: Birkhäuser Verlag, 2004), 49.

[37] Mervyn Susser and Zena Stein, *Eras in Epidemiology: The Evolution of Ideas* (Oxford: Oxford University Press, 2009), 154.

correctly that it was not an infectious agent causing pellagra because in mental hospitals and orphanages, where institutionalized patients and orphans were malnourished, the staff would not contract pellagra even after close contact.[38] Other researchers, because of their belief in an infectious agent, were skeptical of Goldberger's conclusion.[39] Goldberger had even conducted experiments in which he supplemented the diet of orphans with protein and limited the diet of prisoners to a typical poor Southerner's diet and found that pellagra disappeared in the former and appeared in the later, His conclusion, howver, on the role of diet was still not widely accepted by other public health officials. It was Sydenstricker's suggestion to compare income and diet to the incidence of pellagra.[40] The two examined cotton mill villages in South Carolina and found that diet was the causal factor, which explained why wealthy individuals would not get the disease.[41] Their contemporaries praised this work and even today the pellagra studies are often noted as classics in social epidemiology. Harry Marks, however, argued that the two men ignored "the most salient social facts about pellagra," including the fact that African Americans, especially African American women who accounted for 69 percent of the African

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[38] Morabia, "Part I: Epidemiology: An epistemological perspective," 49.
[39] Susser and Stein, *Eras in Epidemiology: The Evolution of Ideas*, 155.
[40] Marks, "Epidemiologists Explain Pellagra: Gender, Race, and Political Economy in the Work of Edgar Sydenstricker," 41.
[41] Joseph Goldberger and Edgar Sydenstricker, "A Study of the Relation of Family Income and Other Economic Factors to Pellagra Incidence in Seven Cotton-Mill Villages of South Carolina in 1916," *Public Health Reports* 25, no. 46 (1920); Joseph Goldberger and Edgar Sydenstricker, "A Study of the Relation of Diet to Pellagra Incidence in Seven Textile-Mill Communiities of South Carolina in 1916," *Public Health Reports* 35, no. 12 (1920). Joseph Goldberger et al., *A Study of Endemic Pellagra in Some Cotton-Mill Villages of South Carolina*, U.S. Hygienic Laboratory Bulletin (Washington, DC: United States Government Printing Office, 1929).

American mortality rate from pellagra, had a disproportionate amount of the deaths.[42]

Pellagra and diabetes share some common themes. One, African American rates of the disease were in excess of white rates. Two, the previous fact was often ignored by the literature. Goldberger and Sydenstricker decided that it would be "disproportionately laborious to secure all the desired data from the negro families."[43] The two were aware that their sample population was "an exceptionally homogenous group with respect to racial stock, occupation, and general standard of living, including dietary custom." The African American families living in the cotton-mill villages were deliberately not considered, so that the study would "[deal] with an exclusively white population, which, with hardly a single exception, was of Anglo-Saxon stock born in the country of American-born parents."[44] They also made unwarranted conclusions writing that white and black tenant families had the same diet, which they did not.[45] Their methodology reflected prevailing attitudes about race and a lack of attention to African American health.

The previous sections examined how practices of public health not only neglected African Americans, but also chronic diseases. Not only was it standard practice to concentrate on the biomedical aspects of diseases, it was also standard practice to exclude African Americans from public health initiatives.

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[42] Marks, "Epidemiologists Explain Pellagra: Gender, Race, and Political Economy in the Work of Edgar Sydenstricker," 35.
[43] Goldberger et al., *A Study of Endemic Pellagra in Some Cotton-Mill Villages of South Carolina*, 9.
[44] Goldberger and Sydenstricker, "A Study of the Relation of Family Income and Other Economic Factors to Pellagra Incidence in Seven Cotton-Mill Villages of South Carolina in 1916," 2678.
[45] Marks, "Epidemiologists Explain Pellagra: Gender, Race, and Political Economy in the Work of Edgar Sydenstricker," 51.

Historical issues of being left out of public health

African American health in the early twentieth century painted a dismal picture. Most African Americans lived in the rural South and rarely, if ever, saw a physician. Their medical care was highly reliant on folk medicine. While the medical-industrial complex of the modern era did not exist and it was also common for poor whites to receive little care, black Americans were far away from the medical research centers, like Boston, that were the centers of medical innovation. Many of these African-Americans did not know much about contemporary medicine and their health. For example, a common, pervasive health complaint was "indijestius," which was an all-inclusive term to describe a variety of aliments.[46] In both the North and the South, the existing medical institutions reflected the *de jure* segregation in the South and the *de facto* residential segregation in the North.[47] The quality of care received at white hospitals versus that received at black hospitals were not equal. Not only was there segregation, there was also a lack of public services for African Americans. In 1948 Mississippi, there should have been four hospital beds per one thousand residents, but there were only five hospital beds for every 100,000 African Americans.[48] Many Southern states even ignored the 1921 Sheppard-Towner Act, for the improvement of maternal and child health, so that they would not need to fund

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[46] Charles S. Johnson, "The Shadow of the Plantation," in *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study*, ed. Susan M. Reverby, *Social Studies in Medicine* (Chapel Hill: University of North Carolina Press, 2000), 46-47. One example is a mother speaking about her son: "My boy's out there is sick. He got indijestus. It jest takes him that way every time he gets a little cold in him (47)." She stated that most of her thirteen children had indijestus.
[47] Colin Gordon, *Dead On Arrival: The Politics of Health Care in Twentieth-Century America*, ed. William Chafe, et al., Politics and Society in Twentieth-Century America (Princeton: Princeton University Press, 2003).
[48] Ibid., 175.

African American public health efforts.[49] At the root of much of the lack of medical care for African Americans was money. African Americans were poor and could not pay for medical treatment. Compounding this was racism. It was not a major concern for most white Americans to improve African American health.

This lack of attention was manifested not only in diabetes, but also other diseases such as sickle cell anemia and malaria. For a better understanding of the issues surrounding the narrative of African Americans and diabetes, it is useful to consider the biopolitical paradigms surrounding the other diseases and their treatment at the hands of the medical community.[50] There was little research into sickle cell anemia, a disease affecting mostly those of African origin, just as there was little research into diabetes in the same population. There were public health initiatives to combat malaria, but they were primarily targeted towards white Americans. An examination of diseases like sickle cell anemia and malaria reveals the biopolitical paradigms around African Americans' health.

Sickle cell anemia is a dominant-genetic blood disorder in which the red blood cells are not round, but sickle shaped. This causes the red blood cells to clot in the veins and arteries. Symptoms include frequent bouts of infections, pain, anemia, and swollen and painful extremities. Those with the rR phenotype, one sickle-cell gene and one non-sickle cell gene, will have some sickle-shaped blood cells—not enough to cause disease, but enough to offer protection against fatal outbreaks of malaria. African Americans have a higher-than-average prevalence of the disease

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[49] Ibid., 181; Edward H. Beardsley, *A History of Neglect: Health Care for Blacks and Mill Workers in the Twentieth-century South* (Knoxville: The University of Tennesse Press, 1987), 137.
[50] Stephen Epstein used the term "biopolitical paradigms" to refer to "frameworks of ideas, standards, formal procedures, and unarticulated understandings that specify how concerns about health, medicine, and the body are made through biomedicine and state policy."

because it is theorized that sickle-cells in rR types protected their African ancestors from malaria in the sub-Saharan malarial areas of Africa. This particular aspect of sickle cell anemia has shaped how physicians and society approach the disease.

Because sickle cell anemia is the most common among those with African ancestry, the medical community regarded it as a race-specific disease. In the late 1990s, the medical community did not regard diabetes mellitus specifically as a black disease, but one of which certain populations are at greater risks than others, such as Native Americans, African Americans, and Asians. At the beginning of the twentieth century, the medical community did regard diabetes to be race-specific. German doctors called diabetes the *Judenkrankheit*, or the Jewish disease.[51] Like diabetes, there were racial connotations to the disease. And, more importantly, the racial connotations influenced the direction of medical research and public health policy.

James B. Herrick and Ernest Edward Irons discovered sickle-cell anemia in the early 1900s.[52] The first cases of sickle-cell anemia were found in African Americans: Walter Clement Noel, a Grenadian dental student, and Ellen Anthony, a cook and housemaid. As sickle cell anemia became part of the disease canon, physicians considered the presence of the disease and African ancestry to go hand-in-hand. A 1947 editorial in *JAMA* stated "[sickle cell anemia's] occurrence depends entirely on the presence of a strain, even remote, of Negro blood."[53] A white person who was diagnosed with sickle cell anemia would be considered to have African

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[51] Tuchman, "Diabetes and Race: A Historical Perspective."

[52] By discovering, I mean that they put a name to a condition that had long exist. This relates back to Charles E. Rosenberg's theory that a disease "does not exist as a social phenomenon until…it is named." See Rosenberg, "Introduction Framing Disease: Illness, Society, and History," xviii.

[53] "Sickle Cell Anemia, a Race Specific Disease," *JAMA: Journal of the American Medical Association,* 133 (1947), 33-34 qtd in Keith Wailoo, *Drawing Blood: Technology and Disease Identity in Twentieth-Century America*, The Henry E. Sigerist Series in the History of Medicine (Baltimore: Johns Hopkins University Press, 1999), 137.

ancestry. A physician in 1943 wrote, "For a long time Johnny's mother attempted to conceal her Negro ancestry by making confusing statements concerning the Italian and Scotch ancestry, which apparently constitutes only minor branches in her family tree…[upon] future questioning] she finally admitted Negro ancestry."[54] Physicians equated sickle cell anemia with African ancestry.

The discourse surrounding sickle cell anemia involved racial disease determinism. The historian Keith Wailoo stated that the history of sickle cell anemia "tells a story about homological technique, *race, and social order* [italics added]."[55] Disease, medicine, and tools require interpretation by doctors to make sense of them, and doctors made sense of them within their existing frameworks of racism and identification. As with diabetes, researchers ignored sickle cell anemia. Congress did not allocate research dollars for the disease until the 1970s. Public statements by President Richard Nixon in 1971 and a controversial editorial in *The New England Journal of Medicine*, in which Robert C. Scott decried the ignorance over sickle cell anemia despite the high prevalence—"about one [out of every] 500 Negro births"—in African Americans, prompted an increased awareness of the disease.[56] The historian Todd Savitt asked, "How could a condition that commonly caused chronic illness and death among blacks and was therefore of great importance to the entire nation, be ignored for so long by both blacks and whites?"[57] The same question could be asked of diabetes. Savitt argued that sickle cell was "rediscovered" in the 1970s

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[54] A. Odgen, "Sickle Cell Anemia in the White Race, with Report of Cases in 2 Families," *Archives of Internal Medicine* 71 (1943): 164, qtd in ibid., 147.
[55] Ibid., 137.
[56] Todd L. Savitt, *Race and Medicine in Nineteenth- and Early-Twentieth-Century America* (Kent: The Kent State University Press, 2007), 39, 48; Robert C. Scott, "Sickle-Cell Anemia--High Prevalence and Low Priority," *New England Journal of Medicine* 282, no. 3 (1970): 164.
[57] Savitt, *Race and Medicine in Nineteenth- and Early-Twentieth-Century America*, 39-40.

after the Civil Rights movements that pushed for greater awareness of black health needs.[58] Where research monies go reflects the priorities of medical research. Both sickle cell anemia and diabetes in African Americans had a low priority on the research agenda.

Malaria, on the other hand, had a high priority on the medical research agendas. Malaria, the disease against which the sickle cell mutation protects, is a mosquito-borne protist disease. *Plasmodium falciparum* is the most deadly strain of malaria, which is transmitted when an *Anopheles* mosquito bites an infected person and carries the parasite to subsequent hosts. Re-infection with malaria is possible and often occurs in regions where it is endemic. Continual re-infection establishes a partial immunity but it disappears when a person leaves the endemic zone. Symptoms of malaria include high fever, chills, and the disease can result in death. Recurrent bouts of malaria can significantly weaken a person and cause neurological damage. It once caused significant mortality and morbidity in the American South, where it was endemic.

By 1951, efforts by the Centers for Disease Control and the National Malaria Eradication Program eradicated malaria in the United States. While the eradication ultimately benefitted everyone, the ways in which public officials controlled the disease before then speaks to the priority officials gave to certain groups, like white Americans. In the 1920s African Americans had malaria mortality rates two to four times those of the whites, whereas in the nineteenth century blacks actually had lower

[58] Ibid., 48.

rates than whites.[59] This rise in mortality happened regardless of the genetic immunity many African Americans had, such as the sickle cell trait and the absence of the Duffy antigen in their blood, which explained their lower rates of mortality in the early parts of the century. But the improvements in sanitation and water use in areas where many whites lived helped improve their rates of malaria but not that of blacks.[60] The historian Edward Beardsley stated that the reasons for this phenomenon are not clear, but it is likely that "a combination of social and economic factors" increased blacks' exposure to mosquitoes while exposure for whites decreased. These social factors included housing: whites lived in areas farther away from mosquito breeding sites, and blacks lived in swampier areas. Even when there were improvements in predominately black areas, the reason was not always simply the desire to improve the health of African Americans.

One way to control malaria is through preventative measures, primarily by controlling the breeding of mosquitoes, the disease vector. While all members of society, white and black, benefitted from the eradication, a closer examination of how public health officials conducted their efforts reveals their presuppositions of whose health was valuable. White Southerners often were the intended beneficiaries of these initiatives. For instance, James A. Haynes, the state health officer of South Carolina from 1911 to 1944, sought to reduce malaria in South Carolina's coastal lowlands. These lowlands had a population that was about two-thirds black in 1920. In 1921, Haynes said to the South Carolina state legislature, "we must get rid of malaria if we

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[59] Beardsley, *A History of Neglect: Health Care for Blacks and Mill Workers in the Twentieth-century South*, 19.
[60] Ibid.

are going to have white immigrants [to the coastal lowlands]."[61] Even with the establishment of public health offices, black health did not improve significantly for reasons that the public health initiatives were not primarily directed at them. For instance, just after World War I agencies for sponsoring malaria control concentrated on urban areas. Excluded from these efforts were the 80 percent of blacks that lived in the rural South, and their rates of malaria continued while rates in urban areas declined.[62] Another part of the reason was the reluctance of white physicians to take part in programs that intruded on their autonomy as well as those that they saw as primarily benefitting African Americans.[63]

Malaria has largely disappeared as a health concern in the United States. While it is still a significant cause of mortality and morbidity in developing countries, efforts to control the mosquito vector in the United States were successful. It is not just the end success that is important though, the racial motivations behind the public health initiatives are revealing. The lesson from malaria is that while the larger picture of the disease indicates successful eradication benefitting everyone in the U.S., there were still significant issues of racism and selectivity present. To whom public health initiatives were targeted and why are essential questions that need to be asked of not only malaria, but also diabetes.

Diseases are not just about biology. The social determinants are often equally important. In examining the health of Southern blacks and Southern white mill-workers, Edward H. Beardsley found that malaria is "on one level simply the result of the presence of *Anopheles quadrimaculatus*…But [it was] just as much the product of

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[61] Ibid., 143.
[62] Ibid., 129.
[63] Ibid., 128.

social facts such as poverty, racism and classism, unconcerned white (and black) doctors, penurious politicians, domineering landowners and mill owners, and New South boosterism."[64] The same could be applied to diabetes: on one level, it is about a body malfunctioning, but it also reflects quality of health care received and broader social conditions.

African American health issues were not completely ignored, but much of the attention paid to them occurred within the African American community. The tone taken within that group about the causes of disease differed from the tone of white physicians.

In 1906, W.E.B. Du Bois published *The Health and Physique of the Negro American*.[65] The main message in the monograph was that it was not due to racial inferiority that African Americans had worse health, but inferior living conditions. Du Bois stated, "With improved sanitary conditions, improved education, and better economic opportunity, the mortality of the race may and probably will steadily decrease until [it equalizes with white mortality rates]."[66] W.E.B. du Bois declared that the death rate of the Negro was undeniably higher than that of whites but with improved satiation, education, and economic opportunities the Negro may become healthier.[67]The same year, the Eleventh Conference for the Study of Negro Problems convened at Atlanta University, a historically black college that is now part of Clark Atlanta University in Atlanta, Georgia. The Conference agreed with Du Bois that it

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[64] Ibid., viii.
[65] W.E.B. Du Bois, *The Health and Physique of the Negro American* (Atlanta: Atlanta University Press, 1906).
[66] Ibid., 73.
[67] W.E.B. Du Bois, "Section 8: The Sick and Defective," in *Eleventh Atlanta Conference: Health and Physique of the Negro American* (Atlanta: University of Atlanta Press, 1906).

was social conditions that caused African Americans' poor health. Their resolution stated that they "did not find any adequate scientific warrant for the assumption that the Negro race is inferior to other races in physical build or vitality."[68] These findings were isolated within the African American community and did not make an impact in the outlook of the medical community.

