

DIABETIC AESTHETIC:  
FROM STIGMATIZING DIABETES TO ACKNOWLEDGING THE LIVED  
EXPERIENCE ON STAGE

by

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Diabetic Aesthetic: From Stigmatizing Diabetes to Acknowledging the Lived Experience on Stage

Thesis directed by Associate Professor Oliver Gerland

This dissertation provides the first systematic study of representations of diabetes in U.S. theater from 1949 to 2018. According to the Center for Disease Control's 2017 National Diabetes Statistics report, 30.3 million people in the U.S. live with diabetes. The World Health Organization identifies diabetes as a chronic disease, which manifests in four different ways: type 1, type 2, gestational, and pre-diabetes. For a disease impacting 9.4% of the U.S. population, diabetes is surrounded by an alarming amount of stigmatizing rhetoric and misinformation. Focusing primarily on dramatic literature and solo performance work that depicts diabetes, this study identifies two stigmatizing narratives rooted in the medical model of disability that commonly occur in dramatic literature. The case studies of these narratives included plays such as Lynn Nottage's *Sweat*, Bekah Brunstetter's *The Cake*, and Robert Harling's *Steel Magnolias*. This study then examines Robbie McCauley's *Sugar* and Irma Mayorga & Virginia Grise's *The Panza Monologues* through the social model of disability as these performances draw attention to systemic factors that produce and impact diabetic bodies. Drawing on theories of complex embodiment, the last case studies include the representation of diabetes in

Marina Tsaplina's *The Invisible Elephant Project* and G. William Zorn's *Lucille*.

Ultimately this project identifies a new framework, a *diabetic aesthetic*, to understand representations of diabetes on the stage that depict the lived experience of people who have diabetes. Diabetic aesthetic brings together an awareness of the role of social forces combined with the emotional and physical ebb and flow of the diabetic body. It draws on the benefits of the medical model for people with chronic illness, the recognition of social barriers presented by the social model of disability and utilizes theories of embodied disability identity to imagine a new way of viewing and expressing this non-visible chronic illness in performance.

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## CHAPTER 1

### INTRODUCTION

#### **1.1 Statement of Purpose**

The purpose of this dissertation is to discover how theater can be used to acknowledge the daily lived experience of people with diabetes. Efforts to represent this lived experience must overcome obstacles such as entrenched stereotypes, negative associations and misunderstandings about diabetes, the non-visibility of diabetes, and the legacy of storytelling that utilizes disability for plot purposes. I argue that in addition to these obstacles, efforts to authentically represent diabetes on stage are often problematic because diabetes is too often framed through the medical model of disability, which seeks to locate and understand impairment in order to discover a cure. In seeking a cure, the medical model becomes hyper-focused on the individual, their biology, and the perception of deficiency.

Attempts to define “diabetes” will immediately reveal the assumed framework of the medical model. Most commonly, diabetes is defined as a group of diseases, of which there can be different types, that all relate to the body not producing or responding to insulin. Insulin is a hormone that regulates both sugar in the bloodstream and our cells’ ability to use glucose for energy. This definition

focuses on malfunctioning biology and suggests an implicit desire for a cure, where the body would correctly produce and respond to insulin. In this project I will often refer to diabetes as a disease, a chronic illness, or a condition. All these terms are in step with the medical model perspective, which sees people with diabetes as needing a cure. However, I acknowledge that not every reader agrees with the perspective offered by the medical model. Some readers may view illness as a friend or a teacher, rather than a problem to be fixed and cured. Scholars such as Rosemarie Garland-Thomson advocate for finding community and developing disability identity because “most of us will move in and out of disability in our lifetimes, whether we do so through illness, an injury or merely the process of aging” (“Becoming Disabled” 2). Where the medical advancements achieved through the goals of the medical model have increased the life chances of people with diabetes, I suggest that the narrow focus on biology, individuals, and the combination of medicine and behavior to cure diabetes has produced stereotypes and misunderstandings that do not fully express the lived experiences of diabetes.

Another model that I believe is useful to expand our understanding of diabetes is the social model of disability. This model views disability as “a culturally and historically specific phenomenon” (Shakespeare 195). This model has traditionally expressed the view that people with impairments are not inherently disabled, but that society creates disability by making full participation inaccessible to everyone. The social model argues that if the social conditions around people with impairments were willing to meet their needs, such people would not experience

disability. Historically, this perspective has advocated for those who have impairments that can be classified as stable and predictable; it has not focused on the concerns of people with chronic illnesses, since such illnesses are often un-stable and not predictable (Wendell, “Unhealthy Disabled” 161). I argue that when theorizing discourses and experiences of diabetes, it is imperative to consider the social model. This model allows us to account for the role society has in constructing a person’s experience of diabetes and the ways that this experience is unique to people of different racial, gender, and socio-economic statuses within the broad category of people with diabetes. The social model opens us up to a deeper understanding of lived experience by encouraging us to see how one’s environment is connected to the individual with diabetes. The model also encourages us to incorporate socio-political histories into our understanding of individual situations. Similarly, the social model helps us to recognize the humanity of the whole person and not reduce a person with diabetes to their biology.

With these models in mind, we can begin to unpack diabetes more fully. Since diabetes is a non-visible disability and must be disclosed interpersonally, it impacts more people than we may immediately realize. The 2017 National Diabetes Statistics Report published by the Center for Disease Control and Prevention (CDC) informs us that 30.3 million people have diabetes, which is 9.4% of the U.S. population. The report further clarifies that 30.2 million people over 18 years of age have diabetes, which means that 12.2% of all U.S. adults are diabetic (“National Diabetes Statistics Report”). Picture yourself in a conference room with your

colleagues: in each group of ten adults, at least one person has diabetes.

Furthermore, not everyone who has diabetes is even aware that they do. The CDC report found that 23.1 million people have been diagnosed, but another 7.2 million, or 23.8% of people with diabetes, have no idea that they are living with blood sugar levels that would qualify as pre-diabetes or diabetes. These alarming statistics indicate that our beliefs around diabetes have major consequences for a significant population in the United States. With so many people impacted, it is important to ask how people learn about what this group needs or experiences. Scholar Sheila Bock argues:

[P]eople's knowledge about diabetes is filtered through different modes of experience—individual, familial, community, cultural—and these factors contribute to understandings of the disease built upon both expert and experiential perspectives. (“Grappling” 135)

I argue that the uneven combination of expert and experiential perspectives that people commonly encounter leaves too many with an understanding of diabetes that is flawed, inadequate, and often simply wrong. Unless a person has diabetes or a close relationship with someone willing to explain its intricacies in-depth, they are likely to absorb inaccurate information about diabetes through narratives in the media, including theater. I suggest that in order to realize accurate and empathetic representations of diabetes, we need to dynamically blend the medical model and the social model in our understanding of the condition. The medical model will help us incorporate accurate terminology and biological facts, and the social model will

enable us to understand larger historical and cultural influences that have contributed to constructing the experiences of the variety of people who live with diabetes.

To describe performances that bring these two models together, I introduce the term *diabetic aesthetic*. Aesthetics, whose meaning stems from the ancient Greek “of or relating to sense perception,” has traditionally been concerned with the philosophy of the beautiful and principles for appreciating that which a society considers beautiful (“aesthetic”; “aesthetics”). In 2006, disability scholar Tobin Siebers revisited the idea of aesthetics to realign it with its original meaning of sensory perception. He defines aesthetics broadly as “the emotions that some bodies feel in the presence of other bodies” (“Disability Aesthetics” 63). Siebers also offers a theory of *disability aesthetics* which “seeks to emphasize the presence of disability in the tradition of aesthetic representation” (64). Unfortunately, the mere presence of diabetes on stage can still result in stigmatizing narratives that do not articulate lived experience, but instead speak to the fears held by creators and viewers. To this point, disability aesthetics also “refuses to recognize the representation of the healthy body— and its definition of harmony, integrity, and beauty—as the sole determination of the aesthetic” (64). This refusal is vital because merely focusing on the presence of diabetes on stage does not address the stigmatizing narratives about it as a marker of personal failure or as a specter to an otherwise healthy body.



In fostering a *diabetic* aesthetic, I aim to show how artists who investigate their lived experience with diabetes on stage often incorporate two important gestures. First, these artists point to the role of social forces in the production and experience of a diabetic body. Second, they express the emotional and physical ebb and flow of a diabetic body. This awareness of both social influence and the chaotic nature of the body is an example of Siebers' notion of "complex embodiment" ("Disability and the Theory of Complex Embodiment" 325). Complex embodiment "embraces what the body has become relative to the demands of it, whether environmental, representational, or corporeal" (326-327). Complex embodiment seriously considers individual embodied experiences influenced by the reflexive impact of environmental realities. In that spirit, I offer diabetic aesthetic as a new framework to express the experience of people with diabetes on stage.

## 1.2 Need for Study

Arguably, the statistics identified above advocate for more robust models to contextualize and understand the reality of diabetes in U.S. society. Unfortunately, what we currently have is a great deal of stigma around diabetes that prevents us from moving towards these goals. Scholars in health humanities such as Kevin L. Ferguson and Sheila Bock have engaged with the prevailing negative stereotypes surrounding diabetes. Ferguson writes that people with type 1 diabetes are feared as "Jekyll-and-Hyde" types who are always "a suspect bunch, never quite in command of their selves and always reliant on the kindness of strangers" (184).

Bock finds that the common negative associations with type 2 diabetes are “obesity and inactive lifestyles” (“Contextualization” 155). These comments are relevant to my project because these stereotypes are prevalent when diabetes appears in the theater. I ask how theater can function as a site of knowledge production about diabetes that deconstructs these common stereotypes. While the project begins by locating a series of these stigmatizing examples in dramatic literature, I ultimately examine artists and playwrights who use their personal lived experience with diabetes to create theater that authentically reflects on and shares their knowledge with others. The works of these performers and playwrights is of interest to me not only because I believe the stage can yield more truthful reflections of the diversity of the human experience, but also because of my own story with type 1 diabetes.

My journey with diabetes began when I was diagnosed with type 1 right before I turned two years old.



Fig. 1: Bianca as a 23-month-old toddler. Day of type 1 diabetes diagnosis.

In this image I am in the play area of the Barbara Davis Center for Childhood Diabetes in Denver, Colorado. I have heard stories from my parents about how much I loved this room as a child. I would happily stay there while they attended classes to undo their own misconceptions about diabetes, and to learn from experts how to care for a child with type 1 diabetes. Over the years, I have gained agency and understanding regarding my own health care such as giving myself injections, counting carbohydrates, and ordering medical supplies. In my early attempts to grasp the scale of managing this illness, my mother and I calculated that over the

course of any given year, I would give myself or receive at least 1,825 insulin injections, which was a conservative estimate.

Despite the necessity of many injections, hospital visits, and diabetes-related crises, much of my adolescence and young adulthood I often hid, minimized, and ignored the care I needed for healthy diabetes management. As a young person, I was entirely mortified at the thought of being different and having a problem that required extra attention. The reckless choice to ignore my diabetes came at a great cost to my health and my family's sanity. I once crashed a car from having a low blood sugar, on another occasion I spent winter break in the hospital from a diabetes-related complication and managed to survive a handful of other avoidable emergencies. In my twenties I began working with a counselor and as a part of the growing self-care, I started sharing more about my needs with diabetes and clarifying the misconceptions I encountered.

My time as a graduate student in the CU Boulder Theater and Dance department has allowed me to experiment with performance as a vehicle for “coming out” with my diabetes. In one class, I created performances about my experience and identified myself as a person with diabetes more regularly inside and out of class. I recall one session, when a guest artist invited students to go around the room and share our name and how we identified. I introduced myself as a person with type 1 diabetes. I noted that several students who introduced themselves after me also choose to disclose mental or physical disabilities as they identified themselves. After the class, our regular instructor remarked that my

choice to identify myself as a type 1 diabetic was surprising to her; yet, to me this element of my identity is as essential and inextricable to my person as my gender, ethnicity, or sexuality. My choice to be more visible and more vocal about my diabetes has provided me with opportunities to confront the stereotypes and misconceptions about diabetes that I encounter daily. Even this academic endeavor to locate and analyze representations of diabetes in the theater is a direct outgrowth of my nascent agency.

This project was born from a heated discussion of the word “crippled” in Tennessee Williams’ play *The Glass Menagerie*. In 2015, I was the dramaturg for our department’s production and got into a disagreement with the director and a faculty member about a scene in which Laura, a central character in the play, says, “Mother... I’m—crippled!” to which Amanda, her mother, responds, “Don’t say that word!” (T. Williams 19). Our debate centered on the choice to cut the word “crippled” from the script; its history of othering and demeaning people with disabilities renders the word problematic. However, I felt a strong urge to keep this line in our production because although “crippled” is a problematic word, Laura uttered it as a desperate plea for her mother to validate her experience as she herself defines it; it seemed vitally important to me that we honor her definition of self. As a person with a non-visible disability, watching the scene in *The Glass Menagerie* flooded me with emotions about feeling unseen, unheard, and disregarded in my own attempts to self-represent.

From this initial feeling of connection to Laura, I began to research the ways that theater participates in disregarding and dehumanizing people with diabetes. I found many troubling examples. But, to my surprise, I also discovered that even as theater can perpetuate stereotypes and stigma, performance is uniquely situated to challenge and deconstruct our understandings of diabetes, stigma, and embodiment, while also entertaining us with narrative. This deconstruction includes dismantling stereotypes and providing ways for people with diabetes to represent themselves and for audiences to engage critical thinking and dialogue afterwards.

Attempts at dismantling stereotypes, encouraging authentic self-making, and examining constructions of the body are inherently concerns of intersectional feminism and disability studies. Thus, the goals of this study fit within the increasing demand for an intersectional, feminist, disability theory (Garland-Thomson, “Integrating Disability, Transforming Feminist Theory” 360; Erevelles and Minear, 381; Wendell, “Toward a Feminist Theory of Disability” 104). From its location in the field of theater and performance studies, this study is uniquely positioned to bring feminist and anti-racist concerns together and to examine them with a disability lens in order to dismantle assumptions about diabetes. The project will show that this lens is vital if we are to correctly understand the social and historical influences that create or impact people with diabetes. Sandra A. Black, a researcher with the Department of Epidemiology and Preventive Medicine at the University of Maryland, states:

Although diabetes can affect any segment of the population, the disease is especially burdensome among certain groups, particularly African Americans, Hispanic Americans, Native Americans, the elderly, those of the lower socioeconomic classes, and women. (543)

This disturbing information demands that we examine why these traditionally marginalized groups also suffer more from diabetes. We desperately need an intersectional, feminist, disability theory to understand this reality. Rosemarie Garland-Thomson contends that “the most compelling and complex analyses of gender intersectionality take into consideration what I call the ability/disability system—along with race, ethnicity, sexuality, and class” (“Integrating Disability, Transforming Feminist Theory” 361). I agree with Garland-Thomson that we must move away from thinking of gender, or disability or any of these identities as a monolithic category to account for the many nuanced experiences that emerge from these overlapping identities. When theorizing about diabetes, we must pay particular attention to the voices of women, people of color, and people with low-income status because as Black reveals, these communities are disproportionately feeling the burden diabetes, especially type 2. Many artists in this project are women. Some are women of color such as Robbie McCauley, Virginia Grise and Irma Mayorga, while others are white women like Marina Tsaplina. For these artists and playwrights who also have diabetes, their art often guides their audience to think about the social, historical, and economic systems that influence their experience of diabetes.

Many of the playwrights that I will look at are generally well-known contributors to U.S. drama and performance art who have been studied as important 20<sup>th</sup> century figures. For example, artists such as Anna Deavere Smith and Lynn Nottage have had volumes of critical theory and scholarship written about their work, yet I suggest that the role and significance of diabetes in their plays has been mostly overlooked by theater scholars. Theatre scholars have focused primarily on the ways these figures have engaged issues of race, class, and gender, and have devoted little attention to the casual remarks about diabetes in their works. Some may argue these artists do not critically discuss diabetes in their work because they merely capture the sentiments of the people they interacted with while developing their scripts. Smith is known for performing interviews verbatim and Nottage distinctively conducts extensive research before writing her plays. Still, these artists have the power to focus our attention, to construct—or deconstruct—influential narratives, and to critique prevailing paradigms. This project looks at the mentions of diabetes in Smith’s *Let Me Down Easy* and Nottage’s *Sweat* to provide analysis of diabetes in these important playwrights’ works.

The need for this study is evident because stigmatizing representations of diabetes reach broad audiences when they are in plays that have become popular on regional and Broadway stages. Take for example Robert Harling’s *Steel Magnolias*, a play which features a character dying from diabetes-related complications. It was produced on Broadway at the Lyceum Theatre in 2005, and regionally at The Cape



Playhouse in June 2018, Sacramento Theatre Company in October 2018, and L.A. Theatre Works in October 2018. Consider also Ken Weitzman's *The Catch* that was produced in 2011 at the Denver Center, or Bekah Brunstetter's *The Cake*, which opened Off-Broadway in March 2019. Both plays discuss diabetes in terms of fear, denial and language about food and lack of control. I propose that the depictions of diabetes in these contemporary, popular plays need to be examined in a comprehensive study. As theater scholars, we need a stronger comprehension of when diabetes is being used as a stigmatizing mark on stage, and we need to analyze the narratives offered by such representation. In so doing we can critically engage playwrights and can work to develop more robust dialogues with audiences to contextualize the remarks made in these popular plays. My hope is that this project will enable playwrights, performers, and audience members to engage more creatively and carefully with representations of diabetes. By engaging with diabetes more thoughtfully, we will move towards empathy and understanding, and can reduce the stigma that increases suffering of people with diabetes.

This dissertation provides the first systematic study of representations of diabetes in U.S. theater from 1949 to 2018. This study traces the historical context of diabetes and contemporary attitudes and how they emerge in live performance. Focusing primarily on dramatic literature and solo performance work that portrays diabetes, this study identifying two common stigmatizing narratives that dominate dramatic literature when representing diabetes on stage. This project then identifies a new framework, *diabetic aesthetic*, to understand representations of

diabetes on the stage that depict the lived experience of people who have diabetes. Diabetic aesthetic brings together an awareness of the role of social forces combined with the emotional and physical ebb and flow of the diabetic body. It draws on the benefits of the medical model for people with chronic illness, the recognition of social barriers presented by the social model of disability and utilizes theories of embodied disability identity to imagine a new way of viewing and expressing this non-visible chronic illness in performance.

### **1.3 Research Questions and Key Terms**

My primary research question is: How can theater acknowledge the daily lived experience of a person with diabetes, type 1 or type 2, without using diabetes as a stigmatizing mark? The sub-questions that I will also consider include: How have playwrights used diabetes as a stigmatizing mark? And, what are the strategies employed by playwrights and solo performance artists to represent the daily lived experience of diabetes? Before directly addressing these questions, I will sift through the terms and offer the definitions that I use in this project. First, I discuss diabetes: its biology, complications, and causes. I follow that foundation with an overview of Erving Goffman's theory of stigma as a social mark. I then develop my approach to the concept of daily lived experience. I conclude the key term section by defining theater and explaining why I use the term acknowledge in arguing that acknowledgement should be the central aim of theatrical practices that represent diabetes.

## **Diabetes 101**

### **Biology**

Diabetes is a chronic illness that has to do with one of our most fundamental human abilities: eating food and converting that food into the energy our bodies need to function properly. When we eat carbohydrates, protein, or fat, these chemical compounds become sources of growth and energy. When our bodies break down carbohydrates, both simple and more complex, they turn into sugar in the blood stream. Once the levels of sugar in the blood stream rise then the pancreas, an organ near the stomach, releases a hormone called insulin. The pancreas is always releasing some amount of insulin into the blood stream, but a rise of sugar in the blood, also known as blood glucose or blood sugars, will trigger the beta cells in the pancreas to produce more insulin. Insulin opens the doors for cells to store or use the sugar as energy.

All types of diabetes result from a combination of genetic and environmental factors that cause something to go wrong with insulin in the body. For the person with type 1 diabetes, the environmental factor is an illness, for example the flu, that causes the immune system to go into action fighting the illness. The genetic factor is the genetic coding that tells the immune system to go into overdrive and kill the cells that make insulin, known as beta cells. While someone is born with the genetic capability to become type 1 diabetic, it takes an environmental factor to trigger the immune system to go into overdrive, which is why people get diagnosed with type 1

at different ages. Once the immune system has destroyed the beta cells, the body of a type 1 diabetic does not produce insulin on its own, which means their cells cannot access glucose to use for energy. After scientists discovered insulin in 1921, a person with type 1 diabetes could perform the daily, minute-by-minute task of calculating and balancing their food and insulin intake. This labor is in the effort to achieve regulated blood glucose levels.

