
The emergence of the disease concept of Gestational Diabetes Mellitus during the late twentieth century was a product of collaborative efforts between physicians, medical researchers, businesses, and government agencies. This work is fundamentally an institutional history of medicine, situated in three specific genres within the field: disease creation studies, the examination of U.S. public health, and healthcare consumer history. This work traces changes in scientific and medical views, as well as the broader shift in how diseases are defined as that process moved out of the medical clinic and research lab into the halls of policy makers and government agencies.

Scientific discovery and understanding emanated from the work of medical researchers, but the post-World War II era in the United States saw government agencies and healthcare businesses gain important roles in defining diseases and in creating consumer identities for patients. This was especially visible with gestational diabetes because many of the women who made up the rising numbers of new cases in the second half of the twentieth century came from lower-income groups who accessed their healthcare through government-subsidized programs like Medicaid. Through a range of historical sources, I examine the development of this dynamic relationship between medical knowledge and practice; business ideologies and approaches in an expanding healthcare market; and government policy on healthcare.
“OUR OBJECTIVE WASN’T TO BELITTLE PEOPLE’S BEHAVIOR”

THE HISTORY OF GESTATIONAL DIABETES, 1921-1991

by

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To Bob, for everything.
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CHAPTER I

INTRODUCTION

This dissertation investigates how the diagnosis of Gestational Diabetes Mellitus (GDM) was created during the twentieth century through the collaborative efforts of physicians, medical researchers, businesses, and government agencies. It traces the changes in scientific and medical views about the condition as well as the broader shift in how diseases are defined, as that process moved out of the medical clinic and research lab into the halls of policy makers and government agencies. Scientific discovery and understanding would emanate from the work of medical researchers, but the post-World War II era in the United States saw government agencies and healthcare businesses gain important roles in defining diseases and creating consumer identities for patients.

The intimate connections that arose by the mid-twentieth century between medicine, business, and the state – a system of political and economic relationships called the Medical-Industrial Complex – became the structure within which medical recommendations and public policies were created to define gestational diabetes and to identify its patient-consumers. The impact of this complex became especially visible with gestational diabetes because many of the women who made up the rising numbers of new cases in the second half of the twentieth century were from lower-income groups who accessed their healthcare through government-subsidized programs like Medicaid.
Through a range of historical sources, including medical archives, contemporary scientific literature, patient and physician communications, oral histories, popular media, congressional records, and epidemiological data, I examine the development of this dynamic relationship between medical knowledge and practice; business ideologies and approaches in an expanding healthcare market; and government policy on healthcare.

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This dissertation is the story of a disease concept. And while that story entails scientific debates in which newer ideas displaced older regimes, this dissertation focuses more on the mechanics of how the disease concept for gestational diabetes became formalized in public policy and how the patient-consumer identities associated with it were formed in the late twentieth century. The “making” of gestational diabetes was not solely the result of medical discovery or of scientific “facts.” It was also the result of policy formation. The broad canvas upon which this history unfolded identified a range of historical subjects – the women who would be diagnosed, the researchers and legislators who designed public policy, the physicians in the real world of clinics, and even the fetuses of affected pregnancies – who themselves became “historical events in need of explanation.”¹

Understanding the imperative to reshape the importance and the meaning of gestational diabetes requires an explanation of the basic physiology of diabetes. Diabetes actually appears in two different forms, which have two different etiologies or causes,

despite the popular modern conception of it as a single disease that is inextricably linked
to obesity and the excesses of Western life. Diabetes, both forms, develops along a
continuum that involves a decreasing ability to metabolize and use the food a person eats
along with a corresponding increase of sugar in the blood stream when the byproducts of
that failing metabolism build up. There is a point along that continuum, today designated
with a number from a laboratory test, when the increased level of sugar in the blood
stream surpasses what a person’s system can manage and becomes poisonous to organs
and systems inside his or her body.

For Type 1 diabetes, the movement along that continuum is rapid and complete;
left untreated, that form can kill in a matter of hours, though it usually takes weeks or
months. Type 1 is a disease that usually appears in young children or adolescents (hence,
the older name of juvenile diabetes), but frequently shows up in adults as well. Type 1 is
often called insulin-dependent diabetes because the complete failure of internal insulin
production causes the person to become dependent on insulin injections for the rest of his
or her life. Although there is not a sole cause of Type 1, the disease emerges when the
insulin-producing cells of the pancreas are destroyed. Most often, that destruction is the
result of the individual’s own immune system becoming “confused” and attacking the
pancreatic cells as though they were an outside organism. The destruction can also
happen, although much more rarely, as a result of a toxic chemical or from an injury to or
disease of the pancreas. As pancreatic cells do not regenerate, Type 1 diabetes is
permanent. And although insulin injections can successfully treat it, no cure exists and it cannot be reversed. Type 1 diabetes comprises about 5 percent of all diabetes cases.

Type 2 diabetes, which is also known as adult-onset or non-insulin-dependent diabetes, overwhelmingly accounts for the majority of diabetes cases in the United States today. Unlike its lethal cousin, Type 2 diabetes does not emerge from a process of cellular destruction. Rather, an unknown mechanism – probably several mechanisms – prevents the insulin that a person with Type 2 makes naturally to work properly. The person with Type 2 diabetes has plenty of insulin, sometimes incredibly high levels, but for a variety of reasons, it does not do its job. Type 2 diabetes is not acutely dangerous because even though the insulin that a Type 2 diabetic makes may not work properly, it still works, and the person with this form of the disease can go for years or decades with few symptoms and little to no awareness that any problem is present. Increased body fat and inactivity magnify the problem of ineffective insulin because both of those factors decrease sensitivity to insulin across the board. Hence, despite popular conception, obesity and inactivity do not cause this form of diabetes.

Physicians’ current understanding of gestational diabetes is that it is most like Type 2 diabetes. As the term “gestational” implies, the condition first appears during pregnancy. Officially defined as “carbohydrate intolerance of variable severity with onset or first recognition during pregnancy,” it involves the appearance of high blood sugars in a pregnant woman who has not previously been diagnosed with diabetes.\(^2\) The

\(^2\) Early on, before the condition was called gestational diabetes, it was identified by the appearance of sugar in a pregnant woman’s urine. The difference in how it was diagnosed was due mainly to the
added physical stress of pregnancy on a woman’s body is thought to uncover a hidden metabolic problem. Typically, after giving birth, the woman’s blood sugars normalize, but many of these women develop Type 2 diabetes within a decade of their experience with gestational diabetes. Just like with Type 2 diabetes, age, weight, and racial/ethnic heritage factor into a person’s likelihood of developing it.\(^3\)

Throughout this narrative I try to refer to the condition by the name that the corresponding historical actors have used, but sometimes the name gestational diabetes is more explanatory, even if less historical. From 1921 to the early 1950s, the condition was most commonly known in the medical literature as glycosuria of pregnancy. For roughly the next two decades, researchers and physicians most often used the term pre-diabetes of pregnancy. By the mid-1970s, gestational diabetes had become the predominant name for the condition and would become the official name that was added to the compendium of diseases maintained by the World Health Organization (WHO). As well, throughout the narrative, although I try to refrain from the ahistorical use of the word “disease,” I allow the word into the narrative when the historical actors use that term in their own portrayals.

The time frame for this dissertation, 1921 to 1991, saw the American social landscape change dramatically. From the discovery of insulin in 1921 to a conference in 1991 organized to clarify the definition of gestational diabetes, America went through the Great Depression, the New Deal, World War II, and the social movements of the 1960s and 1970s. A time of intense efforts at social reform and of the increasing power of the state in the lives of everyday people, life in the United States underwent enormous changes. Cities grew and then fell into decay, a culture of consumerism took shape, and the demographic profile of the nation shifted as huge internal migrations took place.4

This time period also encompassed sweeping changes in U.S. medicine, from structural changes in the field itself to therapeutic advances for a bevy of health issues. Often called the era of “the professionalization of American medicine,” it was a time when healthcare became a full-fledged consumer market, a protective force in people’s lives, a mediator of public behavior, and a source of what many scientists believed to be remarkable discoveries about our bodies, our nature, the perceived similarities and differences between us, and the biological manifestations of our cultural and social concerns.5 During the seventy years of this narrative, American medicine was transformed from a disorganized and poorly regulated system of “snake oil hustlers” and local healers that challenged the integrity of a cadre of educated clinicians to a managed


and authoritative force of organized sanctioning bodies and formal structures for the education and credentialing of healthcare practitioners.\(^6\)

It is within these changes in American life and American medicine that a condition that physicians once thought to be of little significance became seen instead as a disease for which every single pregnant woman should be tested. As scientific understanding changed, the condition took on different names and those names held different meanings for different historical actors. Hence, glycosuria of pregnancy was not exactly the same phenomenon as pre-diabetes of pregnancy, which is not the same condition as gestational diabetes. In medical clinics, glycosuria of pregnancy was the physiology of metabolism and pregnancy gone awry. Businesses in the American healthcare market, however, came to understand and discuss a different condition, pre-diabetes of pregnancy, and viewed it through demographic descriptors like race and socio-economic status, variables that informed their process of risk reduction. In the offices of policy makers, the condition became the disease gestational diabetes, and legislators defined it in simple economic terms: the fiscal impact of diagnosing or not diagnosing it.

Even though gestational diabetes today is thought to be more closely related to Type 2 diabetes, examining the condition historically requires attention to the transformation of diabetes as a whole that was brought about by the discovery of insulin.

This dissertation begins in 1921 with the discovery and production of insulin to treat diabetes. With the discovery of insulin, diabetes was commuted from a quick death sentence to a chronic, but manageable, illness. As such, even though references to the disease date back as far as 1550 BC, diabetes is very much a twentieth-century disease: scientific understanding, medical treatment, and increased prevalence are all twentieth-century developments.

Most scholars who have examined some aspect of diabetes history are medically trained and so their foci have been primarily science-driven, using a biomedical model.7 The two main contemporary works are Michael Bliss’s *The Discovery of Insulin* and Chris Feudtner’s *Bittersweet: Diabetes, Insulin, and the Transformation of Illness*. Bliss’s narrative details the contentious history of the discovery of insulin within a fairly antagonistic international medical community. Feudtner examines the impact that insulin had on the lives of diabetic patients, both in terms of the immediate life-saving effect of the hormone and in terms of the long-term consequences of these patients having a fatal illness transformed into a chronic one. Both narratives portray the urgency and the

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despair felt by patients and their families as well as by the physicians who tried unsuccessfully to help them.\textsuperscript{8}

Like the works of Bliss and Feudtner on diabetes, histories of disease creation in general often focus on the social context of illness, and that focus has illustrated the profound impact that definitions and meanings of health and illness can have for people. For example, lead poisoning went from an unrecognized phenomenon at the turn of the century to a disease of great public concern by the 1990s, when the gentrification of older, historic neighborhoods exposed children in families of higher socio-economic status to lead paint poisoning.\textsuperscript{9} And such studies have given historians new and important ways to portray social structures like class. But they do not explain how a disease can be created through government and medical policies and how certain individuals and groups have experienced that process differently.\textsuperscript{10} In the case of kidney

\textsuperscript{8} Michael Bliss, \textit{The Discovery of Insulin} (Chicago: University of Chicago Press, 1982) and Chris Feudtner, \textit{Bittersweet}. Bliss is an exception to the spate of physicians examining diabetes history; Bliss is a business historian.


Similarly, in the case of GDM, testing for the condition would become an integral part of the system of prenatal care covered by Medicaid because many women who would face a diagnosis of gestational diabetes were poor. That policy makers and clinicians recognized that connection is evidenced by the incredible similarity in the language of policies for expanded access to Medicaid and the guidelines and medical position statements for the diagnosis and treatment of GDM. As gestationally diabetic pregnancies became high risk events, Medicaid coverage extended to poor women with “high risk” pregnancies. At the same time that Medicaid began to include previously ineligible pregnant women for the third trimester of their pregnancies, testing for GDM became a third trimester event. Follow-up care for Medicaid recipients who recently
gave birth came to include sixty days of postnatal care, and physicians focused on the first sixty days postpartum for gestationally diabetic women as well.

Women’s relationship to medicine has drawn an increasing amount of attention from historians outside of the realm of medical tomes, and much of the earliest of that scholarship focused on women as patients. But many of those works presented women as victims or as objects of study.12 Carroll Smith-Rosenberg opened a new perspective that has endured into more recent scholarship, presenting the relationship between women patients and their physicians instead as a site of negotiation in which women retained a significant amount of control.13 Judith Walzer Leavitt took the ideas of doctor-patient negotiation and of the medicalization of female lives and demonstrated that in the move of childbirth from the home to the hospital, women in fact exercised a great deal of control.14 Likewise, diabetic women played an active and important role in the emergence of the specialty field of obstetrical diabetes by refusing to avoid pregnancy


and by refusing to end their diabetic pregnancies. And women patients in the 1950s and 1960s would help physicians make the connection between the temporary condition of glycosuria of pregnancy and a diagnosis of diabetes later in their lives.

**Part I: Diabetic Identity in the Twentieth Century**

Part I of this dissertation addresses the scientific, medical, business, and social elements that together created the context within which a disease concept for gestational diabetes would develop. Chronic diseases were long imagined as a natural process of aging. But that view had changed by the middle of the nineteenth century, and certainly by the early twentieth century. Instead, chronic diseases like diabetes became seen as a problem of epic proportions with the taming of infectious agents like polio, smallpox, and measles. In some ways, the privileging of research and experimentation that had led to success in combating infectious diseases served as an organizing element for connecting medicine to the growing social concerns over chronic illness. The constitutionalism that had scientists asking what made the pancreas dysfunctional in diabetes and had doctors enamored of insulin, gave way to a pragmatism that brought the new actuarial scientists of insurance companies into physicians’ clinics.15 As diabetes physician Elliott Joslin

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proclaimed that Metropolitan Life “furnished practically all the statistical data I ever quote,” physicians began to worry about the looming economic impact of the expanding numbers of diabetics. Investigators tried to put a dollar amount to such amorphous elements as missed work days, unpaid medical bills, and decreased productivity.

Scholars have posited that the problem of infectious disease was merely supplanted by the rise of debility from chronic illnesses – because of the greater visibility of chronic ailments that came with medical knowledge and also because people simply lived long enough to experience chronic illnesses more often when acute infections became less life-threatening. Concurrently, a new line of actuarial scientists sought to protect the bottom line of an emerging host of insurance and health maintenance businesses, with government agencies entering as well into the fiscal support of the American public’s health.

At the same time that chronic illness was gaining much more public visibility, pregnancy was being transformed in science labs, in popular perception, and in courtrooms and congressional hearings. As pregnancy became envisioned less and less as a private and personal experience for women – and more as an environment for the

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growing baby, the unborn child, the “potential human life” – women found they could be held liable for the impact of their behavior, or even their inaction, on the fetus inside them. In the post-\textit{Roe v. Wade} era, that shift would bring professional medical journals to posit that “the care of a pregnant woman involve[d] two patients, the mother and the fetus” and would lead to headlines on Fetal Alcohol Syndrome (FAS) and “crack babies.”

Chapter III, the first chapter of Part I, begins with the early twentieth century transformation of diabetes. Long considered a relatively uncommon condition that was both acute and lethal, it was believed to strike mostly young, white children. By mid-century, however, it would be understood as a chronic illness that afflicted a much broader cross-section of society, and that posed the potential for great public expense. Insulin was an important facet in that transformation, but this chapter argues that insulin’s transformative power was not just in the therapeutic value it brought. Insulin created one of the largest healthcare consumer markets to date, and the consumer identities that emerged from that new market transformed the perception of diabetes and of its patients.

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The construction of this new patient-consumer identity embedded ideas about what constituted responsible health behaviors and acceptable public costs into notions of what it meant to be diabetic.

Chapter IV examines the emergence of a specialty field in medicine concerned specifically with diabetic pregnancy: obstetrical diabetes. The key figure in building the field was Boston physician Priscilla White. But White was not the sole catalyst. Women with diabetes played an essential role as well. As insulin saved the lives of young Type 1 diabetics and improved the health of Type 2 diabetics, those women found they were finally able to become pregnant. Although insulin did not make diabetic pregnancy safe – both mother and baby often died – diabetic women refused to acquiesce to medical recommendations to avoid pregnancy and they refused to end their pregnancies. Their actions forced the creation of the specialty field because it gendered the medical perception of diabetes patients.

Chapter V introduces the condition that preceded gestational diabetes – called glycosuria of pregnancy until mid-century, and then referred to as pre-diabetes of pregnancy. Along with the transformation of diabetes, the rise of risk factor ideology sparked research interest on the condition, both in America and across the Atlantic in European locales. Risk factor ideology was based on the business concept of limiting fiscal risk by identifying economic threats. In the healthcare market, that meant identifying chronic diseases before they could wreak havoc. For pregnant women who
were found to have sugar in their urine, normally a tell-tale sign of diabetes, risk factor ideology made researchers ask what possible health problems that condition portended.

**Part II: Making Gestational Diabetes**

Part II of this dissertation chronicles the “mechanics” of creating the diagnosis of gestational diabetes. The process of creating and defining gestational diabetes became a task of making policies that specified who was at risk and what fiscal and social problems could result from not identifying those at risk. During the 1970s and 1980s, a definition for gestational diabetes developed within the framework of social welfare policy. As such, state policies became embedded in this new disease concept.

Due to an increasing role of the federal government, the rise of a pharmaceutical market, and the emergence of a third-party payer system, medical care became commodified during the twentieth century. Historians have investigated that transition and have recognized that a binding element was the rapidly expanding enterprise of federally-funded medical research. This dissertation expands on those studies by demonstrating how the structure of medical research also became the conduit for bringing business and the state into the formula for defining health and illness. Medical research became a billion dollar industry. It made new career paths for physicians, built new businesses in the healthcare market, and created new agendas for many federal

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agencies.\textsuperscript{22} Medicine, business, and government became bound by a network of grants, new investigative centers, and congressional committees that brought physicians into public policy positions.\textsuperscript{23}

Chapter VII, the first chapter in Part II, examines the rise of a massive diabetes research and healthcare industry that created and supported the careers of many new doctors and researchers. The research enterprise that emerged during the mid-twentieth century, which was funded and supported by healthcare companies and by the U.S. government, brought physicians and scientists together with businessmen and legislators to create fellowships, research centers, and lobbyist positions that brought money and attention to the issue of diabetes and pregnancy. During the 1950s and 1960s, diabetic pregnancy research became a central feature of a growing diabetes industry, bringing scientific interest to the condition of glycosuria of pregnancy. This chapter traces the convoluted paths that research monies followed, using government documents, interviews, committee publications, and institutional publications to demonstrate the deep connections that grew out of those funding efforts.


Chapter VIII argues that an examination of the actual process that reframed the condition of glycosuria of pregnancy – or pre-diabetes of pregnancy – demonstrates the influential role that the state has gained in defining health and illness. Historians of medicine have oft argued that social context influences how diseases are defined and created. This chapter expands that lens by examining instead how the process of creating gestational diabetes conversely shaped the social meaning of the disease in important ways. The creation of gestational diabetes occurred within the bifurcated system of social welfare policy, which mattered for how the disease and its patients became understood.  

During the 1980s, an increasing number of women being diagnosed with the “new” disease received their healthcare through government-subsidized programs for the poor. Efforts to open access to care for those women embedded the language of federal policies into the definition of the disease. Medical recommendations for diagnosing and treating gestational diabetes were worded to mirror the eligibility text of federally-supported programs for the poor like Medicaid and Aid to Families of Dependent Children (AFDC).

Physicians and researchers realized that disease creation was influenced increasingly less by scientific endeavor and more by public policies in the post-World War II environment of connections between medicine, business, and the state. In fact, the


disparity associated with gestational diabetes, from unequal access to care to a disproportionate incidence of health problems for minority women, cannot even be understood without attention to this historical context.
CHAPTER II

PART I: DIABETIC IDENTITY IN THE TWENTIETH CENTURY

The discovery of insulin in a small laboratory at the University of Toronto during the summer of 1921 has been hailed as one of the greatest miracles of modern medicine. Indeed, insulin saved the lives of countless diabetics and transformed physician-turned-researcher Fred Banting into an instant celebrity in medical circles around the world. But “discovery” is a misleading description. Several prominent scientists across the globe had already succeeded in isolating the mysterious secretion of the pancreas. Georg Ludwig Zuelzer in Germany, Ernest Lyman Scott in the United States, the biochemist Israel Kleiner, and the Romanian physiologist Nicolae Paulescu, all had managed to isolate the extract and had demonstrated its effectiveness in dissipating urinary sugar in diabetics well before the Toronto work.¹ Moreover, far from being the miracle cure that media reports portrayed, insulin quickly became a double-edged sword. In fact, it did not cure the dread disease at all; rather, insulin “transmuted” diabetes into a chronic illness, which was difficult to manage and rife with ancillary health problems.²

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Understanding this historical misperception of diabetes and of the impact of insulin is necessary in order to contextualize how, later in the twentieth century, physicians would redefine a condition in pregnant women that had long been depicted as a diabetes mimic. What was called glycosuria of pregnancy early in the twentieth century would become the disease gestational diabetes later in the century. Described in the early decades of the insulin era as transient and relatively benign, it would by 1980 become a disease that garnered significant federal fiscal support for research and attained formal recognition within and without the medical community through its addition to the World Health Organization’s international disease coding manual, the ICD-9. While the actual mechanics of how gestational diabetes was redefined and the specific details of how it became formalized in the healthcare market constitute Part II of this dissertation, Part I addresses the scientific, medical, business, and social elements that together created the context within which that process would play out.

The privileging of insulin as the pivotal event that transformed diabetes has resulted in a misunderstanding of the historical forces that played important roles in shaping the social understanding of the disease and its patients – both before insulin and after. Most scholars today recognize disease and health as concepts that have been socially and culturally constructed, dependent on time and place for their meanings. Yet scientific discovery still too often monopolizes the narrative. Such a focus has caused scholars to neglect a shift during the late nineteenth and early twentieth centuries from

conceptualizing illness as a solid, perceptible break from good health caused by a trigger – an insult, an injury, a germ – to seeing illness and health as relative states along a continuum, with “homeostasis” somewhere in the middle. It is an important shift, not to be overlooked or minimized in this history. Leading up to the “discovery” of insulin, the scientific and medical understandings of diabetes had already begun to change. By the mid-1800s, scientists had begun to think of diabetes as a perfect example of the relativity of health versus illness. They recognized that even though some level of sugar must remain in the blood to support life, extremes at either end represented illness and in between lay a large, grey area between normal and pathological. The experiments and writings of these scientists – like Claude Bernard, Thomas Addison, and Charles Brown-Sequard – contributed to greater knowledge of human physiology at a time when biochemists were finding new ways to identify and measure the constituents of bodily fluids.

In addition to the scientific and medical environment that gave physicians and researchers a new lens through which to understand the myriad systems of our bodies, healthcare in the early twentieth century was a fledgling consumer market that likewise

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4 Garabed Eknoyan, “History: Emergence of the Concept of Endocrine Function and Endocrinology,” *Advances in Chronic Kidney Disease* 11, 4 (October 2004): 371-376; and Georges Canguilhem, “Claude Bernard and Experimental Pathology,” in *The Normal and the Pathological*, transl. Carolyn R. Fawcett (Brooklyn, NY: Zone Books, 1989), 65-90. Bernard coined the term homeostasis to explain the body’s natural tendency to return to a set state. He used the condition of diabetes to demonstrate the idea that health and illness existed along a continuum in which drawing a clear line of distinction was difficult, if not impossible.

5 Canguilhem, *The Normal and the Pathological*. Canguilhem examined the impact of nineteenth-century scientists like Bernard in the ideological shift from an infectious disease model to a chronic disease model in medicine.

shaped the public perception of diseases like diabetes. And patients labeled with a chronic illness, rather than one of the many infectious diseases ceding to medical advances like vaccinations, took on a whole new assortment of social definitions. Costly diseases like diabetes stratified these new patient-consumers by their purchasing power, or lack thereof.\(^7\) Gender also became a dividing line for treating patients, for prioritizing their needs, and for identifying that gray area between healthy and ill.\(^8\)


CHAPTER III  
“IT IS TRULY MIRACULOUS”  
INSULIN AND THE TRANSFORMATION OF DIABETES

On September 24, 1922, Elizabeth Evans Hughes, daughter of then U.S. Secretary of State and eventual Supreme Court Chief Justice Charles Evans Hughes, wrote to her mother from Toronto, “I look entirely different everybody says … gaining every hour it seems to me in strength and weight … it is truly miraculous.”¹ In August of that year, the young Hughes had been taken to Dr. Frederick Banting in Toronto with the hope that a newly discovered treatment for diabetes – insulin – might save her life. Elizabeth Hughes turned fifteen within a few days of her arrival in Toronto yet she was so weak from the effects of diabetes that she could barely walk, and at five feet tall, she weighed only forty-five pounds.²

As Elizabeth Hughes left for her miraculous trip to Toronto, a major shift began in the way that physicians and the general public understood diabetes and in the way that diabetics experienced their disease. At the beginning of the century, diabetes was

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¹ Michael Bliss, The Discovery of Insulin (Chicago: The University of Chicago Press, 1982), 154; quotation from Elizabeth Hughes to her mother, September 24, 1922, Elizabeth Hughes Gossett Correspondence, Fisher Library, University of Toronto.

² In 1922, the new diabetes treatment was actually called isletin; the name change to insulin would occur after production moved to the Indianapolis-based firm of Eli Lilly and Company. On Elizabeth Hughes’s condition when she arrived in Toronto, see Bliss, Discovery, 43-44 and 152-153, and “Mr. Hughes’s Daughter Ill, Taken to Toronto by her Mother for Special Treatment,” New York Times, 18 August 1922, Special Edition, 3.
considered a relatively uncommon disease. With an acute onset and often rapidly lethal outcome, it was believed to be a disease that struck mostly young, white children. By mid-century, however, diabetes was conceptualized in a very different way. The disease would be understood instead as a chronic illness that afflicted a much broader cross-section of society and that was believed to pose the potential for great public expense.

Scientific discovery and increased medical knowledge certainly played important roles in the twentieth century transformation of diabetes, as the introduction of insulin therapy dramatically changed the trajectory of the disease. But the discovery of insulin was not the magical, pivotal event that our historical memory has assigned to it. As with most medical advances, the “discovery” of insulin actually involved a long process of accumulating knowledge that progressed in fits and starts. Moreover, its impact reached beyond simply treating the symptoms of a disease, as it became the cornerstone of one of the first major healthcare markets in the United States.

The privileging of insulin as the pivotal force or moment in a sharply reconfigured disease has emanated, to a great degree, from the vestiges of an old “professional history” edict in studies of medicine and disease. Although the “great men” and “great events” stories told by older, male physicians of years past has given way within the field to complex and nuanced narratives which are more appropriately situated on a broader canvas of social history, studies on medicine and disease still do not attract many historians without a medical degree or some type of scientific training.³ For

³ See, for example, works by William Osler, The Evolution of Modern Medicine: A Series of Lectures Delivered at Yale University on the Silliman Foundation in 1913, http://www.gutenberg.org/files/1566/1566-h/1566-h.htm (accessed August 1, 2012); Harvey Cushing, The
historical works on diabetes, a limited set of scholars has resulted in a dearth of studies overall.

The new insulin therapy indeed catalyzed a significant transformation in the disease during the decades between its discovery in 1921 and the mid-century mark. Perhaps most important, the new extract immediately altered the very course of the disease (insofar as what physicians understood diabetes to be in 1921) by staving off the almost certain death sentence that had previously come with diagnosis. And, as insulin brought increased attention to diabetes, its prevalence rose in tandem with a greater awareness of the disease and of its early symptoms, particularly with the variant that doctors of that time period referred to as mild diabetes, but now call adult-onset or Type 2 diabetes.

Such a narrow focus on insulin in the literature, however, has resulted in the neglect of important social elements that also factored into the transformation of diabetes. For example, diabetic patients became consumers of diabetes care and found their lives defined and stratified to a great degree by their purchasing power within that market. That development, within a political and economic climate that brought American physicians and researchers into business complexes and federal policy roles, contributed significantly to the rapid increase in public concern about the disease. As diabetes shifted from a fatal illness to a chronic and costly disease, new ideas emerged about the personal

responsibility of diabetic patients to “manage” their disease in order to prevent costly health complications that might be borne by public structures.

Insulin became the foundation of an expansive diabetes healthcare market, which was nurtured by the growing connections between medicine, business, and the federal government during the first half of the twentieth century. Changes in how the medical community and the general public understood diabetes, and related changes in the lives of diabetic patients, were intimately connected to the emergence of this consumer market. Efforts by physicians, businesses, and policy makers to inform Americans of new medical and scientific ideas about diabetes contributed to the changing social definition of the disease and to the popular perception of its patients. Public discourse by physicians and policy makers on the growing fiscal concerns associated with diabetes, for instance, created a general fear of the disease and its patients, a concern that seemed at times out of proportion to the actual impact of diabetes. As well, the public and private controls on supply, pricing, and access to insulin were under constant pressure, as participants within that market negotiated for any amount of leverage.

This chapter examines the broad transformation of diabetes and diabetic patients in the first half of the twentieth century through the articles that physicians published in their medical journals and the textbooks and self-help books that they wrote for their colleagues and patients; through the actuarial data sets and government committee reports tracking the anticipated fiscal impact of diabetes; and through the popular media stories and the letters and voices of patients and caregivers who encountered the dread disease.
The Long Road to “Discovery”

The introduction of insulin therapy in the early twentieth century changed the trajectory of a diabetes diagnosis for millions, but a long road of inquiry and research had paved the way for the “discovery” of insulin in 1921. Even though diabetes had gone for centuries without any viable therapeutic options, physicians and scientists had long been interested in the disease. Known references to diabetes date back as far as 1550 BC with the Ebers papyrus, an Egyptian document of medical treatments. For the three thousand years leading up to the discovery of insulin, however, very little progress had occurred in terms of treatment. The lack of success in treating the disease likely played a role in dimming our historical recognition of the scientific work that presaged the Toronto research of the 1920s. During the pre-insulin era, doctors who encountered a suspected case of diabetes usually documented the familiar symptoms of extreme hunger, insatiable thirst, and excessive urination but then could do nothing more than simply wait for the patient’s demise to confirm the diagnosis of diabetes. By the mid-eighteenth century, the presence of sugar in the urine had become the key diagnostic criterion, assessed either by the attraction of ants to the patient’s urine or by the less palatable “taste test” and, eventually, by chemical urine tests. Yet nothing succeeded in commuting the death sentence associated with the disease.

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4 The Ebers Papyrus is an ancient Egyptian scroll that documented symptoms and treatments for many illnesses. The document was purchased by collector George Ebers in 1873. A summary of the sections that are believed to relate to diabetes (based on the 1913 translation by Walter Wreszinski) can be accessed and downloaded in .pdf version online at: http://biology.bard.edu/ferguson/course/bio407/Carpenter_et_al_(1998).pdf (accessed June 23, 2010).

5 The sweetness of diabetic urine had actually been mentioned in various medical writings since before the Middle Ages, but more specific accounts would not appear until the seventeenth and eighteenth
While attempted treatments varied widely across time and space, the course of the illness continued unabated. New treatment strategies arose and then fell into disfavor and, unfortunately, patients continued to die. Even with immense scientific interest in diabetes, researchers vacillated on their theories about the etiology of the disease. Theories ranged from an infectious agent to some sort of organ failure. Well into the nineteenth century, doctors and researchers believed that diabetes was a disease of the kidneys because of its distinctive urinary symptoms. Only when they shifted their attention away from the kidneys did they begin to look for an internal secretion to explain the source of the disease—a secretion believed to be one of the newly discovered hormones that scientists had identified as internal regulators of our daily functioning.

6 Several general works on diabetes history exist but the body of literature is small. Although scientific knowledge of the illness dates back as much as three centuries, much of the scholarship portrays diabetes as a modern disease. Any history of the disease is necessarily entwined with its great twentieth-century transformation brought about by the discovery of insulin. As such, scientific understanding, medical treatment, and increasing prevalence are all twentieth-century developments. Historiographically, I see the scholarship as dividing roughly into antiquity, the pre-insulin era, and the insulin era. I would fix these temporal demarcations at approximately 1550 BCE to 1800 CE, 1800 to 1921, and 1921 to the present. For a brief summary of advances in treatment and diagnostics, see Lee J. Sanders, “From Thebes to Toronto and the 21st Century: An Incredible Journey,” *Diabetes Spectrum* 15, 1 (Winter 2002): 56-60, and Anthony, “The Evolution of Diabetes Knowledge.” For a very detailed chronology of diabetes advances in the United States during the twentieth century, see James Wright Presley, “A History of Diabetes Mellitus in the United States, 1880-1990” (Ph.D. diss., University of Texas at Austin, 1991), and, with more of a focus on Type 2 diabetes, see Aaron Mauck, “Managing Care: The History of Diabetes Management in Twentieth Century America,” (Ph.D. diss., Harvard University, 2010).

7 In the mid-1800s, French physiologist Claude Bernard produced evidence that multiple organs were involved in glucose regulation inside the body. Bernard examined normal and diabetic physiology to disprove the “one organ/one function” idea that had long been the rationale in medical treatments. While
The realization that a connection existed between diabetes and a small, greenish organ adhered to the side of the stomach – the pancreas – initiated the search for a mysterious internal substance that turned the food we ate into usable fuel for our bodies. Two discoveries directed attention toward the pancreas in the search for that substance. One of those discoveries came from a German medical student, Paul Langerhans. In 1869, Langerhans discovered that the pancreas actually contained not one but two types of cells, the acini, which were known to secrete acidic digestive juices, as well as a second set of smaller cells which were embedded like little islands or clusters within groups of acini cells. Although Langerhans himself never figured out the function of this second set of cells, scientists by the end of the nineteenth century would focus on these “islets of Langerhans” after a second discovery turned their attention toward the pancreas.

Roughly twenty years after Langerhans had found those small islands of cells in the pancreas, Oskar Minkowski and Joseph von Mering made an inadvertent discovery in their research work on digestion. After removing the pancreas of a dog to demonstrate the primary importance of the small organ in digestion, the pair encountered an unanticipated result: the dog awoke from surgery showing the tell-tale signs of diabetes, including extreme thirst and frequent urination. Then, sugar appeared in the dog’s urine, he was the first to isolate glucose in the blood and to clarify much about the specific metabolic features of diabetes, Bernard’s work on glucose regulation also initiated an intense scientific search for “internal secretions” or hormones as regulators of many metabolic processes. Moreover, Bernard used his work on glucose and diabetes to demonstrate that science was subject to interpretation, pointing out that it was difficult to distinguish when the “normal” process of glucose metabolism became the “diseased” process of diabetes. For a discussion of Bernard’s work and his contributions, see Georges Canguilhem, The Normal and the Pathological, Studies in the History of Modern Science, trans. Carolyn R. Fawcett (Boston: D. Reidel Publishing Co., 1978), 65-90.
and finally, the dog fell into a coma and died. Repeat experiments produced the same result. Removing the dog’s pancreas resulted in the rapid onset of severe diabetes.\textsuperscript{8} By the end of the nineteenth century, with the discoveries of Langerhans and of Minkowski and von Mering to guide them, scientists began to look in earnest for an elusive internal secretion of the pancreas believed to be missing in diabetes patients. The experiments by Minkowski and von Mering had turned their attention toward the pancreas, and Langerhans’s discovery had pointed toward specific cells within the pancreas.\textsuperscript{9}

The search for an internal secretion to explain the cause of diabetes was also born from excitement over new interpretations of older, Renaissance ideas that an “internal balance of humors” controlled bodily fluids, which in turn maintained good health and function. In the 1860s, French physiologist Claude Bernard began to call this system of balance within the body the \textit{milieu interieur}. And by the 1930s, Walter Cannon, a physiologist at Harvard Medical School, expanded Bernard’s work into a theoretical concept on the functioning of balance and regulation inside our bodies, which he called \textit{homeostasis}. Homeostasis, Cannon explained, kept the pH of our bodies at a constant, maintained our core temperature within a narrow range, and provided a system of internally produced fluids to maintain vital levels of sugar in our bloodstream. Scientists had begun to call these regulatory fluids hormones by the early twentieth century and the fluids were viewed as essential to the proper functioning of the human body. Despite their inability to isolate or even see many of them, early-twentieth century physicians and

\textsuperscript{8} Bliss, \textit{Discovery}, 25-30.

\textsuperscript{9} Sanders, “From Thebes to Toronto,” and Anthony, “The Evolution of Diabetes Knowledge.”
scientists tried to create concoctions from the ground-up organs and glands from which the fluids seemed to emerge, hoping to capture the important extracts.\textsuperscript{10}

Without a name for the mysterious secretion of the pancreas, researchers the world over tried to isolate the substance for decades prior to the group in Toronto producing their injectable serum to treat diabetes. Few narratives on the discovery of insulin acknowledge the work of those prior researchers. Nor do they acknowledge the social forces which influenced the emergence of new scientific ideologies guiding research efforts of the era. In \textit{The Discovery of Insulin}, however, Michael Bliss brought to light the successes of some of these previous researchers, such as the Romanian physiologist Nicolae Paulescu. Bliss has suggested that the work of scientists like Paulescu received little to no acclaim, while the Toronto research team’s similar work quickly garnered recognition, because of differences in the contemporary state of technology and in the accompanying political environment. Paulescu had results just as dramatic as the Toronto researchers but lacked the technology to analyze or purify the experimental serum. Moreover, publication and dissemination of his work was halted

with the outbreak of World War I, and being quite the vocal anti-Semite, Paulescu met with resistance for any level of acceptance within the European and North American scientific communities.\textsuperscript{11}

In the lead-up to the work that came out of Toronto, treatments for diabetes continued to fluctuate along with scientific theories on the cause and course of the illness. As physicians understood the role of acid balance in the body and recognized the presence of acidosis (a dangerous drop in blood pH) in diabetic patients, treatment focused on feeding patients alkaline substances to neutralize the pH shift. Sodium bicarbonate became a standard part of the treatment arsenal. In addition, opium treatment lasted well into the twentieth century for a long list of ailments, diabetes included, because the narcotic reduced patients’ discomfort. Not surprisingly, dietary treatments abounded as well. Dietary treatments, however, were originally based on the notion that patients needed calorie replenishment to forestall the rapid weight loss – a fatal mistake for diabetic patients who were unable to process any but the smallest bits of food. Once that error was recognized, calorie restriction was found to be a more effective remedy.\textsuperscript{12}

No matter what type of treatment was pursued during the pre-insulin era, the prognosis for diabetic patients remained poor. Families watched their loved ones succumb either to the disease itself or, by the late nineteenth century, to the starvation diet that was the only known treatment to extend life for a few short months or, for a

\textsuperscript{11} Bliss, \textit{Discovery}, 20-44.

\textsuperscript{12} Bliss, \textit{Discovery}, 33-44. The foremost proponent of calorie and carbohydrate restriction was Frederick Allen. Allen would become known for a treatment that his colleagues called “the starvation diet.” For the details of his treatment methods, see Frederick M. Allen, \textit{Total Dietary Regulation in the Treatment of Diabetes} (New York: The Rockefeller Institute for Medical Research, 1919).
fortunate few, maybe a year. Even for those adults who presented with a mild case of the disease, the battle may have drawn out longer but still ended with blindness, kidney failure, and rampant infections that resulted in amputations of toes, feet, or whole legs. The children and few adults who developed the severe form of the disease were struck with incredible swiftness and ferocity, many losing their lives within days or weeks. They first developed thirst and hunger while losing weight rapidly and urinating frequently. The shift in blood pH that occurred with the ensuing metabolic failure in severe diabetes, what today is called diabetic ketoacidosis, was usually the immediate cause of death. It was a disturbing death that began with nausea and vomiting and ended with convulsions, a rattled breathing called Kussmaul respirations, and then coma and death.

Dr. Elliott Joslin, a leading expert in diabetes during the first half of the twentieth century, lamented that before insulin most diabetic children died in less than a year even with the best medical management. The only “treatment” that extended their lives at all was the undernutrition of a starvation diet, which often “was permitted by the despairing parents simply for the hope set before them that someone would discover something which might save their child.”13 At the beginning of the twentieth century, as physicians and researchers made huge strides in conquering infectious diseases through vaccinations

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and sanitary practices, Joslin explained that diabetes care had “undergone no essential alteration.”

Even during the first years when insulin therapy became available, coma from ketoacidosis remained the most prevalent cause of death for diabetics. In 1922, the year that insulin became available on a limited experimental basis, Dr. Joslin had eight children die at his clinic in Boston, all eight from diabetic coma. Toward the end of the 1920s, insulin became available commercially, and by that time, nearly all of Joslin’s patients had started insulin therapy, virtually eliminating diabetic acidosis and coma as causes of death.