There was an effort adopted by the federal government to improve African Americans health, which lasted almost two decades, but was eventually dismantled and forgotten. In 1915, Booker T. Washington started the Negro Health Improvement Week, which aimed to improve hygiene. Washington stated, "[Colored people] can be taught what to do to aid in improving their health conditions. Thus the amount of sickness among us can be lessened and the number of deaths annually decreased."[69] By 1939, approximately two million people in thirty-five states participated in Negro Health Improvement Week.[70] In 1930, the U.S. Public Health Service took over the Week, and in 1932, the U.S. Public Health Service created the Office of Negro Health Works, which oversaw the Week. The U.S. Public Health Service had been involved in the National Negro Health Week, sending officers to the Annual Tuskegee Negro Conference and hosting the National Negro Health Week conferences. The Public Health Service even hired an African American dentist, Roscoe Brown, to direct the Office of Negro Health. Mainstream health organizations like the American Red Cross and public health departments worked

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[68] Qtd in Gamble and Stone, "U.S. Policy on Health Inequities: The Interplay of Politics and Research," 100.
[69] Qtd in Sandra Crouse Quinn and Stephen B. Thomas, "The National Negro Health Week, 1915 to 1951: A Descriptive Account," *Minority Health Today* 2, no. 3 (2001): 45.
[70] Phoebe Ann Pollitt, "From National Negro Health Week to National Public Health Week," *Journal of Community Health* 21, no. 6 (1996): 405.

with the Week. In 1951, however, the Public Health Service de-commissioned the Office of Negro Health, because during the time of integration, it believed that black health issues should not be seen separately from those of whites.[71] A brief in the *Journal of the National Medical Association*, noted that National Negro Health News, published by the Office of Negro Health Works, was being discontinued because the need for "attention on the deplorable health conditions of the Negro population" is "no longer apparent" because "health is everybody's business."[72] The U.S. Public Health Service brushed off African Americans from the national agenda even though the need was still there, not "no longer apparent."[73] Victoria Northington Gamble and Deborah Stone, argued that the federal government closed the Office of Negro Health because it was a reminder of segregation and to keep with the trend of integration.[74] The National Negro Health Week, however, has been ignored in public health literature.[75] The historiography, or rather the lack thereof, shows how critical examinations into the history of African Americans public health were not a matter of historical concern.[76] It would not be until 1985, with the establishment of the Office

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[71] Stephen B. Thomas et al., "Historical and Current Policy Efforts To Eliminate Racial and Ethnic Health Disparties in the United States: Future Opportunities for Public Health Education Research," *Public Health Education Research* 7, no. 3 (2006): 325.
[72] "National Negro Health News Ceases Publication," *Journal of the National Medical Association* 43, no. 1 (1951): 59. The brief above this one on page 59 is about the disbandment of the National Association of Colored Nurses. The brief noted that the Associated "voted to disband because it feels its program of activities is no longer necessary." The aim of the association was to promote integration of African American nurses into the profession and the brief notes that the "goal is being achieved." Whether this was the actual reason is another matter of study.
[73] Ibid.
[74] Gamble and Stone, "U.S. Policy on Health Inequities: The Interplay of Politics and Research," 102.
[75] Quinn and Thomas, "The National Negro Health Week, 1915 to 1951: A Descriptive Account," 49. Pollitt, "From National Negro Health Week to National Public Health Week," 401.
[76] Another example of the lack of historiographic examination is in the history of African Americans and tuberculosis. See Roberts Jr., *Infectious Fear: Politics, Diseases, and the Health Effects of Segregation*, 6.

of Minority Health, that there was another federal agency devoted to African American health issues.

In the absence of significant public health efforts to increase diabetes awareness among African Americans, there were efforts within the black community to spread awareness about the disease. Dr. A. Wilberforce Williams, who had a column in the black newspaper the *Chicago Defender* from the 1910s to 1930s, urged his readers with diabetes to abide by a healthy diet, for which he provided a short guide.[77] He also advocated that "education and knowledge are necessary in the prevention and management of diabetes," which Elliott Joslin similarly promoted.[78] Awareness in the African American community, however, was entirely different than awareness and action in public policy. The structure and institutions of public health in the U.S. and the institution were not favorable for African Americans nor the study of diabetes.

State attention to African American health issues

There ware significant changes in medical policy and research in the second half of the twentieth century. The biomedical paradigm waned. With its over-emphasis on the biochemical processes of diseases and pathogens, it lacked the resources to handle the chronic diseases that were dominating the disease landscape.[79] For example, George L. Engel lamented in a 1977 issue of *Science* that medicine was in crisis because of its "adherence to a model of disease no longer adequate for the

[77] Dr. A. Wilberforce Williams, "Diabetes," *The Chicago Defender* 1924.
[78] Dr. A. Wilberforce Williams, "Diabetes Management," *The Chicago Defender* 1934.
[79] Brandt and Gardner, ""The Golden Age of Medicine?"."

scientific tasks and social responsibilities of…medicine."[80] Biomedicine, ignoring the societal factors of disease, was too reductionist. Engel called biochemical defeats in the body, the subject of biomedical study, "but one factor among many in the complex interaction of which ultimately may culminate in active disease or manifest illness."[81] The Civil Rights Movement and de-segregation helped to spur the inclusion of African Americans into health policy. The federal government also became increasingly involved in the management of its citizens, such as social security programs. The change that occurred after the Heckler Report were top-down changes that impacted medical research and public health. Vanessa Northington Gamble and Deborah Stone argued that "major changes in the access of minority Americans to health care came as a result of political action," which was also the mainspring of health disparities policy change.[82]

The 1950s and 1960s saw increased attention to Civil Rights and health discrimination. Oscar R. Ewing of the Federal Security Agency, which ran Social Security and the Children's Bureau, made a speech in 1952 entitled "Facing the Facts on Negro Health" to the Manhattan Central Medical Society. He said, "It is a reflection on the rate of our Nation's progress that we are compelled to think of the health status of the Negro as being something apart from the health status of the people as a whole. None of us can be proud of the fact that there is a special problem of Negro health."[83] Ewing citied that the life expectancy discrepancy between the white and the black was five years for girls and ten years for boys. Ewing's call to

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[80] Engel, "The Need for a New Medical Model: A Challenge for Biomedicine," 129.
[81] Ibid., 131.
[82] Gamble and Stone, "U.S. Policy on Health Inequities: The Interplay of Politics and Research," 95.
[83] Oscar R. Ewing, "Facing the Facts on Negro Health," *Journal of the National Medical Association* 44, no. 2 (1952): 108.

improve the living conditions Negro was a call that would be emphasized during the Civil Rights Era. For example, one of the issues that needed improving was the lack of black doctors—in the entire South there was only one Negro doctor for every 5,300 patients. In addition, there needed to be more public health units in "places where the infant mortality rates are high, and where too many young negro mothers die in childbirth." In 1963, Marcus S. Goldstein, a medical anthropologist who worked at the National Institute of Mental Health in Bethesda, Maryland, also stated that differences in health between whites and blacks could be accounted for by socioeconomic factors and literature was coming out that refuted the idea that blacks were intrinsically unfit.[84] In 1966, Martin Luther King Jr. wrote in the *Chicago Sun-Times,* "Of all forms of discrimination and inequalities, injustice in health is the most shocking and inhuman."[85] Court cases at the time also reflected the push towards racial integration. In 1963, the Supreme Court refused to hear the *Simkins v. Moses H. Cone Memorial Hospital* case. This upheld the ruling of the Court of Appeals, which ruled in favor of the plaintiffs, who sought to stop the racially discriminatory practices of two hospitals in Greensboro, North Carolina. The Simkins case only applied to hospitals that received Hill-Burton funds (the Hill-Burton Act was a federal act providing funds for hospital construction). The 1964 federal court case, *Easton v. Grubbs* broadened the impact of *Simkins* because racial discrimination was also banned in hospitals that did not receive Hill-Burton funds. It was not just calls for social reform that was spurring the inclusion of African Americans in public health matters,

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[84] Marcus S. Goldstein, "Longevity and Health Status of the Negro American," *The Journal of Negro Education* 32, no. 4 (1963).
[85] ""Direct Action" Planned Against Hospital Bias Here, King Says," *Chicago Sun-Times*, 26 March 1966.

but a transformation of how the state approached matters of health care for its citizens.

The rise of the welfare state in the twentieth century contributed to the state's incorporation of diabetes and health disparities into the nation's public agenda. The political meaning of citizenship became biopolitical. State power became highly intertwined with citizen's lives and health, as opposed to the lassiez-faire policies that had characterized much of the country's history. The modern welfare state, characterized by social welfare provisions like health care, arose first in Europe. It developed later and very differently in the United States, due the U.S.'s legacy of the friction between federal and state power.[86] As mentioned before, the Progressives were played a crucial role in making heath part of public policy. Their role, however, faded with the advent of World War I. The Great Depression in the late 1920s and 1930s was another impetus for social change. For instance, in 1935, Congress passed the Social Security Act. There was, however, no program for health insurance. The political liberalism of the 1930s and World War II America shifted towards conservatism post-War. In 1946, Democratic President Harry S Truman attempted to implement a system of national health insurance. This idea had originally been considered in the 1935 Social Security Act, but Franklin Roosevelt dropped the provision in hopes of making the Act easier to pass through Congress. Many moderate Democrats, Republicans, and the American Medical Association opposed Truman's plan, labeling it as "socialized" medicine. Truman's successor, the Republican Dwight D. expressed an interest in health care reform that would direct

[86] Porter, *Health, Civilization and the State: A history of public health from ancient to modern times*, 218-219.

government aid towards the expansion of private voluntary health insurance, authorize federal matching for public assistance recipients, and expand public health programs.[87] However, the conservative political climate of Cold War America linked government health care to Communism, however. In the 1960s, during the Johnson administration, national health care became part of the dialogue again.

In the 1960s with the implementation of liberal policies like President Johnson's Great Society, social programs became more racially inclusive. In 1965, the federal government passed Medicaid and Medicaid, which granted many African Americans the ability to pay for medical care. The 1965 passage of Medicaid and Medicare was part of what Edward Forgotson called the systems integration method. In the systems integration method, "the government directs resources to analyze the social causes of health…then it designs and substantially finances facilities and programs to solve these problems."[88] The federal government increasingly devoted money to the health care needs of African Americans in the 1960s and 1970s. The use of federal dollars decreased the autonomy of state and local health officials, such as those in the South, which had operated under segregationist principles.[89] By the mid-1970s, African Americans increasingly found a voice in the health policy dialogue. There was, however, a reduction in the amount of aid given to African Americans, especially in the inner cities. In the 1980s, there occurred what David McBride called

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[87] Dwight D. Eisenhower, *Special Message to the Congress Recommending a Health Progress, January 31, 1955* (The American Presidency Project, 2012).
[88] David McBride, "Black America: From Community Health Care to Crisis Medicine," *Journal of Health Politics, Policy and Law* 18, no. 2 (1993): 321.
[89] Gordon, *Dead On Arrival: The Politics of Health Care in Twentieth-Century America*.

"crisis recognition" in which the government and public health organizations began to acknowledge of the health problems in black communities.[90]

Medical research reflected this path. There were few studies on diabetes in African Americans in medical journals prior to the 1980s. It was in this atmosphere that the federal agencies began to reform their epidemiological methods. In 1984, Edward Brandt, M.D., the U.S. Assistant Secretary of Health, created a Task Force on Women's Health Issues. In 1985, the Secretary of Health, Margaret Heckler, released the *Report on Black and Minority Health*.[91] The report also moved away from the biomedical perspective noting that: "Health status is influenced by the interaction of physiological, cultural, psychological, and societal factors that are poorly understood for the general population and even less so for minorities."[92] The Heckler Report noted that the prevalence of diabetes was 33 percent higher "in the Black population than in the white population."[93] It was also primarily type II diabetes that caused the excess.[94] Not only did this report note the higher rate, but it also identified lifestyle factors like diet that contributed to the disparities. The Heckler Report did not only target African Americans; it also looked at Hispanics, Native Americans, and Asians, but the analysis of African American health comprised the majority of the report. As a response to the Heckler Report, the Department of Health and Human Services established the Office of Minority Health in 1986 to carry out the recommendations of the Heckler Report. In 1988, the Centers for Disease Control formed an Office of Minority Health and the National Institutes of Health created an Office of Research

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[90] McBride, "Black America: From Community Health Care to Crisis Medicine," 204.
[91] Heckler, "Report of the Secretary's Task Force on Black & Minority Health."
[92] Ibid., 7.
[93] Ibid., 150.
[94] Ibid., 149.

on Minority Health.[95] African American health issues became highly visible in the healthcare agenda. States responded to the Heckler Report by creating task forces on and offices for minority health.[96] This was top-down change that generated interest and attention to African American health.

Those working in public health and epidemiology have noted that the 1980s were a period of change. Leandris C. Liburd, PhD, MPH, the Director for the Office of Minority Health and Health Equity at the Centers for Disease Control and Prevention (CDC), started working for the CDC at the Division of Health Education, part of the CDC's for Health Promotion and Education in 1987. In her own words:

> I was recruited to the agency during the political period of a national interest in minority health that stemmed from the 1985 Task Force Report on Black and Minority Health commissioned by then Secretary of Health and Human Services Margaret Heckler. This report of excess deaths experienced by African Americans and other disadvantaged ethnic groups in the U.S. would institutionalize the federal commitment to address health disparities from the late 1980s to the present.[97]

Neil R. Powe, MD, of the Johns Hopkins University School of Medicine and Bloomberg School of Public Health, wrote that his "first quantitative glimpse of race and ethnic disparities was 23 yr [sic] ago when the [Heckler Report] was released."[98] After the Heckler Report, Powe noted that the "plethora of research studies and ethnic disparities are almost omnipresent."[99]

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[95] Thomas et al., "Historical and Current Policy Efforts To Eliminate Racial and Ethnic Health Disparties in the United States: Future Opportunities for Public Health Education Research," 326.
[96] Ibid.
[97] Liburd, ed. *Diabetes and Health Disparities: Community-Based Approaches and Racial and Ethnic Populations*, xvii.
[98] Neil R. Powe, "Let's Get Serious About Racial and Ethnic Disparities," *Journal of the American Society of Nephrology* 19(2008): 1272.
[99] Ibid.

The Clinton administration, continuing the work of the Reagan and Bush administrations, even pushed for the use of the term "disparities" rather than "differences."[100] The use of the terms is not to be overlooked. Steven Epstein argued, "whereas 'differences' can be constructed as a neutral term, "disparities" is a more manifestly political designation that points to an analysis of social inequalities."[101] It was the official policy of the Clinton Administration to target health disparities. In 1998 under the Clinton Administration, the Department of Health and Human Services in the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry noted, "personal characteristics, such as race, ethnicity, and sex, have been shown to be associated with differential experiences in obtaining quality health care."[102] The Commission headed by co-chairs Alexis M. Herman, the Secretary of Labor, and Donna E. Shalala, the Secretary of Health and Human Services, made it a goal by 2010 to eliminate gaps in racial and ethnic disparities in diabetes as well as in infant mortality, heart disease, HIV/AIDS and other diseases. The particular scaffolding of how to study disease and the role of the state propelled the creation of more facts diabetes in African Americans. In 2000, Clinton signed the Minority Health and Health Disparities Research and Education Act, which formed the National Institute on Minority Health and Health Disparities (NCMHD). The NCMHD aimed to reduce health disparities in racial and ethnic

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[100] Steven Epstein, *Inclusion: The Politics of Difference in Medical Research* (Chicago: The University of Chicago Press, 2007), 273.
[101] Ibid.
[102] The President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, Quality First: Better Health Care for All Americans, (Washington, DC: Government Printing Office, 1998).

minorities and other unhealthy populations. Its mission is also to raise aware about minority health issues and disparities.

The transformation of the state's concern with health in the latter half of the twentieth century spurred increased action and attention to minority health issues. This state transformation altered the way states responded to the health of its citizens and the populations it considered worthwhile of attention. Politics are cannot be separated from public health. As McKinlay and Marceau noted: "Simply by selecting a particular issue for investigation, public-health professionals reveal the aspects of society that are important and amenable to beneficial change."[103] Politics and public health are not "inappropriate bedfellows," because politics is about the distribution of power to groups in society and what groups receive attention.[104]

Conclusion

The fact that the medical and public health literature ignored African American rates of diabetes for much of the century was not simply that researchers did not care. For one, public health was a fledging field at the start of the century, and when it did become part of health policy it concentrated on infectious diseases for most of the century. Medical research was also highly influenced by the biomedical paradigm, so that the technical aspects of diseases like diabetes, received attention before social factors. The state had little direct responsibility for the health of its citizens early in the century. There needed to be the proper contextual scaffolding in

[103] McKinlay and Marceau, "US Public Health and the 21st Century: Diabetes Mellitus," 760.
[104] Ibid., 761.

public health for the facts of the prevalence of diabetes in African Americans to spread.

For public health and policy interventions to occur, however, there needs to be a system through which cases of the disease can be measured and tracked. Studies on the health of a population also rely on statistics of the population. The field of epidemiology, the basic science of public health, which not only studies the distribution of diseases in population, but also investigates the etiological factors of illness, provides the information necessary for evaluations of health in society.[105]

[105] Lester Breslow and Roger Detel, "Public Health and Epidemiology," in *The Development of Modern Epidemiology: Personal Reports From Those Who Were There*, ed. Walter W. Holland, Jørn Oslen, and Charles du V. Florey (Oxford: Oxford University Press, 2007).

Chapter 2: Diabetes & Epidemiology

It has been said that 'if necessity is the mother of invention, the awareness of problems is the mother of research'.
-J.H. Abramson & Z.H. Abramson[1]

Diabetes statistics are not simple reflections of reality. What is studied and how it is studied reveal many of society's biases and assumptions about what disease is and who gets sick. Medical writing is not just about science, but also reflects class, power, and race dynamics. The history of the epidemiological measure of diabetes is important because epidemiology is the measuring tool of public health. Throughout the twentieth century, the statistical methods of epidemiology lent the field the aura of objectivity, that it told the truth of the state of affairs.[2] Interventions to improve health disparities cannot exist if there is no knowledge that the disparities exist.

Important in the change that was occurring in diabetes epidemiology was the waning importance of the biomedical paradigm and the increasing importance of chronic disease epidemiology. At the end of the twentieth century, epidemiology was focused on examining chronic diseases, their risk factors, and population differences.