People with type 2 diabetes are also concerned with blood sugar regulation and the way the body is producing and using insulin. The problem for these folks is that while they can produce insulin, their cells are not sensitive to the message it delivers. The term for a decrease in insulin sensitivity is “pre-diabetes” which is measured by a slightly higher-than-average blood glucose level than a non-diabetic person. If a person’s cells are not sensitive to the message insulin is delivering, then their body will produce more insulin to get the message to the cells to open and intake glucose. A major problem arises when cells become exhausted because they eventually stop producing insulin on their own. The combination of overproduction of insulin, the body’s inability to regulate blood sugars, and elevated blood sugar levels result in increased health complications.

All types of diabetes are considered chronic illnesses. A chronic illness is one in which “physicians do not expect to cure them, and, once diagnosed, patients more or less expect to have to live with them ...patients do not expect to die soon from these diseases” (Wendell, “Unhealthy Disabled” 163). When a disease cannot be cured and will not go away on its own, the treatment required to manage its

impacts is ongoing as well. For people with diabetes, the focus of treatment is maintaining blood sugars within a “healthy” range, or at levels that will not harm the body in the long term.

The first place to start in order to make educated decisions about managing blood sugar is with knowing the amount of glucose a person has in their bloodstream. One can acquire this knowledge by taking a small amount of blood from a finger prick and putting it on a test strip. A small device known as a “glucometer” can then deliver a reading in a few seconds. Since 2016, the FDA has been expanding its approval of a device called the Continuous Glucose Monitor (CGM) as accurate enough for a person to make insulin decisions based on its glucose reading (“Press Announcements”). In short, one basic reality of a person with any type of diabetes is that they must maintain a regular awareness of their blood sugar levels. Treating the blood sugars is different depending on the type of diabetes.

Typically, when a person is initially diagnosed with type 2 diabetes, their doctor’s recommendation is that they change their diet and exercise more often, with the hope of increasing insulin sensitivity. This hope is based on the notion that the person’s cells are still producing insulin on their own; reducing cell exhaustion would reduce the likelihood of burning out those cells. If this recommendation does not lower the blood sugar levels, then the person may be prescribed a pill that suppresses the body’s internal stream of glucose released from the liver and kidney. If these methods do not regulate the person’s blood sugars, they may begin taking

insulin injections to support their cells' ability to intake glucose and use it for energy. Doctors also consider type 2 diabetes to be a chronic condition with no cure, but can be treated with diet, exercise, or medication ("Type 2 Diabetes").

A person with type 1 diabetes must intake their insulin externally. The World Health Organization states that for type 1 diabetics, "access to affordable treatment, including insulin, is critical to their survival" ("WHO"). A person with diabetes can draw insulin into their body in a variety of ways. The two most common are injecting insulin via syringe or via an "insulin pen" (a vial with a needle attached to the top). In the 21<sup>st</sup> century, devices known as insulin pumps or Omnipods have become increasingly common; they are devices that can be programmed to deliver insulin via a cannula inserted into the body. In order to prevent infection and avoid rejection of the cannula, the site of insertion must be changed every 3-5 days. Once a person can give themselves insulin, the issues are when, and how much, and why. An answer to when is that a person must take insulin whenever their blood sugar begins to rise. The most typical situation is when they eat food, especially carbohydrates—though protein, fat, sugar, or caffeine may elevate glucose levels. However, the body also requires insulin to process glucose released from the kidney and liver; this often requires "long-acting" doses of insulin that release slowly over time to process glucose released by these two organs. People with the devices attached to their bodies with a cannula will receive a constant, small amount of insulin to cover the glucose produced by the kidney. In addition, factors such as stress, sleep, exercise, and PMS impact insulin sensitivity,

and all effect glucose levels. All in all, there are many factors to manage when deciding when and how much insulin must be delivered. A person managing diabetes conducts a never-ending exchange between insulin delivery, glucose levels, food, exercise, stress, sleep, and hormones.

## **Complications**

Despite insulin's ability to prolong the lives of people with diabetes, if blood sugars remain improperly regulated, then outcomes known as diabetes complications follow. These complications can be devastating in both short- and long-term ways. First, in the immediate (meaning within minutes or hours), if blood glucose levels get too *low*, a person with diabetes can go into a coma and die. If their blood sugar is low and this issue gets addressed properly, intake of some form of sugar within minutes or hours can resolve the complications. However, if blood sugars go too *high* in a short period of time, a person can get diabetic ketoacidosis (DKA), which occurs when the body cannot access glucose and is forced to burn fat for fuel. This process, known as "ketones," will poison the body and can also, untreated, lead to death ("Genetics of Diabetes"). However, DKA is a short-term problem that can be addressed with insulin. If a person with diabetes maintains high blood sugars over a long period of time, other significant complications can occur. The most common and devastating are "diabetic retinopathy [leading to blindness], nephropathy [leading to kidney failure], and neuropathy [leading to

numbness in hands and feet]” (Martins 117), which can result in amputations—a not-uncommon secondary consequence of diabetes.

Most of the complications mentioned above are unintended consequences of the development of insulin as a drug, which was meant to prolong and improve the life of people with diabetes. When scientists first discovered that insulin could be introduced to the body to regulate glucose levels in 1922, the initial narrative about insulin framed it as a wonder-drug with abilities to prolong life for people with diabetes. Chris Feudtner traces these developments in *Bittersweet: Diabetes, Insulin, and Transformation of Illness* as he explores the suffering a patient endures from long-term insulin-related complications. In this dissertation, I will feature the work of Marina Tsaplina, an artist with type 1 diabetes. In one piece, she holds up an insulin pen and informs her audience, “It is my duty to respond to you, a society that produced me” (*The Invisible Elephant Project* 00:02:56-00:03:06). Her comment and gesture suggest the complex relationship between the medical model and its search for a cure, and the social model, which examines the social, historical, and economic structures that produce our experiences. My research looks at performance like Tsaplina’s to examine this complex relationship. I believe we do benefit from the medical model, which offers us accurate understanding of the biology, but Tsaplina is one among several artists who call us to also examine the social, economic, and historical realities people with diabetes encounter.

## **Causes**



Bringing together the medical and the social models of disability not only helps us to understand the experiences of people who live with diabetes, but it also helps us answer the question of what causes someone to become diabetic. The American Diabetes Association (ADA) states clearly that both family history and environmental causes trigger the onset of diabetes. The ADA explains that “diabetes does not seem to be inherited in a simple pattern. Yet clearly, some people are born more likely to develop diabetes than others” (“Genetics of Diabetes”). The ADA wants readers to understand that “Type 1 and type 2 diabetes have different causes. Yet two factors are important in both. You inherit a predisposition to the disease then something in your environment triggers it” (“Genetics of Diabetes”). To truly understand diabetes, we need medical and social models. As explanatory frameworks, both help us to understand the complex relationship between the genetic and environmental factors that might give rise to diabetes. But as we transition from thinking of diabetes solely in terms of its biological realities and processes and to begin to consider how both the existence and the experience of diabetes are shaped by the negative assumptions people in the U.S. attach to the condition, we need to examine the phenomena of negative assumptions becoming attached to otherwise neutral information. This process of connecting an individual characteristic with other unrelated negative associations is known as stigma.

## **Stigma Theory and Stigmatizing Marks**

Erving Goffman's defines stigma as "the situation of the individual who is disqualified from full social acceptance" ("Preface"). Stigma occurs in social settings when someone reveals "an undesired differentness from what we had anticipated" (Goffman 5). According to Goffman, stigma was first conceived by the Greeks as the physical marks made on the body of a person who was designated a slave or a disgraced person, in order to denote their status (Goffman 5). As Goffman developed his own theory of stigma, he contends that a stigmatizing mark now more commonly refers to a characteristic or social information. Goffman discusses social information as:

information about an individual. It is about his more or less abiding characteristics, as opposed to the moods, feelings, or intents that he might have at a particular moment. The information, as well as the sign through which it is conveyed, is reflexive and embodied; that is, it is conveyed by the very person it is about, and conveyed through a bodily expression in the immediate presence of those who receive the expression. (43)

I will use "mark" for characters in performance in a similar way. By mark in performance I mean information about a character that is abiding, reflexive, and embodied on stage. However, the negative associations that become attached to social information becomes stigma.

Stigma operates by associating one characteristic, like diabetes, with other discrediting qualities. I am most concerned with Goffman's idea that "by definition,

of course, we believe the person with a stigma is not quite human” (Goffman 5). If he is correct (and I think he is), stigma results in dehumanization and discrimination, “through which we effectively, if often unthinkingly, reduce [a person's] life chances” (Goffman 5). The dehumanization that stigma leads to is a central concern for this project, and it reveals a larger cultural ideology of ableism.

One way to define ableism is the belief that the “lesser the ability, the lesser the human being” (Siebers, (“Disability and the Theory of Complex Embodiment” 315). Ableism dismisses a person’s attempts to embrace their disability as pathological. Indeed, this theory contends that “if [people with disabilities] could think of themselves as able-bodied, they would be healthier and happier (316). Ableism, also known as the ideology of ability, celebrates narratives of overcoming disability, furthering the notion that people must “try to erase any signs of change, to wish to return the body magically to a past era of supposed perfection, to insist that the body has no value as human variation if it is not flawless” (326). Of course, when we operate from an ideology of ability, people with diabetes resist ownership and integration of diabetes into their identity because of course to do so would be to accept the diminished value of one’s life. This project identifies stigma around diabetes as an indicator of a culture steeped in ableism. In so doing, this project shows how performance can work against and misunderstandings about people living with diabetes while also validating their humanity and increasing their life chances. This work of “acknowledge” works against ableism and operates as a

dynamic way of engaging diabetes on stage. This act encourages artists to voice their stories and for audiences to provide witness.

### **Acknowledging the Daily Lived Experience**

The relationship between an artist sharing their experience and an audience witnessing this sharing is an acknowledgement. The Oxford English Dictionary defines “acknowledge” as follows: “to accept the authority, validity, or legitimacy of; to accord due recognition to; to own the claim or title of (a person).” As I see it, the three parts of this definition are essential to how performances of diabetes shape our understanding of the condition and the people who live with it. On the one hand, theatre allows an audience, or a gathering of witnesses, “to accept the authority, validity, and legitimacy of” the lived experiences being represented onstage. On the other hand, “to own the claim or title of (a person)” relates to the ability of a person with diabetes to claim ownership of a non-visible disease. Whereas stigma encourages one to hide, acknowledgment suggests an acceptance of one's own self. To “acknowledge” suggests the capacity for agency, which is necessary for a person with diabetes to manage their chronic illness. Such experience is based on a first-hand, embodied knowledge, and is experienced subjectively, personally, and emotionally. This is an important distinction, because some of the playwrights I investigate have had direct face-to-face interactions with people with diabetes, yet I argue that they still depict diabetes in a stigmatizing way. Conducting an interview or having a friend or family member with diabetes

does not always produce knowledge of the daily, lived experience of the condition, especially if the playwright does not make an intentional effort to understand it as an ongoing and complex situation. I hope to see the ongoing, ever-present nature of this chronic illness depicted on stage. This shift requires the participation and voices of people who have themselves dealt with it daily, through personal experiences.

## **Theatre**

One method to change the pervasiveness of ableism, and more narrowly the stigma surrounding diabetes, in everyday life is through theater. Performance events depict characters who embody and enact new ways of interacting with their diabetes. Theater does not passively disseminate ideology, but instead “theater has a direct connection to social change because it has the power not only to show a character’s response but also to reflect the conditions that led to that response” (López xv). Theater can provide a space to witness a different way of interacting with one’s diabetes, a way that is not only responding to the ideology of ability. When we see characters who engage their disability as an identity rather than a biological defect, we discover the positive effects of complex embodiment. This shift in theatrical representation can then work towards shifting the experience outside of it. Shifting the ideology in theater shifts ideology in the culture.

Theater is also persistent in foregrounding the body. The difference between the cinema and the theater is often the presence of live bodies on stage. Theater has

a unique challenge to provide the exposition without the speed of a film or resources of the internet but benefits from the inherent focus on the body. In this dissertation I use the term “theater” to emphasize live bodies functioning as actors in a clearly framed, artistic event. Theater is also uniquely able to encourage social change. Theater scholar Dr. Tiffany Ana López unpacks the power of theater to generating social change:

Theater artists tap into the dynamics of embodiment that define live performance in order to reconstruct the public space of the theater as an arena of witnessing where affect and feeling palpably inform the experience of listening to a story and watching it unfold. Theater intensifies communication and heightens one’s ability to come into awareness. (xv)

Theater asks its audiences for full attention, and who gets to tell their story reveals what the community that has gathered to see and to hear the story values. As Dr. Tiffany Ana López reflects on plays about women: “just the act of entering the theater affirms that women’s experiences are worthy of sharing as the subject of art and merit documentation within the archive of public discourse” (xv). When I read this quote and re-imagine “people with diabetes,” in the place of “women,” I cannot agree more; the experiences of people with diabetes are “worthy of sharing as the subject of art and merit documentation within the archive of public discourse” (xv), especially in the realm of theater, since it is so naturally capable of engaging its

audience. The liveness of the actors combined with the liveness of the audience lends itself so well to a continued dialogue within a community.

Richard Schechner defines theatre as an “event enacted by a specific group of performers; what actually occurs to the performers during a production. The theatre is concrete and immediate” (8). This definition is useful to me as I explain why I focus on diabetes in the theater, when self-representation and activism on the internet and social media proliferates. Indeed, performance and diabetic performativity can be located in many spaces, yet I choose to investigate theater because I am interested in diabetes as a part of Schechner’s definition of theatrical events. I am not looking at the multiple ways in which one could show the doing of diabetes in the world or in digital content; rather, I am interested in the specific context of a theatrical event, which necessarily foregrounds liveness, the body, and the connection performers have with their community—the audience. In Greek, “theater” means “the seeing place,” a definition that emphasizes the role of the audience as witnesses. Traditionally, theater has been a highly visual medium.

However, in order to create a truly diabetic aesthetic for the stage, we must not only focus on the visibility of diabetes on stage. The emphasis on visibility reflect the medical model’s preoccupation with individual’s and maintains a focus on individual behavior. A true diabetic aesthetic will incorporate the accuracy of the medical model, the larger social realities of the social model of disability, and incorporate the embodied identity of disability, in this case diabetes. The concept of disability as an embodied identity emerged from critiques of the social model. These

criticisms include its reliance on visible impairments and limiting understanding of disability identity (Shakespeare 195). Diabetic aesthetic in the theater will bring forth the phenomenology of the lived experience to the seeing place. Some scholars argue that the main problem that arises with diabetes in visual mediums is that healthy diabetes management is visually boring (Ferguson 189). I argue that a diabetic aesthetic for the theater will incorporate the elasticity of the body as well, which reflects the integration as diabetes as a part of one's embodied sense of self. Simply changing the visual appearance of characters with diabetes on stage will not necessarily lead us to new insights about the condition. Disability studies scholars Snyder and Mitchell warn us of thinking of bodies only in visual terms. They ask for a greater engagement with embodied knowledge of marginalized bodies:

Like feminized, raced, and queered bodies, the disabled body became situated in definitive contrast to the articulation of what amounted to a hegemonic aesthetic premised on biology. Within this cultural belief system, the "normal" body provided the baseline for determinations of desirability and human value. (368)

Instead of framing diabetes as a matter of contrast to non-diabetic bodies, we must usher in new knowledge based on the reclamation of the phenomenology of the body (Snyder and Mitchell 368). Theatrical performance offers an effective avenue for reclaiming the phenomenology of the body, or "intimate depths and complex embodiment of disability" (Sandahl 454). If playwrights explore the phenomenology



of the body, audiences gain new insights into the concerns, behaviors, and experiences that might not be easily available with a non-visible, chronic illness.

## **1.4 Methodology and Study Outline**

In the next chapter, I use the medical model to provide a historical overview of diabetes as a medical condition. The overview begins with the earliest recorded symptoms, discusses a variety of treatments over time, and includes the discovery of the “miracle-drug” insulin and other new technologies that have radically shifted experiences of diabetes. The second half of the chapter critiques the medical model by examining the ways it produces stigmatizing attitudes towards diabetes in contemporary U.S. culture.

In Chapter 2, I discuss the possible reasons why representations of diabetes on stage proliferated in the 1980s and 1990s. I argue that the noticeable increase in the mention or the representation of diabetes in plays from these two decades was related to the HIV/AIDS crisis, and the increased stigma it inspired towards what were, in the United States, perceived to be lifestyle-related illnesses.

The following chapter, Chapter 3, looks at eight plays written in the United States that invoke diabetes as a stigmatizing mark. I examine the plays by considering the biographies of their authors and by carefully analyzing their scripts, as well as the spaces of each original performance and its critical reception. My script analysis locates ideas or images associated with diabetes in the text and notes how diabetes is represented as a stigmatizing mark. The types of stereotypes and

stigmas that came up consistently helped me organize my findings into two separate themes; my analysis is organized by theme. The publication dates of the eight plays I analyze spans from 1949 to 2018; together, they show that while medical treatment options for diabetes developed tremendously over these seven decades, stereotypes about diabetes largely remained the same.

In Chapter 4, I examine a 2018 production of Robbie McCauley's *Sugar* and the 2014 2<sup>nd</sup> edition of Irma Mayorga & Virginia Grise's *The Panza Monologues*. These case studies are performances that use the social model of disability to highlight cultural, economic, and historical factors to contextualize diabetes. Each case study includes a brief performer biography, an overview of the development of the piece, and a short production history. My analysis of each case focuses on the strategies the artist used to address the impact of social factors to shape the lived experience of diabetes.

In Chapter 5, I look at Marina Tsaplina performance of *The Invisible Elephant* (2018) alongside the script of G. William Zorn's play *Lucille* (2008). Some critics of the social model argue that it is hyper-focused on visual disabilities and overlooks the embodied identity of disability. These case studies incorporate social realities as well as the embodied identity of having diabetes. The combined awareness of social influences with embodiment is what Tobin Siebers calls "complex embodiment" (325). I argue how diabetes complexly embodied on stage leads to a diabetic aesthetic that de-stigmatizes diabetes and portrays the lived

experience. These are two examples of artists portraying diabetes as a part of their identity, and process of grief and joy that they encounter as a part of that identity.

## 1.5 Limitations and Conclusions

### Limitations

Of the plays I found with “diabetes” as a term in the text, I chose not to include *The Title* (1918) by Bennett Arnold, *Home and Beauty* (1959) by W. Somerset Maugham, or *The Sunshine Boys* (1979) by Neil Simon. All three mention “diabetes” as one disease in a longer list of ailments, but I believe that each playwright stigmatized diabetes as a general illness and in a way that was not specific to diabetes. Similarly, I did not include *Pullman Car Hiawatha* (1932) by Thornton Wilder. While the play mentions “diabetes” in a conversation between two nurses who are listing patients they have seen, discussion of the condition does not extend beyond the statement: “I had a case in Cleveland once. Diabetes” (Wilder 4).

*The Nervous Wreck* (1926) by Owen Davis does not explicitly treat diabetes as a stigmatizing mark for a character, so the play does not figure in my analysis. However, by mentioning a brand of biscuits called “Dr. Wachenhovens Diabetes Biscuits” three times in the script, and thereby linking “diabetes biscuits” with a doctor whose name identifies him as a “whack,” the play suggests that something about diabetes is wacked, ridiculous, or comical.

*Passione* (1981) by Albert Innaurato, *In the Eye of the Hurricane* (1991) by Eduardo Machado, and *Reilly and the Four Hundred* (1994) by Edward Harrigan could have also been included in my analysis. Characters in each play talk about “diabetes” in relation to blood turning to sugar:

BESSIE. Diabetes.

MILKMAN. Oh! Your blood’s turning to sugar. (Harrigan 30)

or

BERTO. I got all this for Pop. You know how much he likes to eat, and I figure in that home---

RENZO. Yeah, you know, sometimes they inject their food, you know.

Sugar in the veins. Hanh? That's hell on us wops, we all got diabetes to begin with. (*He and Berto laugh riotously*). (Innaurato 56)

And lastly,

MANUELA. Diabetes.

MARIO. Have you told her yet?

MANUELA. I'm not going to tell her.

MARIO. That sugar, all that sweet sugar water is killing her. The syrup she has for blood has gone out of control. (*He starts to cry*).

(Machado 31)

Notice that each play discusses diabetes in terms of how the characters perceive what is happening inside the body of another. Plays that show characters hypothesizing about blood turning into sugar reflects the medical model because the

characters are imaging deficient biology. While this use of diabetes is significant, I choose instead to analyze plays that used diabetes to shame or cause harm to a character in the plot. Another example that will not be discussed in this study is P.J. Gibson's *Brown Silk and Magenta Sunsets* (1995), in which the characters Lena and Able discuss the fact that Able's mother is getting discharged from the hospital, which leads to this exchange:

LENA. Diabetes can be an ugly disease. Oh, should you be drinking that?

ABLE. What?