As the insulin era progressed, as diabetes became a disease of chronic complications, lifespans for these patients remained shortened and complicating health problems like “coronary” quickly replaced diabetic coma as the predominant cause of death for diabetics. In fact, about a decade after insulin therapy was introduced, a 1934 editorial in the *New England Journal of Medicine* suggested to its readers that sparing diabetics from coma with insulin simply changed the cause of death. The author asked if diabetics would now die instead from stroke, heart attack, or some other representation of poor control of their health. Even though the “so often hopeless” affliction was manageable with insulin, it had become a chronic disease and many physicians felt it still

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15 These numbers are taken from a hand-written chart by Dr. Elliott Joslin titled, “Causes of Death in Children Reported Aug 1922 to June 1944,” Carton 2, Folder 14, Priscilla White Papers, Schlesinger Library, Harvard University.

remained dangerous. “Survival” would come with life-long difficulties and potentially serious and expensive complications.17

_Diabetes in the 1920s_

During the 1920s, insulin became widely hailed as proof of the progress of modern medicine. Within the confines of medicine, the transformation of diabetes served as sufficient evidence of that progress, even if by the 1930s physicians’ enthusiasm for insulin’s success would wane. For the general public, however, the transformation of diabetes involved more than a scientific discovery or a medical advance. The life-saving effect of insulin therapy had changed the medical approach to diabetes, but the marketing of insulin had shaped a broader and more public set of ideas about diabetes and about the patients living with it. Outside the medical community, as diabetes was increasingly seen as a disease of debilitating medical problems and great public expense, ideas about responsible health behaviors began to develop. Newspapers and popular magazines presented the new image of diabetes as a disease of cost and complications. The new insulin therapy could alter the deadly course of diabetes for many, but the treatment was expensive and its supply was limited.18

Insulin quickly became the foundation of an enormous market for diabetes healthcare at a time when physicians, pharmaceutical companies, and policy makers were building new connections. In their concerted efforts to curb the fiscal toll that they

17 Allan, “Diabetes before and after Insulin,” 267.
believed chronic diseases and poor health could take on the nation, a new force of
government-employed epidemiologists and actuarial statisticians for insurance companies
began studying and explaining the monetary impact of disease. From lost workdays due
to illness to the need for charity or government-subsidized care for lower-income
patients, chronic diseases like diabetes replaced contagions like yellow fever and
tuberculosis as the biggest impending threats to the health of the nation’s workforce. ¹⁹

Tracing the changes in both medical and popular ideas about diabetes within the
context of an expanding consumer market for insulin illuminates important shifts in the
emerging beliefs and social perceptions about the disease and its patients. A growing
public fear of diabetes arose in large part from beliefs that the associated health
complications placed a multitude of hidden costs on public structures. With insulin
rerouting its course, diabetes became one of the newly feared chronic diseases. Insulin
therapy was an expensive commodity for which demand sharply outpaced its availability.
Diabetics found that they were increasingly expected to take on responsibility for
managing their disease, and they found that ensuing health complications were often
attributed to their own personal neglect instead of to the disease process. The popular
media amplified these fears among their readership with stories about the “unknown
diabetic,” suggesting the possibility that a huge number of people were walking around

Harley Warner, Therapeutic Perspective: Medical Practice, Knowledge, and Identity in America, 1820-
with diabetes while somewhat irresponsibly unaware of the health complications that were developing.

Insulin was certainly a major catalyst for these new beliefs, ideas, and perceptions about the disease and its patients. The contemporary understanding of the disease also played a role in how public ideas developed. The medical understanding of diabetes was quite different in the early 1920s, when insulin appeared on the scene, than our current set of ideas. Today, physicians view diabetes as two diseases: Type 1, which has an acute onset of great severity caused by a complete failure of internal insulin production, and Type 2, which usually begins with a mild presentation and very subtle, fleeting symptoms that can take years to be recognized because insulin is still being produced as its effectiveness decreases. By contrast, in the 1920s, diabetes was generally viewed as a single disease with varying levels of severity. The most severe cases usually began in childhood and the more mild cases in adulthood.²⁰ Physicians’ views on diabetes shaped the way they presented information about the disease to the media and to the public. By presenting diabetes as a single disease, attributes that might be specific to only one type of the disease – rapid accumulation of urinary sugar for Type 1 or the beneficial effect of diet and weight loss for Type 2 – were incorporated into a broad misunderstanding of the potential outcomes and of the effective interventions for diabetic patients. For example, in a landmark study on the prevalence and outcomes of diabetes that was published in

1898, Elliott Joslin and a collaborator reviewed all cases of diabetes at the Massachusetts General Hospital over a seventy-four year period but did not distinguish between types or severity in their findings. In their comprehensive study, diabetes was simply diabetes. All outcomes, from recovery to amputations and to death by coma, were presented as potential effects for anyone who encountered the disease.\textsuperscript{21}

With the predominant scientific concept of diabetes as a single disease, the discovery of insulin initially seemed to solve the riddle of what caused the disease. At that time, most scientists believed that an internal lack of the hormone caused diabetes and that some individuals were simply lucky not to have lost all of their insulin production. While that idea is not far from the current understanding of how diabetes develops, insulin would eventually complicate that early theory because the treatment worked miracles for severe diabetic patients but not for mild cases. In many of the mild cases, no injected amount of the hormone seemed to work. While that realization would bring scientists and physicians to develop new concepts about the disease, its variants, and its patients, in the 1920s it resulted in a confused portrayal of the transformed disease to the public.\textsuperscript{22} A complete or near-complete lack of insulin would eventually become

\textsuperscript{21} Fitz and Joslin, “Diabetes Mellitus,” 165-171.

the hallmark feature of only one form of diabetes, the severe form. An inability to utilize insulin despite an apparent abundance of it came to define the mild form. For the general public, however, insulin “cured” diabetics … unless they in some way did not comply with doctors’ orders.\textsuperscript{23}

The realization that insulin was frequently ineffective for the mild type of diabetes would serve to reinforce ideas about (and confusion over) the social characteristics that were beginning to be associated with that form of the illness. Certain social characteristics, like obesity and a sedentary lifestyle, were understood by the 1920s to be factors that aggravated the mild presentation of diabetes. Many patients who presented with the mild form of the disease were overweight, and weight loss through special diets almost always cleared up the symptom of urinary sugar in those patients. The fact that the hallmark diabetes symptom of urinary sugar was modifiable through changes in health behaviors brought physicians early on to criticize the mild diabetic whose disease progressed. In addition, the connection between weight loss and clearing of urinary sugar

led to the misconception that poor diet, overweight, and obesity caused diabetes. In 1924, for example, physician Haven Emerson claimed that the mild form of diabetes was increasing in the United States because Americans were “the grossest feeders … dying of overeating.”\(^{24}\) The editors of the magazine *Science* told readers that diabetes was on the rise and diabetics suffered complications because of “the dietary excesses practiced by the American people.”\(^{25}\) Elliott Joslin warned that those who were overweight or obese and continued to ignore the recommendations of their doctors were killing themselves, that death and debility from diabetes would be their “penalty of obesity.”\(^{26}\) As evidence of his assertion, Joslin even went so far as to proclaim that the Jew was prone to diabetes “because he is fat.”\(^{27}\)

Into the early decades of the twentieth century, diabetes was believed to be more prevalent in whites, to have a higher incidence in urban areas, and to be increasing rapidly among higher-income earners.\(^{28}\) That perception, which is so different from our current understanding, emanated in large part from the types of patients seen by physicians of that era. People who were poor, non-white, or lived in a rural location were

\(^{24}\) Haven Emerson, “Sweetness is Death,” 24.


less likely to be diagnosed with diabetes, or with any non-infectious illness for that matter, because of their limited access to even the most basic health care.

At least with contagious illnesses, patients with marginal access to healthcare could often gain some level of treatment, if for no other reason than the fear that they could infect others. Diabetics, however, were not contagious and they were increasingly seen as responsible to some degree for the public impact of their poor health outcomes. The contemporary image of diabetes on the eve of insulin was reflected in the standard medical training and reference manual of the time, Osler and McCrae’s *The Principles and Practice of Medicine*. The widely-used textbook shaped its recommendations to an upper-class type of patient. Diabetics should live in an “equable climate,” make use of Turkish baths, and have frequent massages – therapies typically not accessible to lower-income, rural, or non-white patients.29

During the twentieth century, the social address of diabetes would shift.30 Early in the century, when descriptive statistics of those affected by such diseases were largely limited by matters of who presented for medical care (or in the case of actuarial summaries, by who purchased life insurance), diabetes was seen most often in middle-to-upper-class homes, and it struck the children in those homes with a certain aggressiveness. Regardless of the various faults or disparities associated with public health programs for the poor and the uninsured today, the mere creation of such programs


fundamentally changed our understanding of the prevalence of non-infectious, chronic diseases across the socio-economic strata.\textsuperscript{31} In the early decades of the twentieth century, however, lower-income patients who encountered diabetes usually found themselves left out of the miracle of survival. As Boston diabetes physician Elliott Joslin noted, “It is the uneducated, untrained, uncare for child in a family with limited resources who is lost.”\textsuperscript{32}

The small handful of North American physicians who received insulin during the latter months of 1922 for treatment trials with patients in their clinics would continue to present this particular social address for diabetes in the way they reported on their trials.\textsuperscript{33} The *Journal of the American Medical Association* and the *Journal of Metabolic Research* published the results from that first experimental distribution, and their articles included photographs of patients before and after insulin therapy. These before-and-after photographs both informed and reflected the contemporary public image of diabetes as a disease transformed by modern medicine.\textsuperscript{34} However, although the dramatic photographs intended simply to put the medical transformation of diabetes on display, they also identified the medical community’s perception of the social address of these early insulin

\begin{thebibliography}{99}
\bibitem{33} There is some disagreement in the literature on who received the initial batches of experimental insulin, but the number was very small. Based on the articles published in the *Journal of the American Medical Association* and in the *Journal of Metabolic Research* on those first trials, it seems that at least ten diabetologists received insulin directly from either Toronto or Lilly in that first distribution. See Bliss, *Discovery*, 148-151; and Steven Gabbe, “Pregnancy in Women with Diabetes Mellitus: The Beginning,” *Clinics in Perinatology* 20 (1993): 508-509.
\bibitem{34} “Mr. Hughes’s Daughter Ill,” *New York Times*. 
\end{thebibliography}
consumers by featuring well-to-do white patients. As Lisa Cartwright and others have argued, medical images displayed for public consumption represent scientific as well as social facets of their subjects. Hence, these medical images of diabetic patients presented a particular social element seen in the definitions of many diseases: class and race.

Historian Keith Wailoo has explained as well in his study on sickle cell anemia, an illness particularly associated with African Americans, “The ways in which diseases are defined, characterized, and dramatized provide a window on social relations and social values.”

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35 Lisa Cartwright, Screening the Body: Tracing Medicine’s Visual Culture (Minneapolis: University of Minnesota Press, 1995). Cartwright explained that while medical images (including medical films, photographs, x-rays, and more) have specific and often very narrow meanings to the physicians who view them, they depict more than just the subjects of the images. Cartwright argued that these images reflect contemporary medical culture as well as the relationship of the lay public to the medical community. Also see Keith Wailoo, Dying in the City of Blues: Sickle Cell Anemia and the Politics of Race and Health (Chapel Hill: The University of North Carolina Press, 2001), 2.
Figure 1. Before and after photos of insulin patient. Copyright 1923 American Medical Association. All rights reserved. Reprinted, with permission, from the Journal of the American Medical Association.

The pictures elicited reactions of shock and wonderment as the world met Billy Leroy, the three-year-old patient of Dr. Ralph Major. A set of two photographs, a before-and-after complement, presented the remarkable outcome of three months of treatment with insulin. The physical changes in the young boy were nothing but spectacular. The first picture showed the emaciated child crying in his mother’s arms as she stood gazing directly into the camera, clad in a dress of high quality fabric and detailed trim. In the accompanying “after insulin” photograph, the young, white patient looked healthy and chubby-faced, dressed in his class-conscious sailor suit.36 Although the articles on these

first trials with insulin therapy were printed in strictly medical publications, they were picked up by the popular media in widely-read publications like *Time* magazine and the *New York Times* newspaper, thus transporting these presentations of diabetic patients to the general public.37

Tracing insulin’s quick leap from discovery to market offers a new perspective on what historians of medicine refer to as the social construction of disease. While Charles Rosenberg brought attention to the need for historians to examine the social context of disease, the formation of a consumer identity for patients has typically not been part of that examination.38 Yet the introduction of insulin therapy was not just a medical event. Almost immediately from its discovery, insulin became an important commodity in a rapidly expanding healthcare market. As such, insulin quickly created a consumer

The special issue of the *Journal of Metabolic Research* was officially recorded as the November 1922 issue but was not published and distributed until the late spring of 1923. The most often cited paper from that issue is H. Rawle Geyelin, George Harrop, Marjorie F. Murray, and Eugenia Corwin, “The Use of Insulin in Juvenile Diabetes,” *Journal of Metabolic Research*, 2 (1922): 767-791.


identity for diabetic patients. Just as people took on consumer identities in other markets, diabetics took on identities as patient-consumers in a growing diabetes market as well.

Despite the broad recognition that social and cultural elements factor significantly in contemporary definitions of diseases and patients, this relationship of insulin’s marketing to changes in popular conceptions of the disease and its patients has received surprisingly little attention. The neglect of this aspect of diabetes history is likely bound up in the hesitancy among scholars to equate a person’s “patient-hood” with a consumer identity, particularly when that identity includes pejorative elements. As historian Nancy Tomes has so deftly explained, “The language of consumerism seems to endorse a market logic that many contemporaries find disturbing when applied to doctor-patient relationships.”39 With many medical advances, social forces worked in tandem with scientific developments to shape the trajectory of events, and such was the case for insulin.

A new definition of diabetes emerged from the medical impact of insulin and from the social impact of its marketing at a time when American medicine was in the midst of an enormous transformation itself. Physicians organized themselves with the construction of professional societies to implement controls over the education and credentialing of their peers; the federal government collaborated with philanthropic associations to review the nation’s healthcare facilities and to draft measures to move control of hospitals out of the hands of churches and local aid societies; physician groups

such as the American Medical Association (AMA) began to press for salary subsidies and federal fiscal support of medical education; and government agencies were created to regulate the production and sale of healthcare products in order to protect the public from unscrupulous businessmen and questionable treatments.40

The growing connections between American physicians, government agencies, and businesses during the first half of the twentieth century formed the bedrock of a nascent healthcare market within the United States. The developing American healthcare market quickly became grounded in the paradigm of risk factor ideology, and medicine in the United States emerged as a powerful force in the everyday lives of the nation’s people. By promoting such measures as the implementation of sanitation practices and the monitoring of the health of the nation’s populace, the AMA and other physician groups came to play key roles in weaving healthcare issues into public policy. The broadening influence of physicians in conveying scientific and medical information would come to play a significant role in creating public interest in diabetes as well.

From Discovery to Market

Popular accounts of diabetes history invariably cite 1921 as that pivotal moment in time when insulin was “discovered,” the scientific understanding of diabetes was transformed, and the medical approach to treating diabetic patients was forever changed. The usual storyline has Dr. Frederick Banting awakening from a dream in which he had a vision of how to isolate a mysterious substance from the acidic environment of the

40 Starr, Social Transformation of American Medicine, 198-232; and Duffy, The Sanitarians, 240-254.
pancreas without destroying it, thus, allowing doctors to capture it and turn it into a life-saving treatment for diabetes. The substance was thought to be one of the many hormones inside the human body. By 1921, most scientists believed that the substance was secreted by the pancreas: a small, greenish, fleshy organ nestled beside the stomach. The story continues that Banting engaged the help of several researchers at the University of Toronto during the summer of 1921 and produced an injectable “cure” for diabetes by winter. Not surprisingly, the actual chain of events was much more complicated.

Throughout the summer and fall of 1921, Banting and two colleagues, Charles Best and J. Bertram Collip, worked in a small, under-funded lab at the University of Toronto practicing experimental treatments for diabetes on whatever groups of stray dogs they could round up. They made the dogs diabetic by removing their pancreases and then tried to cure the dogs by injecting concoctions from ground-up parts of those organs. They used the surgically-removed pancreases of the research dogs at first but quickly moved on to acquiring the organs of cows and pigs from local slaughterhouses because of the large quantities they needed to produce a serum. In spite of tremendous conflict among the group, replete with arguments, fist fights, and relentless threats over secret recipes for their new pancreatic serum, the university’s administration contracted with Toronto’s Connaught Laboratories to help the team purify their serum, increase its production, and attempt treatment in human subjects.41

When they made the leap from keeping a lab dog, Marjorie, alive for seventy days to injecting their experimental extract into the buttocks of public ward patient Leonard

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41 Bliss, Discovery, 129.
Thompson, the Toronto researchers put into play what has been called the greatest miracle of modern medicine. By the end of 1921, the team’s incredible successes in the research lab had brought them to the proposition of the first human trial. In January, they selected a fifteen-year-old boy who was dying in the public ward of the Toronto General Hospital to be given injections of the experimental extract. Thus, Leonard Thompson became the first person saved by insulin. The initial injections, on January 11, 1922, had little clinical effect, but a second set of injections with a new batch of serum on Monday morning, January 23, produced incredible results. By the week’s end, Leonard Thompson was very much alive.42

News of the Toronto group’s new serum to treat diabetes swept headlines throughout the spring and summer of 1922. With their daughter Elizabeth nearing death, Antoinette and Charles Evans Hughes hastily arranged for a trip to Toronto. Until that point, the prominent diabetologist, Dr. Frederick Allen, had been treating young Elizabeth. As the severity of her diabetes increased and her health deteriorated, Allen placed his patient on a starvation diet. The diet forestalled her impending death by limiting the toxic effect of rising levels of sugar in her blood, the result of diabetes preventing Elizabeth’s body from metabolizing the food she ate. By the time she left for Toronto, the severity of her diabetes had reduced her manageable diet down to an average of 405 calories per day along with several days of complete fasting. The diet treatment had kept the young girl alive for three years, an incredible result by any means, but

42 Bliss, Discovery, 111-113 and 120-121. The earliest reference to insulin as “the greatest miracle of modern medicine” that I have found, called isletin at the time, came from an editorial letter written by Elliott Joslin in the Spring of 1922; see Elliott P. Joslin, “Pancreatic Extract in the Treatment of Diabetes,” Boston Medical and Surgical Journal 186, 19 (May 11, 1922): 654.
Elizabeth Hughes paid a high price for those three years. At fifteen years old, she was a semi-invalid. Her life revolved around a horrible diet, with the fasting days “a special nightmare.” In August of 1922, as Elizabeth Hughes was reaching adolescence, a time when she should have been growing taller and stronger, when she should have been entering puberty, she had instead lost nearly half of her body weight and could barely walk. By the end of that year, however, insulin had saved her life.43

As news of the miracle treatment for diabetes spread throughout the medical community, Danish researcher August Krogh came to Toronto to request access to the new treatment. Krogh was a Nobel Prize-winning physiologist whose wife had recently developed diabetes, and he came to request permission to manufacture insulin himself. The Toronto group approved his request, and in collaboration with a prominent Danish physician, Krogh established a laboratory which eventually became one of Europe’s leading pharmaceutical companies, Novo Nordisk. In less than a year, through the work of Krogh and Dr. Hans Christian Hagedorn, insulin became available for sale to European patients.44


44 Available online at: http://nobelprize.org/nobel_prizes/medicine/laureates/1920/krogh-bio.html (accessed October 20, 2010). The physician that Krogh paired with, H.C. Hagedorn, later developed a new insulin formulation with a longer action and fewer allergic reactions for its users. There is disagreement in the literature as to whether Krogh’s wife, Marie, had developed Type 1 or Type 2 diabetes, but given the
Insulin changed the lives of thousands of people; indeed, the new treatment saved lives. Examples of dramatic recoveries like those of Marie Krogh, of Elizabeth Evans Hughes, and of Leonard Thompson certainly demonstrate how quickly insulin altered the medical definition of diabetes. In fact, as one young intern at the Toronto General Hospital during those years wrote later, “After 1922 the chapter on diabetes in every textbook had to be rewritten.” The new extract changed the prognosis, the treatment, and the course of the disease.

With the commodification of the new treatment, however, a unique consumer identity developed for diabetic patients – one that conflated an inability to participate in the emerging consumer market with irresponsible health behaviors. Diabetic patients found themselves transformed into insulin consumers nearly overnight. Insulin was not a cure, but rather a life-long treatment, and its price became a complicated matter for diabetics, insulin manufacturers, physicians, and the general public. An inability to afford insulin had a direct, negative impact on a diabetic patient’s health. The mounting health complications that could follow became seen as a reflection of personal negligence and as a potential burden on society rather than as a reflection of an imbalanced market.

This new populace of insulin consumers emerged toward the end of the Progressive Era in what historian Lizabeth Cohen has called the “first-wave consumer movement.” During a time dominated by the power of business, Cohen explains that these “first-wave” consumer identities were largely shaped by the amount of market

symptomology and the need for insulin therapy, it seems most likely that Marie Krogh had developed Type 1 diabetes and that her life was in jeopardy.

participation individuals could gain. Unlike Cohen’s “citizen-consumers” that emerged later, during the New Deal and post-World War II eras, these “proto-consumers” of the earlier decades of the twentieth century did not experience the same political inclusiveness and personal agency afforded by the purchasing power that later consumers held. 46 Many of these new insulin consumers struggled to afford the only treatment available. Those who experienced a repeated inability to participate in the new market economy found that their identity as diabetic patients was shaped by a critical assessment of their roles as undesirable consumers in the diabetes marketplace. And just when manufacturing of the new diabetes treatment was on the verge of taking a favorable course, with the output of insulin manufacturing rising and production costs beginning to drop, the Great Depression would again place the treatment out of reach for many. 47

Ironically, just as insulin brought survival to many diabetics, their encounters with the complexity and cost of treatment and with the looming risk of debilitating complications made for a difficult lifestyle. The complexity of the treatment regimen, the general confusion between the specifics of the two forms of diabetes, the direct and indirect costs of the disease, the host of related debilities, and the mounting evidence that changes in some health behaviors helped, all created an ideology that diabetic consumers

had to take personal responsibility for their disease and that they were in some way accountable for the problems that ensued. 48

As severe diabetics shifted from struggling with a deadly disease to living with a life-long malady, they adapted to a regimented schedule of multiple daily injections and complicated chemical self-testing of urine samples. Even though insulin treatment replaced the extreme starvation diets of the pre-insulin era, diabetics still had to maintain a strict diet because diet therapy did not become obsolete for either type of diabetes, severe or mild. Along with the laboratory set-up in their bathrooms, diabetics’ kitchens became stations for weighing and measuring all foods and liquids. In addition, patients and physicians quickly realized that insulin therapy was not a simple formula. Normal variations in bodily functions, coupled with irregularities in the strength of new batches of insulin, made patients’ physical responses unpredictable and dangerous – an issue that remains problematic even today. Injected insulin did not act in the exact same fashion as a non-diabetic person’s naturally-produced insulin, and diet still had to be managed around insulin therapy. Too little insulin left an excess of sugar in the blood stream and urine, slowly poisoning organ systems over time; too much insulin, sometimes in an amount as small as the head of a pin, could result in a near complete lack of sugar in the blood stream, followed by convulsions, unconsciousness, and even death. Diabetic patients could not live at their doctors’ offices, however, and so they had to learn to

48 In a very interesting take on the concept of “management” for diabetes treatments, Aaron Mauck examined the different meanings that physicians had for the term. Mauck suggests that the ideas of management and control in diabetes care were intensely debated issues throughout the twentieth century but particularly at mid-century when new treatments and new technologies for monitoring the disease divided physicians over the amount of control that was possible and what was actually necessary; see Mauck, “Managing Care,” 245-303.
manage the new treatment, the new dietary restrictions, and the growing list of unexpected issues on their own.

Along with these unexpected lifestyle changes and the inherent dangers of insulin therapy, diabetes became an incredibly costly disease as insulin prices rose dramatically during the 1920s. During those first years when insulin therapy became available, diabetics could expect to pay $1.20 per day or more, a cost that today would be the equivalent of at least $20 to $37.49 Although the daily cost would fluctuate somewhat, it would continue to increase throughout the 1920s. While these new diabetic consumers were directly confronted with the tremendous cost of insulin, the popular media indirectly brought insulin’s financial impact into the homes of the reading public as well. In 1922, for example, the New York Times’ end-of-year listings of needy families highlighted one story, “Breadwinner Dying.” The family had three children between the ages of eight and fifteen and the mother, “the only one in the family capable of earning a living,” had to spend all of her time caring for her husband, who was dying from diabetes. They

49 The calculation of $20 per day is based on a simple rate of inflation calculator, a representative example of which is available at: http://www.coinnews.net/tools/cpi-inflation-calculator/ (accessed June 28, 2011). For the estimate of $37 per day, I have used the work of Christopher Rutty combined with data on individual salaries from the US Census Bureau. See Christopher J. Rutty, “‘Couldn’t Live Without It’: Diabetes, the Costs of Innovation and the Price of Insulin in Canada, 1922-1984,” Canadian Bulletin of Medical History 25, 2 (2008): 410-412; and U.S. Census Bureau, Table 700, Median Income of People in Constant (2008) Dollars by Sex, Race, and Hispanic Origin: 1990-2008 in “Income, Expenditures, Poverty, and Wealth,” Statistical Abstract of the United States: 2011, 457, http://www.census.gov/compendia/statab/2011/tables/11s0700.pdf (accessed June 28, 2011). Rutty found that average annual salary also needed to be considered in these calculations rather than simply a direct conversion by rate of inflation since the cost of insulin in the early 1920s equaled nearly half of an individual’s weekly salary. Using the data in the U.S. census, the average annual income from Table 700 for all races is $33,161 for males and $20,867 for females, or $27,014 for both sexes ($74.21/day, half of which is $37). Rutty’s calculation set the converted average daily cost of 1922 prices for 2006 at about $120 Canadian/day, which converts to approximately $113 USD/day. Rutty based his estimates on an insulin dosing schedule of 100 units/day, which may be a bit high (see Table 1, p. 418). Other methods available for calculating price changes give estimates that reach as high as $55 per day, but the lowest estimates reached have been used here.
could not afford insulin. In 1922, the case was the paper’s first diabetic listing in the column, “New Neediest Cases.” By the end of the decade, however, similar cases packed the column and instructed the reading public on the fiscal impact of diabetes.\(^50\)

In the decades following the discovery of insulin, the medical community and the general public increasingly came to expect diabetics to take personal responsibility for the management of their illness. These new ideas about diabetes were often voiced in a language that spoke of control, management, and responsibility.\(^51\) Less than a decade into the insulin era, the language of patient responsibility could be seen in a new type of publication in the field of diabetes – self-help books for diabetics. Because the diabetic was “his own nurse, doctor’s assistant, and chemist,” physicians began to write texts on diabetes treatment for the non-medical public.\(^52\) The preface of one of the time period’s most influential and best-selling self-help books, *The Diabetic Life*, instructed diabetics to practice “intelligent co-operation” and “accept the diabetic creed” in order to lead a “normal life.” The author, Dr. Robin D. Lawrence, was a well-known diabetes physician. He insisted that patients follow a prescribed diet that matched with their insulin injections rather than dosing their insulin to meet their eating choices. Allowing patients to eat what they preferred was a “slip-shod” method because “anyone can fatten a diabetic with insulin.” Lawrence recounted an anecdote about two female patients who died because


\(^{51}\) Mauck, “Managing Care.”

they “refused to control their diet” despite warnings from doctors. Not only were their deaths reflective of negligent behavior, “The use of insulin in this way is naturally expensive.”

As early as 1922, diabetes physician Elliott Joslin had begun to speak a similar language of patient responsibility, telling physicians that if they advised their patients on a diabetic regimen, the patient with complications could only be “compelled to say, ‘Doctor … you are not to blame for my present condition.’” It was a language that Joslin would propagate through books and pamphlets similar to Lawrence’s Diabetic Life. In 1937, in A Diabetic Manual for Mutual Use of Doctor and Patient, Joslin hailed the benefit of insulin for helping diabetics to manage their disease responsibly. But, he warned, failure to manage their disease responsibly was no longer a private matter because “the public is watching.” In the next edition, which came out only four years later, Joslin increased his warning to diabetics on the potential for public scrutiny if they failed to manage their care. Joslin added that “carelessness” and “indiscretions” harmed

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53 Robin D. Lawrence, The Diabetic Life, Its Control by Diet and Insulin: A Concise Practical Manual for Practitioners and Patients, 3rd edition (Philadelphia: P. Blakiston’s Son & Co., 1927), vi-vii and 64-65. Dr. Lawrence was diabetic. Diagnosed in 1923, insulin saved his life. Lawrence also became the architect of the first lay diabetes organization when he asked his famous patient, H.G. Wells, to write an appeal to the British public for financial donations to assist with research funding and with the formation of the Diabetic Association in England in 1933. The Diabetic Association, which became the British Diabetic Association to avoid confusion with other organizations, began its Quarterly Diabetic Journal in 1934. See Pressley, History, 392-393.


other diabetics as well by creating a poor public image that could even make it difficult for diabetics in general “to get jobs and keep them.”\textsuperscript{56}

In concert with messages from the medical community about accountability, ongoing problems with access to insulin also helped to shape ideas about what constituted personal responsibility for diabetics in managing their disease. Even before the full-fledged marketing of insulin began, access to it was unequal. Requests for insulin flooded into the Toronto lab after every presentation, research paper, or news story. However, the supposedly standard reply that the new serum still needed testing and refinement was not uniformly applied.\textsuperscript{57} Some of those initial requests came from physicians of prominent and influential families. For example, a physician from Rochester, New York, Dr. John Williams, who was treating the son of James Havens, Sr., a prominent lawyer and vice-president of Eastman Kodak Company, pulled strings to secure insulin. Jim Havens became the first U.S. patient treated with the new pancreatic extract from Toronto. One of the co-discoverers of insulin, Frederick Banting, went to Rochester himself and then had insulin delivered regularly by train to the Havens’ physician. The senior Havens reportedly paid substantial bribes to customs officials to ensure delivery of the extract.\textsuperscript{58} Limited access to insulin therapy made compliance with

\textsuperscript{56} Elliott P. Joslin, \textit{A Diabetic Manual for the Mutual Use of Doctor and Patient}, 7\textsuperscript{th} edition (Philadelphia: Lea & Febiger, 1941), 3.

\textsuperscript{57} Bliss, \textit{Discovery}, 143-144.

\textsuperscript{58} Bliss, \textit{Discovery}, 135-137. Several anecdotes within the diabetes community, as well as several articles, mention a nurse in Boston who was a patient of Joslin’s, Miss Elizabeth Mudge, as being the first American patient. But Mudge began insulin treatment in August; Havens began treatment in May. See also, Feudtner, \textit{Bittersweet}, 89-90; and Steven G. Gabbe, “Pregnancy in Women with Diabetes Mellitus: The Beginning,” \textit{Clinics in Perinatology: Diabetes in Pregnancy} 20, 3 (1993): 507-515.
doctors’ orders difficult, and the handling of requests for the drug illustrates that even though diabetics were expected to take responsibility for their disease, the ability to manage it was often hampered by factors outside of their control.

By the end of the 1920s, although each new vial of insulin had less variability, the issue of access would linger. For example, even those who could actually afford the cost of insulin still needed a physician with access to the new drug. In the early decades of the twentieth century, patients rarely got medications by simply walking into a drug store with a prescription in hand. The U.S. pharmaceutical firm, Eli Lilly and Company, had gained partial patent rights for insulin and distributed it directly to physicians, who then distributed it to their patients. Doctors with a supply of insulin remained a very select group, as did their patients. For one major hospital in New York City, the two thousand units of insulin they received each week barely covered 1 percent of their cases and the hospital had to convene a committee to decide on matters of distribution.

While unequal access to insulin continued to frustrate and frighten diabetics and their families, it also frustrated clinicians who could not acquire the new drug, and drove some to levy intense public criticism for what they saw as professional elitism. George Clowes, the director of research and the supervising chemist for insulin production at Eli Lilly, frequently discussed accusations of an “insulin aristocracy” in his letters and

59 The Committee on the Costs of Medical Care, in its assessment of rural health care, found that as much as 86 percent of medications were dispensed to patients directly from their physicians; see Committee on the Costs of Medical Care, “Inadequacies of Our Medical System, Portrayed in Survey of Rural Vermont,” (1933), 5, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1658442/ (accessed October 30, 2010).

memos, and tried to use the brewing conflict to persuade the Toronto team to allow Lilly to move “as rapidly as possible toward very widespread production.”

The cost of insulin stratified diabetic patients, which effectively erected a substantial barrier to any expansion of their consumer identities into the larger healthcare market that was developing in the United States. That limited consumer identity significantly influenced social perceptions about diabetic patients. The inability to afford insulin, for example, resulted in many lower-income patients being perceived as neglectful of the management of their disease. The pervasiveness of such ideas can be seen in the approach of insurance companies to diabetic customers. Until 1940, diabetics were universally ineligible for life insurance. By the 1950s, some group insurance policies became available, but at much higher premiums for diabetic customers. As historian Jeremy Greene has noted, “Once labeled as diabetics, patients found themselves ineligible for life insurance and were charged double premiums for health insurance.”

The inability of diabetic patients to extend their consumer identities into the broader U.S. healthcare market, such as into the market economy for insurance, would become an increasingly important topic in lay diabetes publications as the century progressed.

Concurrently, the medical understanding of diabetes progressed so rapidly in those first decades of the insulin era that efforts to incorporate new information into the
evolving definitions of the disease resulted in a progression of confusing naming rubrics. Throughout the 1920s and 1930s, physicians tried to convey new scientific discoveries about diabetes to their colleagues and to the general public. What began centuries before as simply “diabetes” moved through a series of delineative labels for physicians: severe versus mild, thin versus obese, insulin dependent versus non-insulin dependent, juvenile versus adult-onset, pancreatic versus insulin-resistant, Type 1 versus Type 2. The chaotic litany of labels reflected the difficulty that physicians faced in staying on top of such rapid changes in the scientific as well as social understanding of diabetes.

The medical community’s differentiation between types of diabetes in professional articles and in their public comments became more common as insulin revealed differences between severe and mild presentations. But the general public’s understanding lagged behind. That confusion emanated in large part from portrayals of the disease in newspapers and popular magazines, which continued to group all information under a single label: diabetes. A New York Times article that reported on the death rate for diabetes extolled the paper’s use of the most recent medical information and actuarial data. Yet the article mixed together different symptoms and causes for each form of the disease into a singular description. Even as the article included a clarification from the Metropolitan Life Insurance Company, which stated that a previous article by the paper had incorrectly implied that insulin was useless instead of explaining that it was helpful only for a particular form of the disease, the article again blurred details on the rise of the milder, adult, diet-controlled form of the disease with the severe, juvenile, insulin dependent form. The paper quoted Metropolitan Life’s disclaimer, “Insulin has
been a great benefit in prolonging the life of young diabetics,” yet broadly posited that insulin still “cannot control the increase of diabetes.”

As physicians continued their efforts to inform the public about diabetes with the most up-to-date information possible, the reporting of healthcare statistics became an important activity in their efforts. The source and compilation of those statistics played a significant role in shaping the message conveyed. The first comprehensive attempts to describe disease epidemiology were based on data from the actuarial tables created by insurance companies. Large insurance companies, such as Metropolitan Life, undertook the task of creating actuarial tables (a method of illustrating the probability of death or disability for individuals and groups) to assess risk investment and to develop health interventions that might extend the life span of policyholders. Of course, then and now, longer life spans for policyholders meant better fiscal outcomes for a life insurance company.

While the adoption of actuarial science by life insurance companies did not dictate public opinion, the ways in which these companies used the information certainly

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64 “Toll of Diabetes Is Rising Rapidly,” *New York Times*, 22 June 1929, 9. Also reporting on the same set of data from 1929, and likewise conflating symptoms and outcomes, was the Science News section of the popular magazine, *Science*. See “Prevalence of Diabetes,” *Science* 69, 1800 (June 28, 1929): x-xi. Another typical example of the conflation of the two main forms of diabetes into a single entity stated, “We know what brings on the symptoms of diabetes, namely, a deficient secretion of certain cells of the pancreas.” Without explaining that insulin deficiency was the hallmark feature of “severe” or “juvenile” diabetes, the guest author, a physician, then continued to confuse readers further by implicating diet and obesity, without specifying that those were important factors in “mild” or “adult-onset” diabetes. See Irving S. Cutter, “Mortality Rates from Diabetes Now Going Up,” *The Washington Post*, 23 August 1935, 15. In 1923, *The Saturday Evening Post* presented the disease to its readers as “diabetes” and summarily lumped all symptoms and presentations into that single-word label. In those early years after the discovery of insulin, confusing reports were not uncommon. Even into the 1940s, however, popular magazines continued the same presentation to its readers. See, for example, Woods Hutchison, “Clearing the Skies for the Sugar-Poisoned,” *The Saturday Evening Post*, 9 June 1923, 20-22, 146, and 149; and Steven M. Spencer, “What You Should Know about Diabetes,” *The Saturday Evening Post*, 15 May 1948, 40-41, 71-72, 74, and 79.
Actuarial tables created the foundation for an ideology of risk factor identification, where non-symptomatic individuals could be assigned a disease label based on their statistical potential for developing a frank case of an illness. In addition, companies like Metropolitan Life fed their interpretations of actuarial data to the media, to the medical community, and to policy makers. At the turn of the century, the Metropolitan Life Insurance Company began publication of its annual newsletter, *The Statistical Bulletin*. The *Bulletin* listed the prevalence and incidence of a variety of diseases as well as other calculations on health in the United States. The data presented in the *Bulletin*, however, came from limited sources: information on life insurance policy holders and, later, from local death certificates as well. Although the addition of death certificates brought the analyses up to a more sophisticated level, the information was still subject to the inherent bias of limited data sources in a newly developing but rapidly expanding market for medical care and for healthcare products.

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65 Greene, *Prescribing by Numbers*, v-ix and 1-17. Greene discusses the rise of epidemiology and biostatistics, arguing that pharmaceutical companies, life insurance companies, policy makers, and health outcomes researchers all began mid-century to use statistics and large data sets to define disease and its precursors numerically rather than symptomatically.

66 For a more detailed discussion on the rise of actuarial science within the life insurance industry and the role of organizations such as The Metropolitan Life Insurance Company in shaping the use of actuarial and epidemiological data, see Amanda M. Czerniawski, “From Average to Ideal: The Evolution of the Height and Weight Table in the United States, 1836-1943,” *Social Science History* 31, 2 (Summer 2007): 273-296. Also, for a discussion of the political forces in the 1920s and 1930s that produced the movement for prepaid health care, see Robert Cunningham III and Robert M. Cunningham Jr., *The Blues: A History of the Blue Cross and Blue Shield System* (DeKalb: Northern Illinois University Press, 1997). Interestingly, Metropolitan Life held no monopoly on health statistics during that era. Hospitals and university-based clinical practices began self-reporting of patient demographics and treatment outcomes at roughly the same time that Metropolitan Life’s *Bulletin* began its run. As early as 1914, Dr. Ernst Codman published the seminal work arguing for accurate and complete statistical measurements in medicine. Codman emphasized that simple reporting of outcomes, such as the numbers of patients treated and the types of surgeries performed, was meaningless and perhaps even misleading without some measure of the effectiveness of treatments. Further, Codman pushed for standardization of reporting statistics to allow
Metropolitan Life’s actuarial tables became the bible of health statistics. The popular media anxiously anticipated the release of the *Bulletin* each year. Even clinicians awaited Met Life’s numbers; Elliott Joslin remarked that Metropolitan Life “furnished practically all the statistical data I ever quote.” The fact that these statistics were skewed because they were based on limited data sources did not stop the media from confidently presenting the reports for public consumption. For example, as early as 1923, *Time* magazine printed an article titled “Medicine: War on Diabetes” and summarized statistics on diabetes from the *Bulletin*. Diabetes mortality was on the rise, the article explained. At that early date of 1923, the disease was particularly prevalent in the big urban centers like New York, with a higher incidence among whites. Rates were “lowest in the southern and western states, largely because Negroes are less susceptible than whites.” Between 1921 and 1939, the identified diabetic population expanded, and researchers for Metropolitan Life predicted a continued and rapid escalation through the 1940s. By the end of the 1930s, in fact, the U.S. Public Health Service (USPHS) had begun using Metropolitan Life’s predictions in reports to Congress, warning of an estimated five hundred thousand or more diabetics in the United States.

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Conclusion

In 1921, a discovery in a Toronto laboratory forever changed the trajectory of diabetes for millions. Insulin lifted the death sentence and, subsequently, transformed long-held scientific and medical ideas about the disease. The new diabetes treatment also became the foundation of an expansive new healthcare market, quickly shaping public ideas about diabetes and diabetic patients in ways that science and medicine had not. Changes in social perceptions of diabetics, as well as the more tangible changes in the daily lives of these patients-turned-healthcare consumers, were intimately connected to the emergence of this consumer market.