A major shift in measuring diabetes rates among African Americans occurred during the twentieth century. In the early years of the century, the data was mostly anecdotal. At mid-century, much of the data came from insurance agencies. It was not until last two decades of the century that there was a concerted effort to

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[1] Qtd in Hays, *The Burdens of Disease: Epidemics and Human Response in Western History*, 3.
[2] Theodore M. Porter, "Statistics and Statistical Methods," in *The Cambridge History of Science: The Modern Social Sciences*, ed. Theodore M. Porter and Dorothy Ross (Cambridge: Cambridge University Press, 2003), 238, 239; Brandt and Gardner, "Antagonism and Accommodation: Interpreting the Relationship Between Public Health and Medicine in the United States During the 20th Century," 172.

deliberately study African American health. Steven Epstein's idea of biopolitical paradigms is helpful when thinking about these changes. He describes these as: "frameworks of ideas, standards, formal procedures, and unarticulated understandings that specify how concerns about health, medicine, and the body are made through biomedicine and state policy."[3] At whom physicians and statisticians focused their attention reveals their value judgments that shaped the picture of who had diabetes.

While African Americans health issues were largely ignored, it was not that the category of race was completely absent in diabetes epidemiology. When it did appear, however, it was used mostly in a descriptive sense without investigation into the role of race as an etiological factor. The U.S. Public Health Service also collected data on race, but the use of race as a category of analysis in examining disease etiology would not occur until much later in the century.[4] The purpose of this chapter is show there needed to be a framework to study not just chronic diseases, but also African Americans to then assess the impact of a disease.

Early diabetes epidemiology

There was little epidemiological research into diabetes in the early twentieth century.[5] Firstly, there were few accurate diagnostics. Measuring sugar levels in the urine was an onerous process that used to involve steps like evaporating the urine. To many physicians evaporating urine probably would have been much preferable to the

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[3] Epstein, *Inclusion: The Politics of Difference in Medical Research*, 17.
[4] Krieger and Fee, "Measuring Social Inequalities in Health in the United States: A Historical Review, 1900-1950," 394.
[5] Kelly West, in 1978, noted: "Systematic epidemiologic studies in diabetes were few prior to 1960." Kelly M. West, *Epidemiology of Diabetes and Its Vascular Lesions* (New York: Elsevier, 1978).

previous method, which was to taste the patients' urine to see if it was sweet.[6] After all, "diabetes mellitus" comes from the Greek words meaning "siphon" and "sweet as honey." In 1933, Charles Bolduan, the director of the Bureau of Health Education in New York City, lamented the lack of data: "Diabetes is much more prevalent than is generally believed, but inasmuch as the disease is not reportable, no figures are thus available."[7] In 1946 and 1947 Herbert Marks, a statistician at the Metropolitan Life Insurance Company, also noted that was a lack of accurate data about diabetes: "The number of persons in the United States with diabetes is not accurately known."[8] Much of the data on diabetic patients were published physicians' notes on what they had seen in their practice. Elliot Joslin was a prolific recorder of his patients. In his publications, each patient was given a number and a description of his or her symptoms and background information. An exception was public health officers in New York City. Because of New York City's well-established Department of Health, which kept vital statistics on cause of death, the public health officers were able to analyze rates of diabetes mortality.[9] In a speech delivered in 1937 to the American Public Health Association (published in 1938), Bolduan even called diabetes "a public health problem," which was decades before the larger public health community

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[6] Charles Bolduan, "Has Diabetes Become More Prevalent," *American Journal of Public Health* 23, no. 12 (1933). Charles F. Bolduan, "Diabetes--An Important Public Health Problem," *American Journal of Public Health* 28, no. 1 (1938). Much of the early descriptions on diabetes focus on the honey-like taste of the urine of diabetics. For example, Thomas Willis (1621-1675) wrote that the urine was "wonderfully sweet like sugar or honey." See Tattersall, *Diabetes: The Biography*, 14.
[7] Bolduan, "Has Diabetes Become More Prevalent," 283.
[8] Herbert.H.Marks, "Recent Statistics on Diabetes and Diabetics," *The Medical Clinics of North America* 31, no.3 (1947), 359; Herbert H. Marks, "Statistics of Diabetes," *The New England Journal of Medicine*, 235, no. 9 (1946), 289.
[9] W. W. Peter, "Diabetes in New York City," *American Journal of Public Health* 18, no. 11 (1928); Bolduan, "Has Diabetes Become More Prevalent."; Bolduan, "Diabetes--An Important Public Health Problem."; Haven Emerson and Louise Larimore, "Diabetes Mellitus: A Contribution to Its Epidemiology Based Chiefly on Mortality Statistics," *The Archives of Internal Medicine* 34, no. 5 (1924).

would agree.[10] Often data that the officials used, however, only used the categories of age and sex, not race. The early surveying of diabetes also only measured mortality, gained through death certificates, because the mechanisms to report diseases largely existed for infectious, communicable diseases.[11]

In these early days of anecdotal data gathering, many physicians believed that Jewish Americans had the highest rates of diabetes. In 1919, Albert Epstein lectured to the National Conference of Jewish Charities: "The testimony of many physicians who have had a large experience with this disease goes to show that it seems from two to six times as frequent among the Jews as it does among the people around them."[12] Without widespread epidemiological data gathering, physicians relied on first-hand experience. Groups with the resources to receive medical care would be the sample from which physicians would draw their conclusions about the disease. As late as 1930, about 80 percent of African Americans lived in the rural South, where they had little contact with formal medical institutions.[13] There was scant mention of African Americans in discussions of diabetes.

There were cases of physicians noting cases of diabetes in African Americans, but largely went ignored and overlooked in the larger discourse of diabetes. In 1898, Dr. Reginald Fitz and Elliot Joslin of Boston, having only encountered one African American patient with diabetes their practice, noted that there must be few cases of

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[10] Bolduan, "Diabetes--An Important Public Health Problem," 21.
[11] Berkman and Breslow, *Health and Ways of Living: The Alameda County Study*, 15.
[12] Albert A. Epstein, "Diabetes Among Jews--Its Cause and Prevention," *Modern Medicine* 1, no. 3 (1919): 270.
[13] Beardsley, *A History of Neglect: Health Care for Blacks and Mill Workers in the Twentieth-century South*.

diabetes in African Americans. [14] They drew their conclusions from the 172 cases of diabetes mellitus seen at Massachusetts General Hospital. In the discussion section of the *JAMA* article, a Dr. West noted that he lived in a "country where there is a large proportion of [negroes]" and that he "never saw a case of diabetes in the negro race." He supported Fitz's and Joslin's assertion that diabetes was rare in blacks, despite the fact "the small proportion [of cases] might be due to the small proportion of negroes in that country.[15] Boston, Massachusetts, the site of the Joslin Clinic, was a center of diabetes research. It was a center of calculation for diabetes, and a center to which few African Americans would have had access for geographic reasons. One of the most important medical textbooks of the day, William Osler's *The Principles and Practice of Medicine*, first published in 1892 and continuously revised, said until the 1920s that diabetes was "comparatively rare in the colored race."[16] Why would, then, physicians study diabetes in African Americans if they thought blacks did not have the disease?

Physicians in the South, where the majority of African Americans resided at the beginning of the century, recorded greater instances of the disease in that population. Dr. Issac Ivan Lemann, a physician in New Orleans, wrote in 1921, "Indeed, it was formerly thought that diabetes mellitus was relatively rare in the negro. While this is not rare in the negro, still the incidence is not as great among them as among the whites."[17] Lemann based these observations on the cases he saw at the Charity Hospital in New Orleans. Dr. Harold M. Bowcock of Atlanta, Georgia, in

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[14] Reginald H. Fitz et al., "Diabetes Mellitus at the Massachusetts General Hospital 1824 to 1898. A Study of the Medical Records & Discussion," *JAMA: The Journal of the American Medical Association* 31, no. 4 (1898): 166.
[15] Ibid., 171.
[16] Qtd in Eugene K. Leopold, "Diabetes in the Negro Race," *Annals of Internal Medicine* 5, no. 3 (1931). Also in Lewis, *The Biology of the Negro*, 282.
[17] Issac Ivan Lemann, "Diabetes Mellitus, Syphilis and the Negro," *The American Journal of the Medical Sciences* 162, no. 2 (1921).

1928, attempted a statistical study of diabetes in blacks.[18] His primary purpose for studying diabetes in African Americans was not to assess the prevalence of diabetes, but to study the "many interesting points of comparison and contrast with the same disease in the white race."[19] Present in Bowcock's work was the idea of the biological separation of races, which held that whites and blacks were biologically different. On the other hand, Dr. Eugene Leopold of Johns Hopkins Medical Center in Baltimore, Maryland was interested in the rates of diabetes in African Americans.[20] Leopold noted that the medical profession considered diabetes to be a "rare disease in the colored race."[21] Leopold analyzed the death rates in Baltimore and found that "for every ten deaths of diabetes per hundred thousand inhabitants among whites, 6.4 negroes died of the disease."[22] His conclusion was that diabetes was not an uncommon disease in blacks. While physicians did acknowledge that diabetes was rising in African Americans, there was not follow-up research on the issue. There were two factors in play: one, there was little measurement into chronic diseases like diabetes, and two, there was a lack of interest in critically examining African American health.

In the first few decades of the twentieth century, the medical community drew conclusions from what they had in front of them—quite literally, the patients they saw in their clinics and hospitals. There was not a framework for seriously examining diabetes, much less diabetes in African Americans, like there would be later in the

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[18] Harold M. Bowcock, "Diabetes Mellitus in the Negro Race: A study of one hundred consecutive cases," *Southern Medical Journal* 21, no. 12 (1928).
[19] Ibid., 994.
[20] Leopold, "Diabetes in the Negro Race."
[21] Ibid., 285.
[22] Ibid.

century. This continued to the creation of ignorance surrounding the issue. It would be decades before there was a systematic effort to study diabetes and even longer to study diabetes in African Americans.

Selected background on epidemiology

Paul Zimmet in 1999, stated, "The growth of studies on the epidemiology and public health aspects [of diabetes] was…necessary for the field to move forward.[23] The epidemiological studies in diabetes helped to influence the U.S. government to "address diabetes as a serious public health issue."[24] The attention to health disparities is a public health issue. Epidemiology evolved in the nineteenth and twentieth century: first, it was a tool to control epidemic infectious diseases; with the epidemiological transition of the mid-twentieth century, it began to focus on non-infectious chronic diseases and then increasingly the social determinants of disease.

The science of modern epidemiology is relatively new with roots in nineteenth century England. Statistical methods and comparisons to figure out determinants of diseases characterize modern epidemiology. There are two key principles: population thinking and group comparisons.[25] Both are used to study diabetes. For instance, a population in question could be African Americans and the groups compared could black Americans and white Americans in the United States.

In population thinking, epidemiologists define a group of people by their social class, race, geography, or age, for example. In group comparisons, researchers

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[23] Paul Zimmet, "Diabetes epidemiology as a tool to trigger diabetes research and care," *Diabetologia* 42, no. 5 (1999): 499.
[24] Ibid.
[25] Morabia, "Part I: Epidemiology: An epistemological perspective," 5.

contrast the afflicted population with a similar population, but not afflicted. It was in the seventeenth century that people used population thinking to analyze health. John Graunt (1620-1674), an English haberdasher, a seller of sewing equipment like buttons, initially used the death rolls kept in London to monitor the plague to observe trends in death. In 1662, he published *Natural and Political Observations Made Upon the Bills of Mortality*.[26] In the book, he examined patterns in deaths from the plague and pestilence. Using the categories of age, sex, location, and time of death, Graunt was able to observe patterns, such as while there was the same proportion of excess deaths in men and women, more deaths were due to violence for men.[27] Such methods form the core of modern epidemiological thinking and is the basis of examining trends in diabetes, such as more women than men have diabetes.

In the eighteenth century, there was the start of the systematized use of group comparisons. For example, in 1747 James Lind (1716-1794), a Scottish physician for the Royal Navy, used a variety of treatments for scurvy. These treatments ranged from quart of cider, a course of seawater, two spoonfuls of vinegar, twenty-five gouts of elixir virtriol—a mixture of sulfuric acid, alcohol, and aromatics like ginger and cinnamon, to two oranges and a lemon.[28] He found that group which had been receiving the oranges and lemon recovered from scurvy. While Lind did not know that it was vitamin C, isolated in 1932, in the citrus that cured the scurvy, a

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[26] John Graunt, *Natural and Political Observations Made Upon the Bills of Mortality* (Baltimore: The Johns Hopkins Press, 1939).
[27] Susser and Stein, *Eras in Epidemiology: The Evolution of Ideas*. Because of this work, Graunt was elected to London's Royal Society, the esteemed society for natural philosophy. Because of his non-aristocratic background, many members of the Royal Society, which was a society for gentlemen, opposed his entry. Gaunt eventually died bankrupt in 1674.
[28] Morabia, "Part I: Epidemiology: An epistemological perspective," 35-36.

nutritional disease caused by the lack of the vitamin. In 1793, the Royal Navy began giving all its sailors an ounce of lemon or lime juice.

Similarly, Ignaz Semmelweis (1818-1865), a Hungarian physician in Vienna, discovered that puerperal fever, the leading cause of maternal deaths in the hospital at which he worked, was caused by contamination from infectious material from cadavers.[29] Semmelweis noticed that the death rate from puerperal fever was higher, from three to almost four times more, in the First Maternity Division at Vienna General Hospital than it was at the Second Maternity Division. The women at the First Division were primarily treated by medical students, while the women at the more crowded Second Division, were primarily treated by nurses. After witnessing one of his co-workers die after accidentally receiving a wound from a scalpel used during an autopsy and suffering the same symptoms as the mothers with puerperal fever, Semmelweis hypothesized that it was the cadaverous material that caused puerperal fever.[30] He implemented the rule that medical students wash their hands with chlorinated lime, a disinfectant. Afterwards the morality rate dropped to around 2 percent from a high of 11.4 percent in the First Division.[31] Before, the medical students had gone straight from autopsies to the delivery room, infecting the women with the cadaverous matter. This idea of group comparisons would become a fundamental theory in looking at health disparities for diabetes.

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[29] Carl Hempel, *Philosophy of Natural Science*, Foundations of Philosophy Series (Englewood Cliffs, New Jersey: Prentice-Hall, Inc., 1966), 3-6.
[30] This was before germ theory, so Semmelweis did not know that it was the bacteria on the cadavers causing the disease.
[31] Alfredo Morabia, "Epidemiological Methods and Concepts in the Nineteenth Century and Their Influences on The Twentieth Century," in *The Development of Modern Epidemiology: Personal Reports From Those Who Were There*, ed. Walter W. Holland, Jørn Olsen, and Charles du V. Florey (Oxford: Oxford University Press, 2007), 23.

In nineteenth century England, epidemiology began to take its modern shape with its weight on mathematical models and statistics. In 1854, John Snow (1813-1858), a London physician, used an ingenious map to track cholera cases in London's Soho district and found that the majority of the cases used the water pump on Broad Street. This showed that the cause of cholera was not miasma, or breathing foul air, but contaminated water.[32] In his book *On the Mode of Communication of Cholera* (1855), Snow used ratios to analyze the cholera rates of two water companies—the Southwark and Vauxhall Company and the Lambeth Company, and the rates of London. Snow's use of method and inference established a model for epidemiology.

Another important Victorian was William Farr (1807-1883), the Superintendent of England's General Register Office, which collected vital statistics. The historian John M. Eyler called Farr, "the first statistical heir of the newly created system of civil registration."[33] With access to the vast network of vital statistics, Farr and his staff were able to assess and compare the risks and impacts of diseases like cholera and tuberculosis. Farr's interest in statistics also mirrored the wider Victorian interest in statistics as tool for social reform.[34] Farr's conception of public health problems were that they were problems with the population. The answer to solving these issues lay in statistical models.[35] John Simon (1816-1904) further built on Farr's work on sanitary statistics. Simon, the first Medical Officer of Health for London,

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[32] Steven Johnson, *The Ghost Map: The story of London's most terrifying epidemic--and how it changed science, cities, and the modern world* (New York: Riverhead Books, 2006). Snow used a dot to represent each case of cholera and found that the houses with the highest concentration of dots got all of their water form the Broad Street pump.
[33] John M. Eyler, "The Conceptual Origins of William Farr's Epidemiology: Numerical Methods and Social Thought in the 1830s," in *Time, Places, and Persons: Aspects of the History of Epidemiolgoy*, ed. Abraham M. Lilienfeld, *The Henry E. Sigerist Supplements to the Bulletin of the History of Medicine* (Baltimore: The Johns Hopkins University Press, 1980), 1.
[34] Ibid., 4-5.
[35] Susser and Stein, *Eras in Epidemiology: The Evolution of Ideas*, 68.

used epidemiology as a critical part of his public health efforts. The role of epidemiology in public health has its roots in Victorian England.

The work in Victorian England could not have occurred contemporaneously in the United States. For one, no such systematized recording of vital statistics existed in the nineteenth century. In 1841, Massachusetts was the first state to implement the registration of births and deaths. Massachusetts also began issuing uniform birth certificates, a novelty at the time.[36] The U.S. Bureau of the Census was critical in establishing standard methods of reporting vital statistics. It was only in 1900 that it introduced standard birth and death certificates.[37] The first government report using these data used the categories of age, sex, nativity, and color (race).[38] By the 1830s, Great Britain had set up statistical bureaus such as the Statistical Department of the Board of Trade and the Poor Law Commissioners.[39] The absence of statistics as a "positive science of the state" in the U.S. speaks to the local and barely professional boards of health around the turn of the twentieth century (see Chapter 1).[40] The development of solid epidemiological foundations would need to develop in American medicine before disease tracking would become important.