LENA. The soda. You know, the sugar. Shouldn't you watch things like that? (109)

Able explains that he is adopted, which is why he does not have to be worried about "possible physical weakness" (159). While these four plays clearly link diabetes and sugar, the plays I choose to analyze use diabetes to suggest other failures about a character that are somehow correlated with this characteristic.

## Conclusions

This dissertation begins with the personal stake I have in the transformation I believe everyone, including theater artists, should work towards. Theater can be a vital site for social change. By providing more nuanced portrayals of diabetes, theater can become a place where new understandings, representations, and dialogues may emerge to generate empathy and compassion about living with

diabetes. By providing audiences with more nuanced understandings of diabetes, we can teach them about the stigmas currently associated with diabetes and can critically engage them in critiquing those stigmas. For this reason, I believe that people with diabetes should author their own stories about the experience for our stages. This greater representation leads to social change by increasing the diversity of human experiences on stage, expanding the cultural knowledge available about diabetes, and increasing empathy in witnesses to these stories.

## CHAPTER 2

### A HISTORICAL OVERVIEW AND CONTEMPORARY ATTITUDES TOWARDS DIABETES IN THE UNITED STATES

#### **2.1 A Historical Overview of Diabetes**

The medical model of disability flourished in the post-Enlightenment era as beliefs about the causes of disability from shifted from “divine punishment, karma, or moral failing” (Shakespeare 195). As Enlightenment thinkers challenged traditional narratives from religion, physicians developed new ideas about the causes of disability as biological malfunction (Shakespeare 195). The understanding that biological processes were responsible for disability and disease made it possible for patients and medical practitioners alike to begin to think of diabetes in terms of finding a cure. I acknowledge that the medical community’s efforts to pinpoint cause and seek a cure have saved and bettered the lives of many people with diabetes. However, I argue that, informed as it is by a Puritan ideology of discipline, the medical model has, perhaps unwittingly, given rise to negative attitudes towards people with diabetes in the U.S.

I argue that physicians have used the medical model to frame diabetes as a disease that can be managed through the careful regulation of the behavior of the

individual. In this narrow perspective, diabetes appears as an issue of self-control, and the individual who, in this logic, has chosen to be out of control, is seen as responsible for the negative consequences of their behavior. While multiple examples in dramatic literature reinforce stereotypes based on this view of diabetes, some artists present diabetes from a more holistic perspective, which I refer to as the social model. Their work addresses the larger historical, cultural, and financial inequities that contribute to the burden of diabetes on the U.S. population.

### **Ancient Greece to the 20<sup>th</sup> Century: A Terminal Illness**

“Diabetes is a mysterious illness...[where] the flesh and limbs melt into urine”  
- Aretaeus of Cappadocia, 2 A.D. qtd. in Feudtner 4

While ancient Egyptians recorded symptoms of diabetes over 3,000 year ago, the earliest physician to recognize and name a group of symptoms as “diabetes” was a Greek physician named Aretaeus of Cappadocia (Ahmed 1, Feudtner 6, Ferguson 190). Around 2 A.D., he noted the “never-ending thirst, copious urination, [and] wasting of the body” as markers of a unique disease (Feudtner 5). The term he coined to describe this disease, “diabetes,” originates from the classical Latin “*diabētēs*,” which translates to mean: “siphon” (“diabetes, n.”). Following Aretaeus’ lead, physicians in Ancient Greece associated this set of symptoms with “to siphon” or “to run through” because of the intense thirst and frequent urination that people experienced. Physicians like Aretaeus were fascinated that, though



patients ate and drank regularly, their bodies nonetheless appeared to be wasting away (Rock 468). The person's body *was* a "siphon," and by the 5<sup>th</sup> century the term "diabetes" was firmly associated with this specific disease ("diabetes, n.").

It was not until centuries later, at the dawn of the Enlightenment in 1674, that an English physician Thomas Willis discovered a connection between the group of symptoms called diabetes and the presence of sugar in the body. In his essay "The Diabetes or Pissing Evil," Willis observed by tasting diabetic urine that it seemed "wonderfully sweet as if it were imbued with Honey or Sugar" (Feudtner 5). In 1776, the physician Matthew Dobson conducted more experiments to prove Willis' theory that diabetes was related to sugar in the body. Dobson went so far as to evaporate a patient's urine and taste the white cake substance that remained. He did this to cement his certainty that diabetes had something to do with sugar (Feudtner 5). Willis' contention and Dobson's confirmation proved with scientific certainty that the urine and blood of diabetics contained sweetness. This discovery led Willis to add the term "mellitus," meaning "honey," to diabetes and the condition was termed "diabetes mellitus" (Ahmed 1).

At this point in history, physicians did not conceive of multiple types of diabetes; all instances were classified as "diabetes mellitus" (Rock 468). However, as early as 1875 doctors noticed groups of symptoms presented in two distinct ways when people were diagnosed with diabetes:

Patients with the first type were relatively young, often children:

weight loss was marked, onset was acute, and death quickly followed.

Patients with the second presentation tended to be older adults: they were often overweight, onset was slower, and they lived much longer. (Rock 469).

The distinction puzzled doctors, but it did not inspire them to change their understanding of the condition. For nearly a century, diabetes continued to be a monolithic diagnosis; the same treatment was generally given to people who presented symptoms in either of these two ways. Physicians believed that the problem for these patients was a biological malfunction of “assimilation”: the body would not properly integrate food for nutrition (Feudtner 5-6). Doctors prescribed special diets, searching for foods that these bodies would assimilate. In 1787, John Rollo recommended that people with diabetes eat “fat and rancid old meats” (Feudtner 6). In 1898, Elliott P. Joslin began seeing children with diabetes and advised that they adhere to a “strict diabetic diet” consisting of “500 c.c. of cream, two oranges, 15 grammes of bread, and a little whiskey” (Feudtner 12-13). The most common diet prescribed was starvation interspersed with “5 percent vegetables [such as lettuce, cucumbers, water cress, broccoli, and the like]” (Feudtner 6). Tragically, no matter the diet, children who presented symptoms of diabetes survived a mere three to six years, and those years were painful. Diabetes was a fatal diagnosis—until early 20<sup>th</sup> scientists discovered insulin.

### **The Discovery of a Miracle Drug: Insulin**

In the summer of 1921, four scientists working at the University of Toronto forever changed the reality that diabetes was a terminal illness. Fredrick G. Banting and Charles H. Best, working under physiologist John J.R. Macleod and alongside chemist James B. Collip, extracted and purified the hormone insulin. For a time, physicians believed that this drug was perhaps the cure for diabetes altogether. By 1922, insulin was available for commercial use, and in 1923 Banting and Macleod jointly received the Nobel Prize in Physiology or Medicine for the discovery of insulin (“The Nobel Prize”).

Insulin therapy quickly replaced starvation diets as the primary treatment of diabetes. The image below demonstrates with visual evidence the powerful narrative that took hold: insulin therapy could bring a person back from the brink of death.



Fig. 2: This photo was published in Chris Feudtner's book *Bittersweet: Diabetes, Insulin, and the Transformation of an Illness*.

Researchers soon discovered that despite its miraculous power to restore the bodies of people with diabetes, insulin did not provide a cure. By the 1930s, researchers had discovered that, over the long term, insulin-therapy created unforeseen consequences: "several health problems had arisen in adult diabetics treated with insulin, including obstructed blood vessels, impaired vision, and damaged kidneys" (Rock 470). Scientists discovered that while patients who presented symptoms of diabetes could live longer within a normal weight range without a starvation diet, problems emerged as a result of the treatment. In fact, "the extension of life afforded by insulin therapy allowed the late complications of diabetes to emerge more clearly" (Rock 470). This range of new impairments, which today are known as diabetes complications, results from elevated blood sugars over time. It took until the 1970s for scientists to focus on blood sugar control as a critical aspect of managing diabetes.

In the 1950s and 60s, research on diabetes established a new understanding of the different types of diabetes. As research techniques designed to measure the amount of insulin in a person's body developed, doctors began to see that some people produced no insulin, while other people produced too much. This distinction among people with diabetes led "researchers to look for other causes for this second type of diabetes, and to understand more fully that there is more than one type of diabetes" ("Joslin Timeline"). In 1959, Solomon Berson, MD and Rosalyn Yalow,

PhD characterized and then labeled the difference: they termed the what they identified to be the insulin-dependent condition “type 1 diabetes,” and the non-insulin-dependent form, “type 2 diabetes” (“History of Diabetes”).

Before the 1970s, doctors monitored patients by analyzing their urine to measure sugar levels in the body. In 1970, the Ames Company released the first glucose meter, which allowed for a person to learn their own sugar level by testing their blood (“History of Diabetes”). It was not until this time that blood sugar levels “became tangible. Glucometers report blood sugar levels within seconds as a two or three digit number. With inexpensive, portable glucometers, diabetes became firmly associated with blood” (Ferguson 192).

Information gained from glucose meters and blood sugar readings confirmed Berson and Yalow’s thesis that there were two types of diabetes. New research has revealed that at least four types of diabetes exist. In 1988 The National Diabetes Data Group introduced a classification system to identify these four types: “1) insulin-dependent or type 1 diabetes, 2) non-insulin-dependent or type 2 diabetes, 3) gestational diabetes, and 4) diabetes associated with other syndromes or conditions” (Harris 1; “History of Diabetes”). This system of classification received global consensus in the 1980s, when the World Health Organization decided to classify the diagnosis of diabetes based on the level of glucose in a person’s blood rather than in their urine (Rock 471).

In the 21<sup>st</sup> century, many new technologies have been introduced to more competently manage glucose levels. Some of these advancements include insulin

pumps, OmniPods, and Continuous Glucose Monitors (CGMs). However, as much as technology has changed and diabetes is no longer considered a terminal illness, there remain major burdens associated with diabetes management. One example is the increasing number of complications like retinopathy, nerve damage, and limb loss that occur as a result of longer life with uncontrolled diabetes. Another area is the high financial cost required to obtain the medicine and supplies needed for diabetes management. For example, in February 2016, *The New York Times* published an article on the increasing costs of insulin while in October 2016, *The Washington Post* alerted its readers to the difficult decisions people with diabetes make between buying insulin or paying their bills (Lipska; C. Johnson). The second article concludes that, "the history of insulin captures one of the mystifying complexities of the pharmaceutical market- how long-standing drugs become more expensive with time and competition fails to hold down prices" (C. Johnson). As people in the United States debate health care reform and how to insure people with pre-existing conditions, people with diabetes often must choose between bearing the cost of medical treatment and the health risks of uncontrolled blood sugars.

The burden of stigma and the general public's misunderstandings about diabetes further contribute to the difficulties people who live with diabetes face. Many children with type 1 diabetes do not get the care they need in school. Administrators are often ignorant of "the routine care they need, such as insulin shots or blood sugar monitoring" (Louis). This lack of care for students can even

result in discrimination, like that experienced by the Pollard family in Oregon whose son was denied entrance into a kindergarten academy because of his type 1 diabetes (Louis).

The world of NFL and ESPN provides another example of the stigmatization of diabetes that abounds in U.S. popular culture through casual remarks and misinformation. Jay Cutler is a professional athlete with type 1 diabetes. He was diagnosed in 2008, when he was 25 years old. In the 2016 NFL season, ESPN commentator Stephen E. Smith disparaged Cutler, who was then the quarterback for the NFL's Chicago Bears, about this diabetes. First, he incorrectly identified Cutler as a type 2 diabetic, then he said: "The way I look at it, we live in an advanced society, where there's medicine everywhere to help you out" (Droste). In this comment Smith implies that modern medicine is so sophisticated that the way Cutler is impacted by his diabetes is his own fault. Smith's casual words diminished and oversimplified the labor of diabetes management. His comment is one among many remarks that illuminate contemporary attitudes towards diabetes that are generally unhelpful, and even dehumanizing, for people with this condition. We must examine our casual remarks about diabetes and investigate how U.S. history leads us to the place where this comment is typical, unquestioned, and representative of a misunderstanding and stigma attached to a biological situation.

## **2.2 Contemporary Attitudes Towards Diabetes in the U.S.**

JEFF. How are you so satisfied all the time Abed? I mean, don't you ever want anything more out of life than cereal?

ABED. Sometimes I like to pour hot cocoa mix into cold milk and drink it like a cold hot chocolate. I call it special drink.  
JEFF. And someday you will know it by its true name, diabetes.  
- "Home Economics," *Community*, Season 1, 2009

The unspoken stigmatizing reflected in Smith's comment is the norm, not the exception. The comment is a product of the broader contemporary attitudes towards diabetes in the U.S., which I believe are the product of U.S. ideology that considers bodily discipline as moral behavior. The philosophical landscape of discipline and control that Foucault identified in Europe was firmly established in the U.S. by the Puritans and has been maintained by capitalism, which encourages participants to spend in excess but maintain control through performative upkeep of their bodies (Williams 437). The perception is that if one is out of control or undisciplined with their body, then they are immoral. By focusing on diabetes management as a performance of discipline and control, the narrow view endorsed by the medical model has contributed to negative stereotypes and misunderstandings that dominate U.S. popular culture. I argue that because U.S. culture makes people with diabetes appear as willfully out of control, adverse to advanced medicine, or unwilling to address a biological deficit, such people are easily discredited and stigmatized.

### **Body Discipline in the U.S. and Puritan Ideology**



In Puritan philosophy, discipline is the primary way of engaging the body. In *The American Dream: A Short History of an Idea That Shaped a Nation*, Joseph Epstein remarks, “the concept of discipline went to the very heart of the Puritan experience” (19). Other central myths of the American Dream contribute to people in the U.S. misunderstanding the nature of chronic illness. These myths include hard work leads to success, a rugged individualism where one is responsible for their own destiny, and the belief that one’s life experience is not determined by privileges at birth. As capitalism developed in the U.S., the belief that a person’s ability to discipline and control their body becomes linked with economic success as well.

Western capitalism encourages people to conform to corporeal norms through discipline of the body while at the same time participating in excess and pleasure, which keeps consumer culture going (Williams 440-441). Sociologist Simon J. Williams argues that middle class notions of health “oscillate[] precariously between bodily discipline and corporeal transgression: modalities which reflect and reproduce fundamental contradictions within western culture and late capitalism itself” (437). Consumer culture firmly links thinness and the moral ideal of control: “Within consumer culture, a premium is placed on the slim, trim, sexually attractive body as the key to success from the boardroom and to the bedroom” (Williams 440). In the capitalist economy of the U.S., there are of course ways to buy products to achieve the “slim, trim, sexually attractive body.” Purchasing goods is one way to achieve the moral performance of health, while another is the

expectation for discipline in adhering to medical advice. Western culture demands eating healthy and exercising as a part of a moral performance of health. U.S. culture stigmatizes those who fail to maintain the balance between excessive behavior and bodily discipline.

### **Lifestyle Panic in the 1980s and 90s in the U.S.**

In addition to Puritan ideology about discipline, there was a re-emergence of harsh rhetoric about personal responsibility around “lifestyles” in the 1980s. During this time, the Republican Party and Ronald Reagan formed a political movement called the New Right. This movement arose in response to the political and cultural upheavals of the 1960s and 1970s, and operated with an “an individualistic, pick-yourself-up-by-your-bootstraps mentality” (S. Wolf 131). This logic of individual responsibility was coupled with the social abandonment of persons who do not meet normative standards of success or belonging. Historians Michael Omi and Howard Winant write that the New Right rhetoric demonstrated an “obsession with individual guilt and responsibility where social questions were concerned (crime, sex, education, poverty)” (125). The paradigm of guilt and responsibility in political rhetoric of the 1980s was especially problematic because it both ignored and then demonized illnesses like HIV/AIDS. Politicians believed that HIV/AIDS resulted from poor lifestyle choices. During these decades of political ideology from the New Right, there was an increase of mentions of diabetes in dramatic literature. In my search for the word “diabetes” in the *Twentieth-Century Drama Database*, there was

one play in each decade beginning in 1918 to 1949 that mentioned diabetes. There was another mention in a play in 1958 and another 1959. While there was one mention in a play published in 1979, there were five mentions in plays published between 1981 – 1995. This data shows an uptick in mentions of diabetes, and many of the mentions feature a character warning another about getting diabetes from drinking or eating sugar.

### **Society Stigmatizes the Person Who Fails to Control Their Body: Fat Embodiment**

The person who is perceived to have failed to control their body is stigmatized, and their failure is construed as individual. One enduring example of a type of body that is highly stigmatized is fat embodiment.<sup>1</sup> Feminist scholars like Naomi Wolf argue that modern, Western ideals of thinness were spread in the media after the white, middle-class women's movement of the 1960's deconstructed domesticity as the dominant force that contained white, middle-class women's political power (3). After feminist thinkers like Betty Freidan deconstructed myths of domesticity and the pressure placed on women to maintain perfect households, the next powerful force to control white, middle-class women's bodies was through the "beauty myth" (N. Wolf 5). Media outlets such as advertising in magazines and TV news stations show images of models and tv anchors as young and thin. These

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<sup>1</sup> I borrow the term "fat embodiment" from scholar April Herndon, who identifies herself as "a large woman violating the ideal figure of womanhood" (120). I prefer fat embodiment over terms like "bodies of size" or overweight because they re-inscribe bias towards a preferred body weight.

images convey that message that to have power and participate in society, women must be young and thin (N. Wolf 20-23). Wolf laments that with the increasing power of the beauty myth, eating disorders and cosmetic surgeries have been rising exponentially and “American women told researchers that they would rather lose ten to fifteen pounds than achieve any other goal” (2). While the thin body is highly valued, fat embodiment is highly stigmatized. Scholar Rebecca Stone Thornberry outlines a list of negative characteristics associated with fat embodiment:

While the slender body evokes images of health, success, balance, and control, a short list of terms associated with fat bodies / people reveals some interesting constructions of fat embodiment. Scientific studies published in the journal *Obesity Research* reveal constructions of fat people as lazy, dirty, smelly, mentally unbalanced, unhealthy, immoral, unpatriotic, and asexual. (29)

Thornberry argues that an entire matrix of negative characteristics is wrongfully associated with weight. The belief that fat embodiment is pathological and stigmatized reveals more about fatphobia and bias against those perceived unable to maintain body discipline than it represents accurate knowledge of medical paradigms of health. April Herndon asserts “while a majority of people in the United States believe that fat is unhealthy, immoral, and often downright disgusting, medical opinions on weight are actually quite mixed” (125). At times those with bias against fat embodiment can lead to the perception that fat people overuse government welfare programs and are undeserving of public resources

(Dodge). This perspective can be summarized as the view that fatness is a “voluntary condition resulting from poor eating habits and sedentary lifestyle [that is]... dangerous to the American purse because accommodation must be suffered by the public writ large” (Herndon 124). This issue has become more visible during fights about ObamaCare in the last decade. In May 2017, Mick Mulvaney, the former White House Budget Director (but as of this writing White House Chief of Staff), discussed plans to repeal parts of the ACA. He defended his plan by saying:

We have plenty of money to provide that safety net so that if you get cancer you don't end up broke...That doesn't mean we should take care of the person who sits at home, eats poorly and gets diabetes.

(Leonard)

The comment misunderstands the causes and nuances of diabetes, and paired with Mulvaney’s desire to defund the ACA, it demonstrates how systemic structures contribute to the barriers and dehumanization a person with diabetes faces.

### **Diabetes is Insufficient Body Control Pt. I: Diabetes and Discipline**

Arguably, the beginning of the relationship between body discipline and diabetes can be attributed to the founder of modern diabetes care: Dr. Elliott P. Joslin. As a twenty-nine-year-old doctor in 1898, Dr. Joslin saw his first patient with diabetes, but soon became a specialist in treating people with diabetes. Dr. Joslin was “a man imbued with Protestant morals” and asked patients to apply extreme discipline to their diabetes care (Feudtner 12). Joslin’s care helped elongate

the lives of patients before insulin was discovered; after it was discovered, he worked with patients well into the 1960s, using his incredible passion to help them manage diabetes. His philosophy espoused rigorous discipline and trusted that “adherence to treatment with diet, insulin and exercise finds ample justification in the good health, comfort and longevity of those who obey the rules” (Joslin qtd. in Feudtner 31).

Dr. Joslin was not wrong that the stakes for his patients were incredibly high; they faced suffering, poor health, and death. However, this intense view of personal responsibility and discipline in order to achieve wellbeing and survival with diabetes has had lingering negative consequences. For example, the entrenched association of diabetes care with personal responsibility leaves no room for scientific research into the ways in which systemic inequities impact a person’s attempts to manage diabetes. Researchers in the 21<sup>st</sup> century such as social scientist Melanie Rock and epidemiologist Sandra A. Black provide new knowledge about the relationship between social systems and the impact of diabetes on communities. Their work challenges the established beliefs started by Joslin that personal discipline is the main factor in controlling diabetes. Yet, the association between diabetes, control, and morality has had enduring consequences.