As diabetes became a chronic disease of debilitating health issues and of the potential for great public expense, ideas about responsible health behaviors emerged. Physicians, businesses, and policy makers informed Americans about growing fiscal concerns with diabetes, and diabetic patients were increasingly seen as personally accountable for managing their diabetes. With insulin therapy, diabetics began to live into adulthood but those longer lifespans allowed the complications of chronic diabetes to

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Probably adding to the perception that diabetes was more prevalent in whites, the data for the USPHS report came from the first National Health Survey, and the life tables created from that data were for white males and females in 1935. Louis Israel Dublin, lead statistician and eventual vice-president of Metropolitan Life Insurance Company, also looked at race as a factor in diabetes outcomes and in other social aspects of medicine. See Louis I. Dublin, "The Problem of Negro Health as Revealed by Vital Statistics," *Journal of Negro Education*, 6 (1937): 268-75. Dublin was a Jewish immigrant from Kaunas, Lithuania (a Jewish enclave established in the thirteenth century) and purportedly became interested in the demographics of diabetes incidence because of the common depiction of mild diabetes as a “Jewish disease.”
emerge. Complications mounted: heart disease, nerve damage, and kidney disease, to name a few.\footnote{71}

The transformed disease experience for diabetics has been a story of healthcare consumerism, constantly shaped by accommodations to the vagaries of insulin therapy and by the duty of responsible disease management. That “duty” of the diabetic patient-consumer had in fact become an integral part of physicians’ discussions by the 1940s. Elliott Joslin told an audience in 1943 that “responsibility” was essential for diabetics, and elaborated that “if a diabetic is not imbued with the necessity, the desire, and the duty to maintain his health, there is little that a doctor can do for him.”\footnote{72} Despite the complexities of living with diabetes, physicians and patients strove for “happiness and normality in those added years.”\footnote{73} However, as insulin changed diabetes from a fatal illness to a chronic and costly disease, diabetic consumers shouldered a new responsibility in striving for normality: managing their disease and preventing complications for the public good.


\footnote{72} Joslin, “The Diabetic,” 497.

CHAPTER IV

“I HAD TO LEARN HOW TO TAKE CARE OF THEM”¹

PRISCILLA WHITE AND DIABETIC PREGNANCY

In December of 1932, Boston physician Elliott Joslin received a letter from Dr. Edward Johns of Ohio about a mutual patient, Susan Thompson, a nineteen-year-old woman with diabetes who had recently eloped. Undeterred by “the danger of pregnancy in her condition,” Susan had become pregnant, and Dr. Johns wrote to ask Joslin for his opinion on a “therapeutic abortion.” Considering “youth and irresponsibility” insufficient grounds for abortion, Joslin emphatically disagreed. But the pregnancy was aborted anyway. Two years later, Susan Thompson wrote to Dr. Joslin herself. She was pregnant again and she asked him to recommend a different physician in Ohio. With the help of an obstetrician who kept in contact with the Joslin Clinic during the pregnancy, Susan gave birth to a healthy baby by cesarean section delivery in September of 1934.²

¹ Nancy Yanes Hoffman to Priscilla White, July 24, 1977, Letter including draft of manuscript titled, “The Soul and the Carcass: Dr. Priscilla White’s Reflections,” 4, Carton 1, Folder 22, Priscilla White Papers, Schlesinger Library of Radcliffe College, Harvard University.

² The case is discussed in Chris Feudtner, Bittersweet: Diabetes, Insulin, and the Transformation of Illness (Chapel Hill: University of North Carolina Press, 2003), 155-157. Susan Thompson is a pseudonym used by Feudtner; Edward Johns is a pseudonym used by this author. The letters which make up the dialogue between the physician in Ohio and Dr. Joslin in Boston are housed at the Joslin Diabetes Center Historical Archives, Joslin Diabetes Center, Boston, Massachusetts: Local Medical Doctor to Elliott P. Joslin, December 5, 1932; Elliott P. Joslin to Local Medical Doctor, December 8, 1932; Local Medical Doctor to Elliott P. Joslin, January 6, 1933; Elliott P. Joslin to Local Medical Doctor, January 10, 1933; Patient to Elliott P. Joslin, April 18, 1934; Elliott P. Joslin to Patient, April 21, 1934; Local Medical Doctor to Elliott P. Joslin, May 3, 1934; Elliott P. Joslin to Local Medical Doctor, May 7, 1934; and Local Medical Doctor to Elliott P. Joslin, September 30, 1934.
Over the next twenty years, thousands of diabetic women like Susan Thompson refused to acquiesce to the medical advice that they avoid pregnancy or that they end their pregnancies. These women dismissed the course of treatment prescribed by physicians who opposed diabetic pregnancy and instead sought out doctors who would support their desire to have children. Their rejection of that medical advice forced the creation of the specialty field of obstetrical diabetes. While many scholars have assumed that specialization reflects an internal mechanism of the medical profession in response to scientific discoveries and advances, this history suggests that the impetus for specialization has also resulted when physicians ceded to social forces, in this case the pressure of women patients with diabetes who wanted to have children in spite of the potential risks.3

Scholars have described the trajectory for obstetrical diabetes as a process in which medical professionals carved out a specialty field based on their increasing

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expertise with specialized therapies for treating diabetes.\textsuperscript{4} Such interpretations miss the way in which a significant push for the emergence of obstetrical diabetes came from the patients. When diabetic women ignored the advice of their physicians, became pregnant, and refused to terminate their pregnancies, the medical profession was forced to respond. Instead of continuing with strategies to preempt or even halt diabetic pregnancies, physicians were forced to think instead about ways to make such pregnancies successful.

The history of obstetrical diabetes runs counter to the accepted scholarship that portrays specialization as a strictly medical development.\textsuperscript{5} Despite the conception of medical specialization as a uniquely scientific process, social forces played a significant role in its emergence. The pervasive refusal of diabetic women to avoid pregnancy once insulin restored their fertility brought a range of reactions from the medical community, and these women’s continued efforts to conceive played a central role in forcing a change in medical approach.

In addition, this history contradicts the wider historiography on women’s relationship to the medical community and on their struggles regarding access to healthcare. It offers an expanded chronology and a broader definition of women’s agency in this area. Historians have typically assigned a much later date for the changes in healthcare access for women. Dubbed the women’s health movement, scholars have


\textsuperscript{5} Weisz, \textit{Divide and Conquer}; Stevens, “Medical Specialization as American Health Policy”; and Gavrus, “Men of Dreams and Men of Action.”
situated its origins as an integral part of second-wave feminism during the mid-1970s. Diabetic women’s actions during the 1930s and 1940s, though rarely recognized as social or political catalysts for such changes, likely had a significant impact on the trajectory of those events because their actions created a profound shift in the way medical professionals conceptualized their identities as women patients. Moreover, diabetic women formed a collective force even without any visible, structured organization. The diabetic women in this story rarely knew each other, except perhaps for the chance encounter in a clinic setting, and probably had limited awareness of the size and scope of their efforts, yet they pursued pregnancy en masse in the face of intense opposition. Their actions brought attention to the specific health concerns of women in the same fashion—though arguably less visibly—with which second-wave feminist groups like the Boston Women’s Health Collective would be credited nearly four decades later.

The key figure in the creation of the field of obstetrical diabetes was Priscilla White, a physician at the Joslin Diabetes Clinic in Boston, Massachusetts, from 1924 to 1974. White responded to her women patients’ desires to have children by trying to make their pregnancies successful. Her approach came to include strict management of

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7 Boston Women’s Health Collective, *Our Bodies, Ourselves* (New York: Simon and Schuster, 1973); Barbara Ehrenreich and Deirdre English, *Witches, Midwives, and Nurses* (New York: Feminist Press, 1971); idem, *Complaints and Disorders: The Sexual Politics of Illness* New (York: Feminist Press, 1977); and Sheryl Burt Ruzek, *The Women’s Health Movement* (New York: Praeger, 1978). The idea of female agency in the medical encounter gained momentum during the 1970s as historians trained in feminist theory began to pen health narratives. Ehrenreich and English detailed a history of bias and oppression for women, emanating in large part from how women had been defined by their reproductive capacity. Although many of these initial narratives have since been criticized as creating a victimization model for women, such revisionist scholars have not yet set the stage so much earlier.
the pregnant woman’s diabetes, intensive fetal monitoring, and early delivery to avoid late-term complications. White’s approach dramatically decreased maternal deaths and fetal losses at the Joslin Clinic during the 1930s and 1940s. Under White’s direction, maternal deaths dropped by over 90 percent in two decades, and fetal losses were cut in half during the same time frame.8

White began to take on increasingly difficult cases during her career because even women with serious diabetic complications refused to be dissuaded from trying to have children. Instead of discouraging them or insisting on ending their pregnancies, White tried to fashion successful treatment strategies for those cases as well. Her efforts legitimated the field of obstetrical diabetes despite a lack of formal recognition from the American Medical Association (AMA). So successful was White’s therapeutic approach that the White Classification System, as her methods became known, remains the foundation for the field today.

**Pregnancy and the Gendering of Diabetes**

Before diabetes physicians could embrace the idea of a medical field that focused exclusively on their women patients, they had to recognize the ways in which the introduction of insulin therapy had exposed significant differences between their men and

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women patients. Prior to the advent of insulin therapy in the early 1920s, differences between men and women with diabetes commanded little attention. However, as the new treatment changed the disease and reconfigured the lives of those living with it, physicians began to shape their medical approaches and disease management strategies around the social gender roles that diabetic patients acquired as they survived longer and longer with insulin.

Early twentieth century medical approaches to diabetic patients had rarely accounted for these issues of adult life because diabetic children seldom lived beyond those childhood years. Although adults with the mild form of diabetes (now known as adult-onset or Type 2) actually comprised a sizeable portion of the diabetic population before the discovery of insulin, diabetic children were the most visible patients during the pre-insulin era. The face of diabetes remained so young during the pre-insulin era, and for the first few years after the introduction of insulin, partly because the severity with which the disease struck children kept their plight in the public eye. Also adding to the perception of diabetes as more a disease of youth, physicians had a less sensitive threshold for diagnosing adults with diabetes during that same time frame. Adults were not diagnosed nearly as often then because the disease usually presented more slowly and with less visible symptoms than in children, and because urinalysis was generally the diagnostic test used, rather than the more sensitive blood testing used today.

With the introduction of insulin therapy, diabetic children finally began to survive the diagnosis. The boys grew into young men, the girls became women, and both became patients living with a chronic, costly disease that had the potential for serious and
debilitating complications. Scholars have examined how insulin changed the lives of those first generations of insulin patients. The new treatment turned the once acute and fatal diagnosis into a chronic malady; even though insulin saved lives, it left diabetics with a life-long regimen that was difficult to follow and that held no guarantee of a return to good health. Missing from the literature on insulin’s impact, though, is how this transformation of diabetes brought physicians to consider gender in the care of their diabetic patients.9

After the discovery of insulin, pregnancy became the overarching concern with female diabetic patients. During the pre-insulin era, pregnancy had been nearly impossible “due to the inhibitive influence of the disease upon the function of reproduction.”10 Between the impact of the disease and the deleterious side effects of the only treatment that showed success in prolonging life at that time – a starvation diet –

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young girls with diabetes rarely survived into adulthood and those who did found that they became infertile. As one physician explained, “Prior to the discovery of insulin the vast majority of diabetic women were sterile.”

In a most ironic twist, when insulin allowed young girls like U.S. Secretary of State Charles Evans Hughes’s daughter Elizabeth to reach adulthood, to live a full life, and to become pregnant, both physicians and the general public began to conceptualize such women as more rife with problems after insulin than before. The paradox of insulin returning women’s health and fertility, only to expose them to the dangers of a pregnancy in the context of diabetes, created incredible anxiety among physicians. In spite of being warned about the dangers of pregnancy, many diabetic women who were saved by the new insulin treatment attempted pregnancy as soon as they regained their fertility.

Pregnancy quickly became one of the most contentious issues in diabetes care during the early decades of the insulin era. The medical community responded to diabetic women’s attempts at pregnancy with increasingly dogmatic directives. Reflecting the intransigent reactions of some physicians, a 1923 editorial letter in the *British Medical Journal* promoted the free dispersal of insulin to diabetic women in

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12 Elizabeth Hughes would go on to graduate from college and marry a prominent lawyer from Detroit. She became a mother of three children and, eventually, a grandmother. However, she spent the rest of her life hiding her diabetic condition as much as possible. Her husband did not discover that Elizabeth was an insulin-dependent diabetic until shortly before their wedding. See Bliss, *Discovery*, 243-244.

return for an agreement to permanent sterilization. On occasion, diabetic women had actually faced the prospect of pregnancy prior to insulin because those who were diagnosed with the severe form of diabetes in adulthood, or those who had developed the mild form of the disease, may not have lost their fertility immediately. Such cases, however, were extremely rare. While the sick and dying child-patient identity of the young Elizabeth Hughes may have been the classic image of diabetes before 1921, the eventual mother of three children and several grandchildren that she became most certainly was not.

Even as insulin became increasingly available and the results of insulin therapy were hailed as remarkable, many physicians would continue to recommend that “pregnancy should be avoided in women who are suffering from diabetes.” Warning that “we believe that diabetics should not have numerous pregnancies,” physicians at the Joslin Clinic in Boston reported that toxemia and preeclampsia were still as much as fifty times more likely in diabetic pregnancies, and they lamented the only slight drop in stillbirths. At Johns Hopkins Hospital in Baltimore the stance was more emphatic, “From the viewpoint of cold logic, diabetic women should not become pregnant.”

The obstetrician on the faculty of the Joslin Diabetes Clinic, Raymond S. Titus, endorsed caution when encountering pregnancy in a diabetic woman. Throughout his

career, Titus would discuss one of his earliest cases in which a twenty-one-year-old diabetic patient went into labor after a seemingly uneventful pregnancy and quickly developed diabetic ketoacidosis, nearly died, and delivered a stillborn infant after twelve hours of labor. The case, Titus said, affected him so greatly that he then began a standard procedure of delivering the baby by cesarean section as soon as medically feasible.

Former colleagues have said that Titus also sterilized many of those diabetic women at the time of surgery, statements that cannot be verified. Nevertheless, repeated references by Titus and his colleagues to early delivery and to limiting future pregnancies speaks to the prominence of the belief among physicians that pregnancy was contraindicated in diabetic women and to the increasingly forceful reactions by physicians to diabetic women’s pregnancies.¹⁸

Throughout the 1920s and 1930s, in spite of all the obstacles they faced, increasing numbers of diabetic women insisted on trying to become pregnant. Although larger diabetes care centers like the Joslin Clinic in Boston would try to develop some level of expertise in working with these new pregnant diabetics, most physicians remained ill-equipped to manage such cases and were all too aware of the history of dreadful outcomes. The growing divide between diabetic women’s desires and physicians’ fears resulted in progressively public struggles between doctors and their women patients. The nature of these struggles, and the extent to which they spilled over

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into other parts of diabetic women’s lives, were reflected in a series of healthcare encounters for one of Dr. Joslin’s earliest insulin patients, a young woman named Sally for whom life became a constant battle to control personal choices: for dating, marriage, and pregnancy. Sally’s local doctors debated among themselves about the young woman’s maturity, her decisions about marriage, and her adherence to their medical advice. And when she became pregnant, they discussed “[whether] she should be aborted.” With Sally’s first pregnancy, by the time she was referred to be seen by physicians at the Joslin Clinic, she was no longer pregnant or perhaps had not been pregnant at all. With her second pregnancy, Sally refused to abort the pregnancy but the infant was delivered dead. Sally’s third pregnancy ended with a therapeutic abortion recommended by a local physician. Sally never became pregnant again.19

In the 1920s and 1930s, continued fears over a history of tragic failures in diabetic pregnancies shaped physicians’ approaches to their female patients. Yet most physicians found that they could not dissuade diabetic women from becoming pregnant. While expressing great hesitancy, physicians at the Joslin Diabetes Clinic responded to that realization by following the lead of their colleague, Priscilla White. White tried to increase the success rates for the pregnancies of her patients through plans for nurse chaperons, lengthy hospitalizations for direct oversight of the women’s diabetic regimen,

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19 Feudtner, *Bittersweet*, 74-77, quote on 75. Feudtner used pseudonyms for all patients discussed with the exception of James Havens. The letters that contained the ongoing discussions about this patient are housed at the Joslin Diabetes Center Historical Archives: Local Medical Doctor to Elliott P. Joslin, November 17, 1929; Elliott P. Joslin to Local Medical Doctor, November 22, 1929; Elliott P. Joslin to Local Medical Doctor, November 26, 1929; Raymond K. Titus to Elliott P. Joslin, December 10, 1929; Local Medical Doctor to Elliott P. Joslin, July 22, 1932; Alexander Marble to Local Medical Doctor, August 9, 1932; Alexander Marble to Local Medical Doctor, September 8, 1932; and Local Medical Doctor to Elliott P. Joslin, March 6, 1933.
and early delivery so that “good results will accrue.”\textsuperscript{20} As White’s colleague Dr. Donna Younger remembered, the issue of pregnancy created a deep divide between physicians, patients, and even families. When the girls and young women were diagnosed with diabetes, Younger explained, the first concern of the parents was whether their daughter would grow up and be able to have children, “It was amazing, you know, … on the first day you’re learning insulin and on the second day, ‘is she going to be able to have children?’”\textsuperscript{21}

In contrast to the approach of the Joslin Clinic, many physicians elsewhere lacked the same level of expertise, and their patients lacked the financial means to seek out such a high level of care. Some physicians readily promoted therapeutic abortions because they saw no other reasonable options. Joseph DeLee, author of the most commonly cited textbook on obstetrical care for that era, advised that in diabetic pregnancies, “it is best to terminate the pregnancy at once.”\textsuperscript{22} It was a stance that DeLee would firmly maintain for almost a decade after the introduction of insulin therapy, when he conceded that “the treatment of diabetes complicating pregnancy has undergone a complete revolution.” However, while he toned down his emphasis on therapeutic abortion in diabetic

\textsuperscript{20} Feudtner, \textit{Bittersweet}, 182-183; and Elliott P. Joslin to Tracy V., January 12, 1931, and January 20, 1931, Joslin Diabetes Center Historical Archives.

\textsuperscript{21} Younger interview.

\textsuperscript{22} Joseph B. DeLee, \textit{Principles and Practice of Obstetrics} 3\textsuperscript{rd} edition (Philadelphia: W.B. Saunders, 1918), 519.
pregnancies, he still ardently recommended against attempting pregnancy in diabetic women – a view which he never relented on.  

The issues that diabetes physicians connected with their male patients differed rather remarkably. In stark contrast to Sally’s experience with the doctors she encountered, John was a twenty-seven-year-old patient who had a much more pragmatic dialogue with his physicians. In letters to his physicians, John asked questions such as whether his lifespan with diabetes warranted further graduate education, and he discussed the employment difficulties that having diabetes had created for him. In one letter, John explained that during a pre-employment physical he was told that company policy forbade the hiring of diabetics. He asked Dr. White to write on his behalf so as to “make it possible for capable and intelligent diabetics [like himself] to secure jobs in the future.” He included a newspaper article as well, which discussed the possibility of denying diabetics a driver’s license.

Similarly, as Jim Havens continued to work as a print artist and do volunteer work in a parachute factory during World War II, the centrality of work defined both his life and the focus of his clinical care. That focus shaped the way in which his physicians conceptualized his life as a diabetic, determining for example the structure of his diabetes regimen and diet to account for such issues as his “fear of having insulin shock while on the job.”

For Sally, however, the life portrayed in her letters, and later in the letters her

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24 Feudtner, Bittersweet, 184-187.
25 Feudtner, Bittersweet, 59.
mother wrote as Sally’s health deteriorated, the focus continued to be her struggle “to feel as well as most normal people” while negotiating with her physicians for personal control over her choices in life – from whether to get a chest x-ray for tuberculosis screening to deciding on changes in her insulin regimen when, with her current regimen, she believed that she was “getting along all right.”

Men diagnosed with diabetes did not completely escape the struggles over personal control such as those that women patients like Sally experienced. Gerald Cleveland, for example, explained that when he was diagnosed with diabetes in 1932, he “felt that the world kind of dumped in on me.” The strict regimen of shots, diet, and urine testing was rigorous enough even with the help of family, but the societal reactions he experienced were extremely difficult as well. In trying to avoid being “separated out” in school and work whenever his diagnosis was discovered, he felt compelled to hide the disease as much as possible. Likewise, his brother Bob, who had been diagnosed in 1925, said that he hid the diagnosis from his fiancé for fear “she’d back off … just like employers did.”

Although diabetic men occasionally experienced some of the same social constraints and reactions that women did, a preoccupation with the dangers of diabetic pregnancies continually defined the therapeutic approach to diabetic women. That central focus resulted in a markedly different approach to women’s diabetes treatments.

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26 Feudtner, Bittersweet, 77-81.
Physicians even portrayed their women patients differently when discussing the progression of the disease. For example, unpredictable swings in blood sugars affected all diabetics who began insulin, but investigations into the causes of those variations focused almost exclusively on women. What would become known as “brittle diabetes” took on a distinctively female image. Use of the term “brittle” began with physician Rollin Woodyatt in the early 1930s. In his original description, he called his patients with extreme swings between high blood sugars and low blood sugars, who were almost all women, “fragile diabetics.” Later, Woodyatt changed the term to “brittle diabetics.” Brittle diabetes is a term that is still commonly utilized today. Used almost exclusively to describe women with diabetes who have blood sugar patterns that are seemingly difficult to control, it is particularly applied to those women with a history of dangerously low blood sugars. Both then and now, the term also implies a connection between poor diabetic control and mental or emotional instability. In studies to determine if an underlying physiological cause for such poor diabetic control could be identified, women have consistently made up at least three quarters of those subjects given a diagnostic code of “brittle diabetes.” While Woodyatt called the low blood sugar patterns in his women

patients “brittle diabetes,” the same issue in Jim Havens had been discussed as “insulin shock while on the job.”

Because of difficulties with diabetic regimens such as strict diets and unpredictable reactions to insulin, both women and men found that their social experiences became inextricably entwined with their medical encounters. But physician Priscilla White found that women and men described distinctly different experiences with their disease. White received hundreds if not thousands of letters, notes, and cards from her patients. Many of her women patients described a disease experience more personal and more connected to issues of the home and family, and expressed such personal concerns as “My greatest hope is that I don [sic] pass this [disease] to my daughter … maybe she won’t have to worry about this problem” and “I try to behave for the sake of my family now.”

Many of White’s academic and clinical notes from the 1930s and 1940s also demonstrate distinctions in her treatment approaches to men and women patients. Beyond the obvious reproductive differences, she noted other physiological variations and ruminated on the resulting social products. For example, White believed that the stunted growth of diabetics, so pronounced during the early years of the insulin era, took a larger emotional toll on her young male patients, even though the weight gain her female patients often experienced resulted in a host of maladaptive and dangerous

30 Unknown author to Priscilla White, date unknown, Carton 1, Folder 1, Priscilla White Papers, Schlesinger Library, Harvard University.
behaviors in her young girls.\textsuperscript{31} By the end of her career, White completely shifted the focus of her practice by creating the Youth Division of the Joslin Diabetes Foundation so that she could concentrate entirely on what she believed were the contrasting emotional problems of male and female diabetics, including issues of body image and adult social gender roles.\textsuperscript{32}

\textit{Deterring Diabetic Pregnancy}

By the 1930s, medical care for pregnancy had improved significantly here in the United States as well as throughout most of the Western world. Yet diabetic women’s experiences with that care differed remarkably from their non-diabetic counterparts. Rather than the range of medical care regimens and monitoring strategies that non-diabetic women were offered as the century progressed, most diabetic women were discouraged from pursuing pregnancy, and therapeutic abortion was a common recommendation if they presented pregnant.

Pregnancy quickly became a polarizing issue in the medical care of diabetic women who had seen their health improve dramatically with the introduction of insulin therapy. Young girls with diabetes had begun to survive into adulthood with the miracle of insulin. Many of these women found they were finally healthy enough to become pregnant, but most physicians were adamantly opposed to pregnancy in a diabetic

\textsuperscript{31} Nancy Yanes Hoffman to Priscilla White, July 24, 1977, including draft of manuscript, “The Soul and the Carcass: Dr. Priscilla White’s Reflections,” 4, Box 1, Folder 22, Priscilla White Papers, Schlesinger Library, Harvard University; quote was based on an interview by Hoffman of unknown date but most likely during July 1977.

\textsuperscript{32} Nancy Yanes Hoffman to Priscilla White, July 24, 1977, 8.
woman. Non-diabetic women were offered an array of new approaches in pregnancy care, but those were usually withheld from diabetic women. Moreover, as diabetic pregnancies increased, physicians responded by intensifying their efforts to dissuade these women from becoming pregnant, or to terminate a pregnancy as soon as it was discovered.

Despite such widespread opposition to pregnancy in diabetic women, Priscilla White of the Joslin Diabetes Clinic in Boston took a different approach. Instead, White accepted and embraced diabetic women’s desires to have children, and she worked to find ways to make their pregnancies successful. White’s efforts would factor significantly into the rise of a medical specialty field concerned exclusively with diabetic pregnancies, obstetrical diabetes. By mid-century, her work would convince physicians around the world to work toward successful diabetic pregnancies, even if many of them still tried to discourage diabetic women from trying to conceive.

The concept of prenatal care, a type of preventive medical care to detect early signs of problems during a pregnancy, offered many of the guiding principles that undergirded White’s approach. The basic tenets of prenatal care had emerged from the early twentieth-century writings of obstetrician John William Ballantyne.\(^\text{33}\) In his widely acclaimed textbook, Ballantyne posited that “the successful treatment of the unborn

infant must [include the] successful treatment of the pregnant mother.” White recognized the applicability of prenatal care to diabetic pregnancies, though she was actually not the first to see the connection. Johns Hopkins’ obstetrician J. Whitridge Williams had written in 1915 that Ballantyne’s approach offered “great possibilities for the diminution in the number of deaths” in diabetic pregnancies. White, however, was the first to fashion a therapeutic approach to diabetic pregnancies by applying the principles of prenatal care.

By the middle of the twentieth century, prenatal care was widely espoused as the most important step toward avoiding potentially serious problems with pregnancies, like death of the mother or baby, birthing injuries, and low birth weight. Likewise, White presented prenatal care as an important facet of medical monitoring to those few physicians who would take on a pregnant diabetic and to the women who came to the Joslin Clinic. In the waiting rooms at Joslin, women found a pamphlet that lauded the benefit of prenatal care and suggested that the avoidance of such care was negligent. The pamphlet authoritatively stated that prenatal care protected the unborn child from danger by enlightening women about the “harm which a mother may do to her child in the uterus.”

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36 Mrs. Max West, “Prenatal Care,” *Care of Children Series*, No. 1 Bureau Publication No. 4, U.S. Department of Labor, Children’s Bureau (Washington, DC: Government Printing Office, 1913), 20. The first ten pamphlets on prenatal and antenatal care produced by the Children’s Bureau are available from the
Statements in the Children’s Bureau pamphlet that health behaviors like diet were “quite within [a woman’s] control” made it seem an appropriate addition to a waiting room for diabetic women. Diet had been an essential treatment for diabetes in the years leading up to the insulin era and it remained a fundamental piece of the management strategy for diabetic women who wanted to have children in the 1930s. The pamphlet stayed in production for more than a decade and revisions to it over the years increasingly highlighted the role of prenatal care and the role of obstetricians in that care. By 1942, the pamphlet defined prenatal care as “the complete supervision of the pregnant woman [by a doctor] until the baby is born.”

Maternal and Child Health Library of Georgetown University at http://www.mchlibrary.info/history/chbu/parents.html (accessed January 10, 2012). A 1942 version of the pamphlet was in the files of Dr. Priscilla White and marked “Do Not Take” suggesting that the pamphlet was part of the reading material for waiting patients; see “Prenatal Care,” Carton 2, Folder 9, Priscilla White Papers.

37 Ibid.
38 Ibid., 4 and 5.
Even though it was certainly not a conversation limited to diabetic pregnancies, the dialectic that women could harm their unborn children through bad health behaviors and poor food choices had been a growing message in the United States. That message had found its way into the waiting room of the Joslin Clinic through the Children’s Bureau pamphlet. Throughout the first half of the twentieth century, physicians utilized a range of venues, like the Children’s Bureau pamphlet, to convey their recommendations to women patients. Yet obstetricians still struggled to convince pregnant women to follow those recommendations. Physicians from the New York Midwifery Dispensary, for instance, left a trail of comments about such discussions in the medical records that they penned. They expressed their frustration when a “patient refused to obey” or
commented that their “patient [was] dismissed for insubordination.”

They lamented that their efforts were often rejected by the very same pregnant women who had asked them for assistance. Hence, it is important to remember that the struggle over medical authority in pregnancy care was not a new battle for physicians as a whole, or for physicians dealing with diabetic women.

Adding to the difficulties these physicians faced, obstetrical physicians had struggled for credibility since the beginning of the century. Even though technological advances in medicine had significantly decreased maternal mortality by the 1930s, which would bring some level of authority to the field of obstetrics, the congressionally-mandated Flexner Report had dubbed obstetrical practice and education in the United States as “utterly worthless” and even labeled the field a danger to women’s health. By the 1930s, that view had tempered somewhat and nearly every hospital, even those that specialized in diabetes, actually had an obstetrician on faculty.

Throughout the 1930s and 1940s, diabetes physicians would become more public and more fervent in their efforts to convince diabetic women to heed their advice and refrain from trying to have children. They insisted that “pregnancy should be avoided in women who are suffering from diabetes” and their efforts to intercede took many routes,


some preemptive and some responsive.\textsuperscript{41} After the new insulin therapy had so dramatically returned diabetic women’s fertility, physicians openly worried that the new treatment would enable diabetic women to become pregnant “as readily as the non-diabetic,” and others cautioned that because of insulin diabetic women would be “less likely to avoid pregnancy” despite being advised about the dangers.\textsuperscript{42} Diabetic pregnancies did increase with the advent of insulin therapy, but the overall rate of pregnancy actually remained lower for diabetic women than for their non-diabetic counterparts. Even so, the mere idea that women with diabetes might choose to become pregnant fueled physicians’ anxieties.\textsuperscript{43} They responded with a slew of articles in professional journals highlighting the dangers of diabetic pregnancies.\textsuperscript{44}

Physicians shaped a compelling language to dissuade diabetic women from attempting pregnancy by focusing on the potential dangers for the woman with

\textsuperscript{41} Louise McIlroy, Gladys Hill, and E.C. Pillman-Williams, “Diabetes and Pregnancy, with the Record of Seven Cases,” \textit{The Post-Graduate Medical Journal} 6, 70 (July 1931): 161.


diabetes.\textsuperscript{45} So forceful was the language in fact that Dr. Boyd Metzger, a physician-researcher from Northwestern University, recalled, “It should be surprising – no, unbelievable – to think that any woman with diabetes even attempted something portrayed as so dangerous.”\textsuperscript{46} Childbirth, in fact, carried significant risks for women well into the twentieth century, not just for women with diabetes but for all women, and maternal mortality also became one of the targets of obstetricians who promoted prenatal care. Even when maternal death rates began to decrease for women in general, both obstetricians and diabetes physicians would continue to talk about the hazards of pregnancy for diabetic women.\textsuperscript{47}

Almost a decade after insulin was discovered, Dr. Sam Davis, a local medical doctor from northern Massachusetts, wrote Elliott Joslin about a young diabetic patient of his who had presented two months pregnant. Referencing an obstetrical textbook, Dr. Davis said that he favored a therapeutic abortion because of the “startling statistics in

\textsuperscript{45} Hadden, “History of Diabetic Pregnancy,” 3; Coustan, “Diabetes Mellitus,” 698; and J. Whitridge Williams, Obstetrics, 6\textsuperscript{th} ed. (New York: Appleton & Co., 1930), 601. Priscilla White summed up what most physicians of her time feared when dealing with a diabetic pregnancy when she said, “Before insulin, coma was the end-result of the pregnant diabetic. No matter what course was adopted the danger was imminent. Surgical intervention with general anesthesia would precipitate it. Fetal death, which occurred in 50 percent of the cases prior to insulin, was a source of coma. If the patient came successfully to term, labor accompanied by partial starvation and over-exertion would bring it on.” See White, “Diabetes in Pregnancy,” 861.

\textsuperscript{46} Dr. Boyd Metzger, interview with author, October 26, 2009, tape in author’s possession.

\textsuperscript{47} One of the early works to examine this was Edward Shorter, A History of Women’s Bodies (New York: Basic Books, 1983), but Shorter’s suggestion that twentieth-century medical advances rescued women from their bodies ignored women’s own decisions and ignored the impact that women’s decisions and actions in fact had on shaping medical science. As Judith Walzer Leavitt explains, “Women’s biological functions may have led society to try to circumscribe women’s nondomestic activities, but women themselves were not bound by their biological functions.” See Judith Walzer Leavitt, “Under the Shadow of Maternity: American Women’s Responses to Death and Debility Fears in Nineteenth-Century Childbirth,” in Women and Health in America: Historical Readings, 2\textsuperscript{nd} edition, ed. Judith Walzer Leavitt (Madison: The University of Wisconsin Press, 1999), 329.
regard to [maternal] mortality” reported in the text. 48 The text advised physicians to intercede as soon as pregnancy was discovered in a diabetic woman. Interceding meant a “therapeutic abortion.” 49

Davis had written Joslin for a second opinion on his patient’s pregnancy, but based on his assertion that he favored a therapeutic abortion, it would seem that he had already decided on the matter. The need for a second opinion suggests that the woman under his care was not in agreement. The pervasive refusal of diabetic women like Davis’s patient to acquiesce to recommendations for interventions such as therapeutic abortions and sterilizations morphed into a powerful force, with scenarios like this one becoming increasingly common during the 1930s and 1940s. Even without a centralized, collective organization, diabetic women forced the medical profession to seek ways to help them have children safely – simply by refusing to stop trying.

An intense focus on maternal mortality as a reason to discourage diabetic pregnancy became a staple argument for obstetricians during this time period. Such an argument allowed for the prescription of abortion or sterilization as a therapeutic intervention rather than as eugenics. In his late 1920s manual for diabetic patients and general practice doctors, London physician Robin D. Lawrence said that diabetic pregnancies were unadvisable and should be terminated because they could threaten

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48 Feudtner, Bittersweet, 74-77.

49 Joseph B. DeLee, The Principles and Practice of Obstetrics, 4th ed. (Philadelphia: W.B. Saunders, 1924), 543. DeLee unequivocally recommended against pregnancy in diabetic women in the first four editions of his text. Then, in 1928, with the fifth edition, although he did not go so far as to condone diabetic pregnancy, he acknowledged that insulin had revolutionized the treatment potential for diabetes in the context of pregnancy and he removed the wording that a therapeutic abortion be performed as soon as the pregnancy was discovered.
women’s lives. He lamented, however, that he had “to leave the choice to the patient as there are no laws of national eugenics.” Though prescient, Lawrence’s statement only lasted for one edition of his manual.

Many physicians also began to use a language that combined science and memory in their attempts to portray the dangers that women with diabetes could face with pregnancy. Hence, as the language of maternal mortality gained momentum, the discourse came to include “memories” of maternal deaths. Physicians called upon such memories, mostly from the decades before insulin, of tragic deaths and of unsuccessful efforts to prevent “accidents.” For example, Elliott Joslin described a case from the days before insulin in which a pregnant diabetic patient of his, who “had eluded [his] observation,” became sick and was subsequently admitted to the hospital for an emergency delivery. Nearly forty years after the incident, Joslin evoked the memory of that case for his audience, “She died, the baby died, and the husband climbed the hill behind the hospital and shot himself.”

Complications with diabetic pregnancies before insulin thus became an important facet of the language of memory used to discourage such pregnancies after insulin. An 1882 article by London physician J. Matthews Duncan also became an oft-cited example of the potential dangers. Of the fifteen diabetic women that Duncan found in his review

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52 Joslin, “The Diabetic,” 490-491. The article was a printing of Joslin’s lecture, The Second Banting Memorial Lecture, delivered at the University of Toronto on February 22, 1943.
of medical records and anecdotal accounts, he reported that eleven died during pregnancy, delivery, or shortly thereafter. Those fifteen women, however, represented twenty-two pregnancies and perhaps as many as twenty more pregnancies prior to the time frame of his review. The women that Duncan included in his review had apparently been undeterred by the danger of pregnancy espoused by their doctors. Even though Duncan’s report was perhaps less dramatic, his findings resonated with physicians for decades to come. Many twentieth century physicians called upon the memory of those eleven nineteenth-century women who died during or after a diabetic pregnancy to discourage their patients from trying to conceive.\textsuperscript{53}

Not all physicians chose to propagate alarm without clarification, however. J. Whitridge Williams tried to allay the fears of his colleagues who discovered sugar in the urine of their pregnant patients by distinguishing between “true diabetes” and what he considered a bevy of insignificant findings, such as lactose (breast milk sugar) or glycosuria (sugar in the urine) limited to the period of pregnancy only. But in his retrospective analysis, when Williams reported that for the cases of so-called true diabetes, 27 percent of the mothers died immediately and 23 percent more died within two years, he had hardly calmed fears.\textsuperscript{54}


Enter Priscilla White

Priscilla White began her career at the Joslin Diabetes Clinic in Boston within the controversial atmosphere surrounding diabetes and pregnancy. Instead of pursuing ways to intercede in those pregnancies like many of her colleagues who preceded her, White immediately began to seek ways to make pregnancy possible for the diabetic women who came under her care. During the 1930s and 1940s, while many physicians continued to oppose such pregnancies and to debate whether diabetes and pregnancy were completely incompatible, White began documenting the methods and strategies she was employing to achieve successful pregnancies for her patients.

White was born in 1900 and was raised by her single mother, as her physician father left the family when she was young. White would never marry and never have any children of her own. She attended Radcliffe College and then Tufts Medical School, where she graduated at the top of her class. Harvard Medical School did not accept women at the time and, since no hospitals in the greater Boston area accepted women into their residency programs at that time, she did her residency training at Worcester Memorial Hospital about fifty miles west of Boston. She worked as a lab assistant for Elliott Joslin one summer while she was a medical student and then accepted an invitation to join Joslin’s faculty in 1924. She was immediately assigned to work with children and women at the clinic in the early years after the discovery of insulin. As insulin was dramatically changing the course of diabetes, her career unfolded in unexpected ways, and she soon found herself managing diabetic pregnancies with no
precedent from which to plan. “She started at a time,” explained Dr. John Hare, a junior colleague and student of White’s, “when you shouldn’t let a [diabetic] woman get pregnant at all because she might die.”

While many of her contemporaries in the 1930s focused on the dangers of diabetic pregnancies, White quickly set about laying the groundwork for decreasing those dangers. The first principle of therapeutic management espoused by White was that “controlled diabetes is essential to fetal welfare.” She quickly followed by noting that while diabetes did have an impact on pregnancy, that impact was due mainly to changes in insulin sensitivity created by pregnancy hormones. The metabolic changes created by pregnancy hormones, she said, could be managed with modifications in the therapeutic approach to diabetes for each trimester of a woman’s pregnancy. And finally, she made the connection that the duration of a woman’s diabetes adversely affected the outcome of her pregnancy because of the host of diabetes-related complications – mostly vascular lesions – that might have accrued for the woman. That connection became the basis of a classification system for evaluating the risks of and for shaping the approach to a diabetic pregnancy.

White recognized that although insulin quickly eliminated many of the problems of diabetes, it did not immediately solve the complications associated with pregnancy in


56 John W. Hare, interview with author, August 11, 2010, tape in author’s possession.

57 White, “Diabetes in Pregnancy,” 862.
the context of diabetes.58 She systematically evaluated what would amount to more than twenty-three hundred pregnancies over her fifty year career, and she adapted her treatment strategies accordingly. By 1928, only seven years after the discovery of insulin and only three years into her career, she already asserted that for her patients “diabetes is no longer a contraindication to pregnancy.”59

The rapid increase in the numbers of patients that Dr. White took on, in the face of an ample number of detractors, reflected the intensity of diabetic women’s desires to have children and of the collective power of their continued efforts. During the first two decades of the twentieth century, before White came on staff, the Joslin Clinic recorded only 10 diabetic pregnancies. Between 1924 and 1938, White managed the care of 128 pregnancies, and from 1938 to 1958, the numbers surged even higher as White and her staff worked with 900 diabetic pregnancies.60


60 “Pregnancies in Diabetes Mellitus, Joslin Clinic, 1898-1977,” Carton 1, Folder 5, Priscilla White Papers.
In stark contrast to the predominant contemporary opinion that pregnancy and diabetes were incompatible, Priscilla White’s increasing successes with such pregnancies told a different story to women, and they sought out her care in droves. As Donna Younger explained, the pregnancy clinic at Joslin expanded rapidly because women would come from great distances to see White. Physicians would refer their more difficult cases as well, “but there was some resistance to referring their patients …

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61 “Pregnancies in Diabetes Mellitus, Joslin Clinic, 1898-1977,” Carton 1, Folder 5, in Priscilla White Papers. In this handwritten chart, the first column, “Date,” lists six time spans: 1898-1918, 1918-1924, 1924-1938, 1938-1958, 1958-1975, and 1975-1977. The second column, “cases no.,” gives the number of cases of diabetic pregnancies for each time frame. The third column, “Mat surv %,” lists the percent of women surviving pregnancy and is probably an abbreviation for “maternal survival”; the survival rate went up to 99 percent for all periods after 1924. The fourth column, “Fetal surv %,” lists the percent of fetal survival.
because they felt they weren’t getting them back … the women wanted to stay with Dr. White.”