Early epidemiology in Europe and the U.S. focused on infectious diseases because they were the most prevalent diseases. It was in the mid-twentieth century that antibiotics, vaccines, and improved sanitation conquered many of the diseases

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[36] James C. Scott, *Seeing Like a State: How Certain Schemes to Improve the Human Condiiton Have Failed*, ed. James C. Scott, Yale Agrarian Studies Series (New Haven: Yale University Press, 1998).
[37] Krieger and Fee, "Measuring Social Inequalities in Health in the United States: A Historical Review, 1900-1950," 393.
[38] Ibid.
[39] John M. Eyler, *Victorian Social Medicine: The Ideas of Methods of William Farr* (Baltimore: The Johns Hopkins University Press, 1979), 35.
[40] Ibid., ix. Eyler called statistics "the positive science of state."

were the main scourges of society, These disease include polio, tuberculosis, typhoid fever, pneumonia, cholera, and measles. As the disease landscape changed, so did what epidemiologists researched. Epidemiologists had to develop new models and procedures to report chronic diseases, because the reporting procedures for communicable diseases were not applicable for chronic diseases, which were conditions like heart disease, cancer, and diabetes.[41] These illnesses were not the quick killers of days past, but slower killers that became more prevalent as people's lifespan increased.

Due to the diseases studied in the early days of epidemiology, epidemiologists' emphasis was on the germs that caused disease. This was the time of biomedicine. Research into disease causation neglected socioeconomic status, ethnicity, race and culture, personal psychology, and gender in the first half of the century. [42] Early American epidemiologists, like those in Victorian England, used categories such as age and sex in their research, but the casual role of these factors in disease etiology were rarely explored. Researchers did realize the importance of these variables in the development of contemporary epidemiology, but not before "the biomedical paradigm uncoupled disease from its social roots" for an increased focus on laboratory science.[43]

Like any other science, however, epidemiology has evolved its practices, standards, and methodologies. Epidemiologists Mervyn Susser and Ezra Susser have

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[41] Berkman and Breslow, *Health and Ways of Living: The Alameda County Study*, 15.
[42] Brandt and Gardner, "Antagonism and Accommodation: Interpreting the Relationship Between Public Health and Medicine in the United States During the 20th Century," 711.
[43] Ibid.

demarcated three eras of epidemiology.[44] The first is the era of sanitary statistics from the mid-nineteenth century to the beginning of germ theory in the late-nineteenth century. The second is the era of infectious disease epidemiology, which ended with World War II. The third, present era is the era of chronic disease epidemiology. Susser and Susser regarded World War II has the turning point between the second and third phase, because post-War it was chronic diseases that were a bigger scourge in developed countries. In 1943, Charles-Edward Amory Winslow, an American bacteriologist, published *The Conquest of Epidemic Diseases* in which he argued that the modern innovations of antibiotics and public health sanitation reduced the role of communicable diseases as major causes of mortality.[45] Even in chronic disease epidemiology it was not immediately or readily accepted that there were environmental and behavioral causes.[46] As the outlook of medicine changed, what epidemiologists measured also changed. Implicit in researching certain diseases over others is that those diseases investigated have a greater medical, economic, or societal significance.

In addition to what was being researched, the subject of study is also important. With the growth of social epidemiology during mid-century, whom the epidemiologists sought to examine in their quest to find out the causes and risk factors of chronic diseases shows what they thought was important. Tellingly, Susser and Susser noted that it was the illnesses of middle-aged men, such as ulcer disease,

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[44] Mervyn Susser and Ezra Susser, "Choosing a Future for Epidemiology: I. Eras and Paradigms," in *Eras in Epidemiology: The Evolution of Ideas* (Oxford: Oxford University Press, 2009). This article was originally published in 1996 in the *American Journal of Public Health*.
[45] Charles-Edward Amory Winslow, *The Conquest of Epidemic Diseases: A Chapter in the History of Ideas* (Princeton: Princeton University Press, 1943).
[46] Susser and Stein, *Eras in Epidemiology: The Evolution of Ideas*, 166.

coronary heart disease, and lung cancer that came to be studied by epidemiologists. The emphasis on *middle-aged men* raises the issue of whose health received attention. It was not the afflictions of women or minorities, but presumably *white* middle-aged men. This theme is recurring though the history of epidemiology during the early twentieth century, in which researchers often ignored the health afflictions of non-whites.

Even epidemiological studies that did analyze social conditions, like Goldberger's and Sydenstricker's pellagra studies in the 1920s, did not take into account the category of race in their findings.[47] They deliberately excluded nonwhites in their studies of mill-towns in the South, because of the inconvenience that would be caused by studying that particular group. The U.S. Public Health Service was interested in studying diseases, but only for the particular populations that it deemed relevant.

Such exclusionary practices were common in post-World War I social measuring. Social measuring became increasingly important in post-war America. Bio-power is characterized by management techniques of populations and individuals. In the Foucaultian notion of bio-power, the body becomes a political entity of the state, a phenomenon with the roots in the eighteenth century.[48] Social science measuring and health surveys are examples of bio-power in practice. Sarah Igo, a historian, described Foucault's concept of bio-power and bio-politics as "a distinctly

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[47] Goldberger and Sydenstricker, "A Study of the Relation of Family Income and Other Economic Factors to Pellagra Incidence in Seven Cotton-Mill Villages of South Carolina in 1916." Goldberger and Sydenstricker, "A Study of the Relation of Diet to Pellagra Incidence in Seven Textile-Mill Communiities of South Carolina in 1916." Goldberger et al., *A Study of Endemic Pellagra in Some Cotton-Mill Villages of South Carolina*; Marks, "Epidemiologists Explain Pellagra: Gender, Race, and Political Economy in the Work of Edgar Sydenstricker."

[48] Michel Foucault, *The History of Sexuality*, trans. Robert Hurley (New York: Vintage Books, 1990).

modern mode of governance more attentive to regulating individual persons than territorial claims."[49] Governments and society saw social statistics as "objective, seemingly nonpolitical instruments for decision making."[50] During the twentieth century, researchers of all kinds valued statistics because they considered statistics to be objective and technically rigorous.[51] President Herbert Hoover (1929-1933) even created the Committee on Recent Economic Changes and the Committee on Social Trends to produce official statistics. Igo argued "official statistics were elevated as ends in themselves, tools for expressing facts about the population."[52] This notion is similar to how statistics of disease were tools for expression of facts about a disease.

Representative statistics of America did not measure the outliers of society, "degenerates, delinquents, and defectives," but whom the researchers considered normal, "average," and "typical" Americans.[53] Social scientists were concerned with the mainstream. One such study was Robert S. and Helen Merrell Lynd's 1929 *Middletown* study of Muncie, Indiana. *Middletown: A Study in Modern American Culture* sought to examine the effects of economic change on a "prototypical" American town that fit what white Americans would envision as an ideal America. Muncie was a homogenous, American town. Sarah Igo argued, "no longer were 'foreign elements' or 'Negroes' deemed crucial to the study. Rather, they became hindrances to locating the typical, and the surveyors instead aimed their questions at Muncie's white native-born residents."[54] The focus on native whites was a deliberate, "carefully considered

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[49] Igo, *The Averaged American: Surveys, Citizens, and the Making of a Mass Public*, 7.
[50] Ibid., 9.
[51] Porter, "Statistics and Statistical Methods," 239.
[52] Igo, *The Averaged American: Surveys, Citizens, and the Making of a Mass Public*, 9.
[53] Ibid., 11.
[54] Ibid., 55.

aspect of the research design."[55] Muncie was actually not the original research site, which was to be South Bend, Indiana. South Bend, however, was culturally and religiously heterogeneous, which Muncie was not. The Lynds saw African Americans and immigrants as "complicating factors."[56] Igo stated that "gender and status divisions seemed to fit the Lynds' intellectuals preconceptions, and their sense of who was truly American, better than did racial, ethnic, or religious ones."[57] The Lynds' study was a study on introspection into the values of American culture and society in the post-World War I period. After reading about the studies, the public saw the *Middletown* studies, which were hugely popular, as the average of American life and an accurate clarification of their contemporary conditions. The unarticulated assumption in the study was that not everyone is worth the same in measurements of society. The research subjects in social measuring and medical research showed whom the researchers felt were worth measuring. Including minorities would have challenged the image of the country white American felt was representative. This not only applied to social science measuring but epidemiological measurements.

The first effort of the U.S. Public Health Service to measure the prevalence of diabetes was the National Health Survey in the winter of 1935 and 1936. Interviewers covered approximately 2.5 million people in 700 households in 83 cities. The U.S. Public Health Service only included urban families. Some rural families were interviewed, but they were excluded from the final analysis.[58] The interviewers recorded 9,182 people stating they had diabetes, which meant that 0.35 percent of the

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[55] Ibid.
[56] Ibid., 57.
[57] Ibid., 59.
[58] Committee on Statistics, "Recent Statistics on Diabetes," *Diabetes* 8, no. 2 (1959): 289.

studied population had diabetes. Extrapolating from this sample, the statisticians at the Public Health Service estimated that there were 500,000 million persons in the country with diabetes.[59] In 1947, Herbert H. Marks, the manager of insurance medical statistics at the Metropolitan Life Insurance Company noted that the best and most recent source of estimates of the prevalence of diabetes in U.S. was still the Survey of 1935-1936.[60] There had been little systematic investigation into the health status of the country since 1936 because World War II occurred, moving state attention to other matters of health.

The National Health Survey of 1935-1936 was the first attempt by the U.S. Public Health Service, which had previously been mainly concerned with acute infectious diseases smallpox and yellow fever, to look at chronic disease and disability. However, this approach left out Africans Americans.[61] The Works Progress Administration (WPA), a New Deal agency, paid the approximately 6,000 interviewers. The study also contacted doctors to verify interview information. Edgar Sydenstricker and Isidor S. Falk initiated the National Health Survey. Both of the famous American health care reformers appealed to the WPA, saying the survey would be a worthwhile investment in determining what the effects of the Depression would be on the health of the working-class.[62] Interviewers went to mostly poor urban districts to find the effect. Slums and wealthy districts were excluded since it was assumed that those in slums never had good health to begin with and that the wealthy

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[59] Herbert H. Marks, "Statistics of Diabetes," *The New England Journal of Medicine* 235, no. 9 (1946): 289.
[60] Marks, "Recent Statistics on Diabetes and Diabetics."
[61] George Weisz, "Epidemiology and Health Care Reform: The National Health Survey of 1935-1936," *American Journal of Public Health* 101, no. 3 (2011). John Shaw Billings had tired to analyze chronic disease rates from 1880 and 1890 census data, but doctors and layman refused to participate.
[62] Ibid., 411.

districts' health would be too good. Black neighborhoods were avoided so that race would not be a confounding variable.[63] The 1935 Public Health Report specifically stated, "This is the first of a series of papers on sickness and medical care among groups of *white* wage-earning families severely affected by unemployment during the economic depression [italics added]" and "Colored sections were excluded to avoid the question the question of racial differences in employment, income, and sickness."[64] This study was groundbreaking in that it looked at morbidity rather than just mortality rates, which is more useful for the study of chronic diseases.[65] When using death certificates to establish causes of death, registration officers only marked it as diabetes if it was the only cause of death or specifically selected as the primary cause. Otherwise, there was a hierarchy to what disease the registration officers would note as the cause of death: cancer, tuberculosis, violence, puerperal fever were all causes of death that had precedence over diabetes.[66] At the same time, the study reinforced existing social divisions and implied that it was possible to gauge the health of a society even while excluding certain populations.

This approach was a continuation of Edgar Sydenstricker's work with Joseph Goldberger on pellagra in the 1910s. In both studies, Public Health officials were making conclusions about diseases without examining the entire population. This

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[63] G. St. J. Perrott and Selwyn D. Collins, "Relation of Sickness to Income and Income Change in 10 Surveyed Communities," *Public Health Reports* 50, no. 18 (1935): 597.
[64] Ibid., 595, 597. The italics are mine.
[65] Weisz, "Epidemiology and Health Care Reform: The National Health Survey of 1935-1936," 411.
[66] Marks, "Recent Statistics on Diabetes and Diabetics," 372. The problems associated with using death certificates to access the cause of death were common. Another example is that appeared to be a significant drop in diabetes mortality between 1948 and 1949 after the ICD-6, the International Classification of Diseases, revised how the cause of death on death certificates would be organized. Timothy A. Welborn, "Diabetes Mortality," in *The Epidemiology of Diabetes Mellitus, An International Perspective*, ed. Jean-Marie Ekoé, Paul Zimmet, and Rhys Williams (Chichester, England: John Wiley & Sons, Ltd, 2001).

exclusion principle was an accepted practice within the epidemiological community. Researchers could ignore a medically—and epidemiologically—significant subset of the population and still have their work repeatedly cited as a classic example of epidemiology—which the pellagra studies were. While these studies represented new directions for epidemiology, it still reinforced exclusionary principles.

The direction of mid-century epidemiological research on chronic diseases also used exclusionary principles. The Framingham Heart Study, the "prototype and model of the cohort study," began in 1948 to examine cardiovascular health.[67] The National Heart Institute, now the National Heart, Lung, and Blood Institute, based the longitudinal study in Framingham, Massachusetts, a suburb of Boston. The first cohort was 5,209 men and women between the ages of 30 and 62. All of the cohorts were residents of Framingham, which in the 1950s was an overwhelming white town.[68] In 1950, presenting the study to the American Public Health Association, Thomas Dawber, the lead investigator, did not once mention race.[69] It was not until 1994 that the Study, under 1990s pressure to include minorities in research, enrolled a diverse cohort, the Omni Cohort I. The Omni Cohort I consisted of 212 men and 294 women of African American, Hispanic, Asian, Indian, Pacific Islander, and Native American origin.[70] In line with the biomedical paradigm, the study investigators were not initially interested in the socio-cultural causes of heart disease.[71]

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[67] Susser and Stein, *Eras in Epidemiology: The Evolution of Ideas*, 188.
[68] Gerald M. Oppenheimer, "Becoming the Framingham Study 1947-1950," *American Journal of Public Health* 95, no. 4 (2005): 603.
[69] Thomas R. Dawber, Gilcin F. Meadors, and Felix E. Moore, "Epidemiological Approaches to Heart Disease: The Framingham Study," *American Journal of Public Health* 41, no. 3 (1951).
[70] Framingham Heart Study, "Omni Cohorts," The Framingham Heart Study, 2012, Last modified March 14, 2012, http://www.framinghamheartstudy.org/participants/omni.html, Accessed March 27 2012.
[71] Oppenheimer, "Becoming the Framingham Study 1947-1950," 608.

When the Framingham Heart Study started, the findings from white participants from suburban Boston were meant to be applied to everyone else, regardless of race or socioeconomic status.

Around the same time as the Framingham Study, in 1947 the U.S. Public Health Service initiated the first community study for gauging the prevalence of diabetes in the United States. The town in which the U.S. Public Health Service would do its testing was Oxford, Massachusetts, a town by Worcester, Massachusetts. The claim to fame for Oxford was that it was the birthplace of Elliott Joslin and Clara Barton, the founder of the American Red Cross. The study investigators called Oxford a "typical New-England town."[72] The U.S. Public Health Service tested 70.6 percent of 4,983 residents who were mostly "native born" of French-Canadian, English, or Scottish ancestry.[73] The investigators drew conclusions about diabetes in the United States from this unrepresentative sample. The underlying assumption of the researchers was that the white citizens of Oxford could provide adequate information on diabetes in the entire country. With the twentieth century faith in statistical methods to tell the truth, whom epidemiologists measured reflected whom society believed was sick. Another assumption of epidemiologists in studying disease are what categorical variables—like age, sex, or race—should be used to examine a disease.

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[72] Hugh L.C. Wilkerson and Leo P. Krall, "Diabetes in a New England Town," *JAMA: The Journal of the American Medical Association* 135, no. 4 (1947): 211.
[73] Ibid.

Changing Categories

An example of significant changes in health statistics is evolution of the categories in the National Health Interview Survey.[74] In 1956, Congress authorized the U.S. Public Health Service to conduct annual surveys of the health of the "civilian, noninstitutional [sic] population" of the United States.[75] Starting in 1957, as part of the National Health Interview Survey interviewers would annually go to families and ask about the health of around 100,000 people. This Survey was an attempt by the federal government to gain a picture of the impact of disease on the country. The Survey estimated factors like the days of restricted activity associated with acute conditions, days lost from school, number of dental visits, and the number of people with acute and chronic conditions, like diabetes. How the Survey classified its data and what it published is an example of how race and other social epidemiological variables came to matter in research. Additionally, because researchers, like Margaret Heckler's Task Force on Black and Minority Health, and government agencies used the National Health Interview Survey's data to gain a picture of the nation's health, how the National Health Interview Survey classified its data then mattered to how the researchers were able to use the information.

The National Health Interview Survey was not the only measure of diabetes in the country, but it was the most comprehensive. It was able to provide more than just mortality data, which generally other studies of diabetes used. For instance, between 1952 and 1964, the journal *Diabetes* featured an annual publication of "Recent

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[74] In many ways, this was the continuation of the work that had been done as part of National Health Study of 1935 to 1936.

[75] U.S. Department of Health, Education and Welfare, *Health Interview Survey Procedure 1957-1974*, Programs and Collections Procedures: Series 1, Number 11, (Rockville, Maryland: National Center for Health Statistics, 1975).