## **Diabetes is Insufficient Body Control Pt. II: Type 2 is More Stigmatized than Type 1**

People often minimize or misunderstand the nature and burden of type 1 diabetes, but it is far less stigmatized than type 2 diabetes. For example, Sheila Bock described a conversation she had at a party in which she mentioned her academic work examining diabetes and stigma to a physician. He told her that he has more sympathy for people with type 1 diabetes than for people with type 2. When she asked what he meant, he explained, “A type 1 diabetic is just walking down the street and gets shot. A type 2 diabetic is in a gang, robs a liquor store, pulls a gun, and then gets shot.” (“Contextualization” 156). This story is shocking, yet also familiar. We must interrogate its meaning because it did not come from an uninformed party guest, but from a physician. The doctor alludes to the blame he attributes to people with type 2 diabetes for having committed the immoral acts that led to their condition. When the physician offered his opinion, he unwittingly articulated an example of Goffman’s stigma-theory. Stigma-theory is an attempt by a normal to “explain [an] inferiority and account for the danger [it] represents, sometimes rationalizing an animosity based on other differences” (Goffman 5). Stigma-theories around type 2 diabetes are rampant. Type 2 diabetes is primarily associated with “‘poor lifestyle choices’ – particularly ‘bad’ eating and exercise habits, and a lack of control- [which] can work to discredit individuals for their supposed lack of self-care” (Bock, “Contextualization” 155). Many believe that people with type 2 diabetes deserve their condition because they did not take adequate care of themselves. These associations are disturbing when marginalized groups such as women, people of color, the elderly, and low-income status people

experience a higher incidence of type 2 diabetes (Black 543). The idea of poor lifestyle choice is a moral framing, like William's argument that health becomes a moral performance of control, discipline, mitigating risks while also participating in consumer culture. When people use type 2 diabetes as a symbol of a person's irresponsible and thus immoral lifestyle, they negate the genetic components as well as the role of culture, history, and economics that relate to food and behavior. The negation of this complexity when thinking about type 2 diabetes is rampant, even in the medical community, and has intersectional ties to class and race as well.

When we examine the issue of class, U.S. culture often stigmatizes type 2 diabetes as the result of an individual's poor choices with food while overlooking structures of inequity with respect to food access. Data from a 2013 Gallup poll reveals that "Americans earning less than \$30,000 a year are more than twice as likely to drink regular soda than those earning more than \$75,000" (Gritz). While some readers may rationalize this data about drinking soda as a choice and not an issue of class, consider the reality that "shoppers who don't have access to fresh produce end up consuming caloric sweeteners in everything from cereal to pasta sauce" (Gritz). Structural conditions become more evident when people live in food deserts and can only shop in markets where there are no fresh tomatoes, but there are multiple aisles with sugary pasta sauce.

When politicians and doctors moralize type 2 diabetes as the result of "poor choices," we cannot properly account for the gender, racial and class disparities that contribute to the situation. Bock's anecdote reveals that even casual party stories



are laden with complex links between diabetes, class, and race. This story “situate[ed] type 2 diabetes and its complications as expected results of a series of bad choices” (“Contextualization” 156). Yet the examples above demonstrate a much larger network of realities created the lived experience of diabetes.

One artist who uses the social model to examine the role of race in U.S. systems is Robbie McCauley. Part of the inspiration for her piece *Sugar* were the reports in *The New England Journal of Medicine* that had “several medical professional[s acknowledging] disparities in health care around African Americans... it stated how the medical professionals had devalued African American people” (E. Johnson 19). The class and race dimensions of New Right politics and who deserves public services like healthcare are important. Joel Dodge writes of the GOP that “Yesterday's welfare queen has become today's health-care king.” If our media, including dramatic literature, furthers the belief that people with type 2 are to blame for their condition because they are reckless, then our responsibility to provide resources for their well-being diminishes. Williams points out that when we look at treating illnesses, “whatever the therapy, *personal* responsibility and lifestyle change is [sic] invariably placed high on the agenda, thereby deflecting attention away from the wider political economy of health and illness” (445). I believe that these philosophies are a product of the medical model, asking us to look for causes and cures. However, I argue that the social model of disability can help us understand other factors impact the daily, lived experience of people with diabetes.

## **Importance of Social Model**

This alarming tendency to locate blame within the individual, rather than to examine a matrix of systemic factors that capture the experience of diabetes or diabetic identity is an example of ableist ideology. Ableist ideology focuses attention on the individual who fails to meet the norm rather than drawing our attention to the norm itself or to the social context that informs it. In other words, the ideology leads us to blame the individual for being abnormal rather than leading us to examine how the system of norms marks them as abnormal. The medical model often does this as well, which is why we need the social model to help us examine the social realities that play a role in creating disability.

In the 21<sup>st</sup> century, “many diabetes specialists readily acknowledge that type 2 diabetes incidence stems from social, cultural, political, and economic conditions” (Rock 480). However, doctors often “lack faith in the feasibility of changing these conditions, [so] they believe in the efficacy of pharmaceuticals” (Rock 480). Melanie Rock asks us to reframe our understanding of diabetes complications considering her understanding of the social model. She argues that the emotional experience of social stratification is powerful enough to raise blood sugars. She goes further to express that “while the underlying causes behind suboptimal diets and physical activity levels vary greatly, many of them boil down to the historical structuring of inequality” (480). I agree with Rock that if we consider more factors than just poor choices, a far more human and complex story emerges around the reality of type 2

diabetes, especially as it relates to historical inequalities. While the medical model de-contextualizes diabetes, inclusion of the social model encourages us to understanding diabetes in context of historical, economic, and cultural factors. The medical model may be the framework that doctors know how to approach this issue most effectively; however, I contend that theater artists can educate doctors, patients, and lay-people with art that incorporates more frameworks to comprehend living with diabetes.

## **2.3 Conclusion**

“The experiences of illness speak about the world of the healthy as well as the world of the sick.”

- Chris Feudtner

U.S. ideology rooted in rugged individualism, discipline, and puritan morality led to moralizing and de-contextualizing diabetes. Making diabetes the consequence of an individual’s moral failing places the blame on a single person and ignores the biases built into institutions; for example, racism in health care systems and classism in food production and consumption (Gritz). The U.S. ideology of individualism and hard work does not account for the impact of these systemic situations.

The main goal of this project is to contribute to undoing the entrenched moralizing, misunderstanding, and ahistorical blame surrounding diabetes. My project begins with the question of how do we tackle the stereotypes and

misinformation about diabetes in theater? Epidemiologist Sandra A. Black argues that diabetes “treatment and prevention efforts should be approached not only on the level of an individual health problem but, even more, as a public health issue” (546). I agree and, like Black, I want to move away from thinking of diabetes in purely individual frameworks. Black continues by arguing that “community interventions, including early screening and lifestyle change, are paramount and must be culturally appropriate” (546). My research partners with Black in this call for action. Theater is a site for the kind of community intervention that she calls for. Theater is always a community endeavor. Theater is a conversation between an artistic team constructing the performance and the audience constructing its meaning. Theater is a site to present new stories and to engage communities in conversation. Theater artists create space where an audience can witness embodied storytelling and start dialogue that continues outside the performance space, in their own communities.

The next chapter discusses misguided contemporary attitudes towards diabetes as reflected in U.S. drama. I contend that, though medical treatments have changed drastically over time, especially in the last fifty years, stereotypes of diabetes on the stage have remained strikingly consistent. The next chapter investigates the prevalence of those stereotypes rooted in the medical model, while chapters four and five will examine how artists are using the social model of disability to turn attention on culturally and historically significant factors impacting a person with diabetes.

## CHAPTER 3

### DIABETES AS A STIGMATIZING MARK IN DRAMATIC LITERATURE (1949 - 2018)

#### 2.1 Introduction

The medical model tends to produce attitudes towards diabetes management that focus on individual behavior and person responsibility. These attitudes have shaped damaging stereotypes and misunderstandings about people living with diabetes. One way these attitudes have spread is through media narratives, including those found in theater, which often reflect and circulate stigmatizing stereotypes back to audiences (Bock, “Grappling” 135). My research indicates that U.S. dramatic literature written between 1949 – 2018 typically circulated two main ideas shaped by the medical model that framed diabetes as a fundamentally individual, biological dysfunction. One narrative is that a person with diabetes is constantly suspect of being out of control, particularly with food. Their lack of control indicates their living with diabetes and experiencing its impacts is a byproduct of their own poor choices. The second narrative about diabetes is that it is a specter which strikes suddenly with fatal consequences. When playwrights conceive of diabetes as an intrusive, horrifying biological dysfunction, they depict

characters who distance themselves, deny, and hide their diabetes. These characters never incorporate diabetes into their identity or express agency in managing their diabetes. These two narratives together reveal a contradictory message: one says that a person is failing if they are not exerting intense discipline to control themselves and their diabetes, while the other says that people must deny, hide, or avoid an association with diabetes. These contradictory messages illuminate the ways playwrights stigmatize diabetes without necessarily giving thought to the impact of their actions.

In addition to these two narratives, playwrights also stigmatize diabetes by using it as a general term without specificity or nuance. To some readers the act of including “type 1” or “type 2” to modify “diabetes” may seem like a minor detail, but the distinction is important. The causes, treatments, and concerns differ for people with type 1, type 2, gestational, or diabetes from other conditions. When playwrights use diabetes as a general term, it demonstrates that they are either unaware or indifferent about these differences and how they create complex lived experiences. The use of a term such as diabetes in daily discourse while dismissing the complexity is a direct contributor to stigmatization (Goffman 5). If playwrights do not indicate which type of diabetes a character has, then it suggests that they are not interested in the reality of living with diabetes but instead use the term “to convey a wide range of imperfections on the basis of the original one” (Goffman 5). The vague and broad associations invoked by the term diabetes include someone

who is out of control and failed in their personal responsibility or using diabetes as a sudden specter to interrupt a person's life with tragedy.

## 2.2 Play Analysis by Theme: Out of Control

“People hear I have diabetes and they treat me like one of those fatties  
with no self-control.”

Sid, *The Catch*

This section contains the plays *Detective Story* (1949) by Sidney Kingsley, *The Catch* (2011) by Ken Weitzman, *Sweat* (2015) by Lynn Nottage and *The Cake* (2018) by Bekah Brunstetter. Although there is over half a century between the writing of *Detective Story* and *The Catch*, *Sweat*, and *The Cake*, themes of anxiety and lack of control remained consistent. These plays contain individual characters who fail to control themselves and their diabetes, or feature characters discussing anxiety around diabetes as an indicator of economic failure. Also, each of these playwrights used diabetes as a broad term in the text. It is worth noting, however, that *Detective Story* was published in 1949, before physicians recognized multiple types of diabetes, and that Weitzman does include specific information about the environmental causes for the character Sid's diabetes. The narrative about personal responsibility and failure is inherently political as these beliefs foster stigma that people with diabetes do not deserve our attention, financial support for health care, or empathy for their lived experience.

### 2.2.1 *Detective Story* (1949) by Sidney Kingsley

Sidney Kingsley is a playwright and director who “brought the gritty drama of mean city streets into the theater” (Flint). He won a Pulitzer in 1933 for his play *Men in White*, a drama about doctors, which was also performed by the Group Theater. He had a reputation as a “slow, careful writer” whose best works were “hard-hitting dramas with a moral and social point of view” (Bordman and Hischak, “Detective Story”). In a preface to the play Kingsley wrote that it was researched at New York City’s 17<sup>th</sup> Precinct. He met with detectives and criminals there and became inspired to write a “completely honest picture” of a police station (Bordman and Hischak, “Kingsley”). *Detective Story* received 581 performances at the Hudson Theatre, a 1,000-seat theatre that is no longer an operational as a Broadway house.

In *Detective Story*, the action takes place over four hours in one setting and focuses on the moral rigidity of Detective James McLeod. While other detectives deal with petty crimes, Detective McLeod focuses on bringing down Dr. Kurt Schneider, a doctor whom McLeod suspects of performing illegal abortions. When McLeod holds Schneider in custody and physically injures him, Schneider’s lawyer threatens McLeod with damaging information about McLeod’s wife. The Lieutenant brings Mary McLeod in for questioning and he learns that years ago she received an abortion from Dr. Schneider. Once McLeod learns of Mary’s past, Mary decides to leave him. In the climax of the play, a criminal grabs a gun and shoots McLeod in the stomach. McLeod prays for forgiveness and asks a reporter to tell his wife he is



sorry for his actions. Interwoven through the main action are several subplots that focus on “vignettes of minor figures: burglars, shoplifters, shady lawyers, and policemen” that create a bustling police station (Bordman and Hirschak, “Detective Story”).

Kingsley incorporates diabetes into the story through one of the subplot characters, a girl whose only title is “Shoplifter.” The play opens with Detective Dakis taking her in for having stolen a pocketbook worth six dollars. The girl must remain in the precinct all afternoon until the night court opens and a judge can hear her case. Shoplifter is completely shocked by her own actions, and tells Dakis, “I didn’t need it. I didn’t even like it. Crazy!” (10). While the events with McLeod and other criminals unfold, Shoplifter is occasionally woven into the scene while waiting for night court: she takes a sandwich, decides not to call her lawyer brother-in-law for assistance, and at one point reassures another woman about how painless it is to have one’s fingerprints taken. While Kingsley has already depicted Shoplifter as a petty criminal who commits reckless theft, it is not until Act Two that we learn of her poor control of her diabetes. Shoplifter tries to strike up a conversation with Dakis and mentions:

SHOPLIFTER. (*feels her pulse*): Gee, I think I’m getting a reaction.

Emotions are bad for me. I got diabetes. I’m not supposed to get emotions.

DAKIS. (*belches, then, indignantly*): I got ulcers—I’m not supposed to eat sandwiches. A hot meal was waiting for me at home. Do me a favor!

—Next time you get yourself arrested before four o'clock. Let a fellow eat a home-cooked meal.

SHOPLIFTER. (*genuinely contrite*): I'm sorry. (127)

This interaction deepens the depictions of Shoplifter as someone who cannot control her base instincts, first with theft and now with emotion. Her lack of control over emotion is now causing a reaction with her diabetes. Shoplifter has noted her quickening pulse, a symptom for a low blood sugar, and the role that emotions can have in causing this episode. Dakis dismisses her and moves on without offering her any help or attention to her concern. This dismissive reaction is odd even for conceptions of diabetes in 1949. During this period, the dominant perspective on diabetes management was Joslin's recommendations of a rigidly controlled lifestyle, diet, and insulin regimen.

The scene then shifts to McLeod interviewing a criminal named Charley who was caught during a burglary. As McLeod questions Charley, Shoplifter intervenes again:

SHOPLIFTER: (*feeling her pulse*): I am getting a reaction. Emotions are bad for me.

DAKIS. (*Checking a stolen article against a list*): Girls with diabetes shouldn't steal pink panties. (131)

The Shoplifter has tried again to bring her medical condition and the elevated situation to the attention of the Detective, but he brushes her off again. Not only does he disregard her distress, but he places the moral responsibility back on her

with “Girls with diabetes shouldn’t steal pink panties” (131). The topic of Shoplifter’s diabetes does not come up again for the remainder of the play. Kingsley reveals his misunderstanding of diabetes when nothing happens to resolve the reaction. If Shoplifter is having a low blood sugar, this is a serious medical issue that demands immediate action.

Kingsley frames Shoplifter’s diabetes as a loss of control, yet never gives serious attention to what she is experiencing. Shoplifter’s traits as a character are recklessness since she has stolen, and she does not know why, and pettiness as she resists calling her brother-in-law for help because of how bad this she thinks it will look. Kingsley uses diabetes but does not take the reality of this character’s situation seriously. When Shoplifter mentions her diabetes and the reaction she is having, Dakis does nothing. Dakis’ response demonstrates that to a moral authority like a police officer in this precinct, the diabetes of a petty criminal is not worth addressing in a meaningful way. He instead belches and makes condescending remarks.

### **2.2.2 *The Catch* (2011) by Ken Weitzman**

Ken Weitzman is a professional playwright and currently the Assistant Professor of Dramatic Writing at Stony Brook University. He received his MFA in Playwriting from the University of California, San Diego and has had plays published by Samuel French and Playscripts. He has taught at UCSD, Emory University, Indiana University where he was the head of the MFA in Playwrighting

(Weitzman “Bio”; “CV”). Weitzman’s idea for *The Catch* was based on true events and it received a full production at the Denver Center Theatre Company in January 2011 (“*The Catch*”). It received national recognition, winning the TCG Edgerton Foundation New American Play Award, as well as regional awards like the Henry Award for The Best New Play in Denver (“*The Catch*”).

The play centers on a man in his thirties, Gary Zipnik, who lost his finances in the dot.com market burst. After Gary lost his career, he also lost his house and wife. In the opening scene of the play, Gary welcomes his father Sid, a Jewish-Polish American man in his late 60s with “diabetes as well as visible burn scars on his face and various parts of his body” to stay with him for a while (Weitzman, “The Catch” 2). Sid has been sent to live with Gary after a diabetes related incident (Weitzman, “The Catch” 7). The rest of the plot focuses on whether Gary will catch and then sell a home-run baseball hit by a mega-star player, Darryl Love. Gary hopes that the money from selling the ball will bring him back his wife Beth. Gary catches the ball but loses it when tackled by a mob of fans. In the chaos, Michael Nomura picks up the ball instead. A legal battle ensues between Gary and Michael over who holds the rights to the legendary baseball. Gary and Michael resolve their dispute and together auction the record-breaking ball. To their horror, Darryl Love becomes enmeshed in a doping scandal, and Gary himself has bid on the ball for \$400,000. After hearing the story from his son, Sid offers to sell his home and alleviate Gary’s debt if Gary will “come down to earth” (93). Gary refuses his

father's help, claiming that "unreasonable people" are the only ones who change the world (94).

Weitzman incorporated diabetes as a fundamental characterization of Sid and a major plot device. In the first scene, Gary welcomes Sid to his apartment, but Sid is upset to have to be there in the first place: "I could be sitting in my own damn house right now. I made my last mortgage payment, you know that? Made it the day before my – whatever you call it – incident" (6). From the first scene, Sid is dismissive of his diabetes and the "incident" he experienced (6). Sid reveals how the "incident" was related to a "mismeasured injection," but Gary reminds him that his lack of control with sugar started the problem:

SID. Jackass. A nursing home, because of one mismeasured injection!

GARY. And quite a bit of sugar.

SID. Am I not entitled to celebrate paying off my damn house!

GARY. Of course. Of course you are.

SID. Damn right I am.

GARY. (*tentatively*) Still, you're a diabetic dad, with a sweet tooth. And if that happens again-

SID. It won't.

GARY. But if it did-

SID. It won't!

GARY. You could have developed ketoacidosis. Gone into a coma. (7)

Gary warns Sid about his diabetes and his lack of control with sugar and sweets, while Sid is defensive and entitled about his sugar consumption. Sid has the self-discipline to pay off a mortgage but behaves entitled and indignant in relation to his diabetes management. Weitzman's characterization of Sid robs him of agency and ownership of vital health management. This conversation between Sid and Gary becomes about Sid's masculinity and his own toughness. Sid responds to Gary's warnings with, "Oh for God's sake, what a little ninny you are" (7). Sid's response equates toughness and a lack of concern for diabetes management. Sid ends his conversation with Gary by claiming, "you will see I can take my medication like a big boy and avoid Chips Ahoy" (7). When Sid goes to the kitchen and opens a cabinet, Gary believes Sid is searching for sugar and tells Sid that Gary doesn't eat sweets (8). It is striking to me that while Gary is the wild risk-taker who catches the baseball, auctions it for wealth, and then ultimately sinks further into debt, he is level-headed, cautious, and heroic when it comes to Sid's health.

Later in the play, Gary comes home to tell his father he is going out to a baseball game. Before leaving the apartment, Gary and Sid have a conversation which situates Gary as the responsible manager of Sid's diabetes, while Sid resists this care:

GARY. I made your meals for the day. They're in the refrigerator. I calculated the glucose content for each item, it's labeled on the containers.

SID. So what'd you make? Tofu-organic-Berkeley-dogshit?

GARY. You have my cell. I'll call you between innings to check in. Will you be all right?

SID. Will I be all right? *Will I be all right?* Am I the one who tanked his business, got his house foreclosed? Was that me? No! I paid off *my* mortgage, buster. Am I all right? Who the hell do you think you're talking to?! (23)

Despite Gary's incorrect gesture of labeling the food based on glucose when people with diabetes calculate insulin based on carbohydrates, Sid resists the care and does not display any agency in his diabetes management. Sid is afraid of the perception that he is out of control and reacts harshly to Gary's efforts. However, Gary's fears are ultimately justified when he comes home to find Sid barely conscious with a severe low blood sugar. Though Sid is defensive about his son's actions, he does create a crisis with an insatiable desire for sugar, which he must hide from his son, and an insulin overdose.