In the days before insulin became available, roughly one third of the Joslin Clinic’s pregnant diabetics died. During White’s tenure, maternal mortality fell to almost zero. Fetal loss dropped quickly as well. Before 1924, the baby died in more than half of the pregnancies. By mid-century, though, 86 percent of Dr. White’s patients gave birth to live infants, and that number rose to 97 percent over the next twenty-five years of White’s career.

From the beginning, Priscilla White’s medical career included roles as both clinician and researcher, and that dichotomy afforded her a unique perspective on the complications of diabetes in pregnancy. Through her research on the make-up of placental blood in diabetic pregnancies, for example, White discovered that the fetus in a diabetic pregnancy was exposed to high concentrations of sugar in the placenta when the mother’s blood sugar was high. In non-diabetic pregnancies, she found, that was not the case. Her immediate response was to translate that finding into clinical practice such that, for her patients, “the treatment of diabetes in pregnancy is along the very same lines as the treatment of diabetes apart from pregnancy,” which meant keeping blood sugars safely as low as possible all the time. To meet that goal, she managed her pregnant patients with smaller doses of insulin given more frequently in order to keep their blood sugar profiles as similar as possible to those of a non-diabetic. That strategy was an incredibly novel approach for the time because the usual approach was a single shot of insulin each day. The purpose of her strategy was to avoid the extremes of high or low

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62 Younger interview.
blood sugars. In another break with traditional recommendations, White encouraged her patients to check urine specimens for sugar frequently, which during the final weeks of pregnancy and especially during labor would be as often as every four hours.\footnote{These recommendations were incredibly time-intensive for Dr. White to teach her patients and were difficult regimens for her patients to follow. Urine testing at the time involved something tantamount to setting up a small chemistry lab in the bathroom with test tubes, chemicals, a Bunsen burner, and collection strips. Home blood glucose monitoring would not become available until the late 1970s, and lab-based blood sugar measurements in a hospital setting were still difficult and time-consuming. See White, “Diabetes in Pregnancy,” 861-872.}

White’s dedication to the women who sought her care played an important role in convincing them to adhere to such difficult diabetes regimens during pregnancy. Other physicians often claimed that women patients could not be convinced to take more than one shot of insulin per day and that they could not be made to check their urine regularly. Colleague Donna Younger recalled, however, that because many of White’s patients came to her with an intense desire to have children, they often made great efforts to follow her advice. While “doctors argued … about whether pregnant women would follow directions,” Younger recalled, “Dr. White’s women, they would take as many injections a day as she told them to.” Extremely dedicated to her patients, White would also often remain with them throughout their labor and delivery.\footnote{Younger interview.}

By the mid-1930s, White believed she had essentially solved the problem of maternal mortality, and she began to challenge the use of that language to dissuade diabetic women from pursuing pregnancy. In an article requested of her by the Canadian Medical Association, she declared that maternal mortality “is fortunately very low” because intensive management of diabetes had allowed her patients to avoid many of the
complications associated with pregnancy.\textsuperscript{65} Miscarriage, she said, was three times more frequent in the pregnancy cases of other physicians who tolerated poorly controlled blood sugars as compared to control cases selected from her own patients. Toxemia and eclampsia, two dangerous complications for pregnancy, had a fifty times higher incidence in diabetics with consistently high blood sugars. White said that stillbirth of an “overdeveloped, macerated fetus” occurred when persistently high blood sugars caused what she called the “overnutrition” of the fetus. And White theorized that hormonal imbalances contributed to complications, a theory which she would pursue for another three decades but which she was never able to establish with certainty.\textsuperscript{66}

White increasingly published articles which declared that maternal mortality was a non-issue in diabetic pregnancies. She authoritatively stated that complications in diabetic pregnancies “do not concern the welfare of the mother.”\textsuperscript{67} Instead, she said, the real issue that needed to be addressed was the death of the unborn child, emphasizing that, “the treatment of diabetes is the simplest part of our problem.”\textsuperscript{68}

Even as late as 1949, White would still find it necessary to confront the language of maternal mortality by physicians opposed to diabetic pregnancies. She declared such language to be an inappropriate defense for avoiding or ending a diabetic pregnancy, repeatedly explaining

\textsuperscript{65} White, “Recent Progress in Diabetes,” 158-161.
\textsuperscript{66} White, “Recent Progress in Diabetes,” 159.
\textsuperscript{67} White, et.al., “Prediction and Prevention of Late Pregnancy Accidents in Diabetes,” 482.
that “fetal not maternal survival constitutes the problem when pregnancy complicates diabetes.”

White’s systematic approach to diabetic pregnancy was also based on her belief that pregnancy was in its own right a “diabetogenic” process. Pregnancy, White felt, could alter any woman’s metabolism in a way that mimicked diabetes. She was aware of the phenomenon in which a pregnant woman with no prior history of diabetes suddenly spilled sugar into her urine and often had a corresponding raised level of sugar in her blood. Although she did not consider the condition at that time to be a true form of diabetes, she said that its appearance – which, in her words, was subtotal, asymptomatic, and transient – helped her to understand the impact that pregnancy had on a woman’s metabolism. Pregnancy itself, she believed, created some of the same metabolic stresses that diabetes created.

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As early as the end of the 1930s, White believed that the threat of maternal mortality was no longer significant, and she designed a systematic program to help other physicians assist diabetic women in pursuing pregnancy. Believing that pregnancy placed an increased stress on a woman’s metabolism, she posited that it could also intensify problems with the control of a pregnant woman’s diabetes. And since the hormonal profile changed with each trimester, the influence of pregnancy on a diabetic woman’s metabolism likewise changed with each trimester. As she explained, “The management of the diabetes during pregnancy varies with the problems of each

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70 Untitled notes, numbered page 1, Carton 1, Folder 3, Priscilla White Papers. The first line reads, “Pregnancy appears to be diabetogenic.” The second line reads, “Temporarily intensifying subtotal D.M. [diabetes mellitus].” The third line reads, “Precipitating overt D.M. [diabetes mellitus].” The fourth line reads, “Revealing Chem. [chemical] and Asymptomatic [diabetes].” The fifth and final line reads, “Producing transient D.M. [diabetes mellitus].”
During the first trimester, she focused on the problem of nausea, which could be a significant issue in the patient on insulin who must be able to take in food to prevent low blood sugars. She also used that time to prepare her patients to make significant changes in their diabetic regimens over the remaining months. The second trimester involved watching for changes in kidney function, which could cause blood sugars to rise, and monitoring the need for increased food intake. Both issues required increases in the dosing of insulin. During the second trimester, though, White advised that “changes in insulin must be made on blood sugar estimations only” because urinary sugar did not necessarily correlate directly with blood sugar during that phase of pregnancy, since all pregnant women experienced a change in how their kidneys filtered sugar and other metabolites after reaching the second trimester.

For the third trimester of pregnancy, White’s main concern was watching for the development of acidosis. Acidosis is a potentially lethal condition in diabetics where blood pH can drop due to a relative insulin deficiency, relative being the operative word here because the same amount of insulin used prior to pregnancy may not be adequate to account for insulin resistance from the influence of pregnancy hormones in the third trimester. Factors that White identified as either contributing to the problem, or increasing the severity of it, were the mother’s increased metabolism, rising carbohydrate

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71 White, “Recent Progress in Diabetes,” 160.
72 Ibid., 160-161.
intolerance, and loss of glycogen stores because of several months of pregnancy, as well as the developing baby’s increasing caloric requirements.\textsuperscript{73}

\textit{Evaluating Risk: The White Classification System}

In 1949, Priscilla White published her classic essay that connected the level of risk for the fetus in a diabetic pregnancy to the length of time that the woman had diabetes. The beginnings of her concept could be seen as early as 1937 in a paper that she and Elliott Joslin wrote along with a husband and wife research team who had partnered with the Joslin Clinic to investigate hormone profiles in pregnancy. Although the focus of the 1937 article was hormone imbalances in diabetic pregnancies, White also presented her theory that the longer the duration of diabetes in a woman the higher the chance of fetal loss in pregnancy.\textsuperscript{74}


White connected a diabetic woman’s health status going into pregnancy with the level of intervention needed to protect the unborn child during the pregnancy. Such a therapeutic approach demonstrated that, unlike many of her contemporaries, she had shifted her clinical focus to a concern for the baby. Because many obstetricians and diabetes physicians of the same era maintained their focus on the pregnant woman, treatment strategies often included terminating the pregnancy in order to protect the life and health of the diabetic woman. For White, however, a successful pregnancy resulted in a healthy baby. She explained that when her women patients refused to relinquish the idea of having children, “I had to learn how to take care of them.”

In a stack of her personal papers was a note that White had written about a patient who committed suicide after two pregnancies “were interrupted.” She wrote, “This suicide answers the question asked so frequently today, ‘Why permit or encourage young women with diabetes to bear children?’ To many, to nearly all, life lacks meaning – may even be unendurable – without successful childbearing.”

That note, likely part of a talk or paper that White was preparing, illustrates two very important forces that guided her work during that era. First, although opposition to diabetic pregnancy was still pervasive, women’s rejection of that opposition was just as pervasive. Second, White’s classification system was shaped by what her patients asked of her: help in having a baby. In response, Priscilla White shifted the medical focus in her clinic to protecting the life and health of the baby in a diabetic pregnancy.

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75 Nancy Yanes Hoffman to Priscilla White, July 24, 1977, Carton 1, Folder 22, Priscilla White Papers.

76 Untitled note, Carton 1, Folder 13, Priscilla White Papers.
Many scholars, particularly historians examining abortion and reproductive rights, have suggested that there was similarly a broad, generalized shift in medical focus from the pregnant woman to the fetus during the mid-twentieth century. However, they have typically presented that shift as a detrimental development to women’s control over their bodies and their medical decisions and suggested that this more public focus on the unborn child became a tool for criminalizing pregnant women’s health behaviors. For example, terminating a pregnancy became portrayed as criminal, even as murder, by those who began to imagine the fetus as a vulnerable person who needed to be protected. Physicians did not escape such indictments either. Medical advances have often influenced political debates about abortion by shaping “the popular understanding of the relationship between a woman and the fetus.”

Historians have characterized this twentieth century shift in medical focus from woman to fetus as the landscape within which women lost a substantial amount of control in decision-making about pregnancy issues. Yet, ironically, Priscilla White encouraged just such a shift in medical attention to the fetus because, for diabetic women, she viewed the focus on women as the restricting influence over personal choice.

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In her now-famous 1949 article, published in the *American Journal of Medicine*, White presented her system for classifying risk in diabetic pregnancies. Her original classification scheme contained six levels of risk, Class A through Class F. The categories were based on a combination of factors such as how long the woman had diabetes and whether she had vascular complications like calcification (hardening) of the arteries, eye and kidney damage, or high blood pressure. Class A had no complications and only required diet treatment; Class F included serious kidney damage. In the lettered taxonomy, she connected the length of time that a woman had diabetes, and any associated vascular complications, with the risk of losing the baby. As the letter for each class increased, the risk to the fetus increased, with one exception – Class F. Of the six classes, the sixth (F) was concerned instead with the risk to the pregnant diabetic woman.\(^{78}\)

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Table 1. The original White Classification System adapted from her 1949 article.\textsuperscript{79}

<table>
<thead>
<tr>
<th>Class</th>
<th>Diabetes Diagnosis</th>
<th>Vascular Complications</th>
<th>% of Study Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Class A</td>
<td>Abnormal glucose tolerance test&lt;br&gt;Diagnosed as adult</td>
<td>No vascular disease</td>
<td>5%</td>
</tr>
<tr>
<td>Class B</td>
<td>Diagnosed as adult&lt;br&gt;Less than 10 years duration</td>
<td>No vascular disease</td>
<td>29%</td>
</tr>
<tr>
<td>Class C</td>
<td>Diagnosed 10 – 19 years of age&lt;br&gt;Less than 10 years duration</td>
<td>Minimal vascular disease (retinal arteriosclerosis, leg vessel calcification)</td>
<td>44%</td>
</tr>
<tr>
<td>Class D</td>
<td>Diagnosed under 10 years of age&lt;br&gt;Greater than 20 years duration</td>
<td>More vascular disease (retinitis, transitory albuminuria, transitory hypertension)</td>
<td>14%</td>
</tr>
<tr>
<td>Class E</td>
<td>Diagnosed under 10 years of age&lt;br&gt;Greater than 20 years duration</td>
<td>Calcification of pelvic arteries</td>
<td>7%</td>
</tr>
<tr>
<td>Class F</td>
<td>Diagnosed under 10 years of age&lt;br&gt;Greater than 20 years duration</td>
<td>Nephritis</td>
<td>1%</td>
</tr>
</tbody>
</table>

Rather than including only cases with the potential for a successful outcome, White included all types of pregnancies regardless of how severe the diabetes-related health problems. She never recommended terminating pregnancies with poor prognoses. As her protégé Donna Younger explained, physicians who claimed to have better outcomes in their clinics had been accepting only cases that would have fit into White’s classes of A or B. Those clinicians had been terminating more risky pregnancies or referring them to facilities like the Joslin Diabetes Clinic. White developed her classification system, Younger explained, “to challenge the idea of terminating a pregnancy … but also to ensure that they were comparing similar patients.”\textsuperscript{80}

\textsuperscript{79} I created this table to offer a visual organization of the information in the text of White’s article, as she did not include any type of table or organizational chart in that article. Other clinicians have created tables, but I could not find one that was organized in a simple and thorough manner. For the list of percentages of cases she reported for each class, White used data from 439 cases of diabetic pregnancies between 1933 and 1938. See Priscilla White, “Pregnancy Complicating Diabetes, 1949,” 612.

\textsuperscript{80} Younger interview.
Although the classification system encountered some revisions over the next decade, mainly to accommodate new treatment and assessment tools like newer types of insulin and specialized lab tests, the basic premise always remained that a woman’s pre-existing, diabetes-related complications dictated a specific treatment plan, one that did not include terminating the pregnancy. White developed her system to classify risk in diabetic pregnancies and to spell out the best therapeutic approaches to decrease the risk to the fetus. The White Classification System was not designed to determine if ending the pregnancy was justifiable. Her inclusion of the entire spectrum of patients was essential in defining the field of obstetrical diabetes with the specific purpose of making diabetic pregnancies safe and successful.

In spite of Priscilla White’s achievements in diabetic pregnancy, the topic of therapeutic abortion in such pregnancies endured well into the 1950s. At a joint meeting of the British, Canadian, and Ontario Medical Associations, a substantial amount of time was spent on discussing contraindications to diabetic pregnancy and on enumerating indications for terminating such pregnancies.\textsuperscript{81} The conference panel on diabetic pregnancy proposed a list of indications for therapeutic abortion such as family history of diabetes and the presence of vascular complications. By that time, some physicians adamantly opposed the concept of therapeutic abortion and when the panel included “the co-operativeness of the patient” and “the size of the family” in its indications for ending a pregnancy.

\textsuperscript{81} J.H. Peel, “Management of the Pregnant Diabetic,” \textit{British Medical Journal} 2, 4944 (October 8, 1955): 871.
diabetic pregnancy, it drew intense criticism from physicians who disagreed with the very premise of therapeutic abortion.

The conversation that ensued over the panel’s recommendations quickly turned into a firestorm. In the panel’s effort to communicate the danger of diabetic pregnancy to a wide audience – one that included both physicians and patients – they had used a language that was authoritative yet personal by including both medicine and memory. They maintained that their stance was medically-informed and that their indications for therapeutic abortion were based on scientific evidence from “recollections” of several hundred cases of troublesome diabetic pregnancies over several decades. They maintained that many other physicians concurred with their indications for discouraging pregnancy in diabetics. Detractors, however, pointed out that their several hundred troublesome diabetics who had presented pregnant, despite being told not to, obviously did not concur with their logic.

The debate continued for six issues of the journal. Within a few weeks of the initial article, Dr. Ivo Drury began the rebuttal by stating bluntly that “there is no medical

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case for therapeutic abortion in diabetics.”84 In their retort, Drs. Peel and Oakley called on such professional language as the “purely medical aspects of the problem.” The final comment on the matter verbalized what had become by mid-century the collective struggle for women with diabetes, “Were their indications for therapeutic abortions to be applied, the diabetic anxious to have children would be much more limited by her physicians than by her disease.”85

By the end of the 1950s, Priscilla White was “undeniably the doyenne of diabetic pregnancy,” a status that allowed her to challenge the opposing views of her mostly male colleagues.86 Although she was not a part of the debate that had played out in the pages of the British Medical Journal, she frequently found herself in the midst of similar challenges. At the 1954 annual meeting of the American Diabetes Association (ADA) in San Francisco, she had been asked to serve on the Diabetes and Pregnancy panel. The moderator for the panel discussion was Garfield Duncan of Pennsylvania. Duncan’s expertise was in obesity as it related to diabetic management, but he had been asked to serve as moderator for the Diabetes and Pregnancy panel because he had engaged in several well-publicized debates about diabetic pregnancy over the years.87 Duncan made clear his trepidation about diabetic women pursuing pregnancy, citing a range of dangers for women from coma and death to an increased risk of insulin resistance that could lead

85 Drury, “Correspondence,” (October 8, 1955): 908.
86 Ibid.
to “brittle diabetes.” Duncan also commented on the poor outcomes of such pregnancies, with maternal and fetal mortality at one end of the spectrum and increased birth weight that could predispose the child to diabetes as an adult at the other end of the spectrum. When Duncan pressed White to admit that diabetic pregnancy should be avoided in many women, she adamantly disagreed. Dr. White countered that there was only one complication that would make her hesitate about pregnancy in a diabetic woman and that was complete kidney failure. 88

**Conclusion**

By the end of the 1950s, physicians world-wide were citing Priscilla White’s work when discussing diabetic pregnancy. The broad recognition of White’s classification system reflected her internationally acclaimed expertise in the management of diabetic pregnancy. 89 But White never achieved the same professional honors and appointments as her colleagues. Even junior associates gained prominent roles over the years, while White was repeatedly passed over. 90

The specialty field that White built, the field of obstetrical diabetes, never became a formalized area of medical specialization. Despite the fact that the specialty of Obstetrics and Gynecology was a founding field of the American Medical Association’s Advisory Board of Medical Specialties (ABMS) in the early 1930s, the Board did not add

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88 The details of the disagreement between White and Duncan had to be pieced together from Duncan’s article a few years after the meeting and from the comments made by Ivo Drury in the six-issue long debate in the British Medical Journal. See Duncan, “The Modern Aspects,” 73-84 and Drury, “Correspondence,” 908.

89 Hare, “The Priscilla White Legacy,” 17 and 20.

90 Hare, “The Priscilla White Legacy.”
subspecialties for obstetrics training and certification programs until the 1970s, when three subspecialties were added: gynecologic oncology, maternal-fetal medicine, and reproductive endocrinology and infertility. Later, a fourth subspecialty was added: female pelvic medicine and reconstructive surgery.  

Obstetrical diabetes has never gained formal recognition as a specialty field of medicine, or even as a subspecialty field in Obstetrics and Gynecology, even though the medical literature has commonly referred to obstetrical diabetes as a field of expertise since the 1940s. Actually, no aspect of diabetes health care has ever gained formal status as a medical specialty field despite multiple applications for official recognition by the American Board of Internal Medicine (ABIM).  

Public and political concern about specific diseases stimulated the rise of medical specialty fields in the United States during the twentieth century, as evidenced by the reactions of governmental, and even private, philanthropic organizations for the funding

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92 American Diabetes Association, The Journey and the Dream: A History of the American Diabetes Association (Indianapolis: American Diabetes Association, 1990), 13-14. In fact, diabetology has never gained that status either but, rather, falls under the auspices of the field of Endocrinology. Obstetrics and Gynecology gained recognition as a specialty field in June 1933, when it became one of the founding disciplines of the Advisory Board of Medical Specialties, an organization supported by the American Medical Association. See http://www.abms.org/About_ABMS/ABMS_History/Extended_History/default.aspx (accessed January 2, 2011). In the 1970s, the ABIM added the word diabetes to the subspecialty of endocrinology so that now the subspecialty is named Endocrinology, Diabetes, and Metabolism. See http://www.abim.org/specialty/endocrinology-diabetes-metabolism.aspx (accessed July 29, 2012).
of research efforts and for increasing access to care from medical specialists. The refusal to grant specialty status for obstetrical diabetes, in the context of much medical and public concern, supports the argument that this area of medical specialization was shaped by forces much less visible historically. Scholars, particularly sociologists and economists, have characterized specialization as an inevitable trajectory emanating from advances in scientific knowledge and from the associated market segmentations in healthcare.  

The depiction of specialization as a uniquely medical or scientific process does not fit for diabetes and pregnancy. Rather, diabetic women increasingly refused to avoid pregnancy. They began to reject recommendations for therapeutic abortions. Diabetic women sought the care of doctors like Priscilla White for their diabetic pregnancies because they believed that she could offer them something better than the general practitioners who were opposed to such pregnancies. The actions of diabetic women who pursued pregnancy forced physicians to develop special skills to assist them.

Obstetrical diabetes developed alongside other important social events that created connections to healthcare for diabetic women, such as the medicalization of pregnancy, the move of birthing from home to hospital, and the increasing difference

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between men’s and women’s experiences with diabetes healthcare. Moreover, new social and scientific ideas about pregnancy had merged with the increasing public attention being cast on the health behaviors of diabetics, and created a social perception, both within and without the medical community, that pregnancy was not simply a personal decision for a diabetic woman. Although medical specialization has been depicted as the natural result of increased knowledge and scientific advances, such an interpretation for obstetrical diabetes dismisses the important push that came from the patients – from women who wanted to have children and who refused to be told that they could not.

Priscilla White was the pivotal figure in the emergence of obstetrical diabetes. Instead of dissuading diabetic women from trying to have families, she chose to help them. Even though the discovery of insulin did not improve diabetic women’s chances of surviving pregnancy at first, her approach reversed that trend. In 1949, she published her methods for success with diabetic pregnancies of varying complexity, and legitimated in many ways the field of obstetrical diabetes by laying down its founding principles. Donald Barnett, who had been one of White’s physician residents, said that White “created the basic reformational question in obstetrical diabetes, at least one of them, which was, ‘How much control [of diabetes] do you need?’” She began her career challenging the contemporary view that diabetes and pregnancy were incompatible. In


95 Donald Barnett, interview with author, August 11, 2010, tape in author’s possession.
defending her decision to reject that ideology, she insisted that her patients’ pursuit of children drove her to make diabetic pregnancies safe. More than sixty years later, the White Classification System remains the foundation for the field.
CHAPTER V
ONLY WHEN PREGNANT

In 1950, Obstetrical and Gynecological Survey published an article on a condition known at the time as glycosuria of pregnancy. Not a normal condition in healthy individuals, glycosuria (sugar in the urine) was diagnostic of diabetes in 1950 – except in pregnant women. Mid-twentieth century physicians generally believed that glycosuria of pregnancy was a temporary event and so did not consider it a true case of diabetes. The idea that pregnancy stressed a woman’s body in a plethora of ways was a widely accepted notion by the end of the 1940s, and glycosuria of pregnancy was believed to be one example of that physiological stress. Glycosuria would sometimes appear toward the end of a woman’s pregnancy, and the predominant theory at that time was that hormonal changes related to pregnancy had caused sugar to “spill over” into the woman’s urine. After giving birth, the urinary sugar disappeared, which relieved any lurking fear that the woman had actually developed diabetes during the course of her pregnancy.\(^1\) The article, however, foreshadowed a shift in scientific thought about glycosuria of pregnancy. The author acknowledged the contemporary medical view on the transience of the condition

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\(^1\) Physicians were aware of the possibility that glycosuria could also signal the appearance of “true” diabetes. If the glycosuria did not resolve after childbirth, then the woman was reevaluated as a new case of diabetes and efforts would immediately go into determining whether she had the mild form, today known as Type 2, or a case of the less common but more severe form, today known as Type 1.
but countered that physicians should not dismiss the condition because, in fact, some women “manifest diabetes only when pregnant.”

The discovery of insulin in 1921 had transformed diabetes, and a cascade of associated shifts in scientific and social thought had created a new public identity for diabetics. The almost certain death sentence was commuted, but diabetics were left to contend with a chronic and costly disease. Diabetic children began to live into adulthood, but they faced a life that included a meticulous and demanding medical regimen. Surviving a diagnosis of diabetes also meant that, as adults, diabetics took on social gender roles. Men became insulin-consumers who had to manage such social responsibilities as job pressures. Women became impending obstetrical disasters, characterized as “brittle” and “fragile,” with pregnancy becoming the defining issue in their patient identities. At the same time, adults began to be diagnosed with the mild form of the disease at an alarming rate as public health officials ramped up campaigns to identify the “million hidden diabetics.” As the mid-century mark approached, the general public heard about the hidden costs of diabetes, the multitude of unknown

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diabetics who posed a fiscal risk to society, and the complexities of a growing diabetes consumer market.

In conjunction with this redefinition of diabetes, the emergence of risk factor ideology played a key role in sparking new research interest in glycosuria of pregnancy.\(^4\) As the social understanding of diabetes had evolved, the perception of its women patients had changed as well. Pregnancy, which was a rare occurrence in diabetics before insulin, became the over-arching concern of physicians. Glycosuria of pregnancy, however, remained out of the purview of physicians and researchers at first. The condition only came under increased scrutiny when the concept of identifying risk factors for disease entered the growing market mentality of the diabetes healthcare sector.

Bolstered by advances in scientific knowledge and by developments in medical technology, risk factor ideology created a conceptual framework that would change the medical definition of the condition within the short span of two decades. Risk factor ideology was a postwar concept which posited that the early detection of chronic diseases like diabetes could allow for medical interventions before such diseases could wreak havoc. This new approach to public health emanated from efforts by insurance companies to reduce fiscal risk by identifying who was most likely to get sick (or die)

and from attempts by pharmaceutical firms to identify potentially treatable – and hence marketable – precursors to disease.

Risk factor ideology undergirded the massive growth and expansion of the American healthcare industry during the postwar years, and it also fashioned an innovative approach to medical research on diabetes and pregnancy. Rather than focusing solely on the laboratory-based research on the biochemical and molecular components of disease, postwar medical researchers were heavily influenced by the inherent challenge of risk factor ideology to search for and identify the early warning signs of chronic illnesses, to stop disease before it even started. They sought to connect information on predictors of disease to the development of interventions that could limit or preempt the disabling results of chronic disease and to therapeutics that could improve patients’ lived experiences with chronic disease.

Within the context of a heightened sensitivity to diabetic pregnancy, risk factor ideology suggested a new way to frame the condition of glycosuria of pregnancy. Up until the 1950s, the appearance of sugar in the urine of non-diabetic, pregnant women had generally been discussed in the medical literature as an aberration. Maybe it resulted from the stress of pregnancy hormones. Maybe the stress of increased blood pressure during pregnancy caused a woman’s kidneys to filter sugar differently. Within the framework of risk factor ideology, however, glycosuria of pregnancy would quickly become an indicator of a woman’s potential to develop diabetes later in life. “The
woman destined to develop diabetes,” general medicine physician William P. U. Jackson declared in 1953, “divulges her future fate [when she becomes pregnant].”5

Reframing Glycosuria of Pregnancy

As the mid-century mark approached, research interest in diabetic pregnancies grew at a rapid pace. Insulin had been available for almost three decades, and as physicians realized greater success in controlling diabetes with the new treatment, scientists’ interests grew in the lingering problems associated with diabetic pregnancies. As well, diabetic women increasingly pursued pregnancy despite warnings to the contrary, and they voiced their own concerns and experiences to their physicians. With more attention to these pregnancies and with more feedback from their women patients, physicians and scientists began to take more note of glycosuria of pregnancy. Over the course of the next two decades, the condition would become seen as less benign and physicians would begin, instead, to describe it as an event that potentially unmasked a hidden disease state. Suggesting that it was something akin to a precursor of the mild, adult form of diabetes, the research that informed these shifting views essentially reframed the medical definition of glycosuria of pregnancy. The naming changes that followed reflected the developing ideas on the condition.

Deciding if glycosuria of pregnancy was a hidden form of diabetes, unmasked by the stress of pregnancy, encompassed much more than science in a laboratory

somewhere. Moreover, the shift in thought about glycosuria of pregnancy actually exposed an unexpected divide within the medical community because labeling someone with a diagnosis of diabetes was not a simple matter. Diabetes had, by the 1950s, become a disease of significant social stigma and of personal challenges for those who encountered it. Even though there were substantial differences between the thin, juvenile diabetics and the older, overweight, mild diabetics, all diabetics faced employment discrimination, difficulty getting insurance, and the constant worry associated with testing urine, measuring food and, of course, the potential for debilitating complications like kidney failure and blindness.  

The stage had been set during the 1940s for the changes in the medical and social meanings of glycosuria of pregnancy that would emerge during the 1950s. For researchers who began to work on glycosuria of pregnancy, the issues included both scientific and social matters. Investigators had been wrestling with how to classify, or

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6 Chris Feudtner examined the transition to a difficult daily regimen for diabetics when insulin “transmuted” their disease from fatal to chronic. Feudtner described both the social stigma that came to be associated with a diagnosis of diabetes as well as the problems of monitoring the disease with complex urine testing procedures, calculations of food components in order to dose insulin correctly, and the management of the sometimes unpredictable insulin reactions. See Chris Feudtner, Bittersweet: Diabetes, Insulin, and the Transformation of Illness (Chapel Hill: University of North Carolina Press, 2003). Until the early 1950s, diabetics were simply denied insurance coverage. Although many began to gain access to insurance during the 1950s and 1960s, the premiums were generally so high that the coverage was unaffordable. The issues of insurance coverage and employment discrimination garnered significant attention in diabetes journals during the 1950s. See, for example, The American Diabetes Association, The Journey and The Dream: A History of the American Diabetes Association (Indianapolis: American Diabetes Association, 1990), 45-46 and 93-94. Also see R.D. Montgomery, “Insurance and Diabetes,” ADA Forecast 2, 1 (1949): 10-12; Editorial Letter, “The Truth about Life Insurance for Diabetics,” ADA Forecast 10, 1 (1957): 2; Paul S. Entmacher, “Acceptability of Diabetics for Life Insurance,” Annals of the New York Academy of Sciences 82, Current Trends in Research and Clinical Management of Diabetes (September 1959): 251-257; and Hugo T. Englehardt and Harvey B. Snyder, “The Diabetic IS Employable,” Journal of Occupational Medicine 2, 9 (September 1960): 427-431.
whether to dismiss, glycosuria of pregnancy in their research cohorts, and no tidy consensus on that issue had emerged by the 1950s. In addition, American and European researchers approached the condition from very different perspectives. While American researchers focused on what the condition meant for the pregnant woman who presented with sugar in her urine, European scientists expended more of their efforts on investigating the potential impact of the condition on the developing baby. Even with divergent scientific approaches, however, research work progressed at a rapid pace.⁷

The new cadre of researchers who began to work on diabetic pregnancies in general, and on glycosuria of pregnancy more specifically, came from a variety of disciplines and from different medical specialties. Their varied backgrounds brought new approaches to these studies. For example, David Hurwitz, a general medicine physician who had also completed a fellowship in obstetrics, teamed up with pediatrician Herbert Miller to investigate why a significant number of diabetic pregnancies still resulted in the death of the baby despite insulin therapy. Indeed, they found that as many as 30 percent of those pregnancies resulted in stillbirths or the death of the newborn shortly after birth. Meanwhile, for non-diabetic women, the fetal and neonatal death rates stood at a much lower 2 percent. In a somewhat novel approach for the time, the pair of researchers took medical histories directly from their older women patients and reviewed earlier events in their medical charts. To their surprise, they discovered that when older women were

diagnosed with adult-onset (or mild) diabetes, more than 8 percent of them reported that they had lost an infant during a pregnancy before they became diabetic. In addition, the research duo was told by many of those women that they had experienced glycosuria during at least one of their pregnancies.  

Another 1940s-era doctor, New York diabetes physician Herman Mosenthal, posited that multiple pregnancies had a cumulative, negative impact on a woman’s metabolism. That cumulative stress, he theorized, might explain why a woman who had experienced glycosuria of pregnancy earlier in her life developed diabetes later in life. In his studies on the impact of pregnancy on a woman’s metabolism, Mosenthal collaborated with obstetricians, pediatricians, pathologists, and even with a handful of epidemiologists who were compiling reports for insurance companies and congressional task forces. To offer support for his theory, he pointed to similar death rates from diabetes for both single men and single women over forty-five years of age, but not for married or widowed women. His assumption was that single women, like the single men

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8 Herbert C. Miller, David Hurwitz, and Katherine Kuder, “Fetal and Neonatal Mortality in Pregnancies Complicated by Diabetes Mellitus,” *Journal of the American Medical Association* 124, 5 (January 29, 1944): 271-275; and Herbert C. Miller, “The Effect of Diabetic and Prediabetic Pregnanies on the Fetus and Newborn Infant,” *Journal of Pediatrics* 26 (1946): 455-461. Although the condition usually produced no noticeable symptoms for women, urine testing had become a standard part of the office visit by the turn of the century, so it is likely that the women had been told that they had sugar in their urinalysis and that it had been consistently recorded in their medical charts. On the widespread use of urinalysis by the early 1900s, specifically for detecting sugar, see Diana W. Guthrie and Selby S. Humphreys, “Diabetes Urine Testing: An Historical Perspective,” *The Diabetes Educator* 14, 6 (1988): 521-525. Also, in an examination of diabetes diagnoses in Civil War veterans, Margaret Humphreys and colleagues found that urine testing had become commonplace; see Margaret Humphreys, Philip Costanzo, Kerry L. Haynie, Truls Ostbye, Idrissa Boly, Daniel Belsky, and Frank Sloan, “Racial Disparities in Diabetes a Century Ago: Evidence from the Pension Files of US Civil War Veterans,” *Social Sciences and Medicine* 64 (2007): 1774-1775.
he studied, had not been pregnant. He pointed out that for married or widowed women over forty-five, however, the rate of diabetes was “far greater than that of males.”

Although his theory was flawed on many levels, Mosenthal suggested that the impact of pregnancy on a woman’s body, particularly multiple pregnancies, accounted for that difference.9

Glycosuria of pregnancy did not go completely unnoticed before the 1950s, but neither did it garner a huge amount of attention up to that point. While physicians like Herbert Miller, David Hurwitz, and Herbert Mosenthal pursued questions about glycosuria of pregnancy with their new research formats, many scientists simply continued to exclude non-diabetic pregnancies with glycosuria from their research cohorts. They justified the exclusion by defining the condition as a temporary and benign, almost normal, effect of pregnancy for some women. Ivo Drury, an obstetrician in Dublin, recalled that when his team began collecting data in the late 1940s for their thirteen-year research project, they adhered to the belief expressed by other researchers that “cases of this type should be clearly separated because they are benign when recognized and their inclusion in the general series weights results rather favorably.”10

As well, Priscilla White, a leading physician-researcher in diabetic pregnancy from Boston, noted that simple glycosuria was insignificant and agreed that it should not be

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included in any study results. It required no treatment, she said, because it would recede spontaneously after the woman gave birth. She went on to espouse several theories on why the condition was not a true case of diabetes, such as the possible spilling of breast milk sugars into the woman’s urine.¹¹

Before mid-century, researchers and physicians alike routinely dismissed the condition. Johns Hopkins obstetrician Nicholson J. Eastman called the temporary condition, which he termed “renal glycosuria,” a false case of diabetes. Many women, Eastman said, presented with the condition and, he elaborated, a “load” of sugar could bring it on, certain medicines often caused it, and all pregnant women’s blood sugars rose enough that sugar might overflow the kidneys for any of them.¹² Moreover, even though a few physicians suggested that glycosuria might be the result of a “diabetogenic” effect of pregnancy, meaning that the pregnancy itself might cause the diabetic-like symptoms, many dismissed even that idea.¹³

¹¹ Untitled notes, Carton 1, Folder 3, Priscilla White Papers, Schlesinger Library, Harvard University. White also used the terms sub-total and transient diabetes in the language she used to describe the condition.


¹³ In handwritten notes, Priscilla White frequently referred to how she believed pregnancy itself could cause the appearance of the temporary condition. She said that diabetes was diabetogenic and could cause “overt” diabetes or precipitate transient glycosuria of pregnancy. In those notes, Dr. White variously referred to the condition as sub-total, chemical, asymptomatic, or transient glycosuria of pregnancy; a representative example can be found in her personal papers; Untitled notes, numbered page 1, Carton 1, Folder 3, Priscilla White Papers. A copy of the note referenced here appears in Chapter 2 as Figure 4. On the rejection of the concept of the diabetogenicity of pregnancy, see Rollin T. Woodyatt, “On the Theory of Diabetes,” *Transactions of the American Clinical and Climatological Association* 56 (1940): 160.
With such an entrenched view of glycosuria of pregnancy as temporary, benign, and self-contained, the sudden interest in the condition at mid-century leaves the historical perception that a remarkable scientific discovery must have catalyzed the new research efforts. The era was indeed rife with changes in the medical approach to diabetes brought about by the introduction of insulin therapy. And the scientific understanding of diabetes physiology certainly underwent enormous changes after the discovery of the new treatment in 1921. In addition, the medicalization of pregnancy had brought birthing inside the hospital under the purview of physicians and, hence, physician-researchers. Diabetic pregnancy had evolved into a subspecialty of its own. And advances in laboratory medicine allowed for greater accuracy in bodily measurements, beginning a shift toward diagnosing diseases with numerical thresholds derived from laboratory tests instead of relying on a patient’s reported symptoms and appearance.\textsuperscript{14}

While these changes in healthcare – increased medical knowledge about diabetes and pregnancy as well as advances in laboratory medicine – played an important role in the shift in thought on glycosuria of pregnancy, women patients likely had a significant

impact as well. Pregnant women have, of course, always worried about possible threats to their babies and have paid careful attention to the course of their pregnancies. Looking at earlier studies, such as those from Herbert Miller and David Hurwitz, it seems that women patients have often told their doctors about experiences with glycosuria of pregnancy years, sometimes even decades, before being diagnosed with diabetes.\textsuperscript{15} Women’s attention to their health and their conveyance of symptoms to their physicians undoubtedly brought greater attention to these possible connections between glycosuria of pregnancy and future health issues. But ultimately, the business concept of risk factor ideology became the cohesive force in reshaping physicians’ understanding of glycosuria of pregnancy. In the 1950s, risk factor ideology would guide the design and direction of the largest research study ever on the condition. What would become known as the Boston Study began in 1954 at the Boston City Hospital and continued for ten years; the results became the basis for revising the way that blood sugar levels in pregnant women were assessed.

\textit{Glycosuria of Pregnancy or Pre-diabetes?}

When a funding source materialized that could pay for an expanded study on glycosuria of pregnancy, it did not take long to find a young, new researcher willing to

\textsuperscript{15} Miller, et.al., “Fetal and Neonatal Mortality”; and Miller, “The Effect of Diabetic and Prediabetic Pregnancies.” I was greatly influenced to pursue the idea of women self-reporting their experiences with glycosuria of pregnancy by the work of Leslie Reagan. In her work on rubella, Reagan found that mothers of children born with certain birth defects were largely responsible for having alerted doctors to the possible connection between their children’s health problems and their experience with rubella infection while pregnant. See Leslie J. Reagan, \textit{Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America} (Berkley: University of California Press, 2010).
try to connect the dots. With the assistance of a National Institutes of Health (NIH) research grant along with matching funding from the U.S. Public Health Service (USPHS), John B. O'Sullivan left his interest in arthritis behind and arrived in Boston in 1954. O'Sullivan began a long-range project to determine if the raised level of blood sugar that corresponded to the appearance of urinary sugar in glycosuria of pregnancy was a risk factor for women developing diabetes later in life.\textsuperscript{16} He collected data on low-income, pregnant women who came to the “Free Clinic” of the Boston City Hospital for healthcare, and he used the newly developed laboratory test for measuring sugar levels in blood.\textsuperscript{17}

The Boston Study incorporated two important elements of modern research design. First, the project was a prospective investigation rather than a retrospective observation and, second, women were enrolled in a consecutive manner in order to avoid selection bias.\textsuperscript{18} In contrast to retrospective research studies such as Herbert Miller’s that looked back in time, women enrolled in the Boston Study were currently pregnant, and the team planned to look forward, watching them prospectively for ten years to see what

\textsuperscript{16} Physicians and researchers had known since before the discovery of insulin in 1921 that the presence of sugar in the urine corresponded directly to sugar in the patient’s blood stream. But the difficulty of measuring blood sugar remained a limiting factor and forced physicians to rely instead on urine testing until mid-century when significant advances in laboratory chemistry made blood tests simpler, quicker, and more accurate.