Statistics on Diabetes," that mostly used diabetes mortality statistics. The journal's Committee on Statistics did not originally classify the data by race, but by 1958, they divided the data between white versus nonwhite.[76] The 1959 edition even stated that diabetes mortality was rising much faster in nonwhites than whites: "Changes in the rates since 1949 showed marked variation: Among white persons the rates have declined nearly one fifth in the case of females, whereas among nonwhites increases have been recorded for each sex—over one eighth in the case of males."[77] Even though, at the time, the non-white population of the U.S. was overwhelmingly black, "Recent Statistics on Diabetes" does not offer a look specifically into diabetes in African Americans. By the last issue, however, in 1964, the journal used the National Health Interview Survey's data to assess variables in diabetes that the Survey did not even use in its own statistical analysis —the variable of black rates versus white rates.[78] For the systematic examination into diabetes in African Americans and to propel those facts into national use, the National Health Interview Survey needed to include the variable of race in its analyses.

Until the analysis of the 1982 data, published in 1985, the interviewers of the National Health Interview Survey observed the race of the participants, but this data was not incorporated into the statistical analysis. The 1970 to 1981 reports all included a statement that declared the data would only be classified by age and sex, but "More detailed analyses of similar data by other social, economic, and

[76] Committee on Statistics, "Recent Statistics on Diabetes," *Diabetes* 6, no. 5 (1957).
[77] Committee on Statistics, "Recent Statistics on Diabetes," *Diabetes 8*, no.2 (1959), 150.
[78] Committee on Statistics, "Recent Statistics on Diabetes," *Diabetes* 13, no. 3 (1964): 313.

demographic categories will be presented in forthcoming reports."[79] The biggest change in the statement during the eleven-year period was that for the 1975 reports, the Introduction began using the phrase "social, economic, and demographic categories" rather than just "demographic variable," used for the 1970 to 1974 reports.[80] The 1982 Estimates noted, "over the years the number of requests for health-related estimates by other characteristics has grown such an extent that data in this summary are presented for more variables [like race, income, and geography]."[81] The underlying assumptions for years was that age and sex were the most important variables in considering health.

In 1969, the National Health Interview Study released a special report on entitled *Differentials in Health Characteristics by Color United States – July 1965 – June 1967*.[82] This reported compared the health indicators for white and non-whites Americans. The definition of race used was: "The population is divided into two color groups, "white" and "all other." "All other" includes Negro, American Indian, Chinese, Japanese, and any other race. Mexican persons are included with "white"

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[79] The quotations is from the 1981 estimates, but the quote appeared the in the same form with a word or two different between 1972-1982. U.S. Department of Health & Human Services, C*urrent Estimates From the National Health Interview Survey: United States, 1981*, Data From the National Health Survey: Series 10, Number 141, (Hyattsville, Maryland: National Center for Health Statistics, 1982). The publications dating from 1963 can all be found on the CDC's website: http://www.cdc.gov/nchs/nhis/quest_data_related_1996_prior.htm.

[80] I examined the surveys between 1970 to 1985. They can be found at Centers for Disease Control and Prevention, "Questionnaires, Datasets, and Related Documentation 1996 and Prior," Centers for Disease Control and Prevention, Last modified 8 March 2011, http://www.cdc.gov/nchs/nhis/quest_data_related_1996_prior.htm, Accessed 2 April 2012.

[81] U.S. Department of Health & Human Services, *Current Estimates From the National Health Interview Survey: United States, 1982*, Data from the National Health Survey Series: 10, Number 150, (Hyattsville, Maryland: National Center for Health Statistics, 1985), 1.

[82] U.S. Department of Health, Education and Welfare, *Differentials in Health Characteristics by Color United States – July 1965 – June 1967,* Data from the National Health Survey: Series 10, Number 56, (Washington, D.C.: U.S. Governent Printing Office, 1969).

unless definitely known to be Indian or of another race."[83] In the questionnaire used between July 1985 and June 1987, there were three options for the interviewer to mark for race: White, Negro, and Other.[84] The instruction for the interviewer was to "Mark without asking."[85] The report found that the differences in health characteristics between whites and non-whites were related more to socioeconomic factors rather than "color" itself.[86] In 1984, the National Health Interview Survey released estimates on health indicators for Hispanics, blacks, and white Americans.[87] The Survey in this report considered black non-Hispanics separate from those of Mexican, Puerto Rican, Cuban, and other Hispanic origins (black Hispanics were part of the Hispanic category). Opposed to the 1969 report, the National Health Interview Study was interested in the socio-cultural implications of being Hispanic, not the particularities of race. The important parts to take away from this study is not its estimates about diabetes rates in the country, however, but how it attempted to look for social causes of health and how its methodology of grouping all non-whites together speaks to a particular cultural logic of viewing society.

In 1990, five years after the Heckler Report, the National Health Interview Survey released a study specifically on the health of black and white Americans.[88] This study noted that black Americans had a higher prevalence of diabetes than white

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[83] U.S. Department of Health & Human Services*, Health Interview Survey Procedure 1957-1974*, 142.
[84] U.S. Department of Health & Human Services, *Differentials in Health Characteristics by Color United States – July 1965 – June 1967,* 53.
[85] Ibid.
[86] Ibid., 1.
[87] U.S. Department of Health & Human Services, *Health Indicators for Hispanic, Black, and White Americans,* Data National from the National Health Survey: 10, 148, (Washington, DC: Government Printing Office, 1984).
[88] U.S. Department of Health & Human Services, *Vital and Health Statistics: Health of Black and White Americans, 1985-87,* Data From the National Health Interview Survey: Series 10, Number 171, (Hyattsville, Maryland: National Center for Health Statistics, 1990).

Americans. It also noted that white Americans saw the doctor more and had fewer restricted-activity days due to acute and chronic conditions than black Americans. The annual estimate publication for 1990 survey, published in 1991, used the variables age, sex, race, family income, and geographic region.[89] The publication of this study showed that it was the difference between white and black health was an matter of concern and interest.

Other studies in the 1960s and 1970s also began to include the data of African Americans and other minorities that lay the framework for making the study of the issue possible.[90] The data collected in the National Health Interview Studies was even later used in the Heckler Report. The evolution of the format and the groups of people that the National Health Interview Study studied show the adoption of the social epidemiological methods to examining not just diseases like diabetes, but the health of groups of people. The increasing attention to factors like race was part of the growth of the field social epidemiology.

Social epidemiology and diabetes

Social epidemiology is the field of epidemiology that is concerned with the social determinants of health, like race, class, and gender. Social epidemiological

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[89] U.S. Department of Health & Human Services, *Current Estimates From the National Health Interview Survey, 1990,* Data from the National Health Survey: Series 10, Number 181, (Hyattsville, Maryland: National Center for Health Statistics, 1991).

[90] Two examples are the Alameda County Study, which started in the early 1960s, and NHANES I (the First National Health and Nutrition Examination Survey), which happened between 1971 and 1975. Both studies incorporated minorities in the samples. See Berkman and Breslow, *Health and Ways of Living: The Alameda County Study*; Ken Gu, Catherine C. Cowie, and Maureen I. Harris, "Mortality in Adults With and Without Diabetes in a National Cohort of the U.S. Population, 1971-1993," *Diabetes Care* 21, no. 7 (1998); Siobhan C. Maty, Sherman A. James, and George A. Kaplan, "Life-Course Socioeconomic Position and Incidence of Diabetes Mellitus Among Blacks and Whites: The Alameda County Study, 1965-1999," *The American Journal of Public Health* 100, no. 1 (2010).

concepts became increasingly common in the latter half of the twentieth century, although the Goldberger and Sydenstricker studies on pellagra in the 1910s and 1920s are also considered social epidemiology.[91] In the first half of the century, epidemiologists commonly did not analytically examine chronic diseases, like diabetes and cancers, which are not caused by infectious agents.[92] Those who paid attention to the social and economic determinants of disease were social scientists and psychiatrists. Between 1950 and 1980 there was an epidemiological shift in which the "individual-level 'risk factors'---environmental exposures and behaviors—in disease aetology" began to receive attention.[93] Until 1980, however, social epidemiology was a "marginalized" subfield of epidemiology.[94] There were still hallmark discoveries in social epidemiology before 1980: mainly, the discovery in 1950s that smoking is a risk factor for lung cancer. The investigators of the Alameda County Study, which started measuring residents of Alameda County, California, in 1965, also included a variety of classes and ethnic groups in the study.[95] Tellingly, however, Mervyn Susser and Landon Myer still noted in 2007 that epidemiologists, while increasingly examining chronic diseases, still focused on the individual behaviors or risk factors.[96] But by the 1990s, social epidemiological methods were becoming more common and factors like ethnicity and health are considered in disease etiology. One common point area of

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[91] Jay S. Kaufman and Richard S. Cooper, "Seeking Causal Explanations in Social Epidemiology," *The American Journal of Epidemiology* 150, no. 2 (1999).
[92] Mervyn Susser and Landon Myer, "Social Epidemiology," in *The Development of Modern Epidemiology: Personal Reports From Those Who Were There*, ed. Walter W. Holland, Jørn Olsen, and Charles du V. Florey (Oxford: Oxford University Press, 2007), 208.
[93] Ibid., 209.
[94] Ibid., 213.
[95] Berkman and Breslow, *Health and Ways of Living: The Alameda County Study*.
[96] Susser and Myer, "Social Epidemiology," 213.

study is the heath gap between black and white Americans.[97] The growth of this field was necessary for epidemiology to move beyond examining biomedical factors to using race in the epidemiological principle of population thinking.

The impact of the efforts towards inclusion in medical research in the 1980s and 1990s also had impacts for epidemiology. For the 1982 report, the National Health Interview Study started classifying its results by race as well as family income, geographic region, and place and residence. Additionally, the 1994 the Framingham Heart Study, in response to the calls for medical research to reflect the diversity in society, enrolled the First Omni Cohort. In the new cohort there were 506 males and females of African American, Hispanic, Asian, Indian, Pacific Island, or Native Americans.[98] The implication for diabetes research was that ways of measuring that did not include race or other social factors would no longer be adequate. Such methods are part of social epidemiology.

It was not until 1978 that there was a "significant gathering of researchers interested in diabetes."[99] In 1978, Kelly M. West published *The Epidemiology of Diabetes and Its Vascular Lesions*.[100] In the introduction West noted, "Until quite recently almost all epidemiologic studies of diabetes were mainly 'descriptive'. Typically, prevalence has been measured and related to certain traditional variables such as age, sex, obesity, or family history of diabetes."[101] Tellingly these traditional variables did not include race. In the book, West declared that the prevalence of diabetes has definitely increased "substantially in the last half-century" and that rates have certainly

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[97] Kaufman and Cooper, "Seeking Causal Explanations in Social Epidemiology."
[98] Framingham Heart Study, "Omni Cohorts."
[99] Zimmet, "Diabetes epidemiology as a tool to trigger diabetes research and care," 499.
[100] West, *Epidemiology of Diabetes and Its Vascular Lesions*.
[101] Ibid., 8.

increased in "certain elements of society (e.g. American blacks and Indians, Africans who migrated to cities, Indians who migrated to South Africa)."[102] West was also interested in the racial differences in diabetes. He had published groundbreaking work on the diabetes rates in Native Americans, raising attention to the dangerously level of diabetes in Native Americans of the Southwest.[103] In the section examining race and ethnics groups in the *Epidemiology of Diabetes and Its Vascular Lesions*, West noted that there may be a genetic difference of the likelihood of developing diabetes in race and ethnic subgroups. West also analyzed diabetes among African Americans. West's opinion of the historical low rates of diabetes in African Americans was that "these low rates in blacks were mainly the result of environmental rather than racial factors."[104] West's work was a comprehensive look into the etiological factors of diabetes.

Standards of epidemiology have also changed to ones in which it is important to measure more than just the basic rates of disease. Allan M. Brandt, writing in 2000, argued that previously, epidemiology was too influenced by the biomedical paradigm, which neglected social factors.[105] For instance, Mervyn Susser and Ezra Susser repudiated the "black box paradigm," a classic feature of chronic disease epidemiology, heavily influenced by biomedicine. The black box paradigm "related exposure to outcome without any necessary obligation to interpolate either intervening factors or even pathogenesis" and ignored critical components of race and

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[102] Ibid., 186.
[103] Kelly M. West, "Diabetes in American Indian and Other Natives of the New World," *Diabetes* 23, no. 10 (1974).
[104] West, *Epidemiology of Diabetes and Its Vascular Lesions*, 203. Emerson and Larimore, "Diabetes Mellitus: A Contribution to Its Epidemiology Based Chiefly on Mortality Statistics."
[105] Brandt and Gardner, ""The Golden Age of Medicine?"."

socio-economic status. [106] For example, the National Health Interview Study only in 1985, with the publication of the 1982 estimates, started to classify the data by more than age and sex.[107] This paradigm neglected to place "exposure, outcome, and risk in societal context."[108] Social epidemiology, which does take into account the social determinants of disease, however, has really only been used since the 1990s.[109]

In 1996, Susser's and Susser's proposals for new directions in epidemiology were "Chinese boxes" and eco-epidemiology to be part of social epidemiology. The approach of eco-epidemiology takes a more holistic view of disease. The development of modern epidemiology with multideterminant analysis of variables such as gender, socioeconomic status, and race proved to be more accurate in examining in the multiple causes of diseases beyond a biomedical approach. Chinese boxes involve the ecology of a disease and is equally concerned with the biological and social factors in the cause, development, and effects of a disease.[110] Such change can be seen in epidemiological studies like the National Health Interview Survey, which since the 1982 report classifies the data by variables like race, family income, and geography.

The 1985 Heckler Report applied the standards of looking at the social determinants of the disease. In the Executive Summary of the report, Heckler wrote, "we [the Task Force] have examined the impact of a broad range of behavioral, societal, and health care issues."[111] By 1980, diabetes was the seventh leading cause of death in America, and thus a growing concern for the state and public health

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[106] Susser and Susser, "Choosing a Future for Epidemiology: I. Eras and Paradigms," 308.
[107] I examined the surveys between 1967 to today. They can be found at Centers for Disease Control and Prevention, "Questionnaires, Datasets, and Related Documentation 1996 and Prior."
[108] Susser and Susser, "Choosing a Future for Epidemiology: I. Eras and Paradigms," 311.
[109] Susser and Myer, "Social Epidemiology," 214.
[110] Mervyn Susser and Ezra Susser, "Choosing a Future for Epidemiology: II. From Black Box to Chinese Boxes and Eco-Epidemiology," *American Journal of Public Health* 86, no. 5 (1996).
[111] Heckler, "Report of the Secretary's Task Force on Black & Minority Health," 1.

officials.[112] The Task Force noted that it was difficult to estimate the true prevalence of diabetes in minority populations because of issues with diagnoses, and that almost 50 percent of cases of diabetes are not reported.[113] Two of the recommendations of the Task Force were: "Environmental factors should be examined as possible contributions to the increased prevalence of diabetes [in minorities]," and that "The [Department of Health and Human Services] should encourage State and local health departments to address the needs of those who have diabetes in areas where high concentrations of minority populations are located."[114] Around the same time, the statistical analyses from the National Health Interview Surveys, conducted annually, began to differentiate minority health status from white health status. In 1990, the National Health Interview Survey even released a special report entitled *Vital and Health Statistics: Health of Black and White Americans, 1985-1987*, which used a variety of socio-demographic variables.[115] Epidemiological practices and the assumptions of what was important in analysis went significant change in the late twentieth-century.

Another recent development in epidemiology is measuring discrimination as a factor in poor health.[116] This method goes beyond identifying race as a variable, but the implications for belonging to that race. In researching the impact of discrimination, epidemiologists are concerned with the outcomes such as the willingness to receive care and the quality of received care. In 1999, such research,

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[112] Ibid., 149.
[113] Ibid., 149, 153.
[114] Ibid., 155.
[115] U.S. Department of Health & Human Services, "Vital and Health Statistics: Health of Black and White Americans, 1985-87."
[116] Nancy Krieger, "Embodying Inequality: A Review of Concepts, Measures, and Methods for Studying Health Consequences of Discrimination," *International Journal of Health Services* 29, no. 2 (1999).

however, was still in its infancy.[117] Researchers have found that racial and ethnic minorities receive a lower quality of care even after they control for access factors like income and insurance.

Hinging on methods of epidemiology that rose to prominence in the late twentieth century was a critical examination in the meaning of race as a category. The following chapter will discuss the relevance of race in diabetes literature.

Conclusion

Epidemiology in diabetes was important in advancing public health efforts of diabetes. Before diabetes in Africans Americans could be targeted, public health officers and researchers had to know that there was even an issue. Paul Zimmet, a diabetes epidemiologist, wrote, "It would be an oversimplification to attribute all progress in diabetes research to the disciples of epidemiology. The growth of studies on the epidemiology and public health aspects, was however, necessary for the field to move forward."[118] Timothy Welborn, an Australian researcher, stated "Well-designed prospective cohort studies will yield much more useful epidemiological data, especially for identifying the magnitudes of the burden of diabetes as well as focusing on underlying causal mechanisms."[119] Systematic studies into the diabetes in minorities were a late-twentieth century phenomenon. For much of the century, epidemiological practices focused on infectious diseases. Even researchers examined non-infectious diseases like pellagra, they often excluded non-whites. However, even with these practices, statisticians at the Metropolitan Life Insurance Company noticed the rising

[117] Ibid., 295.
[118] Zimmet, "Diabetes epidemiology as a tool to trigger diabetes research and care," 499.
[119] Welborn, "Diabetes Mortality," 369.

rates of diabetes in African Americans. This knowledge, however, failed to expand to the larger discussion of diabetes. Later on, as social epidemiological practices became more common, such as in the National Health Interview Study, the groundwork of the data used to analyze black health was established.

Why the findings of researchers, like those of Dublin and Marks that noted diabetes was rising in African Americans, did not receive much attention was not just because mainstream epidemiology at the time did not focus on chronic disease. It was also the widely held opinion of physicians that diabetes was disease of the well-to-do and, often, Jews. This way of thought diverted their attention from the issue in African Americans.