In the next scene, Gary shares the story of how Sid got diabetes with a stranger at the ball park. Gary begins a conversation with the person in line behind him at the concessions, Michael Nomura. They are both in line to purchase sushi at the ball park and Gary shares:

GARY. My father says if they sell sushi here, this isn't a real ballpark. Funny right? He's diabetic. Not because he's overweight, or anything like that. He was burned. Badly. A hotel shower accident. Passed out

under the scalding water. Almost died. The burns, they interfere with insulin absorption. (24)

Weitzman is both evoking and opposing the perception that people with diabetes are overweight and out of control with sugar. Gary denies that Sid is overweight, but Sid is constantly out of control with sugar. In our interview, Weitzman clarified, “once I made the choice of the shower accident, I discovered one of the results of that kind of burn is the development of diabetes.” In fact, hyperglycemia, or elevated blood sugar levels, “is an almost universal finding amongst patients suffering major burn injury” (Mecott et al. 2). A 2010 study published by the National Institute of Health labelled this type of diabetes as “diabetes of critical illness” and “burn stress pseudo-diabetes” (Mecott et al. 1). When Gary shares that the trauma associated with burns caused Sid’s diabetes, he also quickly distances his father from the association of poor eating choices and type 2 diabetes. However, Weitzman explicitly links the character with out of control behavior with sugar. The next time Sid is on stage he is “hunting for something/anything with sugar” (30). Sid desires sugar so intensely that he begins to spoon it straight into his mouth:

SID. Come on, there’s got to be something. Even some non-dairy gluten-free-bullshit.

*(He hunts some more)*

ONE GODDAMN COOKIE, IS THAT TOO MUCH TO ASK!

*Finally he finds something. A sugar bowl. He looks inside. “Yes!” He gets the spoon, dips it in and is about to shovel it in his mouth when he*



*hears Gary. He quickly dumps the spoon in the sugar bowl and puts the bowl back. Gary enters, excited. (30)*

Upon his entry into the apartment, Gary excitedly tells his father about the game, but soon senses something is off. As the conversation escalates, Sid asks:

SID. What? Afraid I smuggled in a king-sized Snickers bar?

GARY. No.

SID. And what if I did, huh? The bitterness I've tasted in my life, I'm not allowed an occasional sweetness? People hear I have diabetes and they treat me like one of those fatties with no self-control. For crap's sake, it was the goddamn burns.

GARY. I know that. Everyone who knows you knows that. And how disciplined you are. You're who I get it from. (31)

This scene represents the strange contradictions that emerge from using diabetes as a stigmatizing mark. Sid was just about to eat granulated sugar straight from the bowl and he touts his entitlement to sugar and defends himself. When Gary questions Sid, Sid retaliates by shaming "fatties with no self-control" (31). Gary praises Sid's discipline, which Sid does not have, by reflecting that it is where Gary gets his discipline, which he does not have. This conversation links diabetes with individual discipline and mastery of corporeal desires, while indicating that both of these men in truth fail to perform the control or discipline they espouse.

At the start of Act Two, Sid returns to Gary's apartment with a grocery bag of candy. A stage direction specifies that Sid is trying to hide the candy from Gary

(54). Once Sid believes he is alone in the apartment with the candy, he proceeds to give himself an enormous dose of insulin:

SID. You in the can?

*No answer. Sid returns to the front room. He has his insulin.*

*He then retrieves his bag from under the couch. He pulls out a large bag of Red Vines licorice.*

*He measures an insulin dose.*

Good for ten of these babies.

*Sid reconsiders, decides on a larger dose.*

Twenty.

*Then a larger dose.*

Home run. (54)

Sid displays recklessness in several ways: he gives himself insulin without testing his blood sugar, which is advisable before giving an insulin dose. Although diabetes can be stigmatized through vague descriptions, there is specificity and openness as Sid draws up insulin and presumably gives himself an injection on stage: “He takes it” (54). However, this character’s behavior results in a life-threatening crisis exacerbated by the conflicting stigma, need, and desire. Sid has stated that people treat him differently assuming his diabetes has to do with obesity and lack of discipline, yet he sneaks candy into the house and gives a reckless insulin dose to compensate. Planning to eat the candy, he takes agency over his diabetes management to give himself insulin, but this action leads to a life-threatening

crisis. The crisis depicts Gary as Sid's life-saver. Gary comes home and finds his father nearly unconscious on the couch (55-56). Gary realizes his father is unresponsive and answering his questions with non sequitur. Gary is quick to take action and save his father's life:

*Gary returns with the sugar bowl and a spoon. He dips the spoon in and holds it out to Sid.*

GARY. Eat this.

SID. No.

GARY. You took too much insulin, Dad. Eat it. (57)

They struggle as Sid refuses and Gary tricks him into opening his mouth for sugar.

*As soon as Sid opens his mouth, Gary pushes the spoonful of sugar into it. He holds Sid's mouth shut, forcing him to swallow it. He does. Then he collapses back on the couch, exhausted.*

SID. (a moment of lucidity)

Please. Please don't tell your brother about this. (58)

Gary continues to feed his father spoonfuls of sugar, and Sid "does as he's told" (58).

Weitzman depicts Sid's shame as so intense that even during this traumatizing, life-threatening low-blood sugar, Sid's main concern is to beg Gary not to tell his brother.

In the next scene, Sid is clearly impacted by the trauma of the low-blood sugar event. Sid is "suddenly elderly seeming after the physical (and emotional) event of the previous day" (60). Sid tells Gary that, "I'd rather not listen to the

voices in my head right now” (61). When Gary begins to explain the legal case he is pursuing against Michael Nomura, Sid quips, “Gary, I’m diabetic, not a retard” (61). As the two discuss the case, Sid explodes that he should have sued after his accident in the hotel shower, the environmental trigger of his diabetes. Sid says, “I did think about it! I did. But I was too prideful. ‘I don’t need help. I fight my own fights.’” (62). While Sid’s behavior is consistently out of control, his pride and toxic masculinity keep preventing him from taking agency in his life. As Gary dreams about the money he will acquire from auctioning off the baseball, he promises Sid a private nurse “for home visits. Twice a day just to check your numbers, then she leaves” (76). I appreciate the specificity Weitzman uses to depict the diabetes management by having a conversation about blood sugar testing, a vital act that has been absent from the play entirely.

In the denouement of the play, Sid desperately tries to help Gary out of his newly acquired debt and Sid’s diabetes comes up. Sid tries to convince Gary of how serious the situation is:

SID. Gary, listen to me. You are in a major hole here. Four-hundred grand to your lawyers, another four-hundred to pay for the ball which, after interest, who knows what it will cost you.

GARY. You walked across Europe, you’re a diabetic, sixty percent of your body was burned.

SID. That’s my story Gary, *mine*. Not yours. (89)

In this final interaction of the play, Gary groups diabetes in the list of ways Sid has overcome difficulty and inspires him to do so as well. Both characters are hiding from the reality of their situations. Gary uses diabetes not as a stigmatizing mark, but as a badge of triumph when it is convenient and inspiring for him, a non-diabetic character. Weitzman depicts Sid's relationship to his own diabetes as out of control and dependent on Gary's presence to care for him.

Ken Weitzman was incredibly generous to have a conversation with me about the writing of Sid and *The Catch* over e-mail. When I asked if there was any particular inspiration behind the character of Sid, Weitzman shared his thoughts that "dramaturgically, Sid is there as a foil to Gary." Weitzman shared more regarding how he created this contrast between Sid and Gary:

Sid thinks Gary's strike-it-rich attempts are nonsense. Sid lived his life with a steady job, saved little by little, bought a modest house, etc. In terms of his diabetes, it was important Sid have some needs and vulnerabilities and that despite his disdain of Gary, he still needs him.

(Weitzman, "Personal interview")

I question Weitzman's view that diabetes is an appropriate device to show Sid's vulnerabilities and need for his son. Using Sid's diabetes as a device to contrast with Gary evokes associations of Sid as out of control and diabetes as a type of failure. While Gary has lost his job, his fortune, and continues in reckless behavior, why does diabetes act as the mark for Sid's inability to control an area of his life?

Can a playwright can show this part of a relationship without removing a character's agency with their diabetes?

I also asked Weitzman if he had conversations with directors or actors about dealing with this subject, either in tone or staging. Weitzman responded that he did discuss the subject with the director and actors. He encouraged them:

not to make assumptions. They do need to [be] educated themselves (if they haven't) but that no two cases, no two people are the same. What does it mean for *this* character to have diabetes, for this character not to take care of himself the way he should, etc. (Weitzman, "Personal interview")

I agree with Weitzman about the nuance and specificity about each individual case of diabetes, but I lament that this portrayal, however well-researched or reflective of life experiences, portrays a person with diabetes as out of control, lacking agency, and relying on an able-bodied person for nearly all of his diabetes management.

Weitzman felt that "it made sense to give Sid a sweet tooth and be a danger to himself. It allowed a character contradiction, something less disciplined about Sid."

However, it reflects both ableist norms as well as the philosophy of the medical model that emphasizes personal responsibility and portrays people with diabetes as suspect, out of control, and failing in their personal discipline.

### **2.2.3 *Sweat* (2017) by Lynn Nottage**

Lynn Nottage is a two-time Pulitzer Prize-winning U.S. dramatist, the first female-identifying playwright to be so honored twice. She attended Brown University and the Yale School of Drama before working for four years at Amnesty International (Knowles 11; Schulman, “The First” 8). She revisited playwriting after thinking “there must be a better way of communicating stories” (Schulman, “The First” 9). Nottage’s well known plays include *Intimate Apparel* (which was the most produced play in the country in the 05-06 season), *Ruined* (which won a Pulitzer), and *Sweat*, her Broadway debut and second-Pulitzer Prize winning play (Schulman “The First” 3, 9-10). Nottage is an Associate Professor in the Theater Department at Columbia School of the Arts and received a MacArthur Genius Grant as well (“About”).

Nottage’s *Sweat* was extensively researched over two and half years of interviews and time with residents of Reading, PA (Schulman, “The First” 3). The play was originally commissioned by the Oregon Shakespeare Festival (OSF) and D.C.’s Arena Stage. It received its world premiere at OSF in 2015, played at the Arena in 2016, and was running at the Public Theatre during the election in November 2016. It officially transferred to Studio 54 in March 2017 (Clement). In addition to winning the 2017 Pulitzer Prize for Drama, *Sweat* was heralded by *The New Yorker* as “The First Theatrical Landmark of the Trump Era” (Schulman, “The First” 1). In his *Times* review, Ben Brantley described *Sweat* as a “bracingly topical portrait of American dreams deferred.” *Sweat* examines the “de-industrial revolution” in Reading, Pennsylvania (Brown 3). To dramatize the change over

time, some scenes take place in 2000, and others in 2008. The primary physical setting of the play is a local bar, tended by Stan, a white American in his fifties who sustained a leg injury during his years working at the plant, and the busboy Oscar, a Colombian-American male who is twenty-two in 2000 and considers leaving the bar to work as a “scab” during a strike at a local steel plant. The customers of the bar are primarily workers from a local steel plant including Cynthia, a forty-five woman of color and her ex-husband Brucie. Their son Chris also works at the plant but considers leaving to pursue a career as a teacher. Chris has a friendship with Jason, a young man in his twenties whose mother, Tracey, a white American of German descent in her forties, is also a fixture at the bar.

The broader theme of the play is the economic anxiety and shame that influences the steel workers over time when a steel plant closes. In Scene 3, Chris and Jason have an interaction set in the year 2000, before the economic downturn. From this point in the historical context of the play, Jason experiences financial security in his job at the plant and dismisses Chris’ plan to leave the plant and pursue teaching as a career.

JASON. Whatever. In four years, max, guarantee you’ll be back begging for your job at Olstead’s. And yo, have you been to Reading High lately? It’s like a prison yard, they got thirty-year-old freshmen. Dude, that don’t pay jack-shit, you’ll have to take a second job just to keep your lights on.” (Nottage 30)



Stan agrees and gently reminds Chris that there isn't better money anywhere than with the job at the plant (30-31). When Chris defends himself by sharing that the machines are too loud and he isn't interested in staying, Jason jabs, "What the floor ain't good enough for you?!" (31). Chris rejects this accusation but asks if Jason has noticed "that shit that's been going on" and mentions they could all be replaced by machines and buttons that do their jobs (31-32). Chris asks if Jason has thought about life outside of the plant, and Jason replies:

JASON. ... Nah, not really. Knock on wood. I plan on retiring from the plant when I'm like fifty with a killa pension and money to burn, buy a condo in Myrtle Beach, open a Dunkin' Donuts and live my life. Right, Stan?

STAN. Not a bad plan.

CHRIS. Really? Dunkin' Donuts, that's your vision, huh? Dunkin'-Fuckin-Donuts?

JASON. Yeah, so?

CHRIS. Punch in, punch out, and at the end of the day you end up with a box of donuts and diabetes. My man, where's your imagination?

You need to get on a bus and do some traveling. (32)

While this scene is the only mention of diabetes in the play, Chris uses diabetes as a stigmatizing mark to criticize Jason and his lack of aspirations beyond the plant. Chris makes the subtle implication that through a lack of imagination and effort, he will end up this lower-class food item, donuts, and a health issue, diabetes. This line

brings back the contemporary attitude held by people like Mick Mulvaney when he said of health care, “that doesn't mean we should take care of the person who sits at home, eats poorly and gets diabetes” (Leonard). The conflation of Jason’s middle-low class aspirations to open a Dunkin Donuts is conflated with laziness and diabetes as the result of these poor choices. Diabetes is added as a description of the unimaginative goals Jason has for his life and missed opportunity. This point is similar to Sid in *The Catch*, and the missed economic opportunity from not suing the hotel in the shower accident. In both cases, settling for a life with diabetes is an example of failure. Additionally, Chris and Jason connect diabetes with donuts and an overconsumption or reckless intake of sugar. Now recall the ways in which sugar consumption is a class issue that is often framed with two different perspectives. There are those who espousing personal responsibility and health as a moral expression of taking care of oneself, and those who view low-income people overconsuming sugar as the result of a lack of affordable and fresh food options. When Chris links donuts and diabetes and dismisses them both as the result of poor economic imagination, he does so because he wants greater opportunities for his own life, economic future and class status.

#### **2.2.4 *The Cake* (2018) by Bekah Brunstetter**

Bekah Brunstetter is a playwright with an MFA in Dramatic Writing from the New School for Drama. She has also written for TV including MTV, ABC, and is a co-producer and writer for NBC’s *This is Us* (Carmichael). Brunstetter is from

North Carolina but currently resides in Los Angeles. *The Cake* was first produced by the Echo Theatre Company at Atwater Village Theatre in Los Angeles in June 2017 (Brandes). *The Los Angeles Times* remarked that this play “explores human conflict from an insightful, slightly offbeat perch with understanding, respect and compassion for opposing points of view- and without dumbing down or sentimentalizing its characters” (Brandes). While the review noted the topic was “timely,” it remains so after the Supreme Court decision in June 2018 to side with Jack Phillip’s decision to turn away David Mullins and Charlie Craig’s inquiry about a wedding cake (O’Donoghue). *The Cake* tells the story of Della, a white woman in her fifties who has a bakery in North Carolina. Della has a mother-like relationship with Jen, a young woman in her thirties whose own mother died. When Jen brings home her same-sex fiancé, Macy, Della is conflicted about Jen’s request to make their wedding cake.

In the first scene, Macy comes into the bakery and meets Della before either woman knows their connection through Jen. As Macy inspects the cakes, she asks Della, “I’m so curious, though: what’re your feelings on the research about sugar and its addictive qualities?” (10). This comment implicates Della’s role offering people treats with sugar in them. Della is immediately defensive, and Macy continues to make her point about the negative impact of sugar:

The latest is that sugar is more addictive than cocaine. And yet it’s in all of our foods, and so basically there’s a new generation of young Americans who are practically *born* with diabetes, because when the

food distributors decided that fat was bad for us, they started to load everything with sugar instead, to give it flavor, as we are humans, and we want to taste nice things, right? (10)

Macy's critique is focused on the negative impact of sugar. Sugar is addictive, but Macy continues to press Della that sugar is also bad because people are born with diabetes. This comment ignores the role of genetics even with people developing type 2 diabetes, let alone type 1. Macy says people are practically born with diabetes implying the decrease personal choice with diabetes that is taken away from the adults eating sugar.

Macy justifies herself by pointing out that people who are so irresponsible with food require tax dollars and care from the public. Macy finishes her point by saying "so in forty years we're going to have a bunch of people who can't provide for themselves, they'll be so fat they can't leave for houses and so basically we'll be supporting them with our taxes" (10). Macy expresses a common bias against fat embodiment, which is the fear that fatness leads to excessive consumption of public funds, rather than a legitimate way of being in the world (Herndon 124). This bias rests on a similar premise of beliefs about diabetes that "fatness [is] a voluntary condition resulting from poor eating habits and sedentary lifestyle and of disabled people as dangerous to the American purse because accommodation must be suffered by the public writ large" (Herndon 124). This sentiment is at the heart of comments like Mick Mulvaney's and the distaste for tax dollars going to immoral lifestyle diseases. Diabetes, similarly to fat embodiment, is pathologized and

distances audiences from responsibility to shape public spaces or gather funds to meet the needs of these people.

When Della responds, she frames the debate by connecting sugar with discipline and self-control. While not disagreeing with Macy, Della responds: “I like to think that people should be able to control themselves” (11). In this interaction diabetes is used as a stigmatizing mark to show how dangerous sugar is and how out of control sugar addiction can be. While the *LA Times* described this interaction as “a laundry list of liberal activist accusations with only passing resemblance to natural conversation” (Brandes), Macy and Della are framing the debate in traditionally conservative rhetoric about personal control and fiscal responsibility with tax dollars.

### **2.3 Play Analysis by Theme: Diabetes as a Specter of Death**

ANNELLE. You know? If I didn't know better, Shelby, I wouldn't even know you'd ever been sick a day in your life.

SHELBY. That's the biggest compliment anyone has ever paid me.

- Robert Harling, *Steel Magnolias*

The second common narrative about diabetes is that it works as a horrifying specter. Playwrights will use diabetes as a threat that appears in the play suddenly and entails death for the character with diabetes. The phantom presence of diabetes illuminates a disturbing structure for the relationship between a person and their

diabetes. The relationship is an antagonistic one, where a person resists ownership of their illness, keeps it invisible to others, and denies it as a part of their identity. This depiction of people leads to a loss of agency, ownership, or power with respect to their diabetes (of any type). We also find a non-diabetic character taking responsibility for the person's diabetes management. This action proves that these narratives are not intended to explore the daily, lived experience of a person with diabetes, but are "actually aimed at everyone but a diabetic viewer" (Ferguson 184).

Each of the plays in this section, *The Cold Wind and the Warm* by S.N. Behram, *Steel Magnolias* by Robert Harling, and *The Pain and the Itch* by Bruce Norris, has a character die as a result of their diabetes. In *Let Me Down Easy* by Anna Deavere Smith, a woman describes her sudden diabetes diagnosis, her uncertainty about surviving, and her distrust of dialysis. *The Cold Wind and the Warm* is set in 1908 when a diabetes diagnosis was the equivalent of a terminal illness, but the play was written in 1958 when insulin therapy was available to prolong life for people with diabetes. *Steel Magnolias* (1988) by Robert Harling and *Let Me Down Easy* (2009) by Anna Deavere Smith both have relevant connections to the lived experience of diabetes: Robert Harling wrote the play in mourning for his sister, Susan Harling, who died from type 1 diabetes-related complications, while Anna Deavere Smith's monologues are based on verbatim interviews. However, Harling and Smith both had agency in the construction of these stories and the stigmatizing "specter of death" trope persists. While Harling and Smith may be reflecting back the internalized shame of people who they spoke with or knew, these

narratives continue to circulate the stereotype that diabetes as an intrusive, individual horror and people with diabetes are powerless with this fracture in their identities.

### **2.3.1 *The Cold Wind and the Warm* by S.N. Behram (1958)**

S.N. Behram was a “reigning Broadway playwright for almost 40 years” who was known for his “glittering dialogue and mordant wit” (Whitman). His works were most popular from the late 1920s (*The Second Man* in 1927) to mid-sixties (*But for Whom Charlie* in 1964). In his *New York Times* obituary, Alden Whitman described his work as:

Plays of manners in which their author, a moralist at heart, offered statements of contemporary truth. His principal characters were persons of cultivated intelligence who talked so brilliantly that they could entertain and instruct without engaging overly much in action.

In *The Cold Wind and the Warm*, Behram's wonderful wit and dialogue are on display. This play tells the story of a young college student named Willie who suffers from unrequited love. The story takes place in a Jewish neighborhood in Massachusetts. *Playbill.com* considers it a nostalgic comedy-drama, which opened at the Morosco Theatre in December 1958 and closed in March 1959 after 120 performances (<http://www.playbill.com/production/the-cold-wind-and-the-warm-morosco-theatre-vault-0000002431>).