\textsuperscript{18} The enrollment approach of study subjects in the Boston Study approximates the design of the current practice of the RCT (Randomized Controlled Trial) where study subjects are put into a calculated, random assignment and the design of that assignment is set to control for possible confounding factors like weight or age. Even though it fell short of the strict standards for study design today, it was a great improvement over contemporary models.
happened without subjective interpretation. Many of those older, retrospective studies had necessarily relied on anecdotal evidence: personal stories about health experiences related informally by patients or clinicians, usually with no means of validation. One previous physician-researcher who had based his findings on anecdotal evidence even acknowledged that his method of simply asking patients about their experiences was “admittedly subject to great inaccuracy,” but he justified his approach by claiming that “there is no reason to believe that diabetics are greater exaggerators.”19 The Medical Director at Boston City Hospital, Hugh Wilkerson, asserted that the Boston Study’s scientific design would revolutionize scientists’ understanding of women’s pre-diabetic experiences with pregnancy because “most current theories on ‘maternal prediabetes’ are based on retrospective studies among diabetic women past the childbearing years.”20

The design of the Boston Study combined clinical observation with a sophisticated statistical analysis. Pregnant women who came to the Free Clinic were given an initial blood test that involved drinking a small cup of liquid with fifty grams of sugar. One hour later, blood was drawn and tested. The blood sugar level was recorded as a baseline measurement. The women were then scheduled for a more involved test called the Oral Glucose Tolerance Test (OGTT). For that test, the women were given dietary instructions for the three days leading up to the test and were instructed to arrive at the clinic in the morning after an overnight fast. They were given a liquid to drink

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which contained one hundred grams of sugar. Following the liquid, a series of blood tests were performed: the first test was drawn immediately and then again at one hour, two hours, and three hours. The women were given the test at several points during their pregnancies, and the test results were inserted into a formula that calculated a running average for the entirety of the study.\footnote{Donna M. Younger, interview with author, August 11, 2010; John Hare, interview with author, August 11, 2010; Donald R. Coustan, interview with author, August 12, 2010; and Boyd E. Metzger, interview with author, October 26, 2009, all tapes in possession of author. The prenatal clinic at the Boston City Hospital was often referred to as “The Free Clinic” because it served mostly indigent clients.

\footnote{For a more detailed discussion on the history of men as the standard patient, see Nancy Krieger and Elizabeth Fee, “Man-Made Medicine: The Biopolitics of Sex/Gender and Race/Ethnicity,” in Man-Made Medicine: Women’s Health, Public Policy, and Reform, ed. Kary L. Moss (Durham: Duke University Press, 1996), 15-36. The authors posited that white men were originally seen by physicians and researchers as a distinct and advanced group, and the idea of white men as the norm grew out of that ideology. Steven Epstein asserts that the idea of “the average body” is not a concept with a long history but, rather, it is a twentieth-century development that emerged with the rise of biomedical research and the need for a standard reference. See Steven Epstein, Inclusion: The Politics of Difference in Medical Research (Chicago: The University of Chicago Press, 2007), 30-52. Yet, as early as the 1830s, Adolphe Quetelet, a Belgian scientist, published works that laid out his attempt to define the “normal man”}}

The main research question in the Boston Study was whether non-diabetic, pregnant women who experienced raised blood sugars during the OGTT developed diabetes later in their lives. Even though the main research question was straightforward, the study team included a complex calculation of continuous averages for the blood sugar levels in their research participants. They tried to compare study test results against the research subjects’ own laboratory values because they believed there was a potential problem in defining the normal range for blood sugar in pregnancy. In 1954, the “normal” range for blood sugars was still based on calculations from thirty-something-year-old, white, male soldiers. \footnote{However, the research subjects in the Boston Study}
were women who were pregnant, mostly non-white, and from a lower-income strata of the population. O'Sullivan and his graduate student assistant, Clare Mahan, chose to calculate a new set of “normal” blood sugar values for the pregnant women enrolled in the study. To create this set of average ranges for blood sugar measurements, they continually recalculated an average range throughout the study enrollment period and then set a statistical threshold to designate an abnormal blood sugar level specific to pregnancy. It was one of the first times that research involving laboratory tests acknowledged real differences in physiology between men and women and considered the state of pregnancy as a factor in how a woman’s body responded to the food she ate, in this case a sugary liquid.23 Although the study’s design elucidated the problematic concept of the “standard male” in physiology, the study’s design arguably furthered the gendering of diabetes.

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Figure 5. Chart of blood sugar measurements.\textsuperscript{24}

\textsuperscript{24} “Oral Glucose Tolerance Test,” Carton 1, Folder 17, Priscilla White Papers. This was a widely used chart from the late 1950s to the late 1960s to assess results of Oral Glucose Tolerance Tests (OGTTs) in pregnant women; note that the standards were calculated from non-obese men between the ages of 15 and 44.
Adding to the complexities of the research design, the women who were enrolled in the Boston Study presented for care at the Boston City Hospital at a time when prenatal care had become a standard recommendation by obstetricians but was not yet widely accepted as a valuable aspect of healthcare by other physician groups.\(^{25}\) Between the mid-1950s and the mid-1960s, many low-income, inner-city women rarely received what obstetricians deemed adequate prenatal care. In fact, many of those women received no care at all during their pregnancies. A number of women could not afford prenatal care or were not aware of doctors’ recommendations about what constituted adequate care. However, other women simply chose to avoid it because they believed that the benefits did not outweigh the costs. Those “costs” were not always counted in dollars. Many low-income women, for example, were deterred by long waits in the crowded waiting rooms of public health clinics; by the struggle of balancing employment, child care, and difficult, or even erratic, appointment schedules; and by the lack of any tangible results of inconvenient visits, like valuable test results to reassure

\(^{25}\) Opinions about the questionable value of prenatal care abounded in that era and were not unfounded as researchers and physicians acknowledge that its effectiveness remains equivocal even today. See Greg R. Alexander and Milton Kotelchuck, “Assessing the Role and Effectiveness of Prenatal Care: History, Challenges, and Directions for Future Research,” *Public Health Reports* 116 (July-August 2001): 306-316. The authors explain that the initial focus of prenatal care was to prevent low birth weight and prematurity, as those were considered to be important indicators of poor prognoses for babies. But the underlying problems that contribute to low birth weight such as poverty have never been addressed. Moreover, poorly designed studies throughout the twentieth century have offered inaccurate assessments of the benefits of prenatal care. For example, as the authors point out, assessing effectiveness by studying women who actually get prenatal care creates an inexplicable selection bias and, yet, that has been the design of most government agency assessments of prenatal care.
them or education to assist them during their pregnancies. Recognizing the potential deterrents to the low-income women in their study seeking prenatal care at their clinic, the Boston Study team sought financial assistance from the Children’s Bureau to create “improved services for prenatal, postpartum, and well child care for the mothers and their children in this project.” The research team shaped the way that prenatal care was offered to encourage the study participants to seek care at their clinic and to encourage them to keep coming back for their follow-up appointments. The need to offer adequate care for low-income, pregnant women was certainly a driver for restructuring the study’s design, but the desire to retain study participants undoubtedly ensured that the necessary changes would be made. By the mid-century mark, research design included attention to “retention,” and a high rate of drop-out or “lost to follow-up” in a study limited the acceptability of its conclusions.

American pharmaceutical companies also played a role in bringing attention to glycosuria of pregnancy. Companies like Merck, Upjohn, and Pfizer helped to acquaint a broader sector of the public to the concepts of risk factors for disease and early warning.

26 On the beliefs and circumstances that contributed to many low-income African American women in Philadelphia avoiding prenatal care during approximately the same years as the Boston Study, see Lisa Levenstein, A Movement without Marches: African American Women and the Politics of Poverty in Postwar Philadelphia (Chapel Hill: The University of North Carolina Press, 2009), 170-173.


signs of chronic disease states as they worked to develop treatments for debilitating illnesses like heart disease and diabetes. Pfizer’s Chief of Operations, Charles Mottley, epitomized that effort when he told an audience at the American Drug Manufacturer’s annual meeting in 1957 that chronic, life-long illnesses were the next frontiers in sustainable markets for the drug industry.\textsuperscript{29} Since its discovery in 1921, insulin remained the only drug therapy available for treating either type of diabetes as the mid-century mark approached. But insulin had to be injected with a needle. Not only was the treatment hard – stabbing oneself with a sharp object is difficult at best – both the enormous cost of the treatment as well as the daily use of syringes added to the social stigma of diabetes. And even though insulin did not work very well for the mild diabetics who were quickly beginning to comprise the majority of patients with the disease, there was no other alternative to offer to those diabetics for whom diet and activity failed to control their disease.

With the possibility of pills to treat diabetes, the idea of expanding the definition of the disease to include an underlying condition, or even a risk factor for diabetes, into the realm of diagnostic and, hence, treatment possibilities became an easier pill to swallow. The development of pills to treat diabetes was no less a miracle in the world of diabetic medicine than insulin had been some three decades earlier.\textsuperscript{30} In 1957, \textit{The

\textsuperscript{29} Greene, \textit{Prescribing by Numbers}, 1-2.

\textsuperscript{30} For a discussion of the development of oral hypoglycemic agents to treat mild, or Type 2, diabetes, see Greene, \textit{Prescribing by Numbers}, 83-147. The first generation of oral agents was a set of drugs called sulfonylureas. They were derivatives of the sulfa antibiotics developed during World War I and World War II. One particular strain of the sulfa drugs could cause blackouts and convulsions in higher
*Saturday Evening Post* enthusiastically presented a four-page spread on the new diabetes pills that could “free thousands of diabetics from their lifelong slavery to the hypodermic needle.” In a telling note for researchers investigating glycosuria of pregnancy, the article even reported on “a young mother who was successfully carried through her pregnancy” with the new pills.31 Researchers investigating the condition certainly found their direction clearer. Likewise, they found that the ethical dilemma of labeling a symptomless condition as a precursor to a disease that came with significant social problems was somewhat reduced if an easier treatment with less stigma existed.

By the late 1950s, within this changing environment of medical care for diabetes, doctors stopped referring to the condition as glycosuria of pregnancy and began, instead, to call it pre-diabetes of pregnancy. The name change certainly reflected how quickly the idea had taken hold that the condition was an indicator of a woman’s risk for developing diabetes.32 However, it is important to recognize that other factors fed into the name change as well. For example, doctors during the 1950s began to rely more on blood tests for diagnosing diabetes when such tests became easier, more affordable, and quicker.

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32 The shift in terminology happened quickly within the realm of research but lagged behind in the world of general medicine. As late as 1970, for example, some general medicine physicians were still referring to the condition as glycosuria of pregnancy. See, for example, H.W. Sutherland, J.M. Stowers, and Colin McKenzie, “Simplifying the Problem of Glycosuria in Pregnancy,” *The Lancet* 295, 7656 (May 23, 1970): 1069-1071.
Blood tests also afforded physicians the ability to select a numerical threshold for defining diabetes (or even for “early” diabetes) instead of waiting for an individual’s internally-regulated threshold for sugar to appear in the urine. With the numerical specificity of a blood test, decisions about defining diabetes or pre-diabetes could potentially bypass any physiological regulatory systems within a person’s body, like urine production, allowing for earlier and earlier cut-off points to be established for defining abnormal pathology.\(^{33}\) Adding to the complexity, even though blood tests were available earlier in the decade and were already widely promoted as the new diagnostic standard, many physicians had resisted the switch from urinalysis because of the need for quick results. As one physician explained, “If a patient came into the ER [emergency room], we would draw blood but it could be two hours before we would get a result; with a urine test, we dipped the stick and had the result.”\(^{34}\)

Adding to the impact of new laboratory tests and new medications to treat diabetes at earlier stages, the American Diabetes Association (ADA) and the American Medical Association (AMA) had begun disease detection campaigns to search for the “million hidden diabetics” that they believed stood to derail the fiscal stability of the fledgling American health insurance industry. Year-round Diabetes Detection Drives began across the nation as results from the enormous, industry-supported Oxford

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\(^{34}\) Younger interview.
Diabetes Survey came out during the 1950s. Researchers reported that the data suggested that as many as one million people in the United States actually had diabetes but did not know it yet.\textsuperscript{35} Popular news magazines like \textit{Time, Newsweek, The Saturday Evening Post}, and \textit{Today’s Health}, all picked up on the detection campaigns and connected those efforts to the language of risk factor ideology by stressing that “early discovery is vital.”\textsuperscript{36}

The general approval within the medical community of the new name pre-diabetes of pregnancy was bound to the ever-expanding connections between risk factor ideology, a growing public concern with “the million hidden diabetics,” and American scientists’ belief that the physiological stress of pregnancy could unmask diabetes. What had been at the beginning of the 1950s a “non-entity,” became by the end of the decade an early warning sign of a woman’s predisposition to develop diabetes. Moreover, not only had glycosuria of pregnancy become a potential predictor of diabetes, but it had become as well an experimental window into how diabetes developed. As physician-researcher Hugh Wilkerson observed, “The ideal state for the investigation of ‘prediabetes’ is to be found in the pregnant woman.” John O’Sullivan, lead investigator


of the Boston Study, and a colleague researcher of his, Norbert Freinkel, reported that
pre-diabetes of pregnancy was the ideal laboratory for studying diabetes because
pregnancy taxed a woman’s ability to produce insulin so much that it “unmask[ed]
chemical diabetes.”

Another prominent obstetrician declared, “It is now well
established that married women who develop diabetes in middle life give obstetric
histories very similar to those of the long-established diabetic.”

Glycosuria of Pregnancy and the Baby

While American researchers continued trying to clarify the link they saw between
glycosuria of pregnancy and the development of diabetes later in a woman’s life,
European scientists were examining the same condition from a different perspective.
Beginning in the early 1950s, a line of research based mostly in European laboratories
ran parallel to the efforts by American scientists. Without the influence of the American
healthcare market’s ideology of risk factor identification, European scientists looked at
the effects of glycosuria of pregnancy on the fetus instead of on the pregnant woman. A
key figure in the European efforts was Jorgen Pedersen, a Danish physician trained in
both internal medicine and obstetrics, who also had extensive research experience in the


laboratories of important chemistry and physiology scientists such as Nobel Laureate Hans Christian Hagedorn, who had developed the first long-acting insulin.\[39\]

In his doctoral research dissertation in 1952, Pedersen proposed a theory that he called “the hyperglycemia-hyperinsulinism hypothesis.” The basic premise was that when a pregnant woman – diabetic or not – experienced a high blood sugar, the fetus experienced it as well. Pedersen suggested that the mechanism which allowed the fetus to experience the mother’s blood sugar was the permeability of the placenta. Additionally, Pedersen theorized that the fetus actually tried to compensate by producing more insulin in order to bring down the high blood sugar. He claimed that this experience before birth, where the placenta failed to block sugar from the mother’s blood and the fetus tried to respond, produced specific problems for the newborn infant such as breathing difficulties immediately after birth. More importantly, Pedersen said, the experience shaped the baby’s developing organ systems in a way that likely determined aspects of its adult health.\[40\] Pedersen’s theory ran contrary to the predominant belief of the time that the placenta protected the baby by acting like a filter and, as such, his theory


undermine a basic premise that had guided American obstetrical thought for over a century. His work would also open the door for American researchers to conceive of the womb as an environment vulnerable to a variety of influences.

Even though research scientists often work in isolation, Pedersen’s studies were intimately connected to the work of other scientists of his era. The work which undergirded Pedersen’s hyperglycemia-hyperinsulinism theory began in the physiology lab of the Steno Memorial Hospital in Copenhagen during the 1940s. There, Pedersen used a technique for sampling amniotic fluid that a British obstetrician, Douglas Bevis, had perfected in a nearby research laboratory – a technique that would later become part of the widely used amniocentesis testing.41 Amniocentesis involves the collection of cells from the fluid that surrounds the fetus by inserting a needle through a pregnant woman’s abdomen into her uterus. The actual needle insertion procedure was not new at all, but a discovery in 1949 had drawn more attention to the procedure. A Canadian neuroanatomist, Murray Barr, had discovered that the cells in the amniotic fluid of research animals differed between males and females. The cells of females contained a

small, extra structure. By the early 1950s, Barr had proven that the extra structure also existed in the cells of human females. In 1956, based on Barr’s discovery, amniocentesis was used for the first time to determine a baby’s gender because of the possibility that the baby had hemophilia, a sex-linked blood disorder. Researchers immediately embraced the new technology for its potential in “the detection of [other] antenatal hereditary disorders.” The belief was that procedures like amniocentesis could help physicians identify, or diagnose, inherited diseases before the baby was born.

Pedersen’s theory on the fetal environment gained momentum through the work of other European researchers and through the studies of scientists working on issues in diabetes and pregnancy. A contemporary of Pedersen’s, Belgian researcher Joseph Pierre Hoet, also began investigating the idea that glucose crossed the placenta in pregnancies complicated by glycosuria. Because many of his older, diabetic women patients reported previous “disturbances during pregnancy,” Hoet had turned his attention toward studying glycosuria of pregnancy. Many of the women that Hoet reported on had histories of miscarriages and stillbirths as long as twenty years before being diagnosed with diabetes.


In addition to their generally problematic obstetric histories, many of his diabetic women patients reported specifically that they had experienced glycosuria of pregnancy. Medical chart reviews that his research team performed confirmed those reports.\(^{44}\)

Another European obstetrician whose work increased the attention paid to the impact of glycosuria on the fetal environment was London physician Sir John Peel. By the late 1940s, Peel had become increasingly concerned with the problems he saw in babies born to diabetic and “pre-diabetic” women. He added research staff to his clinic team to study the “relatively small group of patients” with glycosuria of pregnancy. His scientific interest in the condition emanated, he said, from a concern for fetal size, congenital abnormalities, and intrauterine death in pregnancies that had been affected by the supposedly benign event of transient glycosuria. His research focused on placental function to determine if the temporary condition had somehow “touched” the unborn baby.\(^{45}\) Peel’s research career, however, followed an interesting tract in the European scientific community. By the end of the 1950s, he was tapped to become the Surgeon-Gynaecologist to Queen Elizabeth II, a position that afforded him great sway in political decisions about pregnancy-related healthcare. With the influence bestowed by such an important appointment, he also became chairman of the legislative committee that drafted


\(^{45}\) J.H. Peel, “Management of the Pregnant Diabetic,” 870.
Great Britain’s 1967 Abortion Act, which legalized the medical termination of pregnancy.⁴⁶

Peel’s work on the 1967 abortion legislation was doubtless influenced by the social environment that had intruded into his research laboratory as well as into those of his colleagues. Debates over British physicians’ authority to use therapeutic abortion as a medical treatment preceded similar issues that would dominate headlines in the United States during the 1960s and 1970s. Much like in the United States, the Catholic Church figured prominently in those European struggles, although church officials in Europe tended to take the issue straight to the public rather than through the court system. On October 29, 1952, Pope Pius issued a statement to European media outlets that derided the work of medical researchers in pregnancy. Specifically indicting researchers who studied the impact of diabetes and other metabolic disturbances, he criticized any research that expressed primary concern for the welfare of the mother. Physician-researchers across Europe were incensed as they widely interpreted the papal statement as “valuing the life of the unborn child above that of the mother and as making it obligatory upon doctors to ‘kill’ the mother if they could thereby save the child.” Even though the Vatican released a follow-up statement saying that the Pope was trying only to put the issue into perspective by bringing an important ethical question to the forefront, ⁴⁶ “Obituaries: Sir John Peel,” The Telegraph, 2 January 2006; and Caroline Richmond, “Sir John Peel,” British Medical Journal 332, 7537 (February 11, 2006): 366.
European physician-researchers viewed the statement as infringing on their medical authority and reacted to protect their medical practices.47

By the 1960s, the attention to the fetal environment that had been raised by diabetic pregnancy researchers undoubtedly influenced other pregnancy-related studies, such as scientific work on the impact of thalidomide, the effects of maternal rubella infection, and the recognition of Fetal Alcohol Syndrome (FAS).48 A new vocabulary appeared in obstetrical medicine, and it actually came in large part from the world of diabetic pregnancy research. Alcohol, the rubella virus, and thalidomide became teratogens, substances capable of altering the environment inside the womb. Researchers reported, and then the media subsequently warned the public, that there were potentially dozens of teratogens that could cross the placental barrier and harm the growing baby.49

During the 1960s, the idea that outside forces could harm the fetus also became an over-arching principle in public health efforts and, subsequently, brought significant


49 In 1963, two researchers, Jack Werboff and Jacques Gottlieb, published a research paper on commonly prescribed sedatives that crossed the placental barrier and altered the behavior and learning abilities of research rats. The authors acknowledged the “thalidomide tragedy” but suggested that scientists had already known of the potential for such problems. They began their research, in fact, in the early 1950s shortly after the very public arguments between the Catholic Church and medical organizations in Europe about therapeutic abortion. The authors’ greatest contribution to the trajectory of research in pregnancy came from their statement on the myth of the placental barrier. They stated that they sought to dispel the myth “that the fetus in its protected amniotic environment is immune from insult.” See Jack Werboff and Jacques S. Gottlieb, “Drugs in Pregnancy: Behavioral Teratology,” Obstetrical and Gynecological Survey 18, 3 (June 1963): 420.
changes in the social understanding of women’s private health choices during pregnancy. For example, reaction to the threat of the rubella virus (German measles) in the United States, which could cause serious birth defects if a woman was exposed while pregnant, reconfigured public perceptions about disabilities, abortion, and even personal medical choices. The mass public health efforts at immunization in the wake of the rubella virus scare embedded state policy in the social understanding of personal medical decisions. In targeting children as potential carriers of the virus, immunization campaigns cut across lines of race, class, and gender but created a new idea that it was okay for the state to impose medical interventions on one person in order to protect the health of another person, even if that other “person” had not been born yet.\(^{50}\)

In the wake of an ever-increasing scientific and social concern for the fetus, the media began to report on a slew of drugs, chemicals, foods, x-rays, and even noises that could potentially injure a growing fetus. A *New York Times* article quoted two Wisconsin pediatricians who had spent more than a decade studying potential injuries to the fetus, and they broadly posited that “everything you give a pregnant mother is suspect.” The pair said that drugs, viruses, chemicals, and even vitamins and “enriched foods” could potentially harm the fetus because, as they explained, the placenta did not actually protect the fetus as well as doctors once believed. In fact, they theorized, the placenta could “overload” the fetus with seemingly normal nutrients from the mother’s

\(^{50}\) Reagan, *Dangerous Pregnancies*. 
blood – like iron, amino acids, and sugar – because not only was the placenta not a filter but it could even be a magnifier of the components on the fetal side.51

One or Two Patients in Pre-diabetes of Pregnancy?

The European research focus on the fetus gained such influence world-wide that the investigative team for the American-based Boston Study revised their research protocol to incorporate questions about the impact of blood sugar fluctuations on the developing baby. What had begun as a study to predict the future health of women changed mid-stream. The study expanded to account for a new medical and technological focus that had crossed over the Atlantic: the unborn baby. By the late 1950s, the Boston Study’s preliminary results and reference ranges for women were already being cited in nearly every article on testing strategies for pre-diabetes in pregnancy. In 1957, though, three new outcome measures were added, which addressed the growing concern for the fetus in these pregnancies: (1) complications such as miscarriage, oversized (or premature) babies, and congenital anomalies; (2) blood sugar problems experienced by the newborn; and (3) the impact on the newborn’s health of giving insulin to pregnant women with the condition.52


For American scientists working on diabetes and pregnancy, the pregnant woman had been the main research target for decades, but the European focus expanded the research window. Another young researcher who was influenced by ideas about a fetal environment was Dr. Norbert Freinkel. Freinkel had arrived at the Boston City Hospital during the early years of the Boston Study and, in the late 1950s, after spending a decade in thyroid research, he began studying insulin metabolism in pregnancy when the Boston City Hospital received another major research grant from the National Institutes of Health.\(^{53}\) Within a year, his research also included changes in carbohydrate metabolism during pregnancy. That new research focus became a natural segue for Freinkel to begin conducting studies on the temporary condition of pre-diabetes in pregnancy. Freinkel’s wife, Ruth, actually became an informal research subject for his initial studies on pregnancy metabolism. In order to test his theories, he jokingly explained that he drew blood tests on Ruth “from the fifth day following the conception of [daughter] Susie (I was a very confident young man in those days!).”\(^{54}\)

Over the next decade, Freinkel’s work evolved into an influential theory on how a woman’s health behaviors shaped the environment of the womb. Interchangeably known as “fuel-mediated teratogenesis” or “the tissue culture experience of pregnancy,” he theorized that a pregnant woman’s diet created a unique and specific environment for the developing baby. Suggesting that the food a pregnant woman ate became something

\(^{53}\) The information comes from a personal memoir that Dr. Freinkel wrote; see pages 6-7 of the memoir. The original memoir is in the possession of Dr. Boyd Metzger, who graciously gave me a copy.

\(^{54}\) Freinkel memoir, 6-7.
tantamount to the agar in a petri dish, Freinkel assigned to the pregnant woman “the role of an incubator and a supplier of incubation medium.”55 Freinkel’s emphasis on the way in which events during pregnancy influenced health cycles afterward fit nicely with the premise of risk factor ideology, making his work a natural bridge for incorporating the concept of a fetal environment into studies on diabetic pregnancy.

Few scholars have recognized that the work of these researchers from the 1950s, like Jorgen Pedersen and Norbert Freinkel, actually laid the foundation for connecting a pregnant woman’s health behaviors to the trajectory of fetal development. Looking instead to more recent works, scholars as well as advocates for fetal rights see the concept of a fetal environment as a newer development and have most often contextualized it as a reaction to Roe v. Wade.56 An important exception has been researcher Andreas Plageman, who has called Freinkel’s theory a “forerunner of today’s rapidly expanding


fields of ‘perinatal programming’ and ‘developmental origins of health and disease.’”

As well, Northwestern University’s Boyd Metzger has said that Freinkel was “the driving force [for demonstrating] the mutual interplay between mother and fetus.” Freinkel and Pedersen were indeed the first scientists, Metzger said, who “provided convincing evidence that diabetes begets diabetes.”

More typically credited with creating the concept of a fetal environment is David J. Barker. A British physician who, beginning in the late 1980s, popularized the idea that the nutritional make-up of the womb “programs” the developing fetus, Barker concentrated mostly on hypertension and Type 2 diabetes in his research, but he also held various consulting positions on privately- and federally-funded nutritional programs for pregnant women. Barker’s work often replicated the language used by researchers from the 1950s by discussing how “the growth of a fetus is influenced … by the nutrients and oxygen it receives,” explaining that “insulin has a central role,” and even focusing at length on the condition of raised blood sugars during pregnancy. Yet, even Barker does not credit the work of his European forerunners, such as Jorgen Pedersen, Joseph Hoet, and Sir John Peel, or of their American counterparts, such as John O’Sullivan, Hugh

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59 See Barker’s extensive Curriculum Vitae including a summary of his consulting roles at [http://www.southampton.ac.uk/medicine/about/staff/djb2.page#background](http://www.southampton.ac.uk/medicine/about/staff/djb2.page#background) (accessed December 1, 2012).
Wilkerson, Norbert Freinkel, and Boyd Metzger. The result has been a historical inaccuracy which somewhat exclusively connects the concept of fetal rights to the social movements of the late 1960s and 1970s and that ignores the impact of research on diabetic pregnancy.

Contemporaries of the diabetic pregnancy researchers from the 1950s have suggested that when the American and European research efforts on pre-diabetes of pregnancy merged, the result was that loosely connected scientific findings turned into coherent medical approaches and that popular ideas about the condition of pre-diabetes of pregnancy were formed. In 1960, for example, South African obstetrician William Jackson remarked that the monumental research efforts from both sides of the Atlantic had transformed understandings of blood sugar fluctuations in pregnancy so dramatically that, “We [now] believe that most, and probably all, of the abnormalities which occur in the fetus of the diabetic may also occur in the fetus of the prediabetic.” In a 1962 article on the increased prevalence of diabetes in the mid-twentieth century, geneticist James Neel proposed that the importance of pre-diabetes of pregnancy was not that it was

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“an expression of the mother’s diabetes,” but rather that “this phenomenon is also in part an expression of the infant’s predisposition.”

In fact, Neel’s description of pre-diabetes in pregnancy as a health condition of the unborn child embodied the new ideas about a fetal environment, a focus which was gaining momentum in popular conceptions of pregnancy as well. A mid-1970s article in the *Journal of Perinatal Medicine* reviewed the impact of research into glycosuria of pregnancy, or pre-diabetes of pregnancy, during the 1950s on the then-current approach to patients. The authors reported on a trial of universal screening in their obstetrical clinic to “identify the patient at risk of obstetric problems.” The problems that they investigated, however, (macrosomia, birthing injuries, malformations, fetal morbidity, neonatal deaths, and overgrowth or growth retardation of the baby) were health problems experienced by the fetus or newborn, not the pregnant woman. In a complete reversal

62 James V. Neel, “Diabetes Mellitus: A ‘Thrifty’ Genotype Rendered Detrimental by ‘Progress,’” *American Journal of Human Genetics* 14, 4 (December 1962): 353. The main thesis of Neel’s paper was actually on the increased prevalence of diabetes in the mid-twentieth century, which he theorized was the result of a “thrifty gene” that had offered protection in times of famine but had become detrimental in modern society. His theory quickly gained attention from diverse sectors of medicine and science. But his ancillary argument on the significance of pre-diabetes in pregnancy did not go unnoticed by diabetes and pregnancy researchers. For a summary of the impact of Neel’s “thrifty gene” hypothesis, see Watson Graham, “Commentary: The Thrifty Gene Hypothesis: Considering the Significance of a 47 Year Old Theory,” *New York Medical College Newsletter* (2009), www.nymc.edu/Clubs/quill_and_scope/volume2/graham.pdf (accessed July 23, 2011). Neel later became embroiled in controversy when two of his graduate students accused him of intentionally infecting members of an isolated South American tribe with measles in order to see what the outcome would be for the children born during the outbreak. After several investigative panels, Neel was never charged with any crime and his work was never rescinded as fraudulent, but he was never completely cleared either. That controversy likely played a part in the subsequent downplaying of his comments on diabetes and pregnancy.
from the obstetrical approach prior to the 1950s, the “patient at risk” for their obstetrical group was the unborn baby.  

Conclusion

Risk factor ideology certainly brought increased interest to the condition of glycosuria of pregnancy. The new concept began a process that integrated this interest into the massive medical research enterprise that emerged with the post-war transformation of American medicine. Yet, the role of risk factor ideology in creating interest in glycosuria of pregnancy remains a much more complicated picture. Throughout the 1950s, scientific interest in glycosuria of pregnancy indeed grew as physicians began to ask if it could be a harbinger of diabetes in later life. They even examined the condition with the hope that it could illuminate some new understanding of how diabetes developed.

Risk factor ideology alone, however, could not maintain the momentum. Unlike other conditions that came under scrutiny mid-century as possible precursors to disease,

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glycosuria of pregnancy held no potential for a pharmaceutical treatment and so its utility as a disease concept was limited.\textsuperscript{65} Even though glycosuria of pregnancy was swept up in the rush to identify and target indicators of future disease, clinicians and researchers had not developed any standard therapeutic intervention. As historian Jeremy Greene has explained, the idea of identifying and reducing risks for diseases “naturally emphasized the importance of the asymptomatic patient” because of the potential for lucrative pharmaceutical interventions. Risk factor ideology, Greene explained, has historically been connected to an assortment of therapeutics created by pharmaceutical companies to define and treat these new pre-disease patients.\textsuperscript{66}

Research interest in glycosuria of pregnancy did not emerge from the potential for new drug treatments or therapeutic interventions, even though American researchers spoke the language of risk factor ideology. While the new oral diabetes medications that came out during the 1950s certainly spurred researchers to continue their work on a condition that many physicians were still calling temporary and benign, even the new therapeutics would not be applied to the condition. The merging of risk factor ideology with the concept of a fetal environment became the force that propelled research on the condition forward. Just how much of a driving force the connection between risk factor ideology and the concept of a fetal environment would be became clear during the 1970s

\textsuperscript{65} For example, Belgian physician Jean Pirart criticized American researchers’ exclusive focus on the pregnant woman. See Jean Pirart, “So-Called Prediabetes of Pregnancy,” \textit{Acta Endocrinologica} 20 (October 1, 1955): 192-208.

\textsuperscript{66} Greene, \textit{Prescribing by Numbers}, 6.
and 1980s, when the engine of medical research in the United States transformed a condition with little to no investigational budget into a research enterprise with millions of dollars of state support.
CHAPTER VI

PART II: MAKING GESTATIONAL DIABETES

John Hare, a retired physician from the Joslin Diabetes Center in Boston, told the story of a doctor who became his patient during her second pregnancy. Her first pregnancy had gone well despite being complicated by gestational diabetes. His mid-thirties patient was once again diagnosed with gestational diabetes, but she was “very motivated and tested her blood sugars herself.” After her pregnancy, however, she insisted on having an antibody test that, if positive, would change her diagnosis from gestational diabetes to Type 1 diabetes. Much to Hare’s surprise, the test came back positive. More surprising, he said, his patient was relieved, almost happy, to be diagnosed with a form of diabetes arguably much more serious than gestational diabetes, “She was a patient of mine, yes, and she was also a doctor, but she was determined not to have GDM [gestational diabetes] and, well, she was actually right, but she was so determined to have anything else.”

Part II of this dissertation argues that these social perceptions of gestational diabetes, like those of Hare’s physician-patient, were influenced by the way that the disease concept for gestational diabetes was framed within the bureaucratic channels of social welfare policy. Officially, the disease was codified in 1980, with its inclusion in

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1 John W. Hare, interview with author, August 11, 2010, tape in author’s possession.
the disease coding manual maintained by the World Health Organization (WHO). But the process of defining the disease had been a task of creating policies that specified who was at risk and what fiscal and social problems could result from not identifying those at risk. The language of Medicaid eligibility rules, for example, became intimately connected to treatment standards for this disease because many of the women who encountered the diagnosis came increasingly from lower-income groups. And that connection tagged gestational diabetes with a certain set of pejorative social judgments. Gestational diabetes also became encumbered by the negative perception of diabetes that had developed. Diabetics in general faced a problematic consumer identity by 1980 that portrayed them as personally responsible for the very public financial burden they might cause – through low-income status and through negligent health behaviors like inactivity, overeating, and rejecting medical advice.²

ÒThe connections between medicine, business, and government that became more concrete after World War II resulted in state policies becoming embedded in the definition of this new disease. Research and treatment guidelines for gestationally diabetic pregnancies were translated into healthcare practices through the channels of congressionally-mandated committees and legislative work groups. During the 1970s and 1980s, the demographic picture of gestationally diabetic women became poorer and less white. The low-income and minority women encountering the new diagnosis were marginalized consumers in the healthcare market, but they would gain access to prenatal

care for the condition when Medicaid eligibility policies began to reflect the medical recommendations on gestational diabetes. Both risk factor ideology and the concept of a fetal environment had served as an impetus to improve pregnant women’s access to healthcare. For gestational diabetes, that meant the condition would shift from being an interesting notation in a medical chart to part of the prenatal care package of national preventive health interventions.\(^3\)

As our governmental structure has grown enormously over the twentieth century, much of our social system has come under the control of a large federal bureaucracy, including facets such as electoral participation and healthcare.\(^4\) During the twentieth century, healthcare quickly became commodified through the interplay of the increasing role of the federal government, the rise of a pharmaceutical consumer market, and the birth of third-party payers as liaisons between healthcare providers and consumers.\(^5\)

Chapter VII in this section adds to the literature on the bureaucratization and commodification of healthcare by examining the conduit that bound those elements

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together: the rapidly expanding enterprise of federally-funded medical research. The billions of dollars poured into the growth of research from mid-century on created and supported new career paths for physicians, built new businesses in the healthcare market, and gave new focus to many federal agencies. The system of grants and committees, of departments and centers, and of public policy positions that tapped physician-researchers, together played a significant role in the transformation of gestational diabetes because they formed a structure that connected medicine, business, and government.

Chapter VIII details the actual mechanics of how a condition that was once so thoroughly believed to be benign was transformed into a disease of such importance that every single pregnant woman had to be screened for it. Physician-researchers utilized the power of government structures to frame their concept of gestational diabetes as a serious public health threat, even if an indirect one, into a more formally recognized disease diagnosis. The World Health Organization (WHO), an alphabet soup of committees in the U.S. Congress, and a host of businesses with ties to legislators, all became part of the

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machinery to codify the new diagnostic label. The disease became the third “official” form of diabetes mellitus. It became a priority item on the list of public health issues to be addressed by the National Institute of Child Health and Human Development (NICHD). Several assessment programs in President Johnson’s War on Poverty, like Chicago’s Poverty Program, were convinced to list gestational diabetes as a program target. Testing for gestational diabetes became a part of prenatal care covered by Medicaid for many newly diagnosed women. Even though estimates suggested that gestational diabetes only affected about 3 percent of pregnancies, physicians and policy makers used these channels to push for the implementation of universal screening for the disease.
In a 1948 article, Boston diabetes physician Priscilla White dismissed the significance of a laboratory finding of sugar in the urine of a pregnant woman. Known at the time as glycosuria of pregnancy, the condition could appear suddenly toward the end of a woman’s pregnancy and then go away just as quickly after she gave birth. Although glycosuria, or urinary sugar, was diagnostic of diabetes mid-century, White maintained that in pregnant women such a finding was not necessarily indicative of diabetes, or even of pre-diabetes. Suggesting instead that pregnancy hormones could alter a woman’s kidney function and cause sugar to spill into her urine, White warned her colleagues about the “fallacy of basing a diagnosis of diabetes on sugar in the urine [of a pregnant woman].”

A little over a decade later, in 1960, one of White’s contemporaries wrote about the same condition but posited instead that any sign of glycosuria should be considered abnormal since “glucose tolerance is not impaired in a completely normal person during pregnancy.” Much had changed in a decade’s time. Physicians had known about this

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particular condition since at least the mid-1800s, but a widespread belief in its transience and questionable significance had persisted for a century. Why did medical opinion change so suddenly in the middle of the twentieth century? Certainly, a better understanding of the physiology of diabetes and pregnancy had contributed. Moreover, a small cadre of physicians and researchers in North America and Europe had been studying and writing about the condition for three decades, and kept the medical community at large informed of their findings. But scientific knowledge was not the only factor. The privileging of scientific discovery, or simply of the increased medical knowledge it brings, as the main impetus for changes in definitions of diseases has obscured the impact of factors like health policy and businesses in the healthcare market on transforming our perceptions about health and illness. To understand how opinion on the significance of glycosuria of pregnancy changed so quickly, we must look at the institutional structures that have created shifts in the way health and illness are defined in public policy and in the healthcare consumer market.

This chapter suggests that the sudden change in perspective on glycosuria of pregnancy was fostered by the large influx of money for medical research in the United States that grew out of new connections between medicine, business, and the state – what scholars have called the Medical-Industrial Complex (MIC). In the mid-twentieth century, American medicine, a growing healthcare consumer market, and the federal

government became intimately connected. The ways in which those connections emerged, and how they have changed and grown, is a subject well-studied, but the history of the research industry embedded within the MIC has not been examined quite so well.⁴

The condition of glycosuria of pregnancy had certainly not gone completely unnoticed in the medical and scientific communities but, until the 1950s, discussions about it were largely confined to a few specialized physicians and to a handful of under-funded laboratories. In the late 1950s and early 1960s, however, research on diabetic pregnancy became absolutely central to a growing diabetes industry, and by corollary, scientific interest in the condition of glycosuria of pregnancy grew in tandem. With this new research enterprise, funded and supported by healthcare companies and by the U.S. government, physicians and scientists joined forces with businessmen and legislators to create fellowships, research centers, and lobbyist positions that brought money and attention to the issue of diabetes and pregnancy. The result was the emergence of a massive diabetes research and healthcare industry that created and supported the careers of many new doctors and researchers.

In the second half of the twentieth century, public health policies were fundamentally shaped by the research arm of the MIC and were instrumental in reframing glycosuria of pregnancy from a condition of low priority into a disease that required universal screening for early detection. While scientific knowledge and technological

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advances had indeed informed physicians’ medical understanding of the condition, it still had received limited attention for over a century. The health outcomes research industry linked scientists, clinicians, pharmaceutical representatives, Senators, and Congressmen. The new connections allowed for health policy roles to be created for those studying the condition; for their research findings to be turned into clinical practice and public education; and for proposed initiatives on screening for the condition to be included in national preventive health measures. Throughout the 1960s and 1970s, fiscal support from businesses and from government agencies buttressed research efforts in the diabetes healthcare market as a whole. For glycosuria of pregnancy, that resulted in millions of dollars backing research grants, underwriting conferences, creating and financing investigative centers, and drafting and enacting legislation that helped to turn research on diabetes and pregnancy into a measure of national importance.

Understanding the mechanics of how and why a condition that physicians once believed to be benign and insignificant was redefined into a disease that called for the systematic screening of all pregnant women in the United States adds a new dimension to our understanding of the process that historians of medicine call disease creation. Several recent studies address the role of state policy and of the influence of business on the process of disease creation. For the subset of studies that examine policy and business, “healers and sick people [are] seen within the actual context of their interaction (social and intellectual).” But even this small group of scholars has largely continued to view
scientific discovery as the guiding principle in defining and “creating” disease.⁵ Moreover, their narratives do not recognize the power of medical research in shaping those interactions.⁶ In the case of glycosuria of pregnancy, later called pre-diabetes of pregnancy and then renamed gestational diabetes, medical research became an essential interface between physicians, policy makers, and businesses.