Chapter 3: Cultural Connotations of Diabetes and Race

> We must try to distinguish between the manifold impressions gained by a great number of physicians, and facts; but even the "facts" have suffered rather a variegated interpretation corresponding to the individual attitude of the observer.
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> -Ernst Lyon 1940[1]

In the above passage, Ernst Lyon, a doctor living in what was then still Palestine, was referring to the contemporary medical opinion that Jews had a relatively higher susceptibility to diabetes.[2] His book, *Diabetes Mellitus and the Jewish Race*, tried to disprove that idea.

The medical literature on diabetes for much of the first half of the twentieth century often did not mention African Americans. What it did often mention were Jewish Americans. When discussing diabetes and its prevalence in different races, doctors were talking about Jewish Americans. By the end of the twentieth century, the practice had completely disappeared in the diabetes literature. The 1985 Heckler Report did not include Jews as one of the groups of minorities examined. Had the Report included that category, it would have raised some eyebrows. The picture presented of at-risk populations and groups does not necessary reflect the actual distribution of the disease. It reflects whom researchers and society deems to important to study at the time. As Arleen Tuchman argued, referring to the cultural

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[1] Ernst Lyon, *Diabetes Mellitus and the Jewish Race* (Jerusalem, Palestine: Ludwig Mayer, 1940), 13.
[2] Ibid.

history of diabetes, "medicine, science, and culture reinforced each other helping to construct narratives [of diabetes] that made sense at the time."[3]

Undergirding the epidemiological concepts of group comparison and population thinking is how to define the group. In the diabetes literature of the twentieth century, a common way to define a group is by to use racial categories. How concepts of what constitutes a "race" have changed is present in the literature. While black Americans have always been different from white Americans, how society and physicians defined race was very different in 1900 than how in was in 1985. In the early twentieth century, much of society considered Jews to be a separate race. Physicians and other medical professionals then used these categories in the medical literature. By mid-century, however, there is scant mention of a Jewish race. At the end of the twentieth century, race was often considered a self-identified feature that often had roots in geographic ancestry.[4] The discourse in the medical literature reflects this change.

The implication of belonging to a race is that the characteristics attributed to that group are then applied to the medicine. For instance, at the end of the twentieth century, researchers considered diabetes to be a particular affliction in the obese and lower classes. Since blacks, on average, have a lower socioeconomic status than whites, and low socioeconomic status often is correlated with obesity, researchers target the high obesity rates of blacks as an explanation for their rates of diabetes.[5] Earlier in the century, however, physicians believed that diabetes was a particular

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[3] Tuchman, "Diabetes and Race: A Historical Perspective," 24.
[4] Carol Easley Allen and Cheryl E. Easley, "Racial and Ethnic Minorities," in *Social Injustice and Public Health*, ed. Barry S. Levy and Victor W. Sidel (Oxford: Oxford University Press, 2006), 47.
[5] Maty, James, and Kaplan, "Life-Course Socioeconomic Position and Incidence of Diabetes Mellitus Among Blacks and Whites: The Alameda County Study, 1965-1999," 137.

affliction in the upper classes, not lower classes. In 1924, Haven Emerson and Louise Larimore, who worked at Columbia University's Department of Public Health Administration, stated that diabetes was a disease of the wealthy because of their excess food consumption and idleness.[6] They wrote: "Apparently, among the reasons for the low rate among negroes is the fact that their occupations involve chiefly the use of the heavy muscles of the trunk and legs and arms, whereas the occupations of those among whom diabetes is most common involve the least physical effort."[7] The cultural beliefs researchers had about diabetes and race reaffirm each other.

The third part to the history of how diabetes in African Americans became a major area of research is how cultural perceptions of the disease and race constructed narratives of the disease that made sense to medical professionals and laymen. The late twentieth century study of diabetes in African Americans was a form of race-based medicine, in which researchers targeted questions and interventions to African Americans. It is as much about changing cultural connation about diabetes and what qualifies as "non-white" as it is about the changing focus of public health and epidemiology.

Definitions and meanings of "race" in the early twentieth century

A concept that has shaped the study of diabetes is that there are racially-based differences in the disease. It is still common practice to state that certain populations, defined by their race, are at risk for certain diseases. Work done by sociologists, epidemiologists, and physicians have shown that it is often not race per se, but the

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[6] Emerson and Larimore, "Diabetes Mellitus: A Contribution to Its Epidemiology Based Chiefly on Mortality Statistics," 329-330.
[7] Ibid., 630.

factors for which race often acts as a proxy.[8] These factors can include socioeconomic status, class, and geography. Even in the 1980s, the movements to include minorities (and women) into clinical research were premised on the idea that the findings of research done on white males did not apply equally to other segments of society.[9] In 1986, the year it started, the Harvard School of Public Health's Health Professionals Follow-Up Study, which studies diabetes among other diseases, used the following categories for "major ancestry" to assess race: Southern European/ Mediterranean, Scandinavian, Other Caucasian, Afro-American, Asian/Oriental, and Other origin.[10] The researchers did not distinguish races on the basis of religion but defined it based on geographic ancestry. For researchers to define race by religion would have been inappropriate in the late twentieth century. The definition of race depends on the contemporary social context.

The early twentieth century boundaries between races included nationality and religion, which were much narrower than the terms used later in the century. The number of races existing in this era was extensive. They included the "Nordic, Aryan, Teutonic, Anglo-Saxon, Alpine, Mediterranean, Slav, Celt, Semite, Gaul, Ligurian, Dinaric, Phalic."[11] For example, in 1924, the *American Journal of Public Health* listed the diabetes mortality rates of "various race stocks" based on US Census data. The various race stocks were the Germans, Irish, English, and Scandinavian (Danish,

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[8] Bruce G. Link and Jo Phelan, "Social Conditions As Fundamental Causes of Disease," *Journal of Health and Social Behavior* 35(1995). Marc Schlesinger, "Different and Differenced Takes on Disparities," *Journal of Health Politics, Policy and Law* 31, no. 1 (2006); Kaufman and Cooper, "Seeking Causal Explanations in Social Epidemiology."
[9] Epstein, *Inclusion: The Politics of Difference in Medical Research*.
[10] Health Professionals Follow-Up Study, "HPFS Questionnaires," Harvard School of Public Health, 1986, Last updated 2011, http://www.hsph.harvard.edu/hpfs/hpfs_qx.htm, Accessed 19 November 2011.This was the only time the question of race was asked.
[11] Graham Richards, *'Race', Racism and Psychology: Towards a Reflexive History* (London: Routledge, 1997), 15.

Norwegian, and Swedish).[12] Medical and scientific categories reflected the cultural conceptions of race. European thinkers like Joseph Arthur Comte de Gobineau (1816-1882) argued for the existence of highly specific intra-European racial difference. His book entitled *An Essay on the Inequality of the Human Races* (written between 1853-1855) claimed the preeminence of the Aryan race. Another part of his theories on race is that it is independent of the climate and geography of the area in which a "race" lives—their characteristics are theirs alone. [13] Members of different races were fundamentally different in biology.

One of the various races was that of Jews. It was not just racial theorists that used this category, but a common practice to which the leading diabetes researcher in the country, Elliott Joslin, adhered. In the 1924 published proceedings of a diabetes symposium, Elliott Joslin, noted "[Diabetes] is fifteen times as common among adults and twenty times as common among the fat; *it is much more common among Jews; especially among females* [italics added]."[14] In 1941, he referred to Jews as the "Hebrew race."[15] In 1947, while describing the population of Arizona, Joslin wrote: "Arizona is a state of 113,810 square miles, a population then of 409,000, predominantly American but with many Indians and Mexicans, and a few Jews."[16] In that statement, Joslin differentiated Jews from the "American" population. Joslin published diabetes treatment manuals for the use of patients and physicians alike. In the light,

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[12] "Diabetes Mellitus," *The American Journal of Public Health* 14, no. 4 (1924).
[13] Joseph Arthur Comte de Gobineau, *An Essay on the Inequality of the Human Races* (New York: G.P. Putnam's Sons, 1915).
[14] Elliott P. Joslin, "Symposium on Diabetes: Changes in the Diabetic Clientele," *JAMA: the Journal of the American Medical Association* 82, no. 23 (1924).
[15] Elliott P. Joslin, *A Diabetic Manual for the Mutual Use of Doctor and Patient*, Seventh ed. (Philadelphia: Lea & Febiger, 1941), 163.
[16] Joslin, "The Universality of Diabetes, Its True Incidence and the need for a reorganization of its treatment," 4.

conversational tone that Joslin assumed in his manuals, he repeatedly claimed that Jews had a higher prevalence of the disease.[17] In 1940, writing about the universality of diabetes, Joslin pinpointed certain factors that would lead to a high incidence of diabetes. These factors included where the average age is greatest, where there is a lot of obesity, and where "the proportion of Jews of greatest"[18] Even after the use of Jews as a category largely faded in the rest of the literature, Joslin still used the category, well into the 1950s. The practice of differentiating Jews as a separate race was an accepted and common practice in medicine.

There were doctors that protested this way of classification, but they complaints did not change the existing paradigm. In his 1940 monograph, Ernst Lyon argued that "racial homogeneousness of the Jewish type is nothing but a myth."[19] Lyon's monograph, *Diabetes Mellitus and the Jewish Race*, was dedicated to refuting the idea that diabetes was a racial disease of Jews. The book was published in Jerusalem, not in the United States. *JAMA* did, however, featured a one-paragraph summary of Lyon's book in the section of recently published medical literature. The summary did not weigh in on Lyon's argument.[20] Earlier in the century, in a 1913 editorial in *JAMA*, A.B. Hirsh of Philadelphia, called the use of a Jewish race in the medical

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[17] Elliott P. Joslin, *A Diabetic Manual For The Mutual Use of Doctor and Patient* (New York: Lea & Febiger, 1919); Joslin, *A Diabetic Manual for the Mutual Use of Doctor and Patient*; Elliott P. Joslin, *Diabetic Manual for the Doctor and Patient* (Philadelphia: Lea & Febiger, 1948); Joslin, *Diabetic Manual for the Patient*. The manual is still being published, in continuously revised editions. Since Joslin's death in 1962, the authors have been doctors at the Joslin Clinic.

[18] Elliott P. Joslin, "The Universality of Diabetes," *JAMA: The Journal of the American Medical Association* 115, no. 24 (1940). Other factors were: where there was more women (since Joslin noted more women than men had the disease), close medical supervision between doctor and patient (to foster diagnoses), and accurate death reporting.

[19] Lyon, *Diabetes Mellitus and the Jewish Race*.

[20] "Diabetes Mellitus and the Jewish Race," *JAMA: The Journal of the American Medical Association* 114, no. 22 (1940).

literature, "an injustice."[21] Hirsh argued that Jews "show[ed] admixture [sic] of other race stocks" so they could not be neatly categorized as a race.[22] Tellingly, this tiny two-paragraph article buried between editorials of mundane concerns—about pink stools, rubber bulbs, and eyeglasses—and the section *Queries and Minor Notes,* did not have an impact on the use of Jews as a racial categorization in the medical literature.[23] Physicians and other medical writers used the racial categories that were common in contemporary society.

The early twentieth century's preoccupation with differentiating races also stemmed partly from nativist tensions. The early twentieth century was a time rife with nationalistic tension as immigrants came to the shores of America. This was also the Progressive Era, and many Progressives were anti-immigrant. Americans like Kenneth L. Roberts, a writer for the *Saturday Evening Post* and a novelist, saw immigrants as a threat to American integrity because: "they retained the customs and languages and the ideals of the countries from which they came, and failed utterly to become Americans."[24] The eugenic and anti-immigration thinkers used science to develop intelligence tests, which were so skewed towards "American knowledge" that immigrants reliably failed and confirmed stereotypes. Such concerns can be seen in Dr. M. B. Ball's 1897 letter to *JAMA*. He wished to identify a cause of the reported

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[21] A. B. Hirsh, "Value in Case Histories of Term "Jew" as Racial Designation," *JAMA: The Journal of the American Medical Association* 61, no. 5 (1913): 367.
[22] Ibid.
[23] The titles of the other editorials are: "Phenolphthalein May Cause Pink Stools," "Preservation of Rubber Bulbs," and "The Fitting of Glasses By Unqualified Persons." See *JAMA: The Journal of the American Medical Association* 61, no.5 (1913): 367.
[24] Kenneth Lewis Roberts, *Why Europe Leaves Home: A true account of the reasons which cause Central Europeans to overrun America which lead Russians to rush to Constantinople and other fascinating and unpleasant places which coax Greek royalty and commoners into strange byways and hedges and which induce Englishmen and Scotchmen to go out at night* (New York: Bobbs-Merrill Company, 1922), 4.

rise of diabetes in American hospitals; "in the last fifteen years there has been a great influx of Jews from both England and America…. No doubt other diseases peculiar to races will be found to be on the increase from like causes. At least immigration is a factor that must be considered in a matter of this sort."[25] One such fear during the era was that the race of Anglo-Saxons Americans would become mongrelized if they mixed with lesser races. Roberts wrote in 1922, "The American nation was founded and developed by the Nordic race, but if a few more million members of the…Semitic races are poured among us, the result must inevitably be a hybrid race of people as worthless and futile as the…mongrels of Central America and Southeastern Europe."[26] The historian Eric Goldstein contended, "In the mind of *white* Americans, Jews were clearly racial outsiders in many ways, demonstrating distinctive social patterns, clustering in urban neighborhoods, concentrating in certain trades and professions, and largely marrying within their own group."[27] Intergroup tension causes an "us versus them" dynamic, which in the early twentieth century manifested itself as a racial issue.

The diabetes literature reflected the nativists' concern of increasing immigration to the United States. To J. G. Wilson the rise in diabetes in New York was dependent on the rise of Jewish immigrants to the city.[28] Charles Bolduan, a New York City public health official, also correlated the rising rates of diabetes to the rising

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[25] M.V. Ball, "Is Diabetes Increasing," *JAMA: the Journal of the American Medical Association* 29, no. 6 (1897).
[26] Roberts, *Why Europe Leaves Home: A true account of the reasons which cause Central Europeans to overrun America which lead Russians to rush to Constantinople and other fascinating and unpleasant places which coax Greek royalty and commoners into strange byways and hedges and which induce Englishmen and Scotchmen to go out at night*, 22.
[27] Eric L. Goldstein, *The Price of Whiteness: Jews, Race, and American Idenity* (Princeton: Princeton University Press, 2006), 2. The italics are mine
[28] J.G. Wilson, "Increase in the Death Rate From Diabetes- A Possible Explanation," *Medical Record* 82(1912).

population of Jewish immigrants to New York City.[29] In a 1933 speech to the American Public Health Association, Bolduan declared: "In New York City another factor has led to an increased prevalence of diabetes; namely, the relative increase in the Jewish population. In 1900 this group was about 17 per cent [sic] of the city's population; in 1930 it was approximately 30 per cent."[30] Jews shouldered blame for the increased rates of diabetes.

Race was an important concept in medicine because in the early twentieth century physicians translated racial difference to biological difference. As a function of their different biologies and behavioral traits, races had different susceptibilities to diseases. Physicians and thinkers considered the Jewish body not only to be different, but pathologically sick.[31] In 1902, a Viennese physician found "higher rates of mental and nervous disorders, alcoholism, and suicide among middle-class western European Jews."[32] The same sort of thinking also applied to blacks. For instance, Eugene Leopold, in 1931, referenced the belief that many physicians believed that diabetes in Negros had different manifestations than it did in whites.[33] Additionally, Julius Herman Lewis, a black physician who was an associate professor of pathology at the University of Chicago when he wrote *The Biology of the Negro* in 1942, stated, "Physicians… have attempted to explain, with varying degrees of success, some of the peculiar manifestations of disease in the Negro on the basis of his anatomy….Some of

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[29] Bolduan, "Has Diabetes Become More Prevalent."; Bolduan, "Diabetes--An Important Public Health Problem."
[30] Bolduan, "Has Diabetes Become More Prevalent," 1283.
[31] Mitchell B. Hart, "Racial Science, Social Science, and the Politics of Jewish Assimilation," *Isis* 90, no. 2 (1999).
[32] Ibid., 278.
[33] Leopold, *Diabetes in the Negro Race*, 292. Leopold, taking the minority stance, refuted this idea, arguing that "Diabetes in negroes is not different in any way from the disease as found among white people."

these correlations seem to exist in fact, but others appear to have no other basis than a last resort."[34] The past research to which Lewis could have been referring were the findings of S. J. Holmes of the University of California Berkeley's Department of Zoology and Frederick L. Hoffman. In 1928, Holmes attributed the lower prevalence certain diseases like diphtheria and skin diseases to the fact that blacks have thicker skin that whites do.[35] Thirty years earlier, in 1896, Frederick L. Hoffman, a statistician at the Prudential Life Insurance Company, wrote *Race Traits and Tendencies of the American Negro*, in which he attributed the health issues of Negros to their racial inferiority. W.E.B. Du Bois, in 1899, partially in response to Hoffman, used epidemiological research to argue against the existing view that African Americans had higher mortality rates in the North because they were racially better suited to living in a warmer climate. Du Bois declared that it living conditions like poverty and sanitation were the causes, but his voice was in the minority.[36] Recall that Harold Bowcock's original purpose to study diabetes was to examine the "many interesting points of comparison and contrast with the same disease in the white race."[37] The believable narrative of the time was that different races suffered from different diseases because there were inherent biological and behavioral differences between them.