*The Cold Wind and the Warm* is a memory play narrated from the perspective of Tobey. Tobey begins the play by describing his friendship and admiration of Willie, a young man in love with Myra. Myra is engaged to Dan Eisner, although she openly flirts with other men. In Act One Scene One, we learn that Dan Eisner has been diagnosed with diabetes. In this opening scene, Willie and Tobey are relaxing when they hear oboe music from Dr. Jim Nightingale's office. They go to talk with him, Dr. Nightingale receives a call. After the call, he turns to the boys and informs them of the news:

JIM. (*Cheerfully*): Well the kid was right---somebody *is* dying! (*He picks up his oboe.*)

TOBEY. (*Aghast*): Well---aren't you going to do something?

JIM. Oh, don't worry, it isn't going to happen tonight. (*To WILLIE, as he puts oboe down.*) Diabetes. (57)

Dr. Nightingale shares that the diagnosis is for Dan Eisner, Willie's competitor for Myra's love. While the boys process the news from Dr. Nightingale, their disbelief at the news reflects diabetes as an intrusive horror. They immediately view this diagnosis as a terminal illness, and ponder how Dan will process the diagnosis.

WILLIE. (*Rises*): But Dan Eisner! It's not possible!

JIM. Why? Is he immortal?

WILLIE. (*Stupidly*): But he's going to be married!

JIM. (*Flatly*): Marriage is no cure for diabetes!

WILLIE. (*Crosses up to him.*) But Jim---does Dan know it---have you



told him?

JIM. I've told him what he's got. Let him draw his own conclusions.

He's not an idiot. (*He sits on stool L.*)

WILLIE. Then how can he contemplate---how can he---?

JIM. He doesn't trust me, I guess. Maybe he'll see Professor Jacobi.

WILLIE. But if it's true---then Myra---

JIM. In three or four years she'll be a beautiful widow. That's a good kind of widow to be! (*He sees that WILLIE has been tremendously affected by the news about Dan Eisner.*) Oh, I forgot. You're in love with Myra yourself. Well, bide your time, Willie---. (Behram 25-28)

Willie's concern is not for Dan, but for Myra marrying a person who has a terminal illness. Willie implies that it is unethical for Dan to marry Myra knowing that he will die in a few short years. Willie is conflicted about revealing Dan's diabetes to Myra because his motives are selfish and he wishes to marry her. He asks Tobey's father if he should tell her about Dan's illness:

WILLIE. (*Awkwardly*): Just this afternoon---I found out something---by accident.

FATHER. What?

WILLIE. (*Rises*): About Dan Eisner. He's very sick. He's got diabetes.

FATHER. I am very sorry to hear that. How do you know?

WILLIE. Jim Nightingale told me. It's only a question of time---  
(Behram 57)

While diabetes has been introduced into the plot as the reason for Dan's death, there is a question of how much time Dan will have left. Diabetes has struck this deathly blow to Dan's life, but it is uncertain when Dan will die. When Willie encounters Myra and begins to tell her the news, Dan arrives and interrupts him. Attempting to prevent Willie from telling Myra, Dan kisses Myra. His own denial of the information provides the opportunity for a comic attempt by Tobey to get the news out. Tobey walks in tries to comfort Dan by saying, "The Angel of Death. I know he's after you" (Behram 66). Tobey refers to diabetes as an Angel of Death, which is exactly how diabetes is operating in this play. While perhaps Behram is writing for comedic effect, Dan escalates his attempts to hide and deny his diabetes diagnosis. Myra, confused, asks Dan, "Dan! Is there anything wrong with you?" to which he shouts, "I'm in great shape I tell you! Never felt better in my life!" (Behram 68). Dan uses his fitness to deny his diabetes, and aggressively denounces the accusation that anything is wrong. Dan later chides Willie, "Tell you, Willie, nothing like being engaged to put a fella in top physical condition. Recommend it" (70). Again, a comedic exchange ensues when Tobey comes down and gives Dan advice regarding the Angel of Death. Dan goes "ashen in a rage," "in a fury" and "trembling with anger and with fear too" (70-71). He shouts at Myra that he is in top physical condition, and then calms himself when he explains to her that Willie and Tobey are acting out of jealousy. Dan is again portrayed as in denial. Diabetes is referred to the Angel of Death or the Dark One several times later in the play. Tobey questions Willie's assertion that he will wait for Dan to die by asking

Willie, “(*Shocked, scared*): You mean you're going to wait---till the Dark One takes Dan away?” (Behram 70). The diagnosis of diabetes transforms into a terminal illness titled the Angel of Death or Dark One.

Dan does eventually pass away, which we only discover by meeting Myra years later as a widow. While the specter of Dan's death is threaded throughout the rest of the play, his actual experience with the illness is never discussed. The audience only ever saw Dan vehemently deny the diagnosis, and we never learn of his experience with the illness even as it eventually took his life. This is a clear example of a character keeping diabetes separate from themselves, and diabetes operating as a specter, or an Angel of Death, in the plot to intrude and kill a character. Still, Behram never deeply investigates Dan and his experience with diabetes, but merely uses the tragedy for comedic effect and as a way to move other character's story forward. The ideas associated with diabetes in this play are Angel of Death, unexpected, horror, and death. Dr. Nightingale is casually certain that Dan will die.

The medical model frames diabetes as a biological horror, but also encourages characters to hope for a cure. Tobey's father cautions Willie against Dr. Nightingale's certainty by bringing in the question of a cure, “Can he read the future? How does he know that some cure will not be discovered?” (59). Diabetes itself remains mysterious, and Behram provides no details that explain to an audience what diabetes is or what is happening to Dan. In fact, Dan and diabetes are relegated to the background of the entire action of the play. Act One is primarily

concerned with Willie's desire to tell Myra about Dan's diabetes. In Act Two and Three, Myra and Aaron, Dan's brother, explore their feelings about Dan's death. The only sentiment that Dan expresses about the diagnosis is denial and rage. His denial is connected to his beliefs about his fitness. Tobey speaks of diabetes as the Angel of Death, which is a fitting moniker for diabetes in this play.

### **2.3.2 *Steel Magnolias* (1988) by Robert Harling**

Robert Harling was born in 1951 in Natchitoches, Louisiana. He is a playwright and screenwriter who graduated from Tulane University Law School before going to New York to pursue acting (Carter). Harling wrote the script for *Steel Magnolias* in ten days after the death of his sister (Murray). Susan Harling Robinson's story parallels the character Shelby's journey in the play: a young woman with type 1 diabetes has a baby despite the warnings from her mother and doctors. She eventually needs a kidney transplant and dialysis but dies from these type 1 diabetes related complications. *Steel Magnolias* was first presented in New York at the WPA Theatre on March 22, 1987. It transferred to the off-Broadway Lucille Lortel Theatre on June 19<sup>th</sup>, 1987. Gerald Bordman and Thomas S. Hirschak write in *The Oxford Companion to American Theatre* that the "the comedy-drama was a major Off-Broadway hit and remains very popular in regional and community theatres." In 2005 it received a Broadway run in the Lyceum Theatre from April 4<sup>th</sup> to July 31<sup>st</sup> for 136 performances. The 1987 *New York Times* review calls the show "an amiable evening of sweet sympathies and small-town chatter." When

addressing Shelby's disease, reviewer Mel Gussow does not give much attention to the specifics of what type 1 diabetes is or what it means for Shelby. He merely says: "because of her medical history, the worst may come."

The play centers on the interactions of six women living in Chinquapin, Louisiana in 1987. Truvy Jones owns a beauty shop where the women gather: Annelle Dupuy-Desoto is the newly hired shop assistant; Clairee Belcher is the bored widow of a former major; M'Lynn Eatenton is Shelby Eatenton's mother, while Shelby is the "prettiest girl in town" (Harling 5). Ouiser Boudreaux is a "wealthy curmudgeon. Acerbic but lovable" with a brutish dog Rhett (Harling 5). The play begins on Shelby's wedding day, but as time goes on, Shelby's desire to have a baby wins out over her mother and doctor's concerns about her health and her diabetes. Shelby eventually has a baby, but as a result needs dialysis and a kidney transplant from her mother. These sacrifices from her mother do not prevent Shelby from dying. The women gather in the beauty shop to support M'Lynn and come together over this tragedy.

The information about Shelby's diabetes is not a part of the character description. This evidence alone reveals that Harling did not conceive of diabetes as a fundamental aspect of Shelby's identity on par with being the "prettiest girl in town" (5). However, Harling reveals Shelby's diabetes in Act One Scene One. Shelby suddenly has severe symptoms of a low blood sugar. While Truvy is fixing her hair for her wedding, Shelby suddenly loses control of her body:

TRUVY. (*Shelby's head is beginning to drop forward. She resists Truvy's touch.*) Hold your head up, darling.

SHELBY. Stop it.

TRUVY. Shelby? Shelby? M'Lynn! (22)

M'Lynn and Clairee go into "efficient action" to get Shelby some juice and candy.

Meanwhile, Shelby resists their attempts to help:

SHELBY. Leave me alone.

M'LYNN. Drink, honey. Drink some juice.

TRUVY. Drink the juice, honey.

SHELBY. (*Pushing away the juice, spilling it.*) No! (22)

M'Lynn and Truvy chat about how it was probably the stress of the wedding that caused it, but Annelle, the new shop assistant breaks in to ask, "Excuse me. Should I call the doctor or something?" and Clairee explains, "Shelby's a diabetic" and M'Lynn offers "She's got a little too much insulin, that's all. She'll be fine if we can get something in her" (22). The scene goes on with Shelby protesting and the women forcing and pleading with her to drink the juice. The danger of a hypoglycemic low dawns on Clairee, "She could have hurt herself, M'Lynn? What if this happened when she was driving a car?" (23). M'Lynn adds that there has been additional emotional distress because Shelby's doctor recently told Shelby and Jackson (her soon-to-be-husband) that they cannot have children. As Shelby recovers from the low blood sugar symptoms, M'Lynn observes, "Don't fuss over her... Normality is very important to Shelby" (23). M'Lynn's comment advises dismissing Shelby's

traumatic low blood as the preferable action to Shelby. M'Lynn suggests that openly addressing diabetes and its impacts would be dangerous and abnormal. Diabetes remains at a distance from Shelby's identity as M'Lynn recommends they not make a fuss and openly discuss this horrible incident.

In Act One Scene Two, Shelby finds her mother alone in the shop and to tell her that she is pregnant (34). When M'Lynn is less than excited, Shelby explains herself:

SHELBY. Mama. I want a child.

M'LYNN. But what about adoption proceedings? You have filed so many applications.

SHELBY. Mama. It didn't take us long to see the handwriting on the wall. No judge is going to give a baby to someone with my medical track record. (35)

Again, diabetes is characterized as so dangerous that a judge wouldn't grant an adoption to Shelby and her husband. Shelby is defensive with her mother when M'Lynn grieves, "Shelby. Your poor body has been through so much. Why do you deliberately want to..." and Shelby assures her, "Mama. Diabetics have healthy babies all the time" (36). When the women return to the shop, Shelby shares the news of her pregnancy with them as well (44). After leaving the shop, Truvy acknowledges to M'Lynn that this is not good news, to which M'Lynn repeats Shelby's line: "Diabetic have healthy babies all the time" (45). Harling is using this

phrase as an ominous indicator of the tragedy to come for Shelby as a result of her diabetes.

In Act Two Scene One, eighteen months have passed, and the women are together again getting their hair done at Truvy's Salon. Shelby has mysteriously returned to the town and asks for Truvy to do her nails. While doing her nails, Truvy makes a terrifying discovery:

*(Truvy is working on Shelby's nails. Truvy pushes Shelby's sleeves back to get them out of the way and sees Shelby's bruised arms...)*

TRUVY. Shelby?! What have you done to yourself!?

SHELBY. Oh. It doesn't hurt.

TRUVY. What have you been doing? Have you seen this M'Lynn?

M'LYNN. Yes, I have.

SHELBY. The doctor's been trying to strengthen my veins. They're in terrible shape.

CLAIREE. *(Crosses to Shelby and examines her arms.)* it looks like you've been driving nails into your arms. What's going on here? (59)

Shelby tells the women that she has been on dialysis for a couple of months. She admits that "Having Jack Jr. put too much strain on my kidneys and now they're kaput. That's all. The doctor's said this would probably happen" (59). Shelby casually shares that all she needs is a kidney transplant to be fine. When the women discuss the long wait to get a donor, Shelby tells them that her mother will



be donating a kidney to her the next day (60). As the women are in shock about M'Lynn's major surgery, jokes begin to emerge:

TRUVY. They have to saw you in half?

M'LYNN. They do it on Circus of the Stars all the time.

CLAIREE. This is no laughing matter!

SHELBY. Trust me, Miss Clairee. There have been more than enough tears. (62)

Here the attention on M'Lynn continues and the women apologize for the inappropriate jokes earlier. They are in awe of M'Lynn's calmness, to which she responds, "I'm happy. Look at the opportunity I have. Most mothers only get the chance to give their child life once. I get a chance to do it twice" (62). Diabetes is almost completely made invisible when Annelle comments to Shelby, "You know? If I didn't know better, Shelby, I wouldn't even know you'd ever been sick a day in your life," and Shelby responds, "That's the biggest compliment anyone has ever paid me" (62). Diabetes is both the instigator of this huge harm, and yet also made invisible and detested by Shelby.

In Scene Two, time has gone on and we learn that Shelby has died. The women are gathered in the beauty shop, and M'Lynn explains how the transplant failed and Shelby went back on dialysis (68). The women grieve together and reflect on Shelby's life. These comments display a sense of Shelby's character being at odds with her body. Annelle says, "her poor body was just worn out. It wouldn't let her do everything she wanted to do" (68). M'Lynn later remarks, "I feel great. I could jog to

Texas and back, but my daughter can't. She never could" (70). These women are all keenly aware that Shelby fought a battle with her body, and in the pursuit of her desires, dies.

Diabetes is stigmatized though its absence as well as its devastating presence. Shelby does not visibly manage her diabetes at any time on stage. Diabetes is only mentioned in whispers and offhand comments related to fear (of Shelby driving a car) or incapacity (unable to adopt a baby). When a diabetes-related crisis happens, the other women take care of Shelby and she displays no agency in taking care of herself. The most important thing to Shelby according to M'Lynn is that they quickly move on. M'Lynn remarks that "normality is very important to Shelby," which inherently positions diabetes as abnormal (23). Shelby even assures Annelle that it was the "biggest compliment anyone has ever paid me" for Annelle to observe she never would have known Shelby was sick (62). This line crystalizes Shelby's disidentification with diabetes, as does her behavior on stage.

### **2.3.3 *The Pain and the Itch* (2007) by Bruce Norris**

Bruce Norris is a former actor and current playwright born in Houston, Texas. He is best known for his Pulitzer and Tony award winning play, *Clybourne Park*. The Philadelphia Theatre Company originally commissioned *The Pain and the Itch*, but it received its world premiere at Steppenwolf Theatre Company in 2005 (Norris, "Interview" 3). It premiered in Off-Broadway at Playwrights Horizons in 2006. *The New York Times* praised the sharp dialogue and direction by Anna D.

Shapiro, but remarked that Norris' "aim is to expose and condemn the shallow nature of the liberal views espoused by members of the urban bourgeoisie... but the practices in 'The Pain and the Itch' are too unrelievedly repellent to be mistaken for the real behavior of real people" (Isherwood, "The Pain and The Itch").

The action of the play takes place between two settings: one is a series of flashbacks to Thanksgiving dinner in the home of the married couple Clay and Kelly, their toddler Kayla, Clay's brother and plastic surgeon Cash, their widowed mother Carol, and Cash's young Russian girlfriend Kalina. The other setting is a meeting two months later between the family and Mr. Hadid. The play begins with the family encouraging Mr. Hadid to grieve; however, it is not until the end of Act One that Mr. Hadid accuses the family of killing his wife. This reveal is shocking, and the exposure of the events that lead to the death of Mr. Hadid's wife unfold in Act Two.

The family offers Mr. Hadid an explanation of "events" through a series of flashbacks to Thanksgiving. We learn that Mr. Hadid's wife, an otherwise unnamed character, was a person with diabetes who worked as a maid for this family. Over the course of Thanksgiving, the family thought they saw alarming objects and strange behavior from their maid. The grandmother, Carol, suspects the maid of stealing a loaf of bread while the young toddler, Kayla, discovers a needles in the maid's purse (38, 96-97). Although it has not yet been revealed that the maid has diabetes, elements of her diabetes management are disturbing the family without their understanding of what is going on. Later during Thanksgiving, Clay sets off

the house alarm which automatically notifies the police. When Clay is on the phone with the police, he insinuates to the police that their maid might be the reason his daughter has a genital rash and she should be arrested. The scene switches to the present conversation between Mr. Hadid and the family, and Mr. Hadid reveals, “My wife has the diabetes. She has taken the injection, so now she must eat. We will co-operate with you, we are happy to do this, but please, the medicine requires this” (100). The police did not listen to Mr. Hadid, and he tells the family that on the way to the police station his wife went into a coma and died (101). As the group unravels the true events, Kalina mentions that she had a sickness that she gave to Cash, who was sleeping with Kelly when she was pregnant. The family begins laughing accidentally at Clay asking, how could he *not* know about the affair (102-103)

While Norris is clearly trying skewer the hypocrisy and arrogance of this white, liberal, upper-class family, diabetes is still used as a device to kill a character while having a phantom presence in the home of the family. Yes, their misunderstanding of the situation contributes to the death of the maid, but the horrifying situation of dying in police custody from an insulin overdose is still outrageously cruel and unnecessary. This event also relies on the inability of the maid and the police to communicate, another tragic device to cause harm. In this depiction, diabetes functions as a phantom in the family that haunts them with the discovery of unexplained needles in their home and the maid dies from an insulin dose. At the end of the play, the white, upper-class family is exposed for their selfishness and harmful behavior. The family misinterpreted the maid’s

characteristics such as being a non-English speaker, a foreigner, and a diabetic, and insinuated false ones: she is greedy, a thief, a drug user and child molester. As an audience, we will hopefully see the ignorance and hypocrisy of the family, but in the world of the play diabetes still worked to cause alarm for the family and contributed to the maid's death. Though she is the inciting incident for the plot of the play, Norris gives this character barely any power. She never appears on stage, is never given a name, and never has agency to save her life in a crisis with diabetes.

#### **2.3.4 *Let Me Down Easy* (2009) by Anna Deavere Smith**

Anna Deavere Smith is an acclaimed artist, playwright, and teacher who is known for her style of theatre that combines journalism and performance to understand current events from multiple perspectives. She is best known for her solo performance pieces like *Fires in the Mirror* (which was a runner-up for a Pulitzer) and *Twilight: Los Angeles* (which was nominated for two Tony Awards). She is also a University Professor at Tisch School of the Arts as well as the founding director of the Institute on the Arts and Civic Dialogue at NYU ("About"). Smith conceived, wrote, and performed *Let Me Down Easy* between 2001 and 2009. Smith conducted an estimated 300 interviews to find 21 stories to explore "the power of the body, the cost of care and the resilience of the spirit" (qtd. In Lunden). In a "Note from the Playwright" at the beginning of the script, Smith writes, "These are real people who live or did live in the real world" (4). For the monologue "A Sheet Around My Daughter" that appears about half way through the script, Smith is

performing information that y she gathered from an interview with Hazel Merritt, identified in the beginning of the monologue as a patient at Yale-New Haven Hospital (28). Again, the beginning of the script reminds readers that “the following portraits are based on verbatim excerpts from interviews conducted by Anna Deavere Smith” (6). *Let Me Down Easy* began with Smith’s time at the Yale School of Medicine interviewing patients, doctors and administration (Lunden). The show was originally presented Off-Broadway at Second Stage Theatre in October 8<sup>th</sup>, 2009 (Smith 5). Charles Isherwood wrote in his review of the show for the *New York Times* that it was “not particularly focused at all, though it is continually engaging” because this show, unlike her previous works, is “not tightly focused on a historical event.” In the remainder of his review he examines some of the bigger name vignettes from Lance Armstrong and Eve Ensler, as well as lesser known people with poignant stories. Isherwood does not comment on Hazel Merritt’s monologue in his review.

In the introductory notes for the monologue that incudes diabetes, the main character Hazel Merritt is described as a “heavy-set African American woman in her late 50s” (28). In Merritt’s interview, she introduces herself, and comments on the weather and her hair. After spelling her name, she begins her story: “Well I had pretty good health. Until 1989, when I was diagnosed with diabetes” (28). The way Merritt frames her story of her diagnosis is as a sudden interruption of otherwise “pretty good health.” Merritt says it was “very, very devastating” getting to a point where she needed dialysis (28). One of the ways diabetes is stigmatized here is the

sudden onset that takes the speaker quickly from good health to such extensive kidney damage that dialysis is unavoidable. Merritt narrates this shift without much explanation. However, if Merritt tells us she was diagnosed in 1989, and Smith says she began conducting interviews in 2001, Merritt presumably Merritt had over a decade of living with diabetes in some capacity that she doesn't mention in this interview (Lunden). The ideas or images associated with diabetes in this monologue are unforeseen danger and fear of death, and no deeper exploration of a daily, lived experience with diabetes.