The specter of great public cost with diabetes helped to embed the postwar emphasis on finding risk factors and early precursors to disease into research on urinary sugar and raised blood sugars in pregnant women. As such, many of the scientists working on the condition pushed for state assistance because they believed that government agencies should help this group of new patient-consumers by funding targeted research.

While the postwar era in the United States saw reform-minded New Dealers broadly retreating from the statist programs that challenged the power of capitalism in the

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⁵ Judith Walzer Leavitt, “Medicine in Context,” American Historical Review 95, 5 (December 1990): 1473. For examples of works that incorporate the influence of business and the state, see Jeremy A. Greene, Prescribing by Numbers: Drugs and the Definition of Disease (Baltimore: The Johns Hopkins University Press, 2007); Steven Peitzman, Dropy, Dialysis, Transplant: A Short History of Failing Kidneys, Biographies of Disease (Baltimore: Johns Hopkins University Press, 2007); and Leslie J. Reagan, Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America (Berkley: University of California Press, 2010). Greene examined the role of industry in redefining the asymptomatic states that often precede a diagnosis into disease entities themselves; in his work on kidney disease, Steven Peitzman explained the creation of the broad category of End Stage Renal Disease in Medicare policies to create a channel of access to dialysis treatment; and Reagan examined the legislative work that mandated a universal vaccination program for rubella.

U.S. economy, no such retreat took place in the arena of American healthcare. In fact, at a time when liberals had all but abandoned their efforts at consumer protection through the Office of Price Administration (OPA), they began to tackle those very issues in clinical research through the Food and Drug Administration’s (FDA) new Kefauver-Harris Drug Amendments, which required manufacturers to prove a drug’s effectiveness before bringing it to market, and through the Consumer Bill of Rights, which proclaimed that patient-consumers had basic rights that government was bound to protect such as safety and informed decision-making.

In the realm of diabetes and pregnancy research, what began mid-century as a very small fraction of the federal and industry spending in healthcare would become a million dollar engine by the late 1970s. In 1950, the total research budget of the NIH was approximately fifty-two million dollars, but that allotment grew to over three billion dollars, but that allotment grew to over three billion

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8 For a brief summary of FDA legislation on consumer protection, see [http://www.fda.gov/AboutFDA/WhatWeDo/History/Milestones/ucm128305.htm](http://www.fda.gov/AboutFDA/WhatWeDo/History/Milestones/ucm128305.htm) (accessed June 29, 2012). For a more in-depth summary of the history of the FDA that focuses on the roles of business and research in the development of government regulation for this very unique consumer market, see Philip J. Hilts, *Protecting America’s Health: The FDA, Business, and One Hundred Years of Regulation* (New York: Knopf, 2003).

dollars by 1979. Throughout the 1960s and 1970s, research initiatives on diabetes and
pregnancy in general, and glycosuria of pregnancy specifically, garnered increasing
federal and private funding that supported – even created – the careers of new physicians
and researchers. By the mid-1970s, the budgets for the new diabetes research and
training centers, all of which had diabetic pregnancy as a top focus and nearly half
focused on gestational diabetes, increased research efforts in diabetes alone by another
forty million dollars. Research experience became a key component of physicians’
status as experts and allowed them to inform policy decisions and to support the growth
of investigative initiatives and specialty fields. Congressionally-mandated committees
and legislative work groups followed, and they translated research findings into
healthcare practices and public education efforts. Through that process, a condition in

10 Federally funded projects for diabetic pregnancies rarely focused on gestational diabetes
specifically before 1975, but in the round of funding proposals that went through Congress in 1975, with
projected completion and publication dates in the 1980s, five of the twelve studies on diabetes and
pregnancy focused specifically on gestational diabetes; see National Commission on Diabetes, “Report
of the Workgroup on Pregnancy of the Committee on Scope and Impact,” Report of the National
Commission on Diabetes to the Congress of the United States, Vol. III, Reports of Committees, Subcommittees, and
Workgroups, Part 2, Scope and Impact of Diabetes (11), U.S. Department of Health, Education, and
177-258.

11 Barbara C. Hansen and Marilyn D. Cohn, “Diabetes Research and Training Centers: Science,
Application, Training, and Translation,” Diabetes Care 3, 4 (July-August 1980): 548-553; Lois F. Lipsett,
“Birth of a Clearinghouse,” Diabetes Care 1, 5 (September-October 1978): 308-309; and Miryam Frieder,
Carolyn M. Hickey, Courtney H. Pieczynski, Amanda Drehobl Llorens, Sara Rubin, and Jon Glaudemans,
“Case Study: National Commission on Diabetes,” Focusing Federal Efforts: A Review of Health-Related

12 Daniel M. Fox, “The ‘Milbank Quarterly’,” 185-197. Although dated, the discussions by A.
Hunter Dupree and George Rosen on the postwar collaborations between government agencies and
university-based researchers explains the origins of the complex network that researchers on diabetic
pregnancy found themselves in. See A. Hunter Dupree, “The Structure of the Government-University
Partnership after World War II,” Bulletin of the History of Medicine 39 (1965): 245-251; and George
pregnancy that was once believed to be temporary and inconsequential would become a central tenet of the prenatal care package of preventive health interventions.\textsuperscript{13}

Building a Research Career

“I chose internal medicine first and then I was looking at cardiology,” retired physician Donald Barnett remembered, “but there were NIH [National Institutes of Health] fellowships at the Joslin [Clinic] and when I got down here I realized it was a whole new world here because of the NIH.” Dr. Barnett arrived at the Joslin Diabetes Clinic in 1960 and thus began a clinical and research career that would span more than four decades and would include work with children, pregnant women, and eventually with diabetics who had developed eye complications.\textsuperscript{14} Diabetic pregnancy very quickly became an important focus in the “new world” of medical research that had lured Barnett out of his original calling and led him instead into the profession of diabetes research.

Along with heart disease and cancer, diabetes had become a top target of federal research funding. The actuarial scientists hired by healthcare businesses had also impressed upon policy makers the value of identifying chronic disease early – before such illnesses could wreak havoc on the economy through missed work days and costly medical bills that many patients could not afford. The risk factor ideology introduced by


\textsuperscript{14} Donald Barnett, interview with author, August 11, 2010, tape in author’s possession.
pharmaceutical companies and insurance agencies quickly guided much of the federal investment in research.\textsuperscript{15}

The emergence of a research funding apparatus of such magnitude during the postwar years brought attention to diabetic pregnancy when it built an entire new career path for many physicians. The new physician-scientists followed the road paved by policy makers through government agencies like the National Institutes of Health (NIH). While many of these young physicians had certainly been interested in finding ways to improve patient care, a research career in health outcomes was not necessarily how they had envisioned that undertaking. Norbert Freinkel, who would become the director of the Diabetes in Pregnancy Center (DPC) at Northwestern University in Chicago, had originally started his medical career working on thyroid regulation.\textsuperscript{16} Dr. Oscar Crofford, who became the chairman of the National Commission on Diabetes and the architect and principal investigator for the largest diabetes research study ever, the Diabetes Complications and Control Trial (DCCT), first began working on cell cultures in a pathology and physiology lab.\textsuperscript{17} Dr. John Hare, a protégé of one of the world’s most renowned diabetic pregnancy specialists Priscilla White, went to Chicago to study hematology “but the endocrine program was stronger because of Norbie Freinkel’s funding.” After finishing his fellowship at Northwestern University, Hare said, he “went


\textsuperscript{16} Freinkel memoir, 1-4; and Boyd Metzger, interview with author, October 26, 2009, tape in author’s possession.

to Joslin because of the NIH pay and was assigned to pregnancy with Priscilla White.”\(^{18}\)

The funding opportunities that opened up in the 1960s and 1970s shaped obstetrician and diabetic pregnancy researcher Donald Coustan’s career as well. He was recruited to Brown University in Providence, Rhode Island because “Brown had one of those diabetes center grants and was losing it because they didn’t have an obstetrician that was involved … and we got the center grant renewed after that.”\(^{19}\)

Examining how one researcher’s career took shape in the area of diabetic pregnancy illuminates the enormous impact of the rapid rise in government funding of medical research during this era. Norbert Freinkel would become the key figure during the 1970s in redefining the temporary condition of glycosuria, or pre-diabetes, of pregnancy into the disease gestational diabetes. The enormous growth of funding in medical research on diabetic pregnancy played a significant role in guiding his career in that direction.

Freinkel’s academic profession in diabetic pregnancy research, and his influence with legislators and business interests in that realm, coalesced with his position as Director of the Diabetes in Pregnancy Center (DPC) at Northwestern University, but his road to Chicago began in the 1950s at the Boston City Hospital.\(^{20}\) While his colleague in Boston, John O’Sullivan, began the ten-year-long “Boston Study” on blood sugar profiles in the low-income, pregnant women who presented for care at the inner-city clinic there, Freinkel arrived to pursue a new career path that would take him into the world of

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\(^{18}\) John Hare, interview with author, August 11, 2010, tape in author’s possession.

\(^{19}\) Donald R. Coustan, interview with author, August 12, 2010, tape in author’s possession.

\(^{20}\) Freinkel memoir, 12.
research on diabetic pregnancy metabolism. In October 1952, he began a research position at the Thorndike Memorial Laboratory of Boston City Hospital on a $2,000 per year stipend that was funded through the Massachusetts State Department of Health and, later, through the Children’s Bureau of the U.S. Department of Health, Education, and Welfare.\footnote{Freinkel memoir, 3. Also, on the source of funding for the Thorndike Laboratory, see Hugh L.C. Wilkerson, “Maternal Pre-diabetes and Outcome of Pregnancy – A Preliminary Report,” \textit{American Journal of Public Health} 49, 8 (August 1959): 1034.}

Max Finland, a prominent scientist who was also a member of the advisory board of the National Academy of Sciences, recruited Freinkel to the Thorndike from Walter Reed Army Medical Center in Washington, D.C. During the postwar years, the Academy was one of several institutions that were instrumental in maintaining collaborative connections established during World War II between American government agencies and academic research groups. Those connections had originated through the funding of an American-based network of scientific research, a network which had been needed to replace German knowledge bases lost with the war. In addition, U.S. policy makers had allocated wartime funds to enhance the American effort in biological and chemical warfare and were not ready to cease that initiative with the nominal end of the war.\footnote{The American Chemical Society (ACS) also sought to preserve the connections made during the war by seeking increased government funding for research, by creating a partnership between the chemistry industry and the nascent medical research community, and by fostering relationships with businesses in the new and rapidly expanding pharmaceutical industry. The ACS wrote a report for Congress titled, “The Future Independence and Progress of American Medicine in the Age of Chemistry.” The report suggested that medical research in the United States was falling short because of a lack of funding for collaborative efforts. For a summary of the report, see Van Buren Thorne, “Chemistry’s New War on Disease: Important Report on Need of Intensive Research in Co-operation with Medicine and Other Sciences,” \textit{New York Times}, 19 February 1922, 89. On the influence of German science centers on American endeavors in the early twentieth century, including the development of city infrastructures like sanitary sewer and the creation of research groups of chemists and physicians, see Paul Starr, \textit{The Social Transformation of}
Freinkel was quite aware of the sources of his research funding at Walter Reed, occasionally joking that although his position was deemed medical work on kidney functioning and thyroid physiology, it was really to determine “where to duck and with whom ’when they drop the Big One.’”

In 1956, the allocation of federal funds created a new division at the Thorndike – the Diabetes and Metabolism Division – and Freinkel was recruited to be the director. The funding for new researchers at the Thorndike came from a mixed bag of federal money that emerged with the creation of the Office of Research Grants within the NIH. Senator Lister Hill and Congressman John Fogarty, through their roles in appropriations sub-committees, helped to initiate and then increase the funding of projects within centers like the Thorndike Lab from eighty grants totaling about $780,000 in 1946 to 2,000 funded grants totaling over twenty million dollars by 1953.

The funding of researcher-initiated grants and of collaborative centers that focused on specific diseases was an innovative step in the 1950s, and the Diabetes and Metabolism Division of the Thorndike Memorial Laboratory became a model for

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23 Freinkel memoir, 1; and Metzger interview.

programs to follow.\textsuperscript{25} The establishment of the program at Boston City Hospital, however, was not the result of objective evaluations of patients’ needs, nor even of community-based assessments. Rather, an influential network of people brought in one of the first NIH training grants in diabetes through their connections to businesses and policy makers. As one researcher explained, “There were a few congressman who had diabetes or who had people in their family with diabetes who pushed the NIH, and they convened this congressional task force which came up with goals for funding and areas to investigate for the next five or ten years, and that’s how stuff got accomplished in Washington.”\textsuperscript{26} One of Freinkel’s colleagues – David Hurwitz – had just started a diabetes clinic at Boston City Hospital. For the sake of convenience in the busy schedule of a physician-researcher, Hurwitz began bringing his private patients in to the clinic at Boston City, many of whom were important figures in state and national politics, including the Lieutenant Governor of Massachusetts and several other wealthy clients.\textsuperscript{27}

\textsuperscript{25} Fox, “History and Health Policy,” 350. In a unique role as a historian and a health policy advisor, Daniel Fox explains that in looking at the rise of influence of health outcomes research during this period, historians continue to focus on the failure of compulsory health insurance. But, Fox suggests that “a more important historical problem is explaining how and why health policy in the United States provided vast public subsidies to increase the supply of medical services and linked subsidy for the demand for care to employment or lack of it, to age, or to particular diseases.”

\textsuperscript{26} Coustan interview. Also, former Director of the NIH Harold Varmus has said that advocates for diabetes research have had a long history of adopting “an unusually militant approach,” which included direct and quite public challenges to the funding strategies of the NIH, and even once the picketing of the Illinois home of the chairman of the House Appropriations Subcommittee, whose wife had diabetes. See Varmus, \textit{The Art and Politics of Science}, 166.

\textsuperscript{27} Freinkel memoir, 6-8. This is the same David Hurwitz who collaborated in the 1950s with pediatrician Herbert Miller to investigate the connection between glycosuria in non-diabetic pregnant women and poor outcomes of pregnancy. Hurwitz also had a history of using ties to his wealthy and influential patients for advocacy work as he and his wife, Pearl Birnbaum Hurwitz, had gained grants-in-aid for raising their mentally handicapped child at home in Massachusetts rather than seeking institutionalization for the child, which was quite a departure from the norm in the 1940s and 1950s. See \textit{The Jewish Western Bulletin}, 60, 44 (25 November 1993): 1-2
More the norm than the exception, connections often grew out of these casual and familiar links.

Businesses in the diabetes marketplace also assisted with the creation and expansion of research programs and the funding of salaries for scientists at the Boston City Hospital. With the development in the 1950s of oral hypoglycemic agents (pills for treating Type 2 diabetes), pharmaceutical companies expressed interest in supporting these new research centers as well because of the marketing opportunities that such tangible support could open up. By the end of the 1950s, in fact, Medical Director Hugh Wilkerson had gained substantial “material assistance” for the research programs at Boston City Hospital from several big pharmaceutical firms such as the Ames Chemical Company, Eli Lilly and Company, and E.R. Squibb and Sons. Businesses like Ames, which developed test strips for the new devices being used to measure blood sugars, and both Lilly and Squibb, which produced insulin and diabetes pills, offered financial support in direct and indirect ways. Sometimes funds came through the sanctioned and visible sponsorship of salaries for research assistants, support for conferences, or with small, focused research grants. Company representatives often supported research centers in less visible ways as well, with the creation of on-site libraries or by supplying pharmaceutical samples and trial devices.

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28 Freinkel memoir, 6-8; and Wilkerson, “Maternal Prediabetes,” 1040.

29 Coustan interview; and Metzger interview. The supplying of “samples” and of non-monetary gifts by pharmaceutical sales representatives is strictly forbidden today, but was a common practice until the 1990s. The Prescription Drug Marketing Act was enacted in 1987 and amended in 1992 to restrict the distribution of “gifts” by drug sales representatives. For more information on the legislative history, see U.S. Department of Health and Human Services, Food and Drug Administration, Guidance for Industry: Prescription Drug Marketing Act (PDMA) Requirements, Questions and Answers (Rockville, MD: Food
In 1966, Freinkel left his position as Director of the Diabetes and Metabolism Division at the Boston City Hospital to become the Chief of Endocrinology and Metabolism at Northwestern University in Chicago. He brought with him to Chicago the knowledge of how to gain substantial funding for research and the connections to make it happen. During his tenure at Northwestern, Freinkel would connect diabetes physicians and scientists in the field to other medical professionals, to businesses in the diabetes market, and to legislators who controlled healthcare financing. In addition, Freinkel worked to make research results and developments in treatment strategies from Northwestern accessible to broad sectors of society: areas of the medical community, government officials, popular media, patients, and the lay public.³⁰

Freinkel and his colleagues at Northwestern began a practice of “translating” their research findings into information and education for legislators and for the general public and, eventually, into clinical practice recommendations for women facing urinary sugar, or raised blood sugars, during pregnancy. Although today we have become accustomed to popular media reports on how research advances have given us better healthcare services or improved medications, in the 1960s and even into the 1970s it was a novel concept for researchers to publicize that work. That the Northwestern University researchers broke new ground with their efforts would become apparent during the 1970s.
when their research findings were written into legislative acts like the 1974 Diabetes Research and Education Act and the 1979 reorganization of the World Health Organization’s classification rubric for diabetes.

During the 1960s and 1970s, researchers at institutions like the Diabetes in Pregnancy Center (DPC) at Northwestern University in Chicago gained incredible influence in shaping public health policy. The rapid growth in federal support for medical research built the DPC at Northwestern out of the Division of Endocrinology and Metabolism and allowed the center to become a driving force in formulating policies on pregnancy in diabetic and pre-diabetic women. The connections to legislators that came with the funding of the DPC placed investigators like Norbert Freinkel on congressional planning committees, on task forces within federal agencies like the NIH, and on data review boards that made decisions on prioritizing the dispersal of federal money for medical research.

Such connections allowed for greater sway with issues relating to diabetes and pregnancy, and such links were essential for reframing the condition of pre-diabetes of pregnancy into the disease gestational diabetes. But these connections were not established in a social vacuum. The climate of rising expectations for the promise of medical research developed alongside efforts to improve the state of healthcare in general and, more specifically, to combat the fear of a chronic disease epidemic in the United States. As part of what scholars have called the professionalization of American

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31 The hallmark event in the “epidemiological transition” from infectious agents to chronic illness was the Framingham Study, which was designed to understand the “modern epidemic” of heart disease. See Thomas R. Dawber, Gilcin F. Meadors, and Felix Moore, “Epidemiological Approaches to Heart
medicine, the bevy of federally-funded initiatives to contain communicable disease had also helped to create the foundation for medical research on chronic diseases like diabetes.\textsuperscript{32} Three major federal efforts that set the groundwork had come in quick succession: the Hill-Burton Act in 1945, the formation of the Center for Disease Control in 1946, and the expansion of the National Institutes of Health in 1948. Hill-Burton poured millions of federal dollars into building a national hospital system that answered to government entities, which essentially wrested control of healthcare from voluntary organizations and local municipalities. With urging from the American Medical Association (AMA), Surgeon General Thomas Parron then expanded the scope of Hill-Burton by transforming the old Malaria Control in War Areas office and the venereal disease programs of the U.S. Public Health Service into the Center for Disease Control (CDC) in Atlanta and by giving the new agency a regulatory role over medical research. Over the next two years, the still relatively new National Institute of Health (NIH) was incorporated into the growing public health infrastructure and, by 1948, Congress mandated control of three major research institutes, and their private and state funds, into the umbrella of the NIH.\textsuperscript{33}

\textsuperscript{32} On federal funding for public health efforts to contain infectious diseases, see Starr, \textit{The Social Transformation of American Medicine}, 145-179.

\textsuperscript{33} For more detail on the birth of federal venues for research dollars and on the creation of federally-funded and federally-controlled medical facilities, see John Duffy, \textit{The Sanitarians: A History of American Public Health} (Chicago: University of Illinois Press, 1990), 239-272; and Starr, \textit{The Social Transformation of American Medicine}, 338-351 and 375-378. At the same time, the International Health Conference was held in New York during the summer of 1946. American physicians and policy makers
Those federal initiatives generated a significant level of financial support that would allow physicians to embrace the role of researcher. Diabetes was one of the main targets in those first federally supported research grants, just as it had been with the private, philanthropic agencies like the Rockefeller Institute and the Duke Endowment. Also among those top targets were heart disease and cancer because those three had become the leading causes of death in postwar America, when infectious diseases were significantly ameliorated through antibiotics, vaccinations, and sanitary practices.³⁴

A growing belief in the power of medicine, and in the research that bolstered it, led to federal appropriations for many new programs and initiatives in diabetes care. Widespread public concerns about the rising numbers of “hidden” diabetics converged with the growing belief in medicine and research as the solution to all sorts of public health issues.³⁵ By mid-century, Congress had endowed the U.S. Public Health Service with the budget and authority to fashion specific grants for medical research and education on a range of diabetes issues.³⁶

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³⁵ The Public Health Service Act of 1944 resulted in one of the first in a string of larger government commitments to funding medical research, and it designated medical research as a major priority in national policy. See Starr, *The Social Transformation of American Medicine*, 342-344.

³⁶ In the 1940s, the American Diabetes Association teamed up with the American Medical Association to implement a program to detect the suspected mass of people who had the mild form of
Along with those early moves toward the creation of federal research budgets, physician groups like the American Medical Association (AMA) and the American Diabetes Association (ADA) introduced national campaigns to combat the effects of chronic disease by trying to identify debilitating illnesses before the diseases could take a toll on individuals and on the U.S. economy as well.\(^\text{37}\) However, those programs did not always turn out the way that the enthusiastic proponents of risk factor identification hoped for. In 1963, for example, the Diabetes Association of Greater Cleveland (DAGC) implemented a program endorsed by both the AMA and the ADA to identify the “million hidden diabetics” in the United States.\(^\text{38}\) By the mid-1970s, that program would result in the DAGC having screened over six hundred thousand people for diabetes by setting up booths in shopping malls, sites at businesses, and testing centers at community events throughout the Greater Cleveland area.\(^\text{39}\) However, even before the project in Cleveland was scrapped in the 1970s, it had been deemed a failure. The costs had overwhelmed the diabetes but did not know it because they were not having health problems severe enough yet to send them to a doctor’s office. Suspicions on the large numbers of people with undiagnosed, and therefore untreated, diabetes was a result of the landmark Oxford Study that had found nearly twice as many people with lab tests conclusive of diabetes than the number of people reporting that they had diabetes. See American Diabetes Association, *The Journey and the Dream: A History of the American Diabetes Association* (Indianapolis: American Diabetes Association, 1990), 40-44.

\(^\text{37}\) The ADA began in 1941 as a strictly professional organization open only to physicians but began to allow other medical professionals such as nurses and nutritionists to join the organization during the 1960s. In 1970, ADA members voted to restructure the organization’s constitution to change it into a voluntary organization open to the public that was primarily concerned with funding research, detection drives, and education. See *Journey and the Dream*, 151-160.


\(^\text{39}\) Merkatz, et.al. “Screening Program,” 454.
DGAC and the local city council. Moreover, any analyses on data amassed from the efforts to identify Greater Cleveland’s “hidden diabetics” created heated debates. Local physicians often dismissed the diagnostic results in their patients that had been obtained from the screening drives. They argued over whether the screening was done correctly and belied what they saw as arbitrary recommendations from outsiders for medications for their asymptomatic patients.\footnote{Harold B. Houser, Wilma Mackay, Narendra Verma, and Saul M. Genuth, “A Three Year Controlled Follow-Up Study of Persons Identified in a Mass Screening Program for Diabetes,” \textit{Diabetes} 26, 7 (July 1977): 619-627; and Saul M. Genuth, Harold B. Houser, James R. Carter, Jr., Irwin R. Merkatz, J. Wade Price, O. Peter Schumacher, and Ralph G. Wieland, “Observations on the Value of Mass Indiscriminate Screening for Diabetes Mellitus Based on a Five Year Follow-Up,” \textit{Diabetes} 27 (April 1978): 377-383.}

The fallout from failed programs like the DGAC would spill over into other initiatives. Almost a decade later, because of the history of controversy over the mass screening events by the DAGC, a group of obstetricians working in a low-income, inner-city clinic in East Cleveland would recommend smaller-scale, targeted, “discriminate screening” for raised blood sugars in the pregnant women at their clinic. Because of the financial fiasco from those earlier screening efforts, and the bureaucratic arguments that erupted, the obstetrical group would suggest \textit{focused} screening on \textit{specific} at-risk women to find “a compromise between specificity and sensitivity in order to provide maximum clinical utility and cost effectiveness.”\footnote{Merkatz, et.al. “Screening Program,” 456.}

Debates like the one at the inner-city clinic in Cleveland, Ohio were not unique, and they had emerged from the same climate within which research centers like the DPC at Northwestern struggled to operate during the 1960s. Such arguments reflected the serious fiscal challenges and the delicate nature of
political collaborations faced by physicians starting their new careers in research on diabetic pregnancy.

In that complex social, political, and scientific environment surrounding diabetes and diabetic pregnancy, Norbert Freinkel arrived at Northwestern. Freinkel became Director of the new Diabetes in Pregnancy Center on the heels of the creation of the National Institute of Child Health and Human Development (NICHD) by President Kennedy. Under Freinkel’s direction, the new center at Northwestern secured one of four initial grants from the NICHD, which had been slated to create Major Research Programs (MRPs) across the country. And the recruitment of a highly respected young researcher in diabetic pregnancy metabolism became, of course, instrumental in securing Northwestern University’s designation as a Major Research Program of the NICHD.\(^{42}\)

The first four MRPs were specifically entrusted with combatting the high infant mortality and morbidity seen in diabetic pregnancies by educating pregnant women on the need for good diet, exercise, and regular doctor visits. The President’s sister, Eunice Kennedy Shriver, and her politician husband, Robert Sargent Shriver, were instrumental in the creation of the NICHD and, more important, in the substantial research funding that the agency would garner for investigating birth defects. That focus meshed well with Freinkel’s research work and with the connections he had cultivated before coming to Chicago. The other three programs were established at Cleveland Metropolitan Hospital,
the University of New Mexico in Albuquerque, and Brown University in Providence, Rhode Island.43

The complex set of variables that brought the MRP to Northwestern illustrates how the glycosuria and transient high blood sugars seen in pre-diabetes of pregnancy, or as some researchers were starting to call it by then gestational diabetes, were becoming viewed as something more than simply a temporary condition.44 American investigators had originally studied the condition as an indicator of potential risk for the pregnant woman to develop diabetes later in life, but by the 1960s that line of research had begun to merge with European investigations that focused instead on the impact of raised blood sugars for the fetus in those pregnancies. The funding protocols for the MRPs connected both research foci by emphasizing the impact of a pregnant woman’s health behaviors on the fetus. The MRP protocols required researchers to use their findings to design and

43 Hansen and Cohn, “Diabetes Research and Training Centers”; and The National Commission on Diabetes, “Long Range Plan to Combat Diabetes,” U.S. Department of Health, Education and Welfare, DHEW publication no. (NIH) 76-1018-1024, 76-1031-1033, and 77-1229. These reports do not contain the agency budgets but the creation of the National Commission on Diabetes and the authority for the NCD to set research budgets came out of the National Diabetes Research and Education Act of 1974, PL 93-354. The National Commission on Diabetes was the brainchild of Lee Ducat, a Pennsylvania mother who had a son with diabetes, and Senator Richard Schweiker (R-PA), an influential friend of Ducat’s.

44 Two European researchers, Joseph Hoet and Jorgen Pedersen, are both credited with introducing a new name for the condition: metagestational diabetes. Pedersen is said to have eventually shortened the term to gestational diabetes. It is difficult to tell who coined the term “metagestational diabetes” first and exactly when it came into use. It is entirely possible that Jorgen Pedersen began using the term gestational diabetes before Hoet coined the term metagestational diabetes. In several short historical synopses in medical textbooks, two articles by J.P. Hoet are usually referenced, but instead of using the exact term, both of Hoet’s articles mention metagestational influences or factors and he uses the term diabetes in discussing the condition in pregnancy. Confounding the problem is that both researchers wrote in at least three different languages each. The references in textbooks, though, seem to have taken on a life of their own and became the standard citation. See, Joseph P. Hoet, “Carbohydrate Metabolism in Pregnancy,” Diabetes 3 (1954): 1-12 and Joseph P. Hoet, J.J. Hoet, and A. Gommers, “Endocrine Disturbances of Pregnancy and Foetal Pathology,” Proceedings of the Royal Society of Medicine 52, 10 (October, 1959): 813-816. It seems that the article in which the words were combined and the term was used was an article by Hoet’s physician son. See J.J. Hoet, “Le Diabete de la Gestation,” Bulletin et Memoires de l’Academie Royale de Medecine de Belgique 7 (1969): 118.
implement educational programs to teach women good health behaviors that could protect the health of their unborn babies.\textsuperscript{45}

At the same time that Freinkel was pursuing the MRP funding, Northwestern University had also begun to establish a new link to maternal and infant welfare programs among indigent clients in the Chicago area. Presaging the allocation of MRP funding, but aligning with the intention of NICHD protocols, the dean of the Medical School at Northwestern, Richard Young, sent a letter to the coordinator of a congressional study on indigent health care in urban centers, expressing the medical center’s interest in participating in the proposed “Poverty Program” in Chicago. The program was part of President Johnson’s “War on Poverty,” funded and coordinated by the new Office of Economic Opportunity (OEO).\textsuperscript{46} The Chicago Board of Health had just completed a large-scale study on health problems in the low-income neighborhoods in and around Chicago and had submitted their report to the OEO. The report noted that zero percent of pregnant, indigent clients were seen for care at Northwestern University, and as part of their proposal to develop a medical program for Chicago’s low-income residents, the Board recommended that a new center for healthcare and research should be “attached to or affiliated with a medical school, teaching hospital, [and] community hospital.” The Board of Health did not specifically name Northwestern in their recommendations, but Northwestern University’s medical center was the only institution in Chicago that fit that description: healthcare and research, teaching hospital, and medical school. The

\textsuperscript{45} Hansen and Cohn, “Diabetes Research and Training Centers.”

\textsuperscript{46} Richard H. Young, MD to Dr. Mark Lepper, October 12, 1965, letter in files of Dr. Boyd Metzger, Feinberg School of Medicine, Northwestern University.
proposal specifically requested funding both for the “support of the infant welfare and prenatal clinics” as well as for high caliber research to guide medical care in diabetes and pregnancy.\footnote{Chicago Board of Health, “Preliminary Report on Patterns of Medical and Health Care in Poverty Areas of Chicago and Proposed Health Programs for the Medically Indigent,” Chicago, July 1965, copy available from Records of the Southern Christian Leadership Conference, 1954-1970, Part 2: Records of the Executive Director and Treasurer, Subgroup II, Executive Director, Series IV, Andrew Young, Subseries 3, Administrative Files, \url{http://web.lexis-nexis.com/histvault?q=001565-011-0174} (accessed February 22, 2012). On the utilization of health services by indigent patients, see Table 8 (no page number, inserted between pp. 46-47); on the proposal for health care delivery to indigent populations, see pp. 150-151. I have to thank Dr. Tom Jackson for alerting me to the online archive of SCLC documents that led to finding the report from the Chicago Board of Health, which I knew existed but for which it seemed that no copy had survived. The report included a copy of the letter in Dr. Boyd Metzger’s files from Dean Young of Northwestern University, confirming that the letter indeed referred to the Poverty Program under Johnson’s War on Poverty and that the report referenced in the letter indeed existed.}

Compatible funding for research on diabetic and pre-diabetic pregnancies, and on healthcare for indigent pregnant women, greatly expanded the work of Freinkel’s group at Northwestern. Such complementary funding, like the grant support from the OEO and the monies from the NICHD, resulted in an impressive amount of fiscal support for research on diabetes and pregnancy at Northwestern’s Diabetes in Pregnancy Center. By the time that the NIHCD issued its first annual report to the Director’s Office of the NIH, the Diabetes Mellitus Coordinating Committee (the precursor to the congressionally-mandated National Commission on Diabetes) listed eighteen federal grants through the NICHD that focused specifically on issues of diabetic pregnancies and that totaled over three-quarters of a million dollars for the fiscal year.\footnote{Diabetes Mellitus Coordinating Committee, “First Annual Report to the Director of the National Institutes of Health, Fiscal Year 1974, DHEW Publication No. (NIH) 76-1017, 172-174.}

The funded projects focused on “diabetes in pregnancy and the influence of this disorder on the mother, the fetus and the newborn, and with the influence of age on carbohydrate metabolism.” The addition of
“carbohydrate metabolism” to the research agenda was a direct nod to the condition of pre-diabetes of pregnancy, as that was language used specifically in medical discussions about the condition.\textsuperscript{49}

\textit{The National Diabetes Research and Education Act}

As much as the resources of President Kennedy’s National Institute of Child Health and Human Development (NICHD), Johnson’s War on Poverty programs, the grants from the Office of Economic Opportunity (OEO), and the fiscal support from diabetes healthcare companies like Ames, Squibb, and Eli Lilly helped to support and expand Northwestern University’s DPC, researchers there still faced the problem of turning their findings into recommendations for clinical practice. Increased scientific knowledge and technological advances could not alone change the therapeutic approach to the condition known variously as glycosuria of pregnancy or pre-diabetes of pregnancy.

In the mid-1970s, one of the most far-reaching pieces of legislation for diabetes research ever would open a channel for researchers in diabetic and pre-diabetic pregnancies to affect the clinical approach to such pregnancies by substantially increasing the financial support of their work – through individual grants and through the creation of collaborative research centers – and by bringing researchers into health policy roles in congressional committees. In one of his last actions as President of the United States, Richard Nixon signed into law the National Diabetes Mellitus Research and Education

\textsuperscript{49} Ibid., 172.
Act (DRE Act) on July 23, 1974. Nearly glossed over due to the enormous amount of
time spent on the energy crisis that session, the vote came at the last hour but passed
overwhelmingly. President Nixon resigned two weeks later. The law codified the
National Commission on Diabetes, created the National Diabetes Data Group (NDDG),
specified that the Commission and the NDDG would report directly to Congress, and
mandated the creation and federal support of research centers with $40 million of
financing through several NIH institutes as well as with continued financing through the
NICHD. The NICHD was, of course, already a major funding agency for the MRP at
Northwestern and an important liaison agency for Chicago’s Poverty Program. Under the
DRE Act, though, the budgets at places like Northwestern expanded tremendously and
fell under the management of the House and Senate Committees on Appropriations, as
well as the Committee on Labor and Public Welfare of the Senate and the Committee on
Interstate and Foreign Commerce of the House. The connections were elaborate and the
funding scheme was complex because diabetes and pregnancy research initiatives had
developed piecemeal within the intricate web of ties connecting medicine, business, and
government.50

The 1974 DRE Act created a substantial source of research funding and built a
firm foundation for the DPC at Northwestern to translate research on pre-diabetic
pregnancies into medical interventions. Less recognized, however, was how the DRE
Act embedded the interest of the state in matters of diabetic pregnancy. The creation of

50 National Diabetes Mellitus Research and Education Act, 1974, Pub. L. No. 93-354, 93rd
Congress (July 24, 1974). On the amounts of financing and for a very brief chronology of committee
reports, congressional votes, and actions of sponsors and co-sponsors of the bill, see American Diabetes
committee roles for health services researchers with the National Commission on Diabetes and of lobbyist roles inside the House and Senate Committees on Appropriations had finally opened a channel for prominent researchers like Norbert Freinkel to advise government officials on healthcare policy. The process that Freinkel would follow to turn medical research findings into clinical practice for pre-diabetes of pregnancy had been written into the structure of government agencies. As spelled out by more than half of the text of the DRE Act, the function of the National Commission on Diabetes was controlled by Congress, but its committee members also gained advisory roles in subcommittees within the Senate Committee on Labor and Public Welfare and the House Committee on Interstate and Foreign Commerce. Research needed to be translated into healthcare practices and with the DRE Act that process of translation would go through the United States Senate and the House of Representatives.\(^{51}\)

The channels for researchers created by the DRE Act were actually foreshadowed in the flurry of near-frantic activities that led up to the passage of the bill. In March of 1974, for instance, a private memo circulated at the Joslin Diabetes Clinic about the possibility of increased money for diabetes research through a congressional bill that was in jeopardy of being buried in a “political graveyard.”\(^{52}\) The memo discussed the proposed bill “calling for the expenditure of a considerable amount of funds for research and related activities [concerning diabetes]” and noted that one of the bill’s sponsors, Congressman William A. Steiger, was a member of the Board of Directors at the Joslin

\(^{51}\) National Diabetes Mellitus Research and Education Act, 1974, Pub. L. No. 93-354, 93rd Congress (July 24, 1974), Section 3.

\(^{52}\) American Diabetes Association, *Journey and the Dream*, 162.
Diabetes Foundation. The memo was typed on a small note-sized piece of paper with the list of individuals who were to read it, check their name, and pass it on privately to the next person on the list. Although Congressman Steiger was on the Board of Directors, his name was conveniently left off of the memo’s circulation list.\textsuperscript{53} Those types of information chains, formal and informal, existed in places like Northwestern as well, evidenced by the bevy of letters sent to Congress from researchers in support of the proposed bill. The DPC faculty from Northwestern sent letters to Congress in order to call attention to their research priorities. In 1974, Dr. Boyd Metzger, who had joined Norbert Freinkel at Northwestern, wrote “to lend support to the Diabetes Commission in formulating recommendations to Congress.” His letter delineated the current research progress at Northwestern. Metzger stressed the importance of the research program at Northwestern for connecting their research and medical interventions to the prevention of birth defects by asking, “Can quality of diabetic control be implicated here?” And, when he connected gestationally diabetic pregnancies to “congenital anomalies,” he engaged legislators who had so strongly supported the goals of Eunice Kennedy Shriver’s work in the NIHCD by using familiar language. Because of the work of the NIHCD on such public health issues as the thalidomide scare and the vaccination program for rubella, the linking of “congenital anomalies” with “diabetic control” had a resounding impact.\textsuperscript{54}

\textsuperscript{53} Richard L. Dowling, Ph.D. to Members of the Youth Committee, “Congressional Legislation” March 22, 1974, Carton 1, Folder 25, Priscilla White Papers, Schlesinger Library.

\textsuperscript{54} Dr. Boyd Metzger to The National Commission on Diabetes, undated, in “The Long-Range Plan to Combat Diabetes,” Report of the National Commission on Diabetes to the Congress of the United States, vol. 1, DHEW Publication No. (NIH) 76-1018, 23-26, quotes on pages 23, 25, and 26 respectively. On the
work of agencies like the NIHCD on creating a mandatory, universal vaccination program for rubella, or German measles, see Reagan, Dangerous Pregnancies.
Immediately following the passage of the Diabetes Research and Education Act, Freinkel and his colleagues at Northwestern applied to become one of the new Diabetes Research and Training Centers (DRTC) mandated by the legislation. The program at Northwestern was not converted to a DRTC in that first round of funding, but a collaborator of Freinkel, Arthur Rubenstein of the University of Chicago, managed to secure one of the first eight centers. Those first eight sites all had important connections to policy makers and government agencies, connections that ultimately gave greater standing to their applications for a DRTC and that had been created through the web of new relationships in the research arena of diabetes and pregnancy. Norman Fleischer, who became director of the DRTC awarded to Albert Einstein College of Medicine in New York, started his career with a research fellowship under Oscar Crofford of Vanderbilt (another of the initial eight centers), who because of his earlier work as a lobbyist became the first chairman of the National Commission on Diabetes and the lead investigator for the landmark, multi-center Diabetes Control and Complications Trial (DCCT) mandated through the DRE Act. Fleischer had also worked with Charles Clark of Indiana University (also one of the eight new DRTCs), who would become president of the American Diabetes Association (ADA). And Indiana undoubtedly received higher priority for one of the DRTCs because of Clark’s Robert Wood Johnson Fellowship that had placed him in Washington in a health policy role under Senator Dale Bumpers (D-AR), a role that also connected Clark to Senator Richard Schweiker, the main architect of
the Diabetes Research and Education Act. Suffice it to say that the connections and relationships ran deep.\textsuperscript{55}

Pregnancy had become absolutely central to government-funded diabetes research by the 1970s because it accounted for a majority of the funded studies on diabetes issues and because the clinical investigators who were taking on policy roles came from that area of diabetes research. Of those first eight DRTCs, half identified diabetic pregnancy as the area of priority and the other four also had main projects that focused on diabetic pregnancy.\textsuperscript{56} In 1977, with an additional five million dollars, Congress approved five more DRTCs. The Major Research Program (MRP) at Northwestern was converted to a DRTC and became a fully funded research center in 1977. As Dr. Boyd Metzger explained, the work at Northwestern was mostly in animal models at first because of limited funding. In order to turn their research work into healthcare practices for pregnant diabetic women, they needed the fiscal support that came from DRTC status. Once Northwestern University’s Diabetes in Pregnancy Center received the NIH-controlled funds, “the clinical arm expanded and people and patients came in.”\textsuperscript{57}

Even with the funding and influence that investigators in the field had garnered, the social milieu surrounding diabetes contributed to an on-going lack of widespread acceptance of their research findings. Many clinic-based physicians remained reticent

\textsuperscript{55} Many of these connections were pieced together by examining online Curriculum Vitae and then asking interviewees to discuss the connections. See also Freinkel memoir; Moshe Hod, interview by Mark Perloe, October, 1999, \url{http://www.obgyn.net/avtranscripts/perloe_hod.htm} (accessed October 12, 2009); Metzger interview; Coustan interview; Hare interview; and Snyder, “Oscar Crofford.”