One of the premises of the Tuskegee Syphilis Study was that there were thought to be a separate manifestation of syphilis in whites than in blacks. In 1929,

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[34] Lewis, *The Biology of the Negro*, 18.
[35] S.J. Holmes, "The Resistant Ectoderm of the Negro," *American Journal of Physical Anthropology* 12, no. 1 (1928).
[36] Thomas et al., "Historical and Current Policy Efforts To Eliminate Racial and Ethnic Health Disparties in the United States: Future Opportunities for Public Health Education Research," 325. Gamble and Stone, "U.S. Policy on Health Inequities: The Interplay of Politics and Research," 100. Powe, "Let's Get Serious About Racial and Ethnic Disparities."
[37] Bowcock, "Diabetes Mellitus in the Negro Race: A study of one hundred consecutive cases," 994.

there was a Norwegian study about the effects of untreated syphilis on patients at the Oslo Clinic. Since American physicians believed that syphilis had a different disease course in blacks and whites, the findings of the Norwegian study did not offer conclusive evidence.[38] Physicians also believed that whites were more likely to suffer neurological damage from syphilis because whites thought more, and blacks were more likely to have cardiovascular problems, because they did more physical labor.[39] Allan M. Brandt wrote: "In retrospect the Tuskegee Study reveals more about the pathology of racism than it did about the pathology of syphilis; more about the nature of scientific inquiry than about the nature of the disease process."[40] The same idea applies to the use of race in medical and diabetes literature—that it reveals more about what people thought about race than what race actually is.

The cultural logic of diabetes and the role of race

To emphasis a disease in certain groups and not others also involves beliefs about the disease. Risk factors for diabetes used to include neuroticism. Groups at risk then included the wealthy, because they could afford to eat in excess and be obese.[41] In 1921, Joslin described the diabetes in his hometown of Oxford, Massachusetts:

> On the broad street of a certain peaceful New England village there once stood three side by side, as commodious and attractive as any in the town. Into these three houses moved in succession four women and

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[38] James H. Jones, *Bad Blood: the Tuskegee Syphilis Experiments* (New York: Free Press, 1993).
[39] Susan M. Reverby, "Beyond Apologies and Melodramas: The US Public Health Service Sexually-Transmitted Diseases Studies in Tuskegee and Guatemala" (Wesleyan University, Middletown, CT, 15 February 2012).
[40] Allan M. Brandt, "Racism and Research: The Case of the Tuskegee Syphilis Experiment," in *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study*, ed. Susan M. Reverby, *Studies in Social Medicine* (Chapel Hill: University of North Carolina Press, 2000), 29.
[41] Arleen Marcia Tuchman, "The Art of Medicine: Diabetes and the Public's Health," *The Lancet* 374(2009). Emerson and Larimore, "Diabetes Mellitus: A Contribution to Its Epidemiology Based Chiefly on Mortality Statistics."; Haven Emerson, "Sweetness is death," *The Survey* 53(1924).

> three men—heads of families—and of this number all but one subsequently succumbed to diabetes. The remaining member of the group died of cancer of the stomach at the age of 77 years.[42]

The image presented was that the wealthy citizens of Oxford, living in "commodious and attractive homes," were the ones at particular risk for diabetes.[43] By the end of the century, diabetes in developed countries, like the U.S., disproportionately affected the poor. Previously, fashioning the image of the diabetic involved embracing conceptions of the Jew as the prototypical diabetic while brushing off cases of African Americans with diabetes. These contributed to the persistence of ignorance about the disease in African Americans.

Even though it was not until the 1970s that physicians stated to use the terms "type 1" and "type 2," physicians were aware of the role that diet and obesity played in the development of type 2 diabetes. In the nineteenth century, Etienne Lancereaux, a French physician, used the distinctions *diabète maigre*, thin diabetes, and *diabète gros,* fat diabetes, to describe the disease of the middle-aged and obese.[44] In 1924 published proceedings of the same diabetes symposium in which Joslin declared that the rates of diabetes were higher in Jews, Dr. E. S. Silgore of San Francisco stated, "I believe that a chart showing the amount of automobile distribution in the past decade would correspond closely with the geographic distributions of diabetes."[45] The general conception was that diabetics were fat and fairly well off.

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[42] Elliott P. Joslin, "The Prevention of Diabetes Mellitus," *JAMA: The Journal of the American Medical Association* 76, no. 2 (1921): 79.
[43] In 1947, Joslin admitted that that description contributed to the perception that diabetes was a disease of well-to-do and obese. Joslin, "The Universality of Diabetes, Its True Incidence and the need for a reorganization of its treatment," 7.
[44] Tattersall, *Diabetes: The Biography*, 25.
[45] E. S. Kilgore, "Symposium on Diabetes," *JAMA: The Journal of the American Medical Association* 82, no. 23 (1924).

There was a perceived hereditary tendency of Jewish Americans to obesity. Albert A. Epstein, a physician in New York, read the following in 1919 at the National Conference of Jewish charities: Jews were "over indulgent [sic]" and not active—"his occupations are sedentary and he rarely selects pursuits which require the expenditure of great physical effort."[46] Elliott Joslin wrote in 1924, "The reason that the Jew has more diabetes is not that he is a Jew, but that he is a fat Jew. There is a tendency among Jews to obesity."[47] In 1941, Joslin repeated a similar sentiment: "Obesity is so common in the Hebrew race that it is easy to understand why diabetes is two and a half times more frequent in the Jewish population of Boston than among the rest of the inhabitants."[48] In 1959, Joslin still wrote, "[obesity] accounts in large measure for the predominance of diabetes in Jewish adults."[49] Jews were different from the rest of the white patients in their physical being and thus their rates of diseases were not the same as the rates of "whites."

The neuroticism and ambition of Jews were also seen as causal factors for diabetes, since the medical community believed that mental attributes were factors in the development of diabetes. In 1924, Haven Emerson, a New York physician, wrote "It is not money in the bank, nor being Jew…. that determines the excess of diabetes death…but it would appear quite clearly that when people who have the means to grow fat indulge in their privilege, they develop diabetes more commonly."[50] Dr. Albert Bernheim in 1901 also tried to argue that Jews' predisposition to diabetes was

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[46] Epstein, "Diabetes Among Jews--Its Cause and Prevention," 273.
[47] Joslin, "Symposium on Diabetes: Changes in the Diabetic Clientele," 1887; Elliott P. Joslin, "The Diabetic Problem of Today," *JAMA: The Journal of the American Medical Association* 83, no. 10 (1924). In both articles published in the same year (different issues) Joslin repeats the sentiment.
[48] Joslin, *A Diabetic Manual for the Mutual Use of Doctor and Patient*, 163.
[49] Joslin, *Diabetic Manual for the Patient*, 217.
[50] Emerson, "Sweetness is death," 25.

not due to their race, but the "nervousness, overstrain, overwork, and cares" of the group.[51] Stereotypes of race and beliefs of diabetes went hand-in-hand.

Notions of race influenced how the Jews were discussed in the diabetes literature even when doctors denied that they were talking specifically about race. Dr. Albert Epstein, wrote that it was not due to the race, but the personality of the Jew. He stated "The Jew has a horror of disease and of death and is more apt to magnify than minimize his aliments…The Gentile on the other hand discredits his maladies, and goes to the doctor only when forced to do so."[52] Thus, the higher prevalence among Jews is attributed to their tendency to seek more medical advice.[53] Benjamin Disraeli (1804-1881), the first and only Jewish Prime Minister of Great Britain, even considered that diabetes appearing in Jewish history was a sign of their "precocious cultural attainment."[54] The assumptions underlying this use of race was that a "race" had a set of behaviors in common, which predisposed members to certain diseases.

The perception that Jews were wealthy and thus able to afford an excess of food was not based in reality. While the literature referred to Jews as a single group, there were actually two groups of immigrants that largely made up the American Jewish population.[55] In the mid-nineteenth century, there was a huge influx of Germans Jewish immigrants. From the late-nineteenth century until World War I,

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[51] Albert Bernheim, "Diabetes Mellitus in Hebews," *JAMA: The Journal of the American Medical Association* 36, no. 12 (1901): 825.
[52] Epstein, "Diabetes Among Jews--Its Cause and Prevention," 272. Epstein also argued that "high-strung and nervous" tendencies of Jews are not due so much to their race, but due to the persecution they have suffered throughout their history. Their nervous type was the product of "severe environment during centuries," not an inherent trait of the race
[53] Epstein qtd in H. Morrison, "A Statistical Study of the Mortality From Diabetes Mellitus in Boston from 1895 to 1913, With Special Reference to its Occurence Among Jews," *Boston Medical and Surgical Journal* 175(1916): 67.
[54] Disraeli qtd in West, *Epidemiology of Diabetes and Its Vascular Lesions*, 275.
[55] Tuchman, "Diabetes and Race: A Historical Perspective."

Eastern European Jews migrated in high volume to the US to escape religious persecution. The German Jews went into banking and manufacturing. Many of them became wealthy as industrialists. One such person, Isidor Straus, born in Kaiserslautern, Germany to Lazarus and Sara Straus, moved to the United States in 1854. After the American Civil War, he and his brother, Nathan, started the R.H. Macy Department Store. Other famous capitalists of German-Jewish ancestry include Adolph Ochs, who bought the *New York Times* in 1896. His descendants, the Sulzbergers, still run the company. The Eastern European immigrants, on the other hand, were not becoming captains of industry, and many lived in the densely packed slums of cities. Many of them went to work in factories. One such place where some of these immigrants worked was the Triangle Shirtwaist Factory, which burned down in 1911 and resulted in 146 deaths and 71 injuries. This reality was not reflected in the diabetes and medical literature.

The literature largely treated Jews as a single entity—a caricature of the reality. While not all Jewish Americans had the luxury of becoming fat and developing diabetes, the diabetes literature presented a singular version of the "rich, fat Jew." In 1924, Emerson observed, "Diabetes… kills at higher rate among the Jews than in any other race; these merchants, storekeepers, needle workers, sedentary workers though cheaply fed, suffer from lack of exercise and the very success of their financial resources."[56] Physicians, in their discussion of diabetes, used the image of the group that reinforced their beliefs of diabetes

This particular cultural logic that diabetes was a disease of the wealthy and the neurotic helped doctors ignore the issue in African Americans, even as physicians

[56] Emerson, "Sweetness is death," 25.

noted increasing rates of diabetes in African Americans. For instance, in 1938, Howard Root and Alexander Marble, both doctors who worked at the Joslin Clinic, noted that "Negroes are as prone to the disease as are Whites, and between the ages of ten and fifty-five the rates for negro women are higher."[57] Additionally, Bowcock, Leopold, and Lemann all recorded that diabetes rates in African Americans were not as rare as believed.[58] Even as they stated those options, however, they expressed a sense of surprise at what they found. The cases of diabetes in blacks violated what they had learned about diabetes and blacks. Issac Lemann, writing in 1921, stated, "The average [negro] is happy-go-lucky, living from hand to mouth and from day to day, without great responsibilities and without great ambitions which carry with them great care…its nervous burden is light and its nervous toll is small. *The mental and nervous make-up of the negro is in marked contrast to that of the Jews*…[italics added]"[59] Many believed that the perceived lack of mental stress in blacks prevented them from developing diseases like diabetes, which was the opposite case for the "neurotic Jews." Lemann also called diabetes "notoriously a disease of the well-to-do," which African Americans were not. [60] These works also suggested that diabetes was particularly an affliction in servants and cooks. In 1928, Bowcock noted that obesity was the important etiological factor and almost 30 percent of the Negro diabetics who reported their occupation were domestic workers or food handlers whose occupations "may have presented opportunities for overeating, with the subsequent development

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[57] Howard F. Root and Alexander Marble, "Progress in Diabetes Mellitus," *The New England Journal of Medicine* 218, no. 22 (1938): 919.
[58] Bowcock, "Diabetes Mellitus in the Negro Race: A study of one hundred consecutive cases."; Leopold, "Diabetes in the Negro Race."; Lemann, "Diabetes Mellitus, Syphilis and the Negro."; Issac Ivan Lemann, "Diabetes Mellitus in the Negro Race," *Southern Medical Journal* 14, no. 7 (1921).
[59] Lemann, "Diabetes Mellitus in the Negro Race," 524. Also note Lemann's use of pronouns. He used "it" instead of "he."
[60] Ibid., 522.

of obesity."[61] In 1931, Leopold argued that the female, black diabetics' greatest hindrance to proper care of their disease was their common occupation as cooks and must often taste their cooking: "While the best of colored, as of white, cooks need not taste their cooking to be sure of its proper preparation, many cooks are not so good and must sample the food they prepare."[62] The implication that only a certain type of African American, a domestic worker, would be at risk for the disease. For the most part, the medical literature was not specifically interested in blacks as a category of analysis for this disease. The works of these three men are unique for their time, because they focused on diabetes in African Americans. Later diabetes literature continuously cite the works of Lemann, Bowcock, and Leopold because of the lack of evidence elsewhere.

In published text of Emerson's and Larimore's 1924 speech to the American Medical Association, Emerson and Larimore spend about five pages analyzing diabetes in Jews and less than half a page talking about diabetes in blacks.[63] In the published discussion about this article, Issac Lemann noted that there may even causal role of syphilis in the development of diabetes in negroes, "a notoriously syphilis-soaked race."[64] The actual rates of diabetes may have been higher in Jews than blacks, but the important message for this study is that physicians' cultural

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[61] Bowcock, "Diabetes Mellitus in the Negro Race: A study of one hundred consecutive cases," 995.
[62] Leopold, *Diabetes in the Negro Race,* 292.
[63] Emerson and Larimore, "Diabetes Mellitus: A Contribution to Its Epidemiology Based Chiefly on Mortality Statistics," 604-607.
[64] Issac Leman qtd in ibid., 629. Jim Jones uses the phrase "a notoriously syphilis-soaked race" to describe how physicians perceived syphilis in African Americans. Jones, *Bad Blood: the Tuskegee Syphilis Experiments*, 16-29. In 1916, Aldred Warthin, a pathologist at the University of Michigan, and his assistant Unity Wilson, suggested that latent syphilis caused many causes of diabetes. Aldred Scott Warthin and Unity F. Wilson, "The Coincidence of Latent Syphilis and Diabetes," *The American Journal of the Medical Sciences* 152, no. 2 (1916).

perceptions of a race fed the analysis of the race and a disease. When these cultural perceptions change, the discussion around a disease also change.

Jewish Americans eventually disappear as a category in the diabetes literature. The last mention of Jews as a specific category for diabetes is in 1949 for *JAMA*.[65] The last mention in the *New England Journal of Medicine* is in 1951.[66] Joslin was one of the last users of the term in the medical literature, perhaps proof more than anything that entrenched habits do not fade easily. How did these categories change? "Jews" as a category of analysis disappeared from the literature, although a few instances of examining at Jewish separately still existed in the 1950s.[67] By no means was the growing tendency to look at non-whites in the literature contingent on the fading of the category of Jews. It also was not just about changing practices in medicine and epidemiology. What this does show are shifting priorities and the nature of society itself.

New directions for racial categories in diabetes research

In the later half of the twentieth century, the practice of categorizing Jewish Americans separately from whites fades. In place of that category, the distinction generally becomes white versus non-white. By the end of the century, there is significant research into the health status of specifically African Americans. The

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[65] Elliott P. Joslin, "Treatment of Diabetes Today," *JAMA: the Journal of the American Medical Association* 140, no. 7 (1949). Search done on the *JAMA* online archive. Terms used: Jew[s], diabetes.
[66] Harry Blotner and Alexander Marble, "Diabetes Control: Detection, Public Education and Community Aspects," *New England Journal of Medicine* 245, no. 15 (1951). Search done the *New England Journal of Medicine*'s online archive. Terms used: Jews[s], diabetes.
[67] See the journal *Diabetes's* "Recent Statistics on Diabetes"

paradigm changes, and the societal concerns about race becomes increasingly of white versus black issues.

Around mid-century, there was a huge shift in thinking about Jewish Americans. Overt anti-Semitism became increasingly unacceptable after the Holocaust. During World War II, President Franklin D. Roosevelt and his administration actively promoted policies fostering racial unity. In 1943, ships' manifests stopped listing newly arrived Jewish immigrants as "Hebrews" due to a special exception, which was partially motivated by the Nazi's anti-Semitism and classification. The second-generation immigrants were also becoming more assimilated into American culture and less acutely different from "native" Americans.[68] Jews were also becoming more economically mobile due to the post-war boom. Roosevelt even elevated many Jewish Americans to important positions of public service.[69] Jewish Americans were also moving out of the cities and into suburbs, the new Mecca of the American home. The Federal Housing Administration (FHA) made many of these sales possible. The FHA, however, actively espoused racial segregation. Before World War II, the policies of the FHA excluded Jews from receiving benefits. After the war, the policies became anti-black, excluding African Americans from the new suburbs. Palo Alto, California and Levittown, New York, two prototypes of the post-war suburban boom, were "virtually all white."[70] The Jews were no longer a race, but an ethnicity.[71] For instance, the racial categories for

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[68] Karen Brodkin, *How Jews Became White Folks* (New Brunswick: Rutgers University Press, 1998), 36.
[69] Goldstein, *The Price of Whiteness: Jews, Race, and American Idenity*, 190.
[70] Brodkin, *How Jews Became White Folks*, 47.
[71] Brodkin, *How Jews Became White Folks,* 14. In her piece, she argued, "The word "ethnicity" did not come into use until after World War II, when it became the word of choice in academic and public-

observer-reported race in the National Interview Health Survey from 1957 to 1982 were W (white), B (black), and OT(other).[72] The definition of race used between 1957and 1976 was "The population is divided into two color groups, 'white' and 'all other.' 'All other' includes Negro, American Indian, Chinese, Japanese, and any other race."[73] At the end of the century, classifying Jews separately still occurred in certain types of research, like for Tay-Sachs, a recessive genetic disorder that is especially common among Eastern European Ashkenazi Jews. The distinction is not, however, done on the basis of their religion, but their shared geographic ancestry. Jewish Americans had assimilated, and the social tensions between "racial" groups intensified along color lines—to a white versus non-white paradigm.