Merritt recounts the horror of losing her daughter during her own experience with dialysis, which contributed to her “real bad, bad feelings about nurses and doctors” (30). She concludes the interview by reflecting on her daughter and her own future, “I’m not saying it ‘cause it was my daughter, but she was a very beautiful girl. And, uh, she died. So I’m not having any dialysis” (30). This ends the monologue. The strongest image here is Merritt's description of her daughter covered in blood and her eventual death. Even as she reflects on her daughter, we are still picturing the dialysis through Merritt because she needs it, too. Merritt describes her daughter's dialysis:

MERRITT. And the blood was just coming out and coming out from the thing, and my daughter was just *crying* and the blood was all in her *hair*, all in her face, all on her *jeans*! And, um, you know, all *over*. It had gotten on me, it was squirting all over and it was like a *nightmare*.  
(29)

Merritt displays a denial in the way she talks about diabetes, a behavior that we saw with the character Dan as well as Shelby. She mentions it once, and it becomes a sort of phantom in the background that emerged suddenly for a healthy person and will take her into this bloody process. Merritt conceives of diabetes as an life-threatening specter that renders her from a healthy body to one with devastating kidney damage. Even in the end of the monologue, diabetes remains invisible as Merritt's final comments are on her relation to dialysis, not diabetes itself. While Merritt only mentions diabetes once, and she does so in a way and with a follow-up story that clearly conveys her horror from diagnosis to thinking about what may happen in her future.

## 2.4 Conclusion

To say that playwrights use diabetes as a stigmatizing mark means that in their plays, diabetes discredits and dehumanizes the character. The two narratives of about people with diabetes described in this chapter are fundamentally discrediting and dehumanizing. *The Detective Story* (1949), *The Catch* (2011), *Sweat* (2015), and *The Cake* (2018) portray diabetes through a character's lack of self-control and personal failure. While *The Cold Wind and the Warm* (1958), *Steel Magnolias* (1988), *The Pain and the Itch* (2007), and *Let Me Down Easy* (2009) show diabetes as a sudden and violent danger from which even people with diabetes will go to great lengths to distance themselves. My central claim is that diabetes is too often portrayed in terms of the individual failures of one person and a lack of



ownership over that part of one's sense of self. These narratives do not reflect the systemic issues that impact the lived experience, nor do they encourage a person living with diabetes to cultivate agency, identity, and peace with their illness.

In the following two chapters, my research outlines how five artists are shifting these dehumanizing narratives with their playwrighting and performances. Chapter 4 illustrates how Robbie McCauley, Irma Mayorga, and Virginia Grise are using the social model of disability to examine historical, cultural, and economic factors that shape the lived experience of people with diabetes. Chapter 5 illuminates the work Marina Tsaplina and G. William Zorn. These creators interrogate their relationship to their diabetes, they cultivate an embodied disability identity, and they explore aspects of this through theater. Each of these chapters addresses one of the problematic narratives that has circulated through theater based on misunderstandings produced by the medical model of disability. This research gives hope for a new way to portray the daily, lived experiences of people with diabetes on stage.

## CHAPTER 4

### USING THE SOCIAL MODEL TO EXPLORE THE LIVED EXPERIENCE OF DIABETES WITH SOLO PERFORMANCE ARTISTS

#### 4.1 Introduction

The social model of disability theorizes that while impairments in bodies are real, the experience of disability is a “culturally and historically specific phenomenon” (Shakespeare 195). Since the Union of Physically Impaired Against Segregation (UPIAS) developed the social model in the 1970s, the core tenet of this model is that “disability” is distinct from impairment (Shakespeare 196-7). UPIAS argued that disability was an experience placed on top of people with impairments as a form of oppression and exclusion from full social and political participation (Shakespeare 196-7). Since the 1970s scholars and activists have primarily used the social model to interrogate the experience of the healthy disabled, meaning those whose impairments are stable and predictable (Wendell, “Unhealthy Disabled” 162). My research shows that the social model is also an essential tool to examine the lived experiences of people with diabetes, whose impairments “inhabit a category that is not easily understood or accepted” (Wendell, “Unhealthy Disabled” 163). Stereotypes about diabetes in theater are frequently based in an ableist version of

the medical model that moralizes the behavior of the individual and displaces diabetes from a character's identity. However, this chapter looks at two case studies of artists, Robbie McCauley and Virginia Grise & Irma Mayorga, who created theater that invited their audience to deconstruct these stereotypes and acknowledge the historical inequities that are shaping the daily, lived experiences of a person with diabetes.

There is a growing awareness in the U.S. of social and economic factors that shape a person's lived experience with diabetes. For example, the U.S. Senate held a special investigative hearing on May 8<sup>th</sup> to address the rising cost of insulin, a drug which has been on the market for nearly 100 years ("United States Senate"). It is not clear why the cost of insulin is rising and why there is no generic versions of insulin available to the public. The American Diabetes Association released a report on insulin costs which found "between 2002 and 2013, the average price of insulin nearly tripled." Addressing why the costs keep rising, committee chairman, Susan Collins (R-Maine), outlined a practice called, "evergreening." Evergreening occurs "when pharmaceutical companies obtain patents based on small innovations to extend the exclusivity of a product after its initial patent expires" ("Opening Statement"). Collins noted the impact on those living with diabetes: "We have heard stories from people across the country who have had to ration or skip doses all together to make their insulin supply last longer" (Frieden). Collins recognizes that a person's diabetes management is not solely an issue of personal responsibility and lifestyle discipline. The increase in insulin prices is a matter of life and death for

people with type 1, and even “approximately a third of those with Type 2 require insulin” (“Opening Statement”). Additionally, as scientists are learning more about the causes of diabetes, social factors are becoming more recognized for playing an important role:

Recent epidemiological surveys have consistently found that type 2 diabetes is increasingly found in disadvantaged populations and subpopulations. In the United States, where diabetes statistics are more accurate than in many other developed countries, type 2 diabetes is more common among black, Hispanic, and Native American than among white members of the population; it is more common among women than men and among people with lower levels of education and income. (Rock 473)

This statement is shocking and infuriating. Diabetes is frequently pathologized as an issue of individual, moral failing with out of control behavior. How do we then account for this disproportionate burden of type 2 diabetes on these marginalized ethnicities, genders, and classes? How do we account for spikes in insulin prices?

This increasing awareness in the medical community of the impact of social environments as a part of the cause and cure of diabetes, yet wrong and damaging stereotypes still persist. The work of these artists is vital to shift broader cultural knowledge about diabetes.

The following case study examine artists who deconstruct stereotypes about diabetes while turning their gaze towards these social factors. Their work is a

response to the conditions that shape their lives. The two case studies are, first, Robbie McCauley's solo performance piece *Sugar* and, second, Irma Mayorga & Virginia Grise's collection *The Panza Monologues*. These women of color also respond to a society that created conditions that impact their lives, and particularly the lived experience of diabetes in their communities. This work is vital to deconstruct the stereotypes that emphasize individual behavior and moralize diabetes. My analysis of each case study begins with an introduction to the artist(s) and an overview of the development of the piece. Each analysis draws out three central themes that reflect on the social and historical systems that impact the lived experience of people with diabetes.

## **4.2 Case Study: Robbie McCauley's *Sugar* (2018) New York Live Arts**

“My thought was, ‘You are not going to get away, world, without knowing the story.’”

Robbie McCauley qtd in E. Johnson

### **4.2.1 Performer History**

There are many ways to view Robbie McCauley's place in theater and performance art history. McCauley began acting in a traditional theater program at Howard University. McCauley was an early cast member for Ntozake Shange's *for colored girls who have considered suicide/when the rainbow is enuf*, then a director, a community story circle organizer, and a story gatherer (E. Johnson et al. 25). She

is a Professor Emerita in the Department of Performing Arts at Emerson College in Boston (“Biography”). She is an award-winning playwright. Her identities and biographical story situate her work in several areas. The initial materials for McCauley’s performances focus on race, gender, and class. While I use the social model to examine her work in *Sugar*, McCauley herself uses the term “personal bigger stories” to describe her interest in the intimately personal within larger historical narratives (McCauley, “Chronic Theatre Makers”). In a 2017 interview with Sara Brookner about theatre artists with chronic illnesses, McCauley characterized her interest in stories that “have affected my life, but address a bigger topic... I’m always interested in those larger topics, and how they affect my physical story, my personal story.” McCauley has gained the most notoriety for her solo performance piece *Sally’s Rape* (1989). In this piece that addresses the legacy of slavery and rape, McCauley undresses and stands naked on an auction block while her co-actor, a white woman named Jeannie Hutchins, leads the audience in a bidding chant (McCauley, “Sally’s Rape” 230). She won an OBIE and a Bessie Award for Outstanding Achievement in Performance for this piece (“Biography”).

McCauley’s artistic work in the 1990s continued to investigate community understanding of racism, memory and oral history. Her playwriting and solo performances are traditionally categorized as performance art, “avant-garde,” and feminist theater (“Biography”; E. Johnson 24). Another classification of her work is “identity performance,” a branch of expression that burgeoned in 1980s U.S. performance art (Carlson 173). One prominent feature of identity performance is

the use of autobiographical material as the source for the performance.

Furthermore, while performance art of the 1960s was dominated by white and well-educated artists, the 70s and 80s saw “a much more significant number of performers of color and performers of a lower social class, bringing their different experiences and concerns onto the stage” (Carlson 173). The trend of identity performance established in the history of solo performance opens an important door for a person with a chronic illness to add their experience to this form of live performance.

In the 2000s McCauley developed a piece titled *Sugar*, in which she shares stories about her experiences with racism, her sexuality and gender, and her life experiences as a person with type 1 diabetes. As McCauley takes her personal, lived experiences and situates them within a broader historical context, *Sugar* unpack the personal-bigger story. While McCauley shares stories from her life with the audience, she also uses her body to bring in the history of sugar in the transatlantic slave trade and disparities for African-American communities interacting with the U.S. health care system (E. Johnson 18).

#### **4.2.2 Development of the Piece / Production History**

*Sugar* was developed at the Performing Arts Department at Emerson College in Boston (“Sugar”). McCauley has a brief story to describe the genesis of the project:

Years ago, a friend who was also a theatre person said to me, ‘Why don’t you write about diabetes?’ And my first response was, ‘Eh, I don’t wanna do that.’ As time went on, as I continued teaching and exploring the idea of the personal bigger story, I was having many crises with the diabetes, and felt that it was time to talk about it. I feel that if I’m resisting something, it must be something I need to attend to. I tell my students, if you’re resisting, then go towards it. And I thought, ‘I’m doing the same thing.’ (McCauley, “Chronic Theater Makers”)

In 2014 McCauley realized a connection between her experiences and a larger historical context for the issue she wanted to explore, diabetes. As for these thematic and dramaturgical trends in *Sugar*, McCauley observed:

I have been thinking about how to talk about diabetes through storytelling. I am not an expert but I am connected to my life and the stuff in my life. Being African American, I am very much aware of racism in so many aspects of American culture, and am trying to give voice to that. And I always knew that health care for us was not as it should have been. (E. Johnson 18)

McCauley had been specifically contemplating the role of sugar in her diabetes. As a person with type 1 diabetes, she maintained a complex relationship with sugar because it can save her life during a low blood sugar, or cause complications if she has high blood sugars over a long period of time. While thinking about her relationship to sugar, McCauley had a revelation:



We think of cotton, but the money, the big money was made on sugar, it was the triangular slave trade based on sugar. Sugar was gold. That is what Columbus was looking for. So I just started thinking of these rants and by accident. It was the early 2000s and it must have been after 2007 that I accidentally- and I think accidents are wonderful for work- I accidentally found a journal, the *New England Journal of Medicine*, and I picked it up and there was a whole acknowledgement by several medical professionals on disparities in health care around African Americans and it was official (E. Johnson 18-19)

After gathering published studies on health care disparities, she also gathered more research on diabetes. In 2005 she was gathering research on the disproportionate impact of diabetes in communities of color, but she, like Marina Tsaplina, knew that she needed to respond to the systemic inequalities that had shaped her personal life:

It is not my job to get the facts and be done with it. My thought was, 'You are not going to get away, world, without knowing the story.' And that sounds really big. It makes the world that comes to the performance, and the work that many of us do is the work of giving voice to silent conditions and diabetes is often minimized as a problem because it just related to sugar. (E. Johnson 19)

McCauley acknowledges her work to give voice to her experience and not let it be minimized or silenced. She maintains an awareness of data about disproportionate

burden of type 2 for communities of color and racism in the U.S. health care system. Her comment that diabetes is minimized because of the connection to sugar is a nod to the over-medicalized, individualistic narratives about diabetes that make it a moral issue of control, behavior, and her communities' relationship to sugar rather than one about access to health care.

*Sugar* premiered in 2006 at Ohio State University, in Columbus, OH. In January 2012, McCauley performed *Sugar* as co-produced by Emerson College and Arts Emerson and directed by Maureen Shea. In April 2013 McCauley performed the piece at Brown University, and in December of the same year at Boston College. In 2014 McCauley joked that *Sugar* was still “definitely a piece in progress, I use that word to say that it is about progress but it is also in progress,” while acknowledging it as a “respectable and recognizable piece of performance art” (E. Johnson 24-25). When Johnson asked, “Ultimately, what do you want this piece to say?” McCauley responded:

So many of us have diabetes and it is inconvenient to our lives. I hope to help myself and others live better with it. Doing this performance helps me face how hard it is, and to keep trying to live better. I hope such can happen for others, and that any people can have a good time at the theater. (E. Johnson 25)

In January 2015, *Sugar* was performed at Hartbeat, again directed by Maureen Shea (“Sugar”). In February 2018, McCauley presented the New York premier in conjunction with Lumberyard Contemporary Performing Arts. I was able to attend

the performances on February 2<sup>nd</sup> and 3<sup>rd</sup> and rely on that viewing for the following analysis.

**4.2.3 Data Analysis: Performances of *Sugar* at New York Live Arts on February 2<sup>nd</sup> and 3<sup>rd</sup>, 2018. An earlier version of the script was published in *solo/black/woman*.**



Fig. 3: Robbie McCauley performing *Sugar* at New York Live Arts. Photo courtesy of Kate Enman.

## Overview

*Sugar* was presented at New York Live Arts in a 184-seat proscenium space as a part of the Lumberyard in the City Winter Festival. When I walked into the

venue, the stage was dark and there was a 3D projection of a blue and red anatomically correct heart with blood pulsing through bright veins on a black background. A recorded conversation about low blood sugar played in the background. On stage there were three black folding chairs, a bundle of sugar cane on the ground stage right, and two bags of sugar, both white and brown, tucked upstage behind a piano. The show began when the recording faded away and Chauncey Moore, who composed the music and played the piano during the performance, walked McCauley out in the dark to a seat center stage. Chauncey Moore assists McCauley at various point in the performance.

Theater scholar Ann E. Nymann characterizes McCauley's survival aesthetic, particularly in *Sally's Rape*, with the tools of revision, embodiment, and dialogue (577). I agree with Nymann's findings and contend that McCauley builds on those aspects of her survival aesthetic to bring diabetes to the stage and incorporate it within a larger historical context. This study indicates that the use of storytelling, embodiment, and dialogue are vital additions to convey her story in *Sugar*. McCauley's theatrical strategies deconstruct stereotypes and contextualize diabetes within social conditions, reveling the use of the social model regarding diabetes discourse.

### **Storytelling: Integration and Complexity**

The primary action of *Sugar* is Robbie McCauley on stage sharing stories from her life with the audience. Storytelling is an effective tool to integrate diabetes

on stage not as specter, or isolated incident, but as part of one's life. McCauley demonstrates the multiple ways diabetes affects her person. Consider the opening moments of the performance. McCauley entered the stage in the dark, guided by Moore to a chair center stage. Once McCauley was seated, the stage lights went up and she pulled out a bar of dark chocolate from her purse. McCauley struggled to open the bar of candy, and it became a comedic moment: she wrestled with the wrapper, looked at up at the audience, then looked down at bar again and finally succeeded in opening the chocolate wrapper. After McCauley succeeded with the wrapper, she broke off a corner of chocolate and put it in her mouth. She spoke while still chewing the food in her mouth and expressed a contradiction about sugar: it can give pleasure and eat you up from the inside out. When McCauley included the point that “sugar can eat you up from the inside,” she also alludes to the consequences of too much sugar in her blood stream over a long period of time. However, for a type 1 diabetic, there are instances when eating sugar is a vital act of survival. McCauley began the performance by observing a complicated relationship to sugar, which many non-diabetic people can relate to the tension between sugar’s gratification and its harm.

McCauley proceeded to communicate stories from her life, moving chronologically. She shared stories of food in her home growing up, and an aunt who recognized McCauley might have “the sugar,” a colloquial term for diabetes. McCauley frequently interrupted herself to ask a rhetorical question, which served to integrate reflections on diabetes as her storytelling unfolded. In one instance,

McCauley told the story of a high school romance that ended in heartbreak, and she shifted mid-story to go over the three “D’s of diabetes.” McCauley steps to the side of the three chairs on stage and laments: “The three ‘D’s of diabetes are depression, denial, and drinking.”



Fig. 4: Robbie McCauley performing *Sugar* at New York Live Arts. Photo courtesy of Kate Enman.

McCauley made this claim without using a statistic, though The Mayo Clinic confirms that having either type of diabetes does increase the risk of developing depression (Castro). Instead, she offered her personal experience with drinking and mentioned the time she spent at AA meetings. Depression and drinking are not stereotypical experiences associated with diabetes, but McCauley expresses that her lived experience with diabetes has manifested in these ways. McCauley included

these elements of her lived experience because it is vital for an audience to understand the burden of this chronic illness and the toll it takes on her life and the lives of those in her community.

In a scene towards the end of *Sugar*, McCauley uses a fresh needle to draw from a vial of insulin. She told the audience she needed to use a clean needle because of the germs. Then McCauley looked up at the audience smirking, and admitted she knows “a lot of people who live with a lot of germs.” The audience responded with laughter. I understood this taboo acknowledgement to mean that someone might use the same needle more than once, for reasons such as waste, time and money, all of which are concerns for people living with diabetes. After drawing up a few units, McCauley revealed her stomach to the audience. Before our eyes, she poked the needle into her skin. It was a powerful moment, made even more powerful by the mixture of pain and resiliency that McCauley embodies in front of an audience. McCauley’s agency and ownership of her chronic illness exists in stark contrast to the representations of diabetes seen in the previous chapter. Those portrayals showed diabetes as a crisis that leaps out of the fabric of a character’s life. The examples discussed showed people with diabetes living in crisis or shame, not having agency to care for themselves, and not enjoying full lives.

For an example of the impact of diabetes on her community, McCauley shares a story about a family member. McCauley shared that her family member was diagnosed with type 2 diabetes, and then fell in love with Krispy Kreme donuts. McCauley takes a towel and wiped chalk marks off the ground. She paused to shout,

“A fucking Krispy Kreme! With all the sugar and grease. Who puts that in poor neighborhoods?” McCauley’s outburst implicated the social system of food oppression. Food oppression occurs when “targeted marketing, infiltration into schools, government subsidies, and federal food policy each play a significant role in denying inner-city people of color access to healthy food” (Freeman 2221). McCauley immediately followed this outburst by sharing with the audience that her family member died. Although McCauley does not directly explain the death, it felt to me as an audience member that the diabetes, Krispy-Kreme, and death were all related. These stories investigate the social constructions that influence the lived experience of a person with diabetes.

### **Embodiment: Carrying the Weight**

McCauley strategically used her body to create images that link her personal experiences with diabetes to the historical brutalities that shape and even produce her lived experience. McCauley implicated the “traumas of history [with] the traumas of living with a chronic illness” (Bock, “Grappling” 130). One climactic scene began after the story about the Krispy Kreme. McCauley went over to a bundle of sugarcane on the ground.





Fig. 5: Robbie McCauley performing *Sugar* at New York Live Arts. Photo courtesy of Kate Enman.

She tried to lift the sugar but could not do so. Moore came over to assist her. He lifted the cane onto her back, and McCauley began again with the same text while moving the bundle on her back across the stage. This image placed McCauley's body within two narratives: her own journey carrying the burden of diabetes and the labor that black bodies endured when enslaved and working to produce sugar. McCauley's body carried the weight of her diabetes in the context of the transatlantic slave trade, of which sugar was a staple. Given the Krispy Kreme reference, McCauley also places diabetes in the context of contemporary capitalism

where low-income communities cannot access or afford to spend more money to avoid cheap, abundant high-fructose corn syrup and fast food (Gritz; Freeman). McCauley then indicted global capitalism by placing her body in front of a world map while standing between two bags of white and brown sugar. McCauley scooped her hands into the bags three times and let the sugar flow down back into the bag. Smoke rose up from the bags. With the image of the globe behind her, McCauley talked about Christopher Columbus landing a ship in America while looking for India.