\textsuperscript{56} Hansen and Cohn, “Diabetes Research and Training Centers,” 550-552.

\textsuperscript{57} Metzger interview; and Snyder, “Oscar Crofford.”
about diagnosing a woman with any form of diabetes, regardless of whether it was called glycosuria of pregnancy, pre-diabetes of pregnancy, or gestational diabetes. The negative public perception of diabetic patients, which was especially difficult for diabetic women, made many physicians hesitant to accept lower thresholds for diagnosis. Women with diabetes could become pregnant women with diabetes, a possibility that conjured a sense of immediacy, but the diagnosis was not a benign label. Moreover, in the shadow of the new “perinatal movement” that focused on the well-being of the baby in high-risk pregnancies, pregnant women diagnosed with diabetes – of any form – were responsible as well for a second patient: the unborn child. And when the unborn child became the focus of concern, what diabetic or pre-diabetic women did during their pregnancies was no longer a private matter.58 Boyd Metzger explained, “The diagnosis [of gestational diabetes] was not given lightly … [instead] we wanted to capture people who were so at risk that the pejorative baggage was outweighed by the potential problems for the baby.”59

Diabetes itself acquired a significant social stigma shortly after the discovery of insulin, when the perception of the disease shifted from being seen as an acute and deadly

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58 Merkatz, et.al. “Screening Program,” 453. Also, a review article that discussed the impact of the perinatal movement, or what legal analysts were calling the fetal rights movement, on medical care for pregnant women and on depictions of culpability for pregnant women appeared in 1986; see Dawn E. Johnsen, “The Creation of Fetal Rights: Conflicts with Women’s Constitutional Rights to Liberty, Privacy, and Equal Protection,” The Yale Law Journal 95, 3 (January 1986): 599-625. The issue finally came to a head within the AMA by the late 1980s when a subcommittee within the AMA drafted a position statement on physician responsibility in identifying, defining, and confronting negligent and dangerous health behaviors in pregnant women; see American Medical Association Board of Trustees Report, “Legal Interventions during Pregnancy: Court Ordered Medical Treatment and Legal Penalties for Potentially Harmful Behavior by Pregnant Women,” Journal of the American Medical Association 264, 20 (November 28, 1990): 2663-2670.

59 Metzger interview.
illness of mostly children from higher-income families, to one of a chronic and costly illness of adults from a more diverse and less wealthy sector of society. Detection drives had continued across the nation during the 1960s, and those drives also increased the public awareness of racial differences in the prevalence of diabetes.

Diabetes physicians and researchers often avoided addressing the issue of race directly in professional journals, but the uncomfortable issue of race and diabetes made headlines in 1963 with an accidental discovery on a remote Indian reservation in the Sonoran Desert of southern Arizona. A federally-commissioned study on rheumatoid arthritis among the Pima Indians of the Gila River Community discovered that over two-thirds of adult Pima Indians on the reservation had “hidden” diabetes and at least one-third of pregnancies on the Gila River Indian Community were pre-diabetic.

Researchers and physicians could no longer tiptoe around the issue that certain racial and ethnic groups – Asians, Hispanics, Native Americans, and to a lesser extent African Americans – exhibited both a higher incidence and a greater degree of blood

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60 For a more thorough discussion on the emergence of a pejorative popular image of diabetes, see Chapter 1 of this dissertation; and Chris Feudtner, Bittersweet: Diabetes, Insulin, and the Transformation of Illness (Chapel Hill: University of North Carolina Press, 2003).

sugar increases, especially affecting women during pregnancy. But women in minority
groups found that the recommended educational programs and interventions were
stymied by “payment denials” for the more intensive prenatal care. As John Hare
explained, “Without a recognized diagnosis, women couldn’t pay extra … and those at
the lower end of the threshold were money drains with little gain.”

Although the engine of medical research was growing, investigators had to convince physicians to follow
proposed policies for which no valid statistical data existed, while answering to policy
makers concerned with growing concerns about the uneven rates of the condition in non-
white groups of women – women who generally lacked private insurance.

In the midst of the growing controversy, Norbert Freinkel and Boyd Metzger learned that the World
Health Organization (WHO) planned to revise the diagnostic category for Diabetes
Mellitus in an update to the International Classification of Diseases (ICD). The pair
began to organize a conference, and they invited colleagues in the field to Chicago in
order to draft a recommendation for gestational diabetes to be added to the category of
diabetes as a separate form of the disease.

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62 Hare interview.
63 Ibid.
The First International Workshop-Conference on Gestational Diabetes Mellitus

By the late 1970s, researchers and clinicians working on the disorder realized that in order to implement standardized screening for raised blood sugars during pregnancy and to convince medical practitioners to take seriously the potential problems with the condition, they would have to find a way to transform the condition of pre-diabetes of pregnancy into the disease gestational diabetes. Reporting research findings, publishing articles and position statements, and crafting detailed recommendations had not sufficed. The DRE Act had taken researchers like Norbert Freinkel a long way toward bringing attention to the problems faced by pregnant women who presented with glycosuria or a raised blood sugar, but research findings still needed to be put into clinical practice.

Freinkel and his colleagues organized the First International Workshop Conference on Gestational Diabetes to detail the potential harm to the fetus from the condition, to establish the best methods for detecting it, to explore the possibility of testing all pregnant women, and to decide what therapeutic interventions were justified. The conference was held November 9 and 10, 1979 at the Northwestern University Medical School in Chicago, Illinois, and was financed by the American Diabetes Association (ADA), the American College of Obstetrics and Gynecology (ACOG), the NIH, the CDC, and McNeil Laboratories. McNeil Laboratories was a diagnostics and pharmaceutical company that had been acquired two years prior by Johnson & Johnson, an acquisition that placed Robert Wood Johnson in the position of CEO and united the
company with political lobbyists through the Robert Wood Johnson fellowships that had been established for physician-researchers to learn healthcare policy roles in Congress.64

With over three million live births in the United States each year, at least 3 percent of which Freinkel believed could be diagnosed as pre-diabetes of pregnancy, the increasing national attention paid to preventive healthcare, he claimed, should include as well the nine months of a pre-diabetic pregnancy’s impact on the fetus.65 The conference summary defined the condition as “glucose intolerance with recognition of onset during pregnancy” and recommended diagnosis with the testing criteria established nearly two decades earlier in John O’Sullivan’s study at the Boston City Hospital.66 Freinkel formally submitted the findings and recommendations of the conference to the National Diabetes Data Group and requested that the submission be forwarded to the World Health Organization for use in the upcoming revision of the terminology and classification of Diabetes Mellitus in its international compendium of diseases.67

In 1980, the World Health Organization published the ninth revision of its manual for disease classifications, the ICD-9. Under the category of Diabetes Mellitus, three distinct forms were listed: Type 1 Diabetes Mellitus, Type 2 Diabetes Mellitus, and

67 Freinkel, “Summary and Recommendations,” 501; and Metzger interview.
Gestational Diabetes Mellitus. The process of creating and defining this “new” disease, designated as 648.8 in the international disease compendium, involved as much bureaucratic as scientific labor.\(^{(68)}\) Its creation had essentially occurred in a series of policy meetings, illustrating the extent to which medical research had become an interface between physicians, policy makers, and businesses. The research that established a link between raised blood sugars during pregnancy and potential problems for the pregnant woman and her unborn child was translated into healthcare practices through the channels of congressionally-mandated committees and legislative work groups.

Once Gestational Diabetes Mellitus (GDM) was added to the International Classification of Diseases, Ninth Revision (ICD-9) in 1980, Freinkel and many of his colleagues felt they had cleared the proverbial hurdle. After decades of work, they had finally gained influence in policy decisions regarding pregnant women at risk for gestational diabetes. The decade that followed, though, would be filled with controversy over diagnosing the new disease. With many physicians questioning why the disease should be identified at all, arguments about screening for it had just begun to take center stage. There would be technical problems with changes in diagnostic chemistry – some

\(^{(68)}\) For the full list of diseases under the numerical heading of 648, see: http://www.icd9data.com/2012/Volume1/630-679/640-649/648/default.htm (accessed November 1, 2012); and for the full list of numerical codes for the disease category of diabetes, see: http://www.icd9data.com/2012/Volume1/240-279/249-259/250/default.htm (accessed November 1, 2012). The numerical category of 648 includes “Other Current Conditions in the Mother Classifiable Elsewhere but Complicating Pregnancy, Childbirth, or the Puerperium.” The numerical category of 250 includes all categories of “Diabetes Mellitus.” For a brief summary of references to gestational diabetes as a non-entity in the discussions that led up to that first conference in Chicago, see R.J. Jarrett, “Gestational Diabetes: A Non-entity?” British Medical Journal 306 (January 2, 1993): 37.
laboratories, for instance, used whole blood for testing while others used plasma. There was a lack of up-to-date epidemiological data. Results from the Boston Study that were used to define the disease were questioned because of a series of rounding errors.69

Don Coustan explained, “It had been a Tower of Babylon for all these years” because a convoluted system for implementing policies had taken shape within the intricate funding system that had developed over a period of decades. Recommendations funneled first through workgroups funded by agencies like the NIHCD and the OEO; then through the congressionally-mandated oversight committee, the National Diabetes Data Group; then through the National Commission on Diabetes, a subcommittee that fell under the control of the U.S. House Committee on Interstate and Foreign Commerce; and then through physician review boards in the American Medical Association (AMA). Committee members at all these levels came from a wide range of backgrounds as well – congressional liaisons, physicians, businessmen, the general public – and most “didn’t take all that into account … it was all like ‘sitting in a chair with a slide rule’ kind of thing.”70

69 Coustan interview. Twenty years earlier, John O’Sullivan had rounded his data points from the Boston Study to make the results and conclusions more accessible to physicians, and later, congressional committees had placed their own rounding estimates on top of that data. Then, the World Health Organization created a new formula for converting those lab results to make the data more accessible to policy makers.

70 Ibid.
Conclusion

In 1984, a group of physician-researchers met on the campus of Northwestern University in Chicago for the Second International Workshop-Conference on Gestational Diabetes Mellitus. The first conference, in 1979, had resulted in the recognition of gestational diabetes as a third, distinct form of diabetes when the World Health Organization (WHO) responded to the conference committee’s recommendations by adding the new classification to its compendium of diseases, the *International Classification of Diseases, Ninth Revision* (ICD-9). Officially defined as “glucose intolerance with recognition of onset during pregnancy,” the addition of GDM to the disease manual seemed a straightforward product of increased medical knowledge.\(^71\)

The summary from the second conference hinted at controversy over the “new” disease. The committee stressed the potential risks to both the fetus and the pregnant woman and discussed the need to convince women and their healthcare providers of the seriousness of GDM. The use of more benign terms that avoided the word “diabetes,” they said, was counter-productive to that goal. The physicians and researchers who had worked to codify GDM were well aware that a large number of the women facing the new diagnosis had inadequate access to healthcare, and in their summary, the committee members said that a diagnosis of GDM “communicates the need for ‘high risk’

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surveillance to providers of third-party payments or others responsible for the financing of health care delivery.”72

Researchers understood the need to craft policies that opened access to care for the growing numbers of women who received their healthcare through government-subsidized programs. Their recognition of and concern for that issue could be seen in the language used to define the new disease label – language that mirrored eligibility criteria to government-funded programs for lower-income women. But the use of those bureaucratic channels also shaped women’s personal and public experience of the new disease because of the public perceptions already attached to such social welfare programs. Even though debates about Gestational Diabetes Mellitus were structured around the language of science and medicine, the new disease would be defined within the framework of social welfare policy. Federal policy was embedded in the disease, which would be evidenced by the influence of AFDC, Medicaid, private health insurance, ICD-9 codes, and CPT codes on medical policies about the disease.

Because of the relationship between the medical meaning of GDM, the social understandings of the disease, and the federal policies that shaped its creation, struggles over medical care regarding GDM were shaped by policies outside the healthcare market that could control approaches inside the healthcare market – what economist Kenneth Arrow had famously dubbed “the welfare economics of medical care.”73 Florence Brown explained that intense debates over the influence of federal policy created a challenge for

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72 Organizing Committee, “Summary and Recommendations,” 123.
73 Arrow, “Uncertainty,” 141-149.
clinicians but those debates also even derailed programs. “This is where we really missed the boat,” she said, “because we lose them to follow-up after their pregnancies are over.” Policies for financing medical care have forced the use of outdated diagnostic criteria, but newer research, Brown predicted, “will at least double the number of women diagnosed with gestational diabetes and we’re not ready for that.”

In the post-World War II era, the research industry embedded within the Medical-Industrial Complex substantially influenced healthcare policy in the United States. The network of scientists in the new industry of health outcomes research became linked to clinicians, pharmaceutical representatives, Senators, and Congressmen. The roles they gained in health policy allowed their research findings to be turned into clinical practice and national preventive health measures. The millions of dollars that supported grants, research centers, and legislative initiatives created new career paths for physicians-turned-researchers and turned their work on diabetes and pregnancy into a measure of national importance. The classic history of disease creation has suggested that new concepts of disease emerge from changing social perceptions, but that formula does not fit for gestational diabetes. Scientific advances shaped medical understanding, but the reframing of glycosuria of pregnancy from a condition of low priority into a disease that required universal testing came out of the work of unlikely partnerships, and the public perception of the women diagnosed was a consequence, not a cause.

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74 Florence Brown, interview with author, August 11, 2010, tape in author’s possession.
CHAPTER VIII
GESTATIONAL DIABETES MELLITUS:
MEDICINE, CULTURE, POLICY, AND BUSINESS

In 1980, the World Health Organization (WHO) added a new form of diabetes to its disease compendium: Gestational Diabetes Mellitus (GDM). Inclusion in the classification system granted a sort of officialdom to an illness because by then the manual was being used throughout the Western world to create consensus in diagnostic standards; to compile consistent epidemiological data for statistical analyses; to construct reimbursement strategies for third-party payer systems; and to develop comparable language in medical circles. The new addition was defined as “carbohydrate intolerance of variable severity with onset or first recognition during pregnancy.”

As the 1980s progressed, however, it would become clear that the definition of gestational diabetes was not a matter of medical certainty. Most clinicians did “not view gestational diabetes as a disease but rather as a risk factor.” Women of the Pima Indian tribe in the Sonoran Desert of southern Arizona, who were being diagnosed with the new disease at an alarming rate, found themselves unsure about the diagnosis. One Pima

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woman summed up the collective confusion, “After they told me [I had it], I didn’t have it.” The *Washington Post* told its readers that gestational diabetes was just “a reversible diabetic state” that would go away for women who practiced good health habits.

According to a pamphlet produced by the pharmaceutical firm Becton Dickinson, gestational diabetes was “different than other types of diabetes” because it only happened during pregnancy and then went away. A major study at Mount Sinai Medical Center in New York said that pregnancies complicated by gestational diabetes were mostly in women who were non-white and poor.

This chapter argues that the process of creating gestational diabetes fundamentally shaped how the new disease and its patients became understood. The public confusion about gestational diabetes was in many ways a reflection of the complexity of redefining a biological phenomenon from acceptable to adverse. However, with gestational diabetes the complexity also arose from the impact of elements not typically recognized in studies of disease creation. Gestational diabetes was created within the bifurcated system of social welfare policy, and examining the process that reframed the condition elucidates the role that the state has gained in defining health and illness. Historians of medicine

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5 BD Consumer Healthcare, “‘My Doctor Says I Have Gestational Diabetes …’ What Do I Do Now?” (Franklin Lakes, NJ: Becton, Dickinson and Company, 1991), 4. This was the first printing of the pamphlet; two more versions were printed, the second in 1998 and the third in 2001.

have demonstrated how social context influences the need to define or redefine health and illness, but rarely have they focused on how the mechanics of creating a disease has shaped the social meaning of the disease.

Gestational diabetes quickly began to take on a negative image after being added to the classification rubric for diabetes because it became entangled with the broader view of diabetes as a disease of great public cost, and because many of the lower-income women encountering the diagnosis were defined by the way they accessed their healthcare. Florence Brown, Director of the Diabetes and Pregnancy Program at the Joslin Diabetes Institute in Boston, lamented that women diagnosed with gestational diabetes were often portrayed as culpable, as responsible for their diagnosis through some measure of personal negligence, a view similar to the media portrayal of diabetics in general as bringing the disease on themselves through negligent lifestyles and health behaviors. Even doctors, she noted, would sometimes suggest “that the person who has come to me with gestational diabetes … ate too much, that they’re gluttonous or hedonistic.”

Boyd Metzger, a physician and Professor Emeritus in Endocrinology at Northwestern University, explained that the focus on behavioral interventions with gestational diabetes resulted, to a great degree, in “the policing of lifestyles.” While research showed that lifestyle could influence the timing and the progression of both Type 2 diabetes and gestational diabetes, Metzger said, the connection between behavior and health outcomes was not necessarily so clear-cut for this condition. For Metzger’s

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7 Florence Brown, interview with author, August 11, 2010, tape in author’s possession.
overweight patients who came to the Diabetes in Pregnancy Center at Northwestern, for example, “weight [was] a modifiable variable, but in some ways not.” In fact, one only need look at the number of overweight and inactive people who do not have diabetes to understand the fallacy of equating lifestyle with causation.8

In the reframing of gestational diabetes, from a condition of little notice to a disease that required testing every pregnant woman, the process of creating the disease was itself a significant factor in shaping our social understanding of the disorder and the women being diagnosed with it. Prior to 1980, diagnosing a woman with gestational diabetes was counterproductive: it simply placed a label of diabetes without opening up medical interventions because it did not create a tract for reimbursement. But creating gestational diabetes in an operative sense – adding it to the international compendium of diseases – did not solve the problem of treatment in a functional sense. That solution would depend on proof that detection and intervention reduced health problems for women and their babies in a measurable and cost-effective way.

The process of “creating” gestational diabetes occurred within a bifurcated system of social welfare policy, and that mattered for how the disease and its patients became understood. The number of women being diagnosed with the “new” disease who received their healthcare through government-subsidized programs for the poor grew dramatically during the 1980s.9 Social welfare programs like Medicaid had become seen

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8 Boyd E. Metzger, interview with author, October 26, 2009, tape in author’s possession.

as fostering a “culture of poverty,” and women who sought assistance through such programs were often viewed as lazy and burdensome. Yet in order to diagnose and treat gestational diabetes effectively, it became necessary to craft policies that opened access to care for the substantial number of women who utilized public assistance programs. And that resulted in the language of federal policy from programs like Medicaid becoming embedded in definitions of the disease. For example, the wording for medical recommendations to diagnose and treat gestational diabetes would eventually mirror the eligibility text of federally-supported programs for the poor like Medicaid and Aid to Families of Dependent Children (AFDC).

Examining the actual process that reframed the condition also clarifies the role that the state has gained in defining health and illness. Historians debate the extent to which disease is socially constructed, and explain, for instance, that definitions of illness and health depend on such elements as time and place. For the purists of social construction, disease does not even exist until we name it. But many historians of medicine are medically trained, and the world of medicine privileges the reductive side of science – never completely dismissing social forces but viewing scientific knowledge and technological advances as the fundamental sources for defining illness. Certainly, for gestational diabetes, social constructs like time and place mattered; the condition had for over a century prior been viewed as temporary and mostly benign. Likewise, increased


medical knowledge and technological developments had changed physicians’ understanding of blood sugar variation and its consequences in very meaningful ways.\textsuperscript{12} Diabetes had already become a popular topic in the news by the 1980s, and as attention to “the obesity epidemic” grew, the assumption followed that obesity and diabetes went hand-in-hand.\textsuperscript{13} Such publicity also emphasized the increasingly disproportionate incidence of diabetes in minority populations. The Centers for Disease Control reports that, as a whole, diabetes affects over eight percent of the U.S. population, and non-white racial and ethnic groups experience prevalence rates as much as twice that of whites.\textsuperscript{14} Indeed, minority and low-income populations have long been known to have poorer health in almost all measures of healthcare and to have less access to everything, from preventive medicine to treatments for acute illnesses.\textsuperscript{15}

\begin{itemize}
  \item \textsuperscript{14} Although the terms “prevalence” and “incidence” are often used interchangeably by the lay public, each is a different measure of a disease’s occurrence. Prevalence refers to the total number of individuals who are affected by a condition at a specific point in time; incidence refers to the number of new cases in a particular time period, usually a calendar year. The distinction is important when examining rates of chronic illness in populations because prevalence gives us an understanding of the cumulative impact of a disease while incidence gives us an understanding of variations in diagnosis from one year to the next. These statistics are from the “National Diabetes Fact Sheet, United States, 2011” published by the Centers for Disease Control, \url{http://www.cdc.gov/diabetes/pubs/pdf/ndfs_2011.pdf} (accessed November 12, 2012).
  \item \textsuperscript{15} For a summary on race-based versus class-based disparity, see Vincent Navarro, “Race or Class versus Race and Class: Mortality Differentials in the United States,” \textit{Lancet} 336, 8725 (1990): 1238-1240. In 2003, the Institute of Medicine produced the benchmark government document on racial disparity in health care in the United States; see Smedley, et.al., \textit{Unequal Treatment}. The study, however, did not directly address class-based inequity because the United States is one of few Western nations that do not collect class-based data on health care utilization. For a more recent overview of the issue of health disparity in the United States, see Ichiro Kawachi, Norman Daniels, and Dean E. Robinson, “Health Disparities by Race and Class: Why Both Matter,” \textit{Health Affairs} 24, 2 (March/April 2005): 343-352.
\end{itemize}
Historians of medicine have typically examined the bureaucratization of healthcare to explain these unequal measures of health. Medical sociologists and physicians, on the other hand, have discounted such a relativist approach.\textsuperscript{16} Accepting biological differences as real, they have asked instead what these studies on health disparity actually measured and how those data have become embedded in policy.\textsuperscript{17} There are benefits to each approach, and each in some way acknowledges how social context has historically shaped definitions of disease.\textsuperscript{18} But with the post-World War II connections that emerged between medicine, business, and the state – often dubbed the Medical-Industrial Complex – physicians working on the condition that would become gestational diabetes recognized that disease creation was influenced increasingly less by scientific endeavor and more by public policies and business structures that addressed issues like disparity in access to care. In fact, the disparity that emerged with gestational


\textsuperscript{18} Rosenberg, “Disease in History.”
diabetes, from unequal access to care to disproportionate health problems, has not been solved – and cannot even be understood – without attention to its historical context.

Diagnosing Gestational Diabetes

In 1980, the World Health Organization (WHO) published the ninth revision to its International Classification of Diseases (ICD-9). By the middle of the twentieth century, the ICD had become the internationally accepted source to create a common language for identifying diseases and for tracking the causes of death and debility. Updating the compendium had become necessary because of rapid increases in medical knowledge and because of the never-ending development of new and different ways to name diseases, a development that if left unchecked stood to make meaningful diagnosis impossible across a wide range of diseases.19

One of the revisions slated for the 1980 version of the compendium was the taxonomy for Diabetes Mellitus. Even by mid-century, the existence of two types of diabetes was commonly agreed upon by medical professionals, but the convoluted naming rubrics to distinguish one type from the other had made understanding of the disease and distinctions between its patients difficult for even the most skilled doctor.20 A clear naming rubric was devised to identify and separate the two forms of diabetes, with one becoming Type 1 Diabetes Mellitus to replace the various names of juvenile


diabetes, severe diabetes, or insulin-dependent diabetes, and the other becoming Type 2 Diabetes Mellitus to encompass the plethora of names like fat, mild, non-insulin dependent, diet-controlled, or adult-onset diabetes. But unexpectedly for most physicians who relied on the disease compendium for filing insurance claims and for filling out death certificates, a third form of diabetes also appeared in the ICD-9, Gestational Diabetes Mellitus (GDM).

Gestational diabetes, at that time also called glycosuria of pregnancy or pre-diabetes of pregnancy, was not a newly discovered disease in 1980, nor was it even rare or unknown. Physicians had known for over a century about the appearance of glycosuria (or sugar in the urine) in some pregnant women, an event that most doctors of that time believed was confined to pregnancy. With the development of more sophisticated laboratory tests, it became understood that women with glycosuria usually had an accompanying rise in blood sugar. But after gestational diabetes was added to the taxonomy of Diabetes Mellitus, arguments arose among healthcare practitioners about diagnosing the disease – about how to test, who to test, and even whether to test at all.21

While complicated, and involving quite a bit of laboratory science, the details are important in order to clarify the extent to which the policies that followed from these debates highlighted the social characteristics of certain groups of women who faced diagnosis. Women from different racial/ethnic backgrounds and from different socio-

economic levels did not have the same correlation between symptoms like glycosuria and physiologic responses to tests for the disease like a high number in a blood test. For example, white women generally “spilled sugar” into their urine at much lower corresponding blood sugar numbers than African American women or women of Asian descent. African American and Asian women had even higher prevalence rates when diagnosis switched from the symptom of glycosuria to a number in a blood test. And Native American women had prevalence rates as much as eighteen times higher than whites with that switch. Physicians wrestled with the question of whether changing to a number in a blood test incorrectly negated the higher “tolerance” that some non-white women’s kidneys seemed to have for managing blood sugar or whether it displayed a more accurate level of risk. There would be no clear-cut answer as to whether it was appropriate to change the diagnostic standards in a way that dismissed fluctuations in physiology that had previously distinguished diverse populations. Moreover, the blood test to be used for diagnosis, the Oral Glucose Tolerance Test (OGTT), came with its own set of problems, and disagreements ranged from which blood components should be used to how much of a glucose load was necessary.22

Despite the appearance that debates over the logistics of testing were simply pragmatic, the dialogue was often fueled by concerns over the growing disparity in who was being diagnosed. With some practitioners questioning whether gestational diabetes was even a disease, calls began immediately for a “systematic screening program,” for “unanimity in considering the criteria for … screening of these patients,” and for “better guidelines for detection and control.”

Intense discussions ensued over uneven prevalence rates and even over what the disparity meant. Donald Coustan, an obstetrician who was a member of the committee tasked with setting the initial guidelines, the National Diabetes Data Group (NDDG), said that no simple solution for these confounding arguments appeared on the horizon. As the parameters for positive and negative test results were somewhat arbitrary to begin with because of the lack of an inflection point in the data, Coustan said, “It was a strawman to say that gestational diabetes isn’t really a disease.”

The premise of the OGTT was that the pregnant woman whose blood sugar response was still functioning but compromised would be revealed with an overload of

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24 Donald R. Coustan, interview with author, August 12, 2010, tape in author’s possession. The “gold standard” for determining a threshold number, or range of numbers, that delineate the difference between normal and abnormal involves a process of balancing averages from large cohorts with the search for what is called an inflection point in the data—a point where the plotted line of results either levels out or changes slope, indicating a variation from the normal pattern. For gestational diabetes, no studies have ever found an inflection point, including the recent Hyperglycemia and Adverse Pregnancy Outcomes (HAPO) Study for which Boyd Metzger was the principal investigator and Donald Coustan was a collaborator. Both physicians discussed the HAPO results in their interviews and both explained that the absence of an inflection point meant that diagnostic thresholds were somewhat arbitrary.
sugar. The test involved drinking a measured amount of liquid sugar and then having blood drawn at a series of time intervals to assess the physiological response to the “glucose load.” Even determining the measured amount of sugar to be used in testing began with some confusion. As Coustan explained, “In the non-pregnant world – men – seventy-five grams is the standard [amount of sugar] to use but in pregnancy it’s one hundred,” and that difference was the result of layers of policy changes. The circle of changes began with the U.S. Army because, like nearly all laboratory tests in use today, the original test subjects were young men in the Army. The U.S. Public Health Service (USPHS) first changed the test to 100 grams of sugar, in part to distance American researchers from their European counterparts. A federally funded study at the Boston City Hospital, a congressional task force, and the World Health Organization (WHO) would also add changes to the design of the test and to the interpretation rubric. In the end, “the world moved on to 75 grams” with the belief that blood sugar control in pregnancy should be as sensitive in the pregnant state as in the non-pregnant state, while “we [in the United States] were stuck with 100 grams.”

Adding to the disjuncture, different clinical groups decided that they would design their own procedures for the OGTT, based in large part on the laboratory technology with which they were familiar. Some practices decided to use whole blood samples while others used plasma. The glucose load for the test varied from 50 grams, to 75 grams, to 100 grams because of confusion over screening versus diagnostic testing. While some

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facilities tested women after an overnight fast, others had their patients eat a “mixed meal” before testing. Women might be diagnosed after a single test or might have a preliminary test that led to yet another set of tests with the standard three hours of blood draws. Disagreement existed over the threshold or cutoff number for diagnosis. And researchers debated whether population-specific criteria should be developed.26

In addition to the problems with the design of the OGTT, the interpretation of test results was complicated by unresolved questions about race and class in medicine and science. Recognition of race- and class-based affinities for certain diseases had a long history, and such trends were once broadly held to be indications of physiological inferiority. The higher rates of many diseases in African Americans and in non-white immigrant groups were still being investigated, but were spun in a new context in the latter part of the twentieth century. For infectious illnesses, the fear of contagion had driven much of the medical inquiry. For chronic diseases, however, researchers had begun looking for social artifacts that contributed to a disproportionate burden of disease on certain marginalized groups. For example, when investigators began looking at the high rates of stroke deaths among African Americans, they tried to determine whether a cultural aversion by African Americans to seeking medical care had played a role, or whether a bias on the part of physicians had contributed to a dismissal of early symptoms.27

26 Ibid.

As the disparity in prevalence rates for GDM increased throughout the 1980s, the widening gap prompted accusations that the diagnosis was merely a new form of scientific racism. Yet the glycosuria, and later the high blood sugars, associated with gestational diabetes were very real and some women experienced potentially dangerous raised blood sugars during pregnancy. Although gestational diabetes became encumbered with pejorative social images, claiming the existence of some type of broad conspiracy theory to relegate poor patients to demeaning roles through the ways in which their access to medical care has been defined is an unsustainable argument. On the other hand, being in a healthcare role – whether as a doctor, a pharmaceutical rep, or as a policy advisor – did not grant immunity to the influence of social and cultural perceptions of individuals and groups.

By the end of the 1980s, African American, Hispanic, Asian, and Native American women would be much more likely to face a diagnosis of GDM than non-Hispanic white women, ranging from about two times more likely for African American women up to ten times more likely for Native American women. Researchers tried to

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28 Greene discusses this issue as it relates to ideas about motivations to label patients, but his main point is that disease prevention efforts were not carefully concealed marketing deceptions; see Greene, *Prescribing by Numbers*, 5 and, as it specifically relates to screening for diabetes, 98-105.

explain the increasingly visible racial and economic disparity in gestational diabetes that arose during the 1980s. Some explanations were based on a supposition that certain groups of women were predisposed to deranged blood sugars during pregnancy because of an underlying metabolic defect or because bad health habits such as inactivity and poor diet were culturally ingrained. Others countered that such explanations neglected to acknowledge that screening programs for gestational diabetes focused more on women who were non-white and poor. As proof, healthcare analysts pointed out that indicators of socioeconomic status such as mode of payment for healthcare services, usually defined as private insurance versus federally- or locally-subsidized reimbursement programs, were correlated with the likelihood that a woman would be tested for GDM and more than doubled the likelihood she would be diagnosed with the disease. Opposing factions could not agree on whether increased testing in these groups of women was good because it signaled better access to care, or if it was bad because it reflected social and cultural beliefs about maternal responsibility in historically marginalized groups of women.\textsuperscript{30}

The connection of race and class to risk for gestational diabetes seemed like a new phenomenon to many in the 1980s, but how much had the demographics of women at risk for gestational diabetes really shifted? A look back at the seminal study on gestational diabetes, conducted at the Boston City Hospital from 1954 to 1964, suggests that at some level the perception of race- and class-based disparity had already existed much earlier than the 1980s. Demographic data on the women were not included in the

\textsuperscript{30} Berkowitz, et.al., “Race/Ethnicity,” 968 and 970-972.
first published articles on the Boston Study (which came out in the 1960s). In later papers, however, the principal investigator, John O’Sullivan, described the study cohort as “the lower half of the socioeconomic spectrum.”

Donna Younger, a physician at the private-practice Joslin Diabetes Clinic across town at the same time, characterized O’Sullivan’s subjects as poor, non-white, and unable to pay for their medical care, “His population was people who came to the outpatient clinic at Boston [City Hospital], which in the 1950s and 1960s, well, that was not private practice, and it was poor socioeconomically.” The women went to the “Free Clinic” at the Boston City Hospital because they had nowhere else to go and the research team, Younger said, understood the vulnerability that the women faced in trying to get medical care when they enrolled them in the study back in the 1950s and 1960s.

**Screening for Gestational Diabetes**

In the mid-1980s, the American Diabetes Association (ADA) stepped into the debate over testing for gestational diabetes, with many of the physicians on the scientific board of the organization hoping for consensus on diagnostic standards. The ADA’s work on debates over gestational diabetes resulted in one of the organization’s first official position statements. The position statement on diagnosing GDM was published in diabetes-specific, general medicine, and obstetrical journals, which gives some indication of how widespread the controversy had become. The ADA stated the

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32 Donna M. Younger, interview with author, August 11, 2010, tape in author’s possession.
organization’s support for the use of a 100 gram test on all pregnant women, even though that contradicted the guidelines from the WHO. Further, the ADA recommended laboratory analysis should be done on plasma instead of whole blood, even though data from earlier studies had been from whole blood samples. And although sounding innocuous enough, the ADA recommended that physicians implement a screening program before actual diagnostic testing. The suggestion was for a single-sample blood test that could cast a wide net and identify any potential blood sugar abnormality without regard to what researchers called a “false positive.” Then, only those women who had an abnormal screening result faced the actual diagnostic testing for GDM. The diagnostic test occurred between the 28th and 32nd weeks of pregnancy, which placed the test well inside the parameters of what is commonly denoted as the third trimester of pregnancy. The procedure for the diagnostic test involved a baseline blood draw at the initiation of the three hour test, immediately followed by the ingestion of a liquid with 100 grams of sugar and then a series of blood draws at specified times over the next three hours.33

The ADA position statement only increased the disagreements. Because the guidelines were in opposition to those established by the WHO, without any explanation for the discrepancy, physician groups responded with a slew of unofficial position statements of their own. Family practice doctors generally advocated routine but not

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universal testing; public health workers wanted screening programs to be connected to public assistance programs like the nutrition services in the Women, Infant, and Children program (WIC); midwives advocated the screening of targeted populations only; and physician groups in certain low-incidence geographic areas designed recommendations specific to their patient populations. Many physicians actually supported the ADA’s recommendation for screening before testing in order to narrow the testing population. They were hesitant to endorse universal testing because they disagreed on who should be tested and on whether gestational diabetes was even a disease. A sizable number of women facing diagnosis came from lower-income backgrounds and from non-white racial and ethnic groups and cost-efficiency seemed unlikely for gestational diabetes in that type of patient population.

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The demographic trend toward lower-income status and non-white race and ethnicity was not restricted to the realm of gestational diabetes. Many chronic diseases during the 1980s were “discovered” to affect non-white racial and ethnic groups in disproportionate numbers. Improvements in access to healthcare and increased laboratory-based screening for chronic diseases like diabetes and heart disease uncovered a multitude of previously unnoticed health problems in marginalized groups by the end of the 1970s. But many of the women who would be diagnosed with gestational diabetes during the 1980s entered the U.S. healthcare market when they became pregnant and had to seek prenatal care through Medicaid programs. Cost-efficiency and measurable reductions in health problems became complicated for these groups of women by the restrictive structure of Medicaid.

Health disparity, then, was not a new controversy in the 1980s, not even for gestational diabetes. In fact, as early as 1975 the National Commission on Diabetes (a congressional workgroup created with the 1974 National Diabetes Mellitus Research and Education Act) had proposed that all pregnant women in the United States should be tested for gestational diabetes in the third trimester of their pregnancies because of the need to protect the health of the fetus. The Commission’s recommendations called upon important social concerns in an attempt to prod policy makers to initiate federal fiscal support for programs. They nodded to the national focus on diabetes and on drives

35 Smedley, et.al., Unequal Treatment.

to identify the unknown diabetics who loomed in the shadows as a potential financial nightmare. The Commission had also engaged the new “perinatal movement” that expressed public concern for the health of unborn children. But with no government-sponsored initiative and no agreement within the insurance industry to offset the costs of such a major health screening program, a recommendation to screen all pregnant women in the United States was impossible to implement. Although physicians whose patients paid out of pocket or through private insurance reimbursement for their healthcare could conduct testing for their pregnant patients, physicians working with low-income women could not.

The language of science and medicine in these arguments effectively clouded the role that social perceptions began to play in how to diagnose and treat the new disease. As the demographics of GDM women became poorer and less white during the 1980s, class and race increasingly shaped women’s experience with the disease, sometimes affecting whether they were screened at all and certainly changing what types of healthcare they could get once diagnosed. Clinicians who were more likely to work with poorer patients, like public health nurses and family medicine physicians at inner-city clinics, argued for targeted screening based on their understanding that women in certain racial and ethnic groups were more likely to have higher blood sugars after drinking the sugary liquid used in testing. Because of the increases in indigent clients that resulted

37 Pregnancy and healthcare costs became major issues in medical research by 1980. By the late 1970s and early 1980s, “reproduction and women’s health” was the top publication topic for health services researchers, and coming in at number seven on the list was “the uninsured and underinsured.” See Daniel M. Fox, “The ‘Milbank Quarterly’ and Health Services Research, 1977-1990,” The Milbank Quarterly 69, 2, Health, Society, and the “Milbank Quarterly”: Essays in Honor of David P. Willis’ Editorship (1991): 193.
from the expansion of Medicaid, community health clinics resisted the implementation of universal testing with the concomitant costs and treatment implications. By contrast, obstetricians and diabetes specialists supported universal testing. They talked about the clear connection between interventional medicine and long-term costs. Specialty practice physicians also lauded the benefits of early interventions that large-scale screening offered. Their privately insured patients eagerly sought the new therapies being introduced into the healthcare market.

Throughout the 1980s, as disagreements about testing procedures for gestational diabetes filled medical journals and spilled over into other academic disciplines, the very public debates about testing predominantly focused on details associated with procedures, laboratory chemistry, technology, and the potential for diagnostic errors. Though important issues to be tackled, those detail-oriented arguments obscured how the social characteristics of women facing diagnosis quietly shaped the debates and the policies being crafted. Procedural and technical problems certainly abounded, as many factors in testing such as the component of blood used and the formulas for setting numerical thresholds were rife with problems. But, as the 1980s progressed, many women who faced a diagnosis of gestational diabetes came from a lower-income bracket of American society and were more often African American, Hispanic, Asian American, or Native American.

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38 Swinker, “Routine Screening for Gestational Diabetes Mellitus in a Family Practice Center”; Macupa, “A Proposal for Detecting and Managing Gestational Diabetes by Coordinating Existing Services”; and Jowett and Nicol, “Gestational Diabetes: Are the Right Women Being Screened?”

By the end of the 1980s, the social concerns that undergirded these debates became more visible when the diagnosis and treatment of gestational diabetes became intimately connected to policies that governed Medicaid eligibility. Many doctors continued to view screening for gestational diabetes as risk assessment (whether a woman had a greater chance of developing diabetes), but others posited that its disproportionate application to groups of women with conditional access to medical care made it function like a surveillance tool. It was broadly understood by then that the disease was being identified more often in non-white and poor women. Coupled with mounting interest, that focus helped to publicize the demographic issues.40

Family Medicine physician Cheryl Levitt poignantly described the problem that many physicians had begun to struggle with. A diagnosis of GDM labeled pregnant women as high risk, exposing them to “a cascade of interventions” such as ultrasound, more lab tests, and Cesarean section deliveries. For the family medicine doctor trying to adhere to “low interventionist” obstetrics in order to avoid extra procedures and costs, Levitt said, following the official recommendations for testing and the rules on qualifying low-income patients for the recommended care, created at best a difficult situation.41

40 A PubMed search for gestational diabetes from 1980 to 1991 returned over ten thousand records. When Boyd Metzger looked at trends just within the American Journal of Obstetrics and Gynecology, he found that only one paper per year was published between 1975 and 1979, but that trend doubled to two papers per year for the period of 1980 to 1984. And, from 1985 to 1990 the journal published an average of one paper per issue. See Boyd E. Metzger, “1990 Overview of GDM: Accomplishments of the Last Decade – Challenges for the Future,” Diabetes 40, suppl. 2 (December 1991): 1.