In addition, there was growing awareness within the medical community that diabetes was not just a disease of the rich and well-fed, but the poor and obese. In the second half of the twentieth century, there started to research that challenged to notion that diabetes was a disease of the well-to-do. In 1947, Joslin stated that the majority of the "unrecognized diabetics in the country belong[ed] to the low income group.[74] He even stated that the majority of the "recognized diabetics" in Indianapolis, Indiana were "Negroes or in the lower strata of the white inhabitants."[75] While in his 1978 landmark piece on diabetes epidemiology Kelly West mostly cited

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policy vocabularies to describe those who had been formerly discussed as members of a less-than-white race, nation, or people."

[72] U.S. Department of Health & Human Services, *The National Health Interview Survey Design, 1973-84, and Procedures, 1975-83*, Programs and Collections Procedures Series: Series 1, Number 18, (Hyattsville, Maryland: National Center for Health Statistics, 1985), 21.

[73] U.S. Department of Health & Human Services, *Health Interview Survey Procedure 1957-1974*. U.S. Department of Health & Human Services, *The National Health Interview Survey Design, 1973-84, and Procedures, 1975-83*.

[74] Joslin, "The Universality of Diabetes, Its True Incidence and the need for a reorganization of its treatment," 7.

[75] Ibid.

literature that stated diabetes was more common in the upper- rather than lower-classes, he did, however, mention recent literature that suggested rates in diabetes would be higher in the lower than upper classes.[76] For instance in 1973, West examined data from the Metropolitan Life Insurance Company and found that mortality rates were somewhat higher in men of lower income versus men of higher women. The mortality rates were significantly higher in women of lower income versus women of higher women. West presented a possible explanation, which was that it may be due the "corpulence of poor women now prevailing in the main segments of U.S. society."[77] West also noted that those with family incomes of less than $5,000 had a known diabetes rate of 4.02 percent, but the rate in families with incomes greater than $10,000 only had a known rate of 1.37 percent. West's explanation was, again, that poor American women were fatter than their richer counterparts.[78] The National Health Survey of 1971-1972 also found that both black and white women below the poverty level had higher rates of obesity than black and white women above the poverty line.[79] The findings in the 1970s that the Pima Indians of the American Southwest had extraordinary high rates of the disease was another challenge to the paradigm that diabetes was a disease of the well-to-do. Their lifestyles underwent a drastic change on the reservations. The Pima Indians, formerly farmers, began to live off government food rations, which differed significantly from the traditional low-fat and low-sugar diets, and adopted a sedentary lifestyle, causing

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[76] West, *Epidemiology of Diabetes and Its Vascular Lesions*, 274-277. This was in the "Social and Economic Status" sub-section to his discussion of the "Factors Associated With Occurrence of Diabetes"
[77] Ibid., 276.
[78] Ibid., 276-277.
[79] Ibid., 277.

high rates of obesity. The Pimas that live in Mexico, not the reservations of the American Southwest, pursue a traditional lifestyle of farming and do not have the same rates of obesity or diabetes.[80] In 1971, researchers at the National Institute of Arthritis and Metabolic, found that conservative estimates that the rate of diabetes in the Pima Indians was at least 50 percent of those thirty-five and older.[81] The authors noted that this was the "highest prevalence of diabetes yet reported."[82] Diseases Kelly West in 1974, documented the rates of diabetes in Native Americans.[83] No longer was diabetes in the domain of the well-fed and idle.

Like how Jews were a highly visible group in the twentieth century due to nativist tensions, the "poor" black also rose in prominence. In late 1967, a group of American senators, among whom included Robert Kennedy, travelled to Jackson, Mississippi. They saw heart wrenching of cases of Southern children, which included many black children, suffering and wasting away from malnutrition.[84] It struck the attention of the national media and political activists.[85] Also during the time, Civil Rights activists raised attention to the dismal medical services for African Americans.[86] There was growing awareness in the public consciousness of the living conditions of black Americans.

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[80] Tattersall, *Diabetes: The Biography*, 188.
[81] Peter H. Bennett, Thomas A. Burch, and Max Miller, "Diabetes Mellitus in American (Pima) Indians," *The Lancet* 298, no. 7716 (1971).
[82] Ibid., 125.
[83] West, "Diabetes in American Indian and Other Natives of the New World."
[84] Beardsley, *A History of Neglect: Health Care for Blacks and Mill Workers in the Twentieth-century South*, 291.
[85] Ibid., 274-275, 291.
[86] Herbert Morais, *The History of the Afro-American in Medicine* 4th ed. (Cornwells Heights, Pennsylvania: The Publishers Agency, Inc, 1976). Goldstein, "Longevity and Health Status of the Negro American."

By the 1950s and 1960s, the pushing of Civil Rights activists raised the issue of black-white racial inequality to the forefront of American consciousness. Additionally there were efforts to create more equitable medical conditions for whites and non-whites. For instance, the 1950s were when many hospitals were integrated. In Chicago there was a committee, the Committee to End Discrimination in Chicago Medical Institutions, which examined the treatment of blacks in hospitals. The committed noted that blacks were often turned away from hospitals.[87] The 1964 Civil Rights Act and 1965 creation of Medicare and Medicaid mandated inclusion and prohibited discrimination.[88] Statisticians at the National Health Interview Health Survey and the Metropolitan Life Insurance Company had measured diabetes rates previous to the 1980s, but in 1980s there was a strong policy decision to look at the variable of race in health.

In January of 1984, President Reagan's Secretary of Health and Human Services Margaret Heckler's annual report card on Americans' health to Congress, *Health, United States, 1983,* noted that "there was a continuing disparity in the burden of death and illness experienced by Blacks and other minority Americans as compared with our nations population as a whole."[89] In the executive summary of the *Report of the Secretary's Task Force on Black & Minority Health*, Heckler underlined the above statement for emphasis. In the executive summary of the Heckler Report, it stated, "Data from the National Center for Health Statistics (NCHS) reveal that diabetes is more prevalent among minority groups than in the general population and that the excess of morbidity and mortality among minorities occurs overwhelmingly in

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[87] Morais, *The History of the Afro-American in Medicine* 147.
[88] Gamble and Stone, "U.S. Policy on Health Inequities: The Interplay of Politics and Research," 103.
[89] Heckler, "Report of the Secretary's Task Force on Black & Minority Health," ix.

type II (NIDDM)."[90] The report did not just single out African Americans as an at-risk population; it also pointed out other groups like the Pima Indians and Hispanics. This eye-opening report brought health disparities to the national forefront. Sandra Gadson, a president of the National Medical Association, which represents black physicians, called the Heckler Report "unprecedented" and that "it sent shockwaves through the media and the public health sector."[91]

The 1980s were a decade of change in which the concerns about African American health resonated through society. Also in the mid-1980s, the National Health Interview Study began to look at race as variable in health (The Task Force on Black & Minority Health even used the data from the National Health Interview Study in its analysis.).[92] The introduction to the 1982, explaining the changes, noted "over the years the number of requests for health-related by other characteristics [than just age and sex] has grown such an extent that data in this summary are presented for more variables."[93] In 1990, the National Health Interview Study came out with a special issue that compared the health of black and white Americans between 1985 and 1987.[94] The trend to incorporate minority health issues was part of the federal government's growing emphasis on health disparities and the medical movements for inclusion as well as growing attention to racial disparities in health. Policies and statistics both changed.

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[90] Ibid., 149.
[91] Gadson, "Health Equality: The New Civil Rights Frontier."
[92] U.S. Department of Health, Education, and Welfare, "Health Interview Survey Procedure 1957-1974."; U.S. Department of Health & Human Services, "The National Health Interview Survey Design, 1973-84, and Procedures, 1975-83."
[93] U.S. Department of Health, Education, and Welfare, *Current Estimates From the National Health Interview Survey: United Sates, 1982,* Data From the National Health Survey: Series 10, Number 150, (Hyattsville, Maryland: National Center for Health Statistics, 1985), 1.
[94] U.S. Department of Health & Human Services, *Vital and Health Statistics: Health of Black and White Americans, 1985-87.*

Jessie Daniels and Amy J. Schultz documented the increase in the research on health disparities in medical research. They found that between 1980 and 1989 there were fewer than twenty publications on the subject. In the next decade, between 1990 and 1999, there were more than 130 publications. Between 2000 and 2004, there were over 700 publications on the topic.[95] With the increase in measuring racial health disparities, researchers began to question the epidemiologic practices of using race as a category.

In the diabetes literature, the groups that are focused in the literature not only reveal who is at-risk, but also the priorities of society and the state. For instance, with the rise in the Hispanic population there is increased attention to this group. Other groups, like the white residents of Appalachia also have distressingly high rates of diabetes, but there is little study into this group. A PubMed, an online database of science and medical literature, search for articles published between 1980 and 1999 with the terms "diabetes" and "Appalachia*" in the title or abstract resulted in 4 articles, and 20 articles since 2000.[96] A similar search with the terms "diabetes" and "Hispanic*" or "Latino*" resulted in 422 articles published between 1980 and 1999, and 2,005 articles from 2000 to April 2012.[97] Comparatively, the search, using "diabetes" and "African American*" or "black*," resulted in 1,196 articles between

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[95] Jessie Daniels and Amy J. Schultz, "Constructing Whiteness in Health Disparities Research," in *Gender, Race, Class, and Health: Intersectional Approaches*, ed. Amy J. Schultz and Leith Mullings (San Francisco: Jossey-Bass, 2006).

[96] I conducted the search on PubMed.gov, 8 April 2012. Terms searched in the title or abstract: "diabetes," "Appalachia*." Date of publication: 1980 to 1999 and then 2000 to 8 April 2012.

[97] I conducted the search on PubMed.gov, 8 April 2012. Terms searched in the title or abstract: "diabetes," "Hispanic*," or "Latino*." Date of publication: 1980 to 1999 and then 2000 to 8 April 2012.

1980 and 1999, and 4,086 articles from 2000 to April 2012.[98] To an extent, researchers investigate the actual prevalence of a disease, but as the history shows, it also results from cultural emphases placed on certain groups. Arleen Tuchman stated, "The picture [of diabetes] that is being reproduced in the professional and popular literature of at-risk populations reflects the kind of data that are being collected, not necessarily the actual distribution of the disease."[99]

Conclusion

Medicine does not occur in a vacuum. The particular cultural logic of race that dictates what researchers examine and how they do so is inextricable from the medicine. Medical research first portrayed diabetes as a particular affliction of Jews. By the end of the twentieth century, medical research portrayed diabetes as a particular affliction in African Americans. Tellingly historical epidemiological research into diabetes among African Americans consistently refers to the works of three men—Bowcock, Leopold, and Lemann—because these men provided the only glimpses into an early twentieth century studies of diabetes in African Americans. Explaining research into diabetes in African Americans is more than explaining epidemiological practices and the structure of medicine and public health in American, it is about the conceptions of a disease and of races in American society. In the early twentieth century, physicians did not consider African Americans and diabetes to be a significant issue to study. Not only did they see few African

[98] I conducted the search on PubMed.gov, 8 April 2012. Terms search in the title or abstract: "diabetes," "African American*," or "black*." Date of publication: 1980 to 1999 and 2000 to 8 April 2012.
[99] Tuchman, "Diabetes and Race: A Historical Perspective," 31.

Americans in their practice, but there was already another race that a tendency to diabetes—the Jewish race. The particular cultural logic of diabetes as a disease of the fat, neurotic, and rich also framed how physicians thought about the disease. As race relations in the United States mostly became about white versus black, the government and groups began to pay attention to those categorical differences in medicine.

Historically, physicians considered that there were race-specific diseases. For instance, drapetomania, was considered a Negro disease, in which slaves suffered from the inexplicable desire to run away from their owners. The emphasis on race-specific diseases changed over the century, but did not completely disappear. What replaced it was a way to thinking of the relative risks and predispositions groups of people had to a disease.

Over the century is there a shift in the image of the diabetic. It was once a rich, fat Jew. By the end, it was often of a poor, obese black American. The picture that the medical literature projects of a diabetic reflects the data that physicians and epidemiologists collect, but how they collect that data is dependent on groups that are culturally visible. Confirmation biases and self-fulfilling prophecies have a role in diabetes research. Researchers have a pre-conception that a group of people have or do not have a disease, and will design studies to further explore those beliefs. For example, perceptions that Jews were predisposed to diabetes, caused physicians to look for the disease in that group. Once there is a new paradigm of study exists, researchers will then use that paradigm as a springboard for further research, creating self-fulfilling prophecies.

Conclusion

There is always something new going on in diabetes.
-Elliott P. Joslin[1]

Diabetes in African Americans was a significant medical and public health issue at the turn of the twenty-first century. How did that happen if at the turn of the twentieth century many physicians and epidemiologists believed that African Americans had a degree of immunity to the disease? The short answer is that in 1985 the Heckler Report bought the health disparities of African Americans to the nation's attention. The Heckler Report was a product of decades of change in public health, epidemiology, and perceptions of diabetes. The facts in the Heckler Report, such as the one that showed that there was a significant difference in the rates of diabetes in whites versus those in blacks, travelled fruitfully. In her discussion of travelling facts, Mary Morgan introduced this idea of travelling fruitfully. Facts travel fruitfully when these bits of knowledge find new uses and users.[2] The knowledge that there existed striking contrasts in the health of white and black Americans, spurred physicians, public health officials, and epidemiologists to study the disease in African Americans.

Yet for the facts of the Heckler Report to travel well and fruitfully there had to be significant changes in the terrains and boundaries of travel—neither the Heckler report nor its impacts could have occurred until there was significant structural and methodological changes in how the public health officials approached the health of black Americans, how epidemiologists measured the health of African Americans, and

[1] Elliott P. Joslin, *A Diabetic Manual for the Mutual Use of Doctor and Patient*, Seventh ed. (Philadelphia: Lea & Febiger, 1941).
[2] Morgan, "Travelling Facts," 18.

how physicians regarded race and diabetes.[3] The facts of diabetes in African Americans existed beforehand, but they existed anonymously among all the other facts that fail to resonate. There needed to be a spark to be attention on those facts.

My approach in this thesis was to look at three systems that undergirded the acknowledgement that diabetes was a public health problem in African Americans. The first was structure and priorities of twentieth century public health. The second was epidemiological practices. The third was perceptions of diabetes and race. It required change in all three systems to produce a believable and acceptable narrative that diabetes was a major disease in African Americans. Each alone only constituted one aspect. I avoided the arranging the overall history chronologically, because the trends in each are separate and often independent from each other. It is possible, however, to think of the history in two phases.

The first is the U.S. from the turn of the twentieth century to post-World War II. During this time, concerns about infectious diseases dominated the medical landscape. Epidemiological studies and the early, fledging field public health largely concentrated on these diseases. African American health issues were also not political issues. Amidst all this, researchers noticed a rise in the rates of diabetes. Many physicians attributed this rise to the influx of Jewish immigrants. These physicians also believed that diabetes was a disease primarily of the well-to-do. These beliefs and practices reaffirmed each other so that not only would a narrative that diabetes was an issue in African Americans be discontinuous with existing frameworks of belief, but also not impel further study.

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[3] Mary Morgan uses the term "terrains of boundaries of travel" as a metaphor to described the landscape through which knowledge becomes disseminated. See Morgan, "Travelling Facts," 31-33.

The second period is post-World War II. Epidemiological and public health practices shifted to studying chronic diseases. Epidemiological studies also began to include and analyze the social determinants of health, like race. These studies revealed previous categories used to characterize diabetics (primarily type 2 diabetics) such as the "idle rich" "[members of] the learned professions" were insufficient to describe increasing rates of diabetes in the lower classes.[4] On top of this, studying and ameliorating the health of its citizens also became an increasing concern of the state. Such changes were necessary for the creation and findings of the Heckler Report, a state-sponsored epidemiological investigation into the health of minority, to send "shockwaves through the media and the public health sector" and stimulate further research into diabetes in African Americans.

Diabetes in African Americans was not a new area of study in the 1980s and 1990s. There were scattered bits of research throughout the century, which affirmed that diabetes was not rare in African Americans. The statisticians at the Metropolitan Life Insurance Agency differentiated African American rates of disease from white rates since the 1920s and show discrepancies between white and non-whites of disease. The significance of these facts of disease, however, remained hidden and did not travel into the broader discourse of the disease. The contextual scaffolding and the landscape of the times before the 1980s were not ripe for this type of research.

Scientific and medical discoveries have given us facts about our bodies and the health of society. Such facts include information on the proportion of African

[4] Emerson and Larimore, "Diabetes Mellitus: A Contribution to Its Epidemiology Based Chiefly on Mortality Statistics," 612, 619.

Americans who have diabetes compared to other groups or the rate at which the incidence rate of diabetes in African Americans is growing. At the end of the twentieth century, such facts of diabetes in African Americans travelled fruitfully.

The history of a disease, beyond the chronicle of scientific and medical discoveries, matters because it makes sense of how we study and examine the disease today. Just because African Americans had a high prevalence of diabetes does not make the study of diabetes in that group inevitable. The attention paid to groups and diseases reflects the values we place on those groups and the diseases. Take the contemporary example of the attention and money lavished on breast cancer, but then relatively little on schizophrenia in the homeless. Or take the example of neglected tropical diseases, which affect over a billion people worldwide, which are "neglected" in medical research and in the medical discourse. This study of diabetes, tracing the scaffolding of the factors that eventually allowed for the awareness of the issue in the 1980, shows that facts of disease do not exist separately from the history surrounding them. The knowledge about a disease is not just created in the laboratory.

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