The panoply of different approaches that physician groups promoted to test for and diagnose gestational diabetes also exposed deep divides within the U.S. medical community in spite of the supposed unifying force of the mid-twentieth century professionalization of American medicine.42 Arguments for targeted screening discussed the logistics of testing procedures, but the intention of targeted screening was to limit the number of poor patients needing expensive treatments. In 1980, for example, the Cleveland Regional Perinatal Network (CRPN) reported on a pilot project to test the feasibility of a simple, inexpensive blood sugar measurement as a pre-screening tool for gestational diabetes. The report focused on the simplicity of the pre-screening test, and explained that it could be used well before the recommended testing in the third trimester of pregnancy. But the purpose of pre-screening was to decrease the number of women referred for the Oral Glucose Tolerance Test (OGTT). The impetus for the study was inextricably tied to the web of policies controlling healthcare reimbursement and the perceived fiscal burden of the clinic’s non-white, low-income, inner-city patient population.43


43 Irwin R. Merkatz, Method A. Duchon, Toyoko S. Yamashita, and Harold H. Houser, “A Pilot Community-Based Screening Program for Gestational Diabetes,” Diabetes Care 3, 3 (May-June 1980): 453. While the study report did not characterize the clinic’s clientele except to say that it was “heterogeneous” racially and socioeconomically and that patients were supported by “diverse community groups,” the CRPN was created in 1975 with funds from the Robert Wood Johnson Foundation (RWJF). The Regional Perinatal Programs of the RWJF had been designed to address the high infant mortality rates among inner-city and rural low-income families. In the 1980s, support for the CRPN was largely taken over by the philanthropic Cleveland Foundation and by the Ohio Department of Health, Bureau of Child and Family Health Services – programs also designed to assist poor women and their families. For information on the development of the RWJ Foundation’s Regional Perinatal Networks, see Sharon Begley
Throughout the 1980s, concerns about the cost of healthcare for the indigent motivated many clinicians to claim that a universal testing program for gestational diabetes cast too wide a net. Testing a population of women who had a higher likelihood of a laboratory result above the cutoff would be a disaster, they said, because many of those women did not have health insurance and thus had no resources to pay for the suggested extra diagnostic and treatment procedures. Yet, if they raised threshold values to make the net smaller, women who may have been identified at corresponding private clinics, who may have needed the preventive interventions and could pay the extra costs, would then be missed. For example, at the Joslin Diabetes Clinic the clientele in 1980 was overwhelmingly privately insured patients. The Joslin continued to use the lowest values for testing even when calls came to revise them. As Donna Younger explained, if the thresholds for diagnosing gestational diabetes were raised, even though gestational


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diabetes was only a small part of their practice, many of their GDM patients would have been missed. The calls to raise the thresholds, Younger said, were generally from clinics and facilities with a much more varied population than what they saw at the Joslin.

Younger elaborated, “In fact, we didn’t see many Blacks here … we were a private group practice but we would always try to give care to people who would submit their financial data.” Poor pregnant women would gain better access to medical care for the condition during the 1980s. But policies that connected testing for GDM to eligibility criteria for social welfare programs also created a link in the social perceptions of those public assistance programs with many of the women being diagnosed. On many levels, Younger lamented, it was dilemma for clinicians.45

_Gestational Diabetes and Medicaid_

Several pieces of legislation during the 1980s that expanded Medicaid services also opened avenues for medical care to certain women facing a diagnosis of gestational diabetes. Although the changes in Medicaid coverage make for a dense history of acronyms and convoluted rules, the complicated pieces of social legislation are important to understand because they became embedded in the developing definition of gestational diabetes. During the 1980s, a series of government-contracted studies and legislative actions prompted both federal and state governmental bodies to broaden medical care coverage for pregnant women, and several of those actions were specifically important for women at risk of being diagnosed with GDM.

45 Younger interview.
Between 1980, when gestational diabetes was added to the World Health Organization’s disease classification manual (the ICD-9), and 1986, when the ADA published its first official position statement on the new disease, the most rapidly expanding groups of gestationally diabetic women were the same expanding groups of women becoming eligible for Medicaid. And they were characterized by poverty, lower educational background, and non-white race. Even though no sophisticated demographic analyses of gestationally diabetic women existed at that time, there was broad acknowledgement that non-white race/ethnicity and lower socioeconomic status were strong predictors of GDM. In fact, even as early as 1980, both race and socioeconomic status had been listed as priority areas for further research on gestational diabetes.

As a background, it is important to remember that healthcare in the United States had a very different complexion prior to the advent of Medicare and Medicaid. Before 1965, expenditures for medical care made up only 5 percent of the U.S. economy and the government contributed less than a quarter of that. Within five years, those numbers

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47 See, for example, some of the discussions in journal articles on race and socioeconomic status with regard to screening and diagnosis: John B. O’Sullivan and Clare M. Mahan, “Insulin Treatment and High Risk Groups,” *Diabetes Care* 3, 3 (May-June 1980): 482-485; Merkatz, et.al., “A Pilot Community-Based Screening Program,” 453-457; and Pettitt, et.al., “Gestational Diabetes,” 458-464.


Although Medicaid legislation broadened women’s access to healthcare, its impact was initially limited to very poor women. Many pregnant women benefitted, but until the early 1980s eligibility was restricted to women who were already receiving cash payments through the Aid to Families with Dependent Children program (AFDC). Since AFDC payments fluctuated with the sometimes arbitrary decisions of policy makers and
local oversight committees, only very poor, single women who already had children became consistently eligible for the variety of healthcare interventions that Medicaid offered, like prenatal care programs. As historian Linda Gordon has explained, the inadequately funded programs of AFDC were incredibly stigmatizing because of their eligibility requirements and surveillance policies as compared to the “unemployment insurance” and “earned pensions” that Medicare granted to men and the old-aged. The restrictive policies of Medicaid compared to the open, inclusive policies for aged men and women covered by Medicare created and perpetuated a socially bifurcated system of healthcare. The scrutiny and stigma with Medicaid, as well as an inability to navigate the complexity of the system, likely prevented many eligible women from even trying to gain access to healthcare.51

In 1983, the Institute of Medicine’s (IOM) Committee to Study the Prevention of Low Birth Weight reported to Congress that the two main factors preventing access to adequate prenatal care were financial and cultural – the inability to pay and a lack of understanding about prenatal care. The IOM recommended congressional funding for programs to educate women about prenatal care and funding to increase access to

51 Linda Gordon, Pitied but Not Entitled: Single Mothers and the History of Welfare, 1890-1935 (New York: The Free Press, 1994). For an idea of the complexity of the application process, see the “Notes from the Field” section of the October 1986 issue of the American Journal of Public Health; Judith Jones, Deputy Director of the Center for Population and Family Health at Columbia University in New York, reported on a program at Presbyterian Hospital in a low-income neighborhood of New York City where they hired staff to assist clients with the ten-page application form which was available only in English and for which Medicaid reviewers would not help clients with completion. See Judith E. Jones, Lorraine Tiezzi, and Jacqueline Williams-Kaye, “Overcoming Barriers to Medicaid Eligibility,” American Journal of Public Health 76, 10 (October 1986): 1247.
community-based programs.\textsuperscript{52} Congress acted on those recommendations with three specific pieces of legislation. With the Deficit Reduction Act of 1984, the federal government mandated that all states that requested matching federal Medicaid funds had to begin providing access to prenatal care for single, pregnant women with no children (a group not entitled to welfare coverage up to that point) as long as those women satisfied the specified income criteria for AFDC eligibility. Medicaid coverage for pregnant women who met AFDC requirements was then extended further with the Consolidated Omnibus Budget Reconciliation Act of 1985 by eliminating restrictions on family structure. What would become important for women who had been diagnosed with gestational diabetes was that Medicaid coverage was extended for AFDC ineligible women during the third trimester of their pregnancy and for their first sixty days postpartum. Finally, in 1986, the Omnibus Budget Reconciliation Act gave states the option to request matching funds in order to cover all pregnant women who fell below the federal poverty level (which was higher than the cut-off for AFDC eligibility) if they had “high risk” pregnancies. The 1986 legislation also allowed states to expedite Medicaid applications for high risk pregnant women in need of prenatal care who were already in the third trimester of pregnancy at the time they presented for care.\textsuperscript{53}


What has been missed in historical examinations of these legislative changes is that the congressional responses to the needs of low-income pregnant women were intimately connected to the work of researchers in the field of diabetes and pregnancy. In 1983, after postwar diabetes detection drives throughout the United States had left an unpleasant taste with the directors of several government agencies because of the costs incurred and the confusion created among the lay public, a belief still remained in the value of detecting raised blood sugars in pregnant women. Clinicians, Senators, agency heads, and international health organizations had moved away from large-scale screening efforts for diabetes in general, but they still articulated a belief that “pregnant women in particular should be singled out for diabetes screening because of the potential deleterious effect of diabetes on the outcome of pregnancy.”

Through their persistent efforts, researchers working on gestational diabetes kept alive a belief in the value of detecting raised blood sugars in pregnant women. Clinical investigators like Norbert Freinkel, John O’Sullivan, and Boyd Metzger sat on legislative workgroups such as the National Diabetes Data Group, the National Commission on Diabetes, and the World Health Organization’s Expert Committee on Diabetes Mellitus. And they brought with them to meetings of those workgroups their knowledge about the demographics of the population of women facing pregnancies complicated by gestational diabetes. Years after the National Commission on Diabetes abandoned the search for the

“hidden diabetic,” it still listed as one of its main goals “diabetes case finding for all pregnant women.” The Commission reported as well on racial differences in the use of prenatal care and linked those findings to the changing demographic make-up of gestationally diabetic women. During the early 1980s, for example, congressional task force reports stated that non-white women (African American, Hispanic, and American Indians) used prenatal care significantly less than white women, yet they had a higher likelihood of undetected blood sugar problems affecting their pregnancies.

Although Medicaid became the source of healthcare access for many of the new gestational diabetics that the public came to know, which suggested a simple and straightforward connection to social welfare policy, the reality was more complex. As historians have pointed out, there exists an inherent bias in the American system of employment-based private insurance and the system of rights-based pension systems versus entitlement programs that often categorize individuals and groups as fiscal and


social drains on the nation.57 One goal of Medicaid was, of course, to carve out a way for ill people to get a minimum standard of care regardless of their economic and social status. Another goal, albeit less clear to the general public, was to protect the public from diseased individuals (sometimes because of contagion, but in today’s world more because of the burden of illness on the political economy).58

Public policy to protect the nation’s health is not the monolithic entity that typically appears in studies on health policy and disease creation.59 The policies and structures that factor into disease definitions vary, and they do not influence disease definition in the same way. Infectious diseases like tuberculosis, syphilis, or more recently AIDS (or HIV infection as the structural formula has reshaped its name) certainly entailed a whole laundry list of public protection efforts that chronic diseases like diabetes do not.60

Beyond the caveats for infectious versus chronic disease, who encounters disease has played a significant role in policy formulas and it has shaped in very meaningful


59 The standard works include Starr, Social Transformation; and Duffy, The Sanitarians. More recent challenges to those monolithic presentations have been Greene, Prescribing by Numbers; Steven Peitzman, Dropsy, Dialysis, Transplant: A Short History of Failing Kidneys, Biographies of Disease (Baltimore: Johns Hopkins University Press, 2007); and Nancy Tomes, “Merchants of Health: Medicine and Consumer Culture in the United States, 1900-1940,” Journal of American History 88, 2 (September 2001): 519-547.

ways the experience of disease both for the patients identified and for the public who see them. For example, women have always had a more difficult time than their male counterparts in gaining consistent access to healthcare and, hence, their experiences with medical care and with being diagnosed with a disease have played out differently.61 While men with private insurance could weigh treatment options and ask about the panoply of medications available to them, women who entered the healthcare system under Medicaid struggled simply to acquire the state-defined minimum level of care. In the twentieth-century United States, health insurance developed as an employment-based system that left many women in a precarious position by the 1980s. Few women gained health insurance through their own employment status because they struggled to gain jobs with the same benefits as men. Rather, most women became add-ons or dependents to their husbands’ plans. And women with no husband, or whose husband did not have adequate health insurance through his employer, found that they increasingly had to turn to programs like Medicaid as their “safety net.”62

During the 1980s, Medicaid legislation dictated the financing of healthcare for a significant group of women who encountered gestational diabetes. While a handful of clinicians drafted informal position statements on the screening, diagnosis, and treatment of gestational diabetes, the recommendations from physicians who had participated in the


62 Gordon, Pitted But Not Entitled.
First International Workshop-Conference on Gestational Diabetes Mellitus (FIWC) would mirror the language of Medicaid eligibility rules. Pregnant women should be tested between the 24th and 28th week of pregnancy, the third trimester of pregnancy. Medical management “should include high risk pregnancy surveillance and nutritional counseling.” And younger women should be an acceptable group to test for GDM.

Table 2. Summary of Medicaid policies and GDM guidelines, 1980 to 1986

<table>
<thead>
<tr>
<th>Year</th>
<th>Legislative Index</th>
<th>Medical Index</th>
<th>Medicaid Policy</th>
<th>GDM Guidelines</th>
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</table>
| 1980             | FIWC              | Increased matching federal funds | Universal screening | Testing of groups with risk factors:  
Age  
Weight  
Prior pregnancies |
|                  |                   | Women already receiving AFDC | | |
| 1983             | IOM Report to Congress | Matching funds for prenatal education | ADA and ACOG call for prenatal education | ADA promotes need for research on cultural barriers to access for prenatal care |
|                  |                   | Research funds for cultural barriers to access for prenatal care | | |
| 1984             | Deficit Reduction Act | Prenatal care for first-time pregnancies | | Age (30, 25, or 24 yoa) dropped from most risk factor lists |
| 1985             | Consolidated Omnibus Reconciliation Act | SFWC | Coverage for AFDC ineligible women:  
1. During 3rd trimester  
2. For 60 days postpartum | Screening week 24 to 28  
Testing for GDM after 28th week (3rd trimester)  
Retesting of GDM women within 60 days postpartum |
| 1986             | Omnibus Reconciliation Act | ADA Position Statement on GDM | Prenatal care for all women below federal poverty level  
“High risk” pregnancies eligible | Women with GDM classified as “high risk” pregnancy |

63 During the 1980s, obstetricians, family medicine practitioners, public health nursing groups, and midwifery associations drafted their own sets of guidelines which unfortunately resulted in a confusing amalgamation of recommendations. For example, see Beard and Hoet, “Criteria for Screening Tests for Gestational Diabetes,” 768-773; Swinker, “Routine Screening,” 611-614; Ziporyn, “Gestational Diabetes,” 465-470; Scherger and Hudson, “Routine Screening,” 177-178; Macupa, “A Proposal,” 94-97; and Jowett and Nicol, “Gestational Diabetes,” 98-100.

The recommendations on gestational diabetes actually presaged many of the changes to Medicaid eligibility. The language used by the FIWC committee appeared nearly verbatim in the expansion of Medicaid coverage. The Omnibus Budget Reconciliation Act opened access to women with “high risk pregnancies.” Access to prenatal care was streamlined for women in the third trimester of pregnancy with the Consolidated Omnibus Budget Reconciliation Act. Medicaid eligibility shifted in favor of younger women with first pregnancies after the passage of the Deficit Reduction Act of 1984. Pregnant women without children (generally meaning first pregnancies in younger women) were allowed into the Medicaid system. Prior to that, women who did not already have at least one dependent child were ineligible for Medicaid because of the link to criteria for AFDC eligibility.\textsuperscript{65} Through the connection between GDM guidelines and the expansions in Medicaid eligibility, younger women from non-white racial groups, who were at increased risk of diabetes, gained better access to government-funded prenatal care.\textsuperscript{66}


The Second Workshop on GDM

In 1984, Norbert Freinkel’s research group at the Diabetes in Pregnancy Center at Northwestern University organized a second conference on gestational diabetes. The purpose of the conference, which was an invitation-only workshop, was to clarify official recommendations and policy statements on testing for and diagnosing gestational diabetes, to review new research on the condition, and to examine the impact of new policies for the financing of healthcare delivery. The workshop participants had all experienced the substantive changes in healthcare financing since the first conference, and many probably came to the second conference with a significantly different view of healthcare financing.67

Medicare and Medicaid had both expanded since the first workshop, and both were being contracted out in some instances, with reimbursement depending on diagnostic and procedure codes approved by policy makers rather than physicians. For the attendees of the second conference, the changes wrought by the growth of what Arnold Relman called the “new Medical-Industrial Complex” had resulted in their

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67 To set some of the context for the professional discourse about the costs of care for gestational diabetes, consider that right after the first conference, Arnold Relman, the editor of the New England Journal of Medicine, published a very influential editorial that suggested the practice of healthcare, particularly for chronic diseases like diabetes, was moving away from a system that focused on the delivery of quality care toward an entrepreneurial system that focused on payment structures and reimbursement schedules from government agencies. Relman’s editorial was commented on in various journals in the months after its publication, including diabetes journals, but by the time that the second workshop convened, Relman’s predictions had come to fruition. Arnold S. Relman, “The New Medical Industrial Complex,” New England Journal of Medicine 303 (1980): 963-970.
medical practices being controlled to a large extent by “third-party payers” and by the chairs of House and Senate subcommittees on healthcare – individuals and groups who were well removed from real patients. 68 Yet while many physicians sharply criticized the amorphous policies of Medicaid, some praised at least the intent of “providing the indigent with some aid in meeting health care costs.” 69 For investigators working on the problems of access to care for women facing a diagnosis of gestational diabetes, working within the structure of this “new Medical-Industrial Complex” was a reality, not a conspiracy. 70

By the mid-1980s, guidelines concerning the diagnosis and management of GDM had become inextricably linked to policies that governed Medicaid eligibility. Physician groups necessarily modified their approaches to accommodate the narrow eligibility criteria for Medicaid that many of their newer patients faced. But women with GDM were certainly not a homogenous group and that fact complicated the formulation of


69 Vertis R. Thompson, “President’s Column: Crisis in Health Care for the Poor,” Journal of the National Medical Association 72, 11 (1980): 1038. Vertis Thompson was the President of the National Medical Association (NMA), the black counterpart to the white-dominated American Medical Association (AMA). The journal of the NMA published frequent editorials and position papers in support of expansions in Medicaid coverage, often suggesting that NMA physicians should be tolerant of administrative problems because of the lack of any other programs with as much potential opportunity to benefit black Americans.

70 When the term “Medical-Industrial Complex” was first coined in the late 1960s, it came with a very negative connotation. Those early tomes used the term to accuse physicians of participating in a broad conspiratorial campaign to demean marginalized patients and to insert themselves into an enlarging consumer market. See Barbara Ehrenreich and John Ehrenreich, “The Medical Industrial Complex,” Health PAC Bulletin (November 1969): 1-9; Harold B. Meyers, “The Medical Industrial Complex,” Fortune 81 (January 1970): 9; and Barbara Ehrenreich and John Ehrenreich, American Health Empire: Power, Profits, and Politics (New York: Random House, 1970), 95-123.
broad guidelines. Although non-white and poor women faced an increasingly higher likelihood of becoming GDM patients, they were not the only pregnant women at risk. For example, women with their own health insurance who attended private clinics could certainly be diagnosed as well. The increasing diversity of women at risk for GDM complicated the formulation of broad medical guidelines. Moreover, not only was it hard to explain gestational diabetes to the general public, but confusion even ran rampant within the medical community as well.\(^7\) 

The guidelines that came out of the first workshop on GDM showed up nearly verbatim in Medicaid policy, and the guidelines from the Second International Workshop-Conference on Gestational Diabetes Mellitus (SIWC) would also mirror that language. The guidelines from the second workshop were published in 1985 and the ADA shortly followed with its first official position statement on gestational diabetes. The new guidelines from the second workshop came on the heels of the Deficit Reduction Act of 1984 and the Consolidated Omnibus Reconciliation Act of 1985. Those pieces of legislation had expanded Medicaid coverage to low-income pregnant women who were not eligible for AFDC if they were in the third trimester of pregnancy, and they had extended the period of coverage to include sixty days postpartum. The recommendations from the second workshop, which were then echoed in the ADA

\(^7\) A more detailed look into the confusion and disagreement within the medical profession follows in this chapter. To give one very telling example, though, in 1990 the Southern Medical Journal published a set of guidelines from the Southern Medical Association (SMA) regarding diagnosis and treatment of GDM. In that position statement, the SMA recommended urine testing at every prenatal visit to screen for urinary sugar. Glycosuria, or urinary sugar, had not been used for any form of diabetes screening or diagnosis for at least three decades by that point. See William J. Watson, “Screening for Glycosuria during Pregnancy,” Southern Medical Journal 83, 2 (February 1990): 156-158.
statement, zeroed in on the third trimester of pregnancy as well. And GDM guidelines from the second workshop added instructions for postpartum care, recommending that GDM women be retested at the first postpartum visit or at least within sixty days of delivery. Women whose postpartum testing was normal were to be diagnosed as “previous abnormality of glucose tolerance,” while those women whose OGTT remained abnormal after pregnancy would be reclassified as either “impaired glucose tolerance” or “diabetes mellitus in nonpregnant adult.” The post-partum diagnoses, then, continued the “high risk” eligibility category for Medicaid coverage.72

Even though many women gained access to healthcare with the expansion in Medicaid coverage, it was not a panacea for gestationally diabetic women. The summary of the second workshop made it clear that research on gestational diabetes had played a significant role in creating financial help for poor women in need of prenatal care and that, in turn, Medicaid policy had played a major role in the classification of GDM as a disease. Indeed, the workshop’s summary justified the disease status for GDM in that it “communicates the need for ‘high risk’ surveillance to providers of third-party payments or others responsible for the financing of health care delivery.”73 Despite the expanded coverage, however, many women who faced an encounter with gestational diabetes when they became pregnant still had no way to get medical care. There were women who were too poor to pay for healthcare but not poor enough to qualify for federal assistance. And


73 Organizing Committee, “Summary and Recommendations,” 123.
those who became eligible for Medicaid still faced restrictions on where they could get care and on what conditions had to be met to continue their eligibility.

Poverty was known to be a factor in poor health, but its connection to a specific diagnosis like gestational diabetes had not been established, and measures to help those women progressed haltingly. A research study in the mid-1980s, however, examined the state of insurance coverage for people with diabetes and established a direct link between bad health and the inability to pay for healthcare. The study also found that the problem worsened when the data were sorted by gender and race. The researchers reported that non-white, female diabetics in poor health were more likely to be receiving Medicaid assistance or else were completely unable to pay for their healthcare.74

The problem of gestational diabetes in the Gila River Community of the Pima Indians during the 1980s embodied the clash between programmatic issues and the ever-increasing social concerns about uneven rates of diabetes diagnoses. In 1980, a remarkable diabetes problem was unfolding for the Pima Indians of the Sonoran Desert of southern Arizona. The prevalence of diabetes was as much as eighteen times higher (and rising) than in the rest of the United States, and nearly half of all pregnant Pima women could expect to have their pregnancies classified as gestationally diabetic according to the guidelines being supported by the ADA. Researchers and physicians working on the reservation recommended increased diagnostic efforts and the creation of

treatment and education plans. But concerns about the cost of such high rates of diagnosis created calls for changing the diagnostic thresholds in order to bring the numbers of Pima women being diagnosed into line with other sectors of society. In a trend that would become a common-place argument in racial disparity studies of the 1990s, the idea to change diagnosis criteria was often presented as an effort to avoid scientific racism.75

The enormous scope of the problem of gestational diabetes for Pima women was complicated by the structural changes in the Bureau of Indian Affairs (BIA) and in the Department of Health, Education, and Welfare (DHEW). The Indian Health Service (IHS), formerly a committee within the Bureau of Indian Affairs, had been separated from the BIA and placed under the jurisdiction of the Department of Health, Education, and Welfare in the mid-1950s. With that move, the IHS faced much stricter fiscal control than had been the case when it was still under the larger budget pool of the Department of the Interior.76 Then, in 1979, DHEW was restructured, with education being pulled out into a separate department and DHEW being renamed and restructured as the Department of Health and Human Services (DHHS). Richard Schweiker (R-PA), the architect of the 1974 Diabetes Research and Education Act, became the head of the newly reorganized


76 In 1954, healthcare was transferred out of the Bureau of Indian Affairs (BIA). The BIA remained a part of the U.S. Department of the Interior, but Indian Health Affairs became an agency of the U.S. Department of Health, Education, and Welfare, where the majority of federally subsidized programs resided. See the online history archives for the Department of Health and Human Services, [http://www.hhs.gov/about/](http://www.hhs.gov/about/) (accessed January 28, 2012).
department. Although Senator Schweiker’s interest in diabetes would seem to bode well for those working on the problems facing Pima women, it did not.

The lack of support and, hence, the absence of increased funds to combat the gestational diabetes problem led to confusion among Pima women about the diagnosis. Women were tested and told that their blood sugars were raised, but then nothing changed in the course of their healthcare during pregnancy or afterward. As Dr. David Pettitt explained, “The level of glucose intolerance associated with increased morbidity and mortality, and hence what constitutes gestational diabetes” was not easy to define for directors of federal agencies with no medical background.77 Colleagues of Pettitt called for skipping the screening procedure, which they deemed “a satisfactory method” because of the enormity of the problem. But setting a different diagnostic threshold in a population of women whose healthcare was financed by the U.S. government was not going to be a decision left to a group of researchers. The Indian Health Service’s (IHS) budget had already suffered cuts during the 1950s and 1960s and the problem of diabetes prevalence and the cost of dealing with diabetic health complications were only increasing.78

Another program facing challenges, which served mostly Mexican American women, claimed that the NDDG guidelines let physicians decide to avoid testing some women. The authors explained that GDM was a “serious and expensive health problem” among Mexican-Americans, who the authors also warned had “the highest fertility rate of

77 Ibid., 458.
78 Beard, et.al., “Screening for Gestational Diabetes,” 469.
any race or ethnic group in the U.S.” and, yet, there was a complete lack of any published studies or funded proposals that focused specifically on this group of women. Their overall experience with gestational diabetes was “unlike that reported by other academic obstetric clinics.” Over 70 percent of their patients, the authors said, were non-white, poor, and lacking in access to prenatal and obstetric care because of the restrictive reimbursement policies of state-subsidized screening and treatment programs. The authors concluded that the unique North American definition and approach to GDM hampered the implementation of cost-effective interventions for a significant population of women and their children because it allowed for subjective decision-making about screening and testing.  

Conclusion

The creation of gestational diabetes had involved a process of translating science into public policy, and many of the specific policies that guided that process fell under the large umbrella of social welfare. The language used to define the new disease and its patients was fundamentally connected to the expansion and revisions that occurred to Medicaid legislation. The connection to Medicaid was simple on the one hand because the increasing numbers of women during the 1970s and 1980s who were found to have the symptoms and laboratory results that defined gestational diabetes were disproportionately poor and non-white. By the 1970s and 1980s, those women were

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traditionally receiving their healthcare through government-subsidized clinics and Medicaid programs. As the numbers of lower-income and non-white women who fit the criteria for being diagnosed with gestational diabetes increased, the language used for expanding Medicaid eligibility mirrored the language used in diagnosing and treating gestational diabetes.

By the early 1980s, however, government-controlled programs like Medicare and Medicaid limited doctors’ reimbursement claims to conditions identified with approved ICD-9 codes only and to treatments specified with valid CPT codes.80 Already defined by the very public process of utilizing such government services as Medicaid, the growing number of low-income women who found their pregnancies complicated by GDM carried specific social labels with them into those medical clinics. As economist Kenneth Arrow had predicted in 1963, the market-driven nature of healthcare necessitated programs like Medicaid, but little did Arrow know at that time how such programs would become embedded in the process of disease creation and definition.81

As the growing prevalence rates of GDM became increasingly disparate, some healthcare providers argued that the diagnosis reflected a deep-seated scientific racism in

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80 ICD-9 codes are the numerical codes for diseases in the World Health Organization’s International Classification of Diseases. Although a version 10 exists, in the United States physicians and insurance companies still use the 9th version with modifications specific to our American billing structure, the ICD-9-CM (for Clinical Modification). For more explanation, see the informational statement from the Centers for Disease Control at http://www.cdc.gov/nchs/icd/icd9cm.htm (accessed December 1, 2012). CPT (Current Procedural Terminology) codes are used for insurance billing and government reimbursement programs. For a good explanation of diagnostic and billing codes, see a recent newsletter from the Indiana Academy of Family Physicians at http://www.in-afp.org/clientuploads/9-5-11%20IAFP%20Anthem%20ICD%20Coding.pdf (accessed December 1, 2012).

American medicine. However, the blood sugar fluctuations that came to be part of the definition of gestational diabetes were real events. In fact, some women from non-white racial and ethnic groups, who had no prior diagnosis of diabetes, experienced potentially dangerous raised blood sugars during pregnancy. Just as diabetes in general had taken on a pejorative image, the diagnosis of gestational diabetes became encumbered by negative social depictions. As legal scholar Ruth Gordon has explained, being a black woman with diabetes had made her susceptible to doctors’ preconceptions for years. In the early 1990s, when she changed doctors, she said she began that first visit by stating that even though she was an overweight black woman with diabetes, she was a lawyer, “I ended that discussion before it even started.”

Florence Brown, director of the Diabetes in Pregnancy Center at the Joslin Diabetes Center in Boston, Massachusetts, explained that GDM took on multiple meanings because the complex eligibility and reimbursement strategies for government-subsidized healthcare “resulted in a simple labeling process.” Low-income women diagnosed with GDM gained access only to the diagnostic testing and therapeutic interventions approved by government committees, which were not necessarily the same as those recommended by physician groups. For example, nutritional and educational interventions were not covered. And even though physicians were the ones with direct contact with patients, Brown explained, “We [have had] to go through policy makers and the insurance industry, and it’s not to their advantage now to think about the long-term

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cost of care later.”\textsuperscript{83} Gestational diabetes was a disease connected to state policy, but it had become as well a disease defined by race and class, and a disease for which treatment strategies were not completely under the purview of physicians.

Brown’s insights were also based on a long history of women’s struggles with healthcare policy. Legislation such as Aid to Families with Dependent Children (AFDC) and sections added to Medicaid that pertained to pregnancy and unborn children had already forced pregnant women to bow to state intrusions in order to attain any level of public assistance. And even though welfare assistance for pregnant women and single mothers remained a predominantly “white” program throughout the 1970s, the popular perception was that state programs were supporting non-white women.\textsuperscript{84} Public sentiment, as echoed by eugenicists like William Shockley of Stanford University, was that programs like AFDC encouraged “dysgenic reproduction among blacks” and, hence, perpetuated “genetically carried disabilities.”\textsuperscript{85} Somewhere in the intersection between

\textsuperscript{83} Brown interview.

\textsuperscript{84} The program Aid to Families with Dependent Children (AFDC) was originally titled Aid to Dependent Children (ADC) and originated with the creation of the Social Security Administration in 1935. Contrary to public perception, a 1961 Congressional Report on the program found that over half of the recipients were white, single women with one or two children and with no cohabiting male in the household. See Robert H. Mugge, “Aid to Families with Dependent Children: Initial Findings of the 1961 Report on the Characteristics of Recipients,” \textit{The Bulletin, March 1963} (Washington, DC: Social Security Administration, 1963). Public Law 87-543, the Public Welfare Amendments of 1962, changed the name to AFDC. In 1965, Public Law 89-97, the Social Security Amendments of 1965, added prenatal and postnatal care to Medicaid, and established a link between Medicaid eligibility and AFDC assistance; see Kaiser Commission on Medicaid and the Uninsured, “Medicaid Legislative History, 1965-2000,” \url{http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&pageid=14255} (accessed July 29, 2012).

\textsuperscript{85} On the views professed by William B. Shockley, see interview by Tony Brown, 1974, \url{http://www.youtube.com/watch?v=sAszZr3SkEs} (accessed July 29, 2012).
medicine and policy, “GDM became the stepchild; it became the disease that nobody wanted but nobody could ignore.”86

The main argument against increasing the number of women diagnosed with gestational diabetes was that the cost would be huge. That argument was borne of the perception that GDM women did not pay for their medical care. Hence, although “efficient, user-friendly, economical ways [to treat GDM]” were needed, those methods were up for debate by a wide array of non-medical groups who wanted to contain costs. Research on gestational diabetes required money. Pharmaceutical companies, diagnostic companies, health insurance companies, and federal agencies supported that research, but by controlling the funding “they dictate[d] medical strategies.”87

Dr. George Dunea epitomized the physician who opposed the expansion of government-subsidized healthcare programs like Medicaid. A nephrologist at Cook County Hospital in inner-city Chicago, and also the editor of the British Medical Journal in the 1980s, Dunea voiced his displeasure with legislation that extended Medicaid coverage to a larger number of low-income pregnant women and poor children.88 He wrote a scathing editorial in 1979 on the proposed changes to Medicaid, claiming that cost containment and expansion of eligibility criteria were simply incompatible. In his “Letter from Chicago” column, he charged President Carter with dispensing “placebo

86 Metzger interview.
87 Coustan interview.
therapy,” and he called Secretary of Health, Education, and Welfare Joseph Califano “a wet nurse.”

Dunea believed that his medical practice had been directly affected by a similar situation. In the Social Security amendments of 1972, President Nixon had signed into law Section 2991 of Public Law 92-603. That legislation pledged complete Medicare coverage for chronic dialysis in kidney patients. With the proportion of lower-income, black Americans on dialysis already three times higher than their white counterparts by 1972, Dunea’s inner-city, low-income clinic was charged with the care of a considerable number of dialysis patients for whom payment came from federal programs that he saw as inept, difficult to manage, and beleaguered by fraud and underfunding.

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89 George Dunea, “Letter from Chicago: Coming of the Stork,” British Medical Journal 2, 6195 (October 13, 1979): 912. About a year after that editorial, Dunea wrote another editorial on the possible impact of prepaid health insurance programs on Medicaid. In that column, Dunea expounded on his complete distaste for both Medicare and Medicaid, claiming that “some of the larger inner city plans, developed to serve the poor by contract with Medicaid, have been plagued by fraud, administrative ineptitude, and slow reimbursement from the state.” Dunea also sarcastically posited, “Perhaps in caring for indigent patients HMOs might offer certain advantages, because registration with one plan would limit the welfare patient from wandering from doctor to doctor, from hospital to hospital, shopping around.” See George Dunea, “Letter from Chicago: Prepaid Health,” British Medical Journal 281, 6232 (5 July 1980): 44.

90 On the implementation of Medicare coverage for dialysis, see Steven J. Peitzman, Dropsy, Dialysis, Transplant: A Short History of Failing Kidneys (Baltimore: The Johns Hopkins University Press, 2007), 113-116. Dr. Dunea’s comments were likely motivated as well by the controversial case of Dr. Constantine Hampers, a fellow nephrologist from Boston. Dr. Hampers left his position at an academic research hospital in Boston in the early 1970s to open a dialysis clinic that functioned as a private facility that billed Medicare for treatment of patients. The for-profit venture which quickly became quite like a fast-food chain of pop-up dialysis clinics by the late 1970s relied on federal reimbursements but made Hampers into a multi-millionaire. Adding to the drama, Hampers’ attorney wife had faced bribery and fraud charges in the early 1980s when she served as Revenue Commissioner for Massachusetts, and their physician son later lost his medical license after being convicted of an array of charges including phony prescriptions, identity theft, and harassment of some of his female patients. For a short summary of the Hampers’ case which includes a link to a three-part series by the New York Times, http://blogs.westword.com/latestword/2010/09/louis_hampers_bail_for_doc_accused_of_prescription_drug_fraud_set_at_25_million.php (accessed August 5, 2012).
Gestational diabetes was “created” within the framework of social welfare policy out of necessity. Because of the demographics of the most rapidly growing population of women being diagnosed with gestational diabetes during the 1980s, Medicaid policies became part and parcel of the definition of the disease. The reframing of gestational diabetes occurred within the structure of government-subsidized healthcare, and the social understanding of the “new” disease and its patients took shape from a set of policies within that structure. That process has resulted in the state gaining a substantial role in defining health and illness.
CHAPTER IX

EPILOGUE

On Tuesday, September 5, 1989, Norbert Freinkel was attending a concert in Leningrad with his wife, Ruth. He was sixty-three years old and at the height of a career that had brought him international influence. He had travelled to Russia to establish a working relationship with several Russian physicians who were involved in research on gestational diabetes. The international connections that Freinkel had been working on would culminate with the Third International Workshop-Conference on Gestational Diabetes Mellitus in 1991. But Freinkel would not chair that conference in 1991. He collapsed unexpectedly that night during intermission. He had a heart attack and could not be revived. On receiving the news back in Chicago, Boyd Metzger said, “I don’t even know how to explain the shock.”¹

The physicians and researchers who had worked on creating the diagnosis of gestational diabetes sought to increase access to care for groups of marginalized women in the healthcare market. On Freinkel’s motivation, Metzger said, “Norbie genuinely believed that he had scientific insight of such value that it could allow clinicians to maybe change the trajectory of a person’s life before they were even born.” Yet he struggled with policy makers, who often called his work “theoretical.” And they insisted,

¹ Boyd E. Metzger, interview with author, October 26, 2009, tape in author’s possession.
Metzger continued, that policies needed to be based on data and cost-benefit analyses, not theory.\(^2\)

Gestational Diabetes Mellitus (GDM) was created within the framework of social welfare policy because, as Donald Barnett suggested, “It could be no other way.”\(^3\) The institutional process of creating gestational diabetes – through public policies and healthcare business plans – assigned to women facing the diagnosis a consumer identity in the healthcare market. Many of the women diagnosed with the new disease accessed their healthcare through programs like Medicaid. Coupled with the increasingly negative portrayal of diabetes in general, as a disease of bad lifestyle choices and great public cost, gestationally diabetic women’s health behaviors also came under scrutiny. Florence Brown posited that the perception of GDM women as undesirable consumers in the healthcare market and as irresponsible patients evolved as well from the “politics of healthcare that treated women patients differently.”\(^4\)

The disease concept of gestational diabetes took shape within a collision between science, business, and politics. The discovery and marketing of insulin attached a consumer identity to diabetes patients. And when insulin therapy allowed diabetics to survive long enough to take on adult social gender roles, pregnancy became the central focus for diabetic women. The gendering of diabetes care played an important role in bringing attention to the condition of glycosuria of pregnancy, and that attention would help to create a billion dollar medical research industry. Within that framework,

\(^2\) Ibid.
\(^3\) Donald Barnett, interview with author, August 11, 2010, tape in author’s possession.
\(^4\) Florence Brown, interview with author, August 11, 2010, tape in author’s possession.
redefining glycosuria of pregnancy, a condition once thought to be of little importance, into a disease that required testing all pregnant women became a process that involved the production of public policies on access to healthcare. When the growing numbers of women who faced a diagnosis of gestational diabetes came increasingly from low-income groups, those policies were crafted under the umbrella of social welfare.

As Boyd Metzger took over the leadership of the Diabetes in Pregnancy Center at Northwestern University after the death of Norbert Freinkel, planning for the workshop in 1991 continued. Metzger also took over the planning of what would become the largest research study to date on gestational diabetes, the Hyperglycemia and Adverse Pregnancy Outcomes Trial (HAPO).5 Data collection for the study was completed in 2006, but the results would not be published until 2008. HAPO was a long-range, prospective study of blood sugar levels in pregnant women around the world. One of the main goals of HAPO was to establish the range “above which the risk was very high and below which the risk was very low.”6

But HAPO only continued the controversy. The data showed no inflection point, a position on the graphed data comparing blood sugar level to bad events, where the slope

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6 Coustan interview.
of the plotted line significantly changes grade (signifying a change in risk). And when
the study group convened a committee to select the point where they believed the level of
risk required intervention, “it had to be arbitrary … and people were shocked that then
seventeen percent of the population would be identified as having gestational diabetes.”
Florence Brown summarized, “We’re missing a lot of people by using the old criteria …
and a labeling process is not going to help us much, but a long-term treatment approach
will.” Metzger explained that the intent of HAPO “was not to capture people at risk for
the diagnosis as much as to capture people who were so at risk that the pejorative
baggage was outweighed by the potential problems.” He continued, “Our objective
wasn’t to belittle people’s behavior.”

Disease creation has been characterized by historians as a process where a
biological event is defined – or redefined – by shifts in its social understanding. But the
history of GDM suggests that changes in social understanding are not always the
catalysts. The making of GDM involved nearly a century of scientific and bureaucratic
efforts. Those efforts formed a conceptual framework to address the potential problems
that the condition posed for women, their unborn children, and the general public.
Physicians and researchers collaborated with businesses in the diabetes healthcare market
and with legislators who held the purse strings for funding on scientific efforts. Although
debates about gestational diabetes were structured around the language of science and

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7 Ibid.; and Metzger interview.
8 Brown interview.
9 Metzger interview.
medicine, they were grounded in economic, legislative, and ideological considerations. While historians of medicine emphasize the social construction of disease, that formula does not work for the history of gestational diabetes. Much like with pharmaceutical companies’ diffusion of risk factor ideology and with the selection of study subjects in medical research designs, the mechanics of creating gestational diabetes informed our social understandings of the women who became patients.11

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