Fig. 6: Robbie McCauley performing *Sugar* at New York Live Arts. Photo courtesy of Kate Enman.

She challenged the narratives of personal responsibility and blame in relation to diabetes. She helped the audience understand that sugar's history is carried in the bodies of people with diabetes today.

### **Dialogue: Reorienting Our Associations**

Third, McCauley engaged her audience directly to help them understand her experience and rather than minimize it, grasp the magnitude of this experience. During the show, McCauley conducted a direct dialogue, asking the audience questions and gathering their responses, and culminated the exchange by offering us a metaphor. Continuing the power of her embodiment within larger historical contexts, let us consider this scene. After dragging her hands through the bags of white and brown sugar, McCauley stepped beyond the stage apron and requested that the audience participate with her. She asked for one word in response to her question, but the word cannot be “good” or “bad.” She asked for four people to answer, “What do you think about the war in Afghanistan?” Four voices spoke up from the audience: “terrible,” “endless,” “relentless,” and “atrocities.” After the four people in the audience offered these words, McCauley took their words and explained that she was at war with her body: diabetes is her own body at constant war with her heart and soul, and that war is “terrible,” “endless,” “relentless,” and an “atrocities.” She conveyed that her experience of chronic illness is *like* the war in Afghanistan and used the audience's own words to teach them about her experience. She deconstructed the belief summarized by the ESPN commentator

Stephen E. Smith who shared the belief that modern medicine is advanced, so diabetes isn't a big deal. She used dialogue to deconstruct that stereotype and to build a new narrative that highlighted the non-visible struggle and pain of living with diabetes.

The metaphor of war may be particularly suited to describe managing an illness whose main focus is control and discipline. The constant battle against a body that transgresses boundaries is what scholar Simon J. Williams calls the problem of the "recalcitrant body" (438). This is the state of bodies that are:

always threatening, through their libidinal flows and corporeal desires, their pleasures and their pains, their agonies and their ecstasies, to 'overspill' the culturally constituted boundaries which currently seek to 'contain/constrain' them. (Williams 438)

As we have saw in the previous chapter, there is a focus on control and discipline of the body and blood sugars in diabetes discourse, especially with respect to insulin therapy, food monitoring, and exercise. McCauley and other people with diabetes are living in constant battle to control and discipline their inherently recalcitrant bodies. The difficulty, daily labor, and traumas that ensue from high and low blood sugars feel war-like to McCauley. McCauley uses the assumptions people have about the war in Afghanistan to re-orient her audience's associations about the experience of living with diabetes. To conclude the scene, McCauley stepped back on stage, drank a juice, and tested her blood sugar.

## Summary

In the final scene of *Sugar*, McCauley explicitly engaged with the medical model in a demand for a cure. She closed the show by commenting on all the "new stuff out there" related to diabetes. She talked about technology, sugar-free snacks in the grocery store, "diabetes this and that in many places." She vaguely described insulin pumps, OmniPods, and CGM systems as "boxes you can attach to your skin." McCauley then abruptly shouted "I WANT A CURE! I want a cure." The audience responded with plentiful clapping and cheering. This moment posed a return to the medical model, whose primary goal is to find a cure for biological deficits in the body. I propose that this act illuminated the need for the social model to work in conjunction with the medical model, as:

Some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate. Therefore, some very much want to have their bodies cured, not as a substitute for curing ableism, but in addition to it. (Wendell, "Unhealthy Disabled" 161)

McCauley drew the audience's attention to the historical context for communities of color's relationship to sugar. McCauley's work deconstructs the stereotype that people are merely sitting at home, lazy, eating too much sugar, and getting diabetes (Dodge). Still, no amount of social justice will elevate every burden of her daily reality managing type 1 diabetes. However, McCauley's last words on stage are defiant and resilient: "Diabetes was supposed to kill me. But I ain't dead. Yet." Otis

Redding's "(I Can't Get No) Satisfaction" begins to play and McCauley dances off stage (McCauley, "Sugar: A Work-In-Progress" 17). McCauley's display of frustration and resiliency disrupted the traditional stereotypes around diabetes. Her piece looked at social conditions that constructed lived experience, but still reached for the medical model in her call for a cure. McCauley exerted agency and ownership over her diabetic body rather than exhibiting passivity and the denial exemplified by characters with diabetes in the previous chapter. She utilized storytelling, embodiment, and dialogue to communicate her daily lived experience. These findings challenge the notion that diabetes is only represented in live performance as a specter of shame, blame, and death.

#### **4.3 Case Study: *The Panza Monologues* (2<sup>nd</sup> edition published in 2014) by Irma Mayorga & Virginia Grise**

"As we gazed down our center's street lined only with fast-food options and thought about the composition of the city's working class neighborhoods, usually Mexican American or African American residents (where fast food corporations flourished) ...we realized, we had panzas, lots of *panzas*, but other factors were also implicated in how they came to be."

- Irma Mayorga

##### **4.3.1 Playwright(s) History**

Virginia Grise is a “curator, artist and activist” who holds an MFA in Writing for Performance from the California Institute of the Arts (“About”). She has multiple accomplishments as a playwright, performer, and author. Her 2010 play *blu* won the Yale Drama Series Award. In 2017 she published the performance manifesto *Your Healing is Killing Me*. Irma Mayorga is a scholar, playwright, director, dramaturg, designer, and teacher whose “inquiry examines contemporary theater and performance by U.S. people of color, theater and performance by women, Chicana/o Expressive Culture” (“About”). She earned her M.F.A. in Costume Design from the University of Wisconsin-Madison and attended Stanford University for a Joint PhD in Drama and the Humanities. As an instructor Mayorga has taught courses at Dartmouth College, Florida State University, and University of Texas, San Antonio.

In the “Foreword” to *The Panza Monologues*, Dr. López summarizes the commonalities between these scholars:

Notably, both Grise and Mayorga are the daughters of working-class families, came into adulthood after the crucible of the Chicana/o Civil Rights movement of the 1960s and early 1970s, and are first-generation college-educated women who turned to the arts as a form of expression and documentation. Both are also the children of military families and had the opportunity to travel and move across multiple types of borders, achieve advanced degrees as theater artists, and freely pursue careers in the arts. (xvii-xviii)

Dr. López marks Grise and Mayorga's histories of traversing borders, and I believe that these monologues help us move across our entrenched assumptions about diabetes towards new perspectives. In 2002 both women were working at the Esperanza Peace and Justice Center (EPJC) in San Antonio, Texas. In their daily meetings and office conversations, *The Panza Monologues* were born.

#### **4.3.2 Development of the Piece / Production History**

In "Chapter One/ Uno" of *The Panza Monologues*, Mayorga pens the "origin story" of the piece (3). In terms of who had which role developing the script, she considered herself the director and producer, while Grise was the performer (3). Mayorga and Grise's relationship began through EPJC in San Antonio in the summer of 2002 (3-2). Dr. López tells the beginnings of the monologues as a series of office conversations at the EPJC center:

*The Panza Monologues* evolved from the Chicana practice of everyday life and the conversations Grise and Mayorga observed, cultivated, imagined, recorded, re-created, and enacted in and for their Mexican-majority hometown, San Antonio, Texas. Grise and Mayorga's goal in beginning to draft the play by observing and collecting *panza* stories and writing their own was to create a piece of theater that conveyed the kind of epiphanic moments when one connects with a story being told and feels genuinely moved to higher ground personally, politically, critically, and spiritually. (xv-xvi)



When writing the monologues, they specifically asked for stories and memories from co-workers at EPJC including Bárbara Renaud Gonzáles, Petra A. Mata and María R. Salazar (Grise et al. xix).

### **Production History of *The Panza Monologues***

The piece was first produced at ALLGO (Austin Latino/Latina Lesbian, Gay, Bisexual, and Transgender Organization). This world premiere was at Tillery Street Theater, Austin, Texas in November 2004 (Grise et al. xix). There is also a DVD that captures Grise performing the monologues directed by Mayorga. This performance was “recorded in front of a sold-out audience at Plaza de la Raza in East Los Angeles in 2008” (“Store”). The DVD is intended for “classrooms, community screenings, workshops, and Panza Parties” (“Store”).

#### **4.3.3 Data Analysis: *The Panza Monologues* published second edition script.**

##### **Overview**

Grise and Mayorga structured *The Panza Monologues* similar to Eve Ensler’s *The Vagina Monologues*, with each monologue articulating a different story from the viewpoint of one specific body part. Instead of giving the vagina a voice as Ensler does, Grise and Mayorga focus on the “panza,” the Spanish word for “belly” (Grise et al. xxiii). While all of the monologues examine the conditions of the Tejana

body, “My Sister’s Panza” and “Noticias” are the two monologues that specifically reference type 2 diabetes. I argue that “My Sister’s Panza” and “Noticias” do not use type 2 diabetes as a shortcut to signal other discrediting qualities of the character in the monologue, but they explicitly critique the economic and historical construction of San Antonio that produced Latinx bodies with type 2 diabetes. My readings indicate that Grise and Mayorga use three key strategies to reflect on the social construction of diabetes. They deconstruct stereotypes about diabetes by depicting the sister with diabetes in “My Sister’s Panza” as sexual and independent, while showing the pain of the mother reflecting on cultural practices that impact her daughters. The monologue highlights also diabetes as an ongoing presence in their lives, not merely a specter. Secondly, in the monologue “Noticias,” Grise and Mayorga present socio-historical and economic facts while foregrounding a woman dancing *zapateado*, a traditional Mexican dance. Lastly, they curate audience engagement before and after the monologues to ensure critical thinking. When Grise and Mayorga focus the conversation and investigate stereotypes about diabetes, they do more work to guide an audience through deconstructing stereotypes about diabetes. These dialogues encourage critical thinking about social constructions and illuminate the ideology about diabetes internalized by many Americans.

### **Cultural Identity, Grief and Diabetes**

The social model critiques social systems that stigmatize individuals with an impairment, thereby preventing them from full social participation. Stigma disqualifies a person from full social acceptance, and Goffman reminds us, “by definition, of course, we believe the person with a stigma is not quite human” (Goffman 5). This dehumanization often indirectly leads to discrimination and decreased life chances (Goffman 5). For a person with type 2 diabetes, the most common stereotypes are being out of control with food and immoral lifestyle choices (Bock, “Contextualization” 155). “My Sister’s Panza” deconstructs these dehumanizing associations with type 2 diabetes, and instead depicts the sister character as a person with agency, sexuality, and an ongoing, complex relationship with diabetes.

“My Sister’s Panza” tells the story of a woman who lost her *panza* due to the dissolution of her marriage. The performer of the monologue explains that her sister and ex-husband met from “one of those corny ‘I’d never do that’ ads” (Grise et. al 61). When the performer explains “my sister had the *panza* then. That’s what amazed her. This guy loved her, really loved her – big, beautiful *panza* and all,” she clarifies that the husband found her sister’s fat embodiment attractive (61). Before including details about the sister’s type 2 diabetes, the author characterizes her as a sexual being because of her belly.

The performer then shifts the story to recall just how far back in time her sister had a *panza*. This is where the story of the diabetes diagnosis emerges:

Seven, when she slowly became more and more thirsty each day,  
itching for water at every moment, and then she'd pee hot streams of  
burnt yellow, every thirty minutes. Until finally, mamá took her to see  
the doctor man. (61)

This story highlights one of the major aspects of a lived experience of diabetes that often goes unexplored when playwrights use diabetes as a specter. Although to describe a character's thirst and extreme need to urinate is not glamorous, it is specific, accurate, and characteristic of a diabetes diagnosis. The inclusion of these details describes the experience of diabetes in stark contrast to stereotypes where diabetes emerges suddenly and quickly means death for the character. We have seen numerous examples such as *Let Me Down Easy*, *Steel Magnolias*, *The Pain and the Itch*, and *The Cold Wind and the Warm* where the revelation of the person's diabetes status is sudden and not a part of the ongoing narrative. As Ferguson argued, this "one excessive moment"-type of display makes the daily lived experience of the disease invisible (189).

After describing her sister's emerging symptoms, the performer of "My Sister's Panza" includes another element often ignored when playwrights stigmatize diabetes. The performer humanizes her sister by focusing on the vulnerability inherent to an encounter with a doctor and a disease diagnosis.

The doctor, he looked her over, up and down, and bled her, putting her  
gushing life force into vials for the lab.

The tests came back and there it was: sugar, sugar running *como* syrup in her urine, turning it golden sunset yellow, poisoning her pancreas. Poor little pancreas that couldn't keep up with her *panza* as it grew bigger and more round. (Grise et al. 62)

The performer characterizes this experience in poetic but accurate ways. To say the doctor “bled her” is a more colloquial than a doctor took her blood or took “her labs,” and highlights the sister’s vulnerability.

The performer moves on to depict how the diagnosis impacted the family culture and reflects on cultural norms for her Mexican family. While this may seem similar to the examples like Gary and Sid in *The Catch* or M'Lynn and Shelby in *Steel Magnolias*, it is notably different. Both *The Catch* and *Steel Magnolias* rely on tropes of a person with diabetes as out of control and immoral, while the able-bodied family member is in control and occupying the moral high ground. This is especially true when the person with diabetes finds themselves in a life-threatening crisis. However, Grise & Mayorga depict the stress of asking an entire family to embrace changes to their lifestyle in order to help the afflicted family member:

The doctor told us: it was diabetes.

“What’s that?” Our *mexicana* mother didn’t know what he meant when he said we had too much of us around to love. She said, “That’s the way kids are supposed to be.” But, to save us, we had to change—everything. All our *comidas* had to change, now, today, this minute! No more *tortillas de harina* smeared with butter, no more *Barbacoa*

Sundays, or *Arroz con Pollo* Fridays. No more *capirotada* piled five layers high. No more ice cream man bells.

But worst of all, they made mamá go to a nutritionist to learn how to cook out her love. They were teaching her how to lose the savings of our panza banks. (62)

This text portrays the complexities around culture, food and identity. Food can be an act of love, a remembrance of family history and culture, and it can be the product of habit. The diabetes diagnosis is not merely a moral failing of the sister who is “out of control” or extreme with poor eating habits. The doctor asks the mom to change the food she makes for her children, which is connected to a personal identity as a mother and cultural identity as a Mexican women. Asking the mom to change these behaviors is not only a matter of will and control, but “food is often central to expressing social and individual identities, prescribed food choices have the potential to interfere with a newly diagnosed patient’s social world and sense of self” (Bock, “Contextualization” 173). There is a tremendous amount of pain and vulnerability when a mother learns she has been hurting her children by living out these personal and cultural identities.

The monologue also reflects on the role the mother plays by passing down cultural norms and history through food. Women often are expected to maintain links to culture through food. In fact, this expectation is one reason why women experience a higher burden around type 2 diabetes:

the role that women play in the family, may affect women's vulnerability to diabetes. Women are often the keepers of culture, the family members who pass on cultural practices, such as what foods are served for holiday celebrations or what activities family members are encouraged to engage in. This responsibility to maintain cultural practices and pass them on to younger generations can make it difficult for a mother or grandmother to successfully make lifestyle changes. (Black 545)

For the *mamá* character, her role with food also means love and survival for her family and children. The performer explains the mother's view of her children's *panzas* as symbols of love and survival:

Our *panzas*, they are what told her that her kids were never 'over her dead body' gonna starve. Even if we sometimes did. Mamí was crushed, broken. What had she done to her baby's pancreas? She didn't know, but she learned to poke my sister with life-giving shots to keep her *bebida* alive. (Grise et. al 62)

This description disrupts the stereotypical image that diabetes is an accumulation of an individual's bad choices. It also has the specificity of needles, shots, and the damage to the pancreas. The social model allows us to appreciate the immense resiliency required of the family as it reckons with the diagnosis by changing their lifestyle and cultural identity.

In the conclusion of the monologue, the performer reveals that the husband eventually leaves her sister for a younger woman, and the sister is heartbroken. After the loss of this relationship, the performer notes that this is when her sister's *panza* went away. During the months of anger, heartbreak, and fighting with the ex-husband, her sister "stopped eating. Stopped the *panza*" (63). However, the story concludes with a twist that would surprise an audience member who strongly correlates type 2 diabetes and obesity. The audience learns that even though the sister has "stopped eating until every roll of her *panza* was gone," her blood sugars were not under control (64). The sister's diabetes did not go away, and with out-of-control blood sugars her life is in great peril (64). The performer tells the audience that her sister:

Measured her blood sugar to find sky-high readings of sugar, sugar,  
sugar. And I know, as she slid the needle of her insulin shot under her  
skin, she wondered how much would it take to take away the *panza*  
pain for good? (64)

This story deconstructs the stereotype that type 2 diabetes equals obesity, and that thinness means perfect health (Bock, "Contextualization" 155; Thornberry 28). In fact, the performer describes her sister's extreme weight loss paired with the high blood sugars and concludes the monologue with a question for the audience, "I wonder if the doctor would think she'd done enough to help control the sugar sweetness of her diabetes now?" (Grise et al. 64). Closing the monologue with a question means that the performer is not going to give the audience catharsis, and



together we must stay with the sister's frustrations and hurt. The complexity of the sister's story, including her sexuality, family dynamics, vulnerability in the medical system, and weight loss humanize her and challenge our assumptions about diabetes.

## **Historical and Economic Context in San Antonio**

The monologue that follows "My Sister's Panza" is "Noticias," which puts type 2 diabetes in a larger socio-historical, economic context. "Noticias" is not a monologue *per se*, but a scene during which multiple headlines from *San Antonio Express-News* rotate on a screen while a woman dances the *zapateado* in the foreground. The *zapateado* belongs to a category of dance known as folk or ethnic dance. Anya Peterson Royce offers a definition of ethnic dance as a "dance performed by members of an ethnic group to make a statement about their identity as members of that group" ("Ethnic Dance"). The *zapateado* is a dance connected with the identity of the Zapotec, who are an indigenous group in southern Mexico (Royce). One category of dance for this group is the *son*, which is a combination of the waltz and fandango (Royce). *Zapateado*, meaning "heel work," is a section of the *son*. The *son* is also like other Mexican Indian dances, but still "distinguishes the Zapotec both from other Mexican Indian groups and from the Mexican (Spanish) national culture" (Royce).

The stage directions of "Noticias" describe a dancer moving center stage to perform a "*traditional zapateado- a percussive dance, the heartbeat of Mexican son*"

(65). The dancer “*pounds out rhythms with her feet on a wooden tarima (platform) that echo throughout the theater*” (65). Another way to describe the *zapateado* dance is as an individual dance, rather than a partner dance, where one will keep their feet close together and “literally jump side to side” (Tiburcio 00:00:47-00:00:50). The feet move quickly, a percussive sound ensues, and music often accompanies the dance as well. After this introduction to “Noticias,” then the headlines from the *San Antonio Express-News* rotate across a screen. Notably, the performer of the monologues remains seated at the altar during the dance and slideshow (Grise et. al 65).

In my reading of this scene, Grise and Mayorga reveal the interconnectedness of economic and racial disparities to issues such as weight and type 2 diabetes. Mayorga describes realizing this interconnectedness while the monologues developing out of office chats between herself and the other Tejana women working at the Esperanza Peace and Justice Center (EPJC):

As we gazed down our center’s street lined only with fast-food options and thought about the composition of the city’s working class neighborhoods, usually Mexican American or African American residents (where fast food corporations flourished) ...we realized, we had *panzas*, lots of *panzas*, but other factors were also implicated in how they came to be. We each tried to break it down, sort it out: personally, systemically, racially, culturally, and historically. (Grise et al. 9-10)

Mayorga realizes that the issue of body composition and health status is far more complex than individual poor choices. While a major component of diabetes care is ownership and personal responsibility, I argue that in order to move away from thinking of diabetes only in terms of stigma and blame, we must do a better job taking these complex factors into account. The format for the monologue “Noticias” encourages intellectual engagement as well as awareness of the labors of these working-class Mexican women. In addition to labor, the dance expresses cultural identity. Dance, like food, is a marker of cultural identity, and is a means to maintain cultural identity in the face of shifting realities for food as a cultural marker, whether by shifts in the San Antonio landscape or a doctor who recommends a different diet for the family.

The slides themselves display facts about weight for residents of San Antonio like “S.A. ranks as nation’s fattest city on fed list . . . study shows 31.1% of Alamo City residents are obese” or “More than 30% of Hispanic children across the country are overweight, compared with 25% of Anglo children” (65). The presentation of these facts functions as an observation, an invitation to consider *why* S.A. is the nation’s fattest city, and *why* Hispanic children are more obese than Anglo children. The facts do not provide answers, but the audience’s minds are engaged while reading them as they experience the physical effect of the *zapateado* dancer and music. I contend that the role of the *zapateado* dancer signifies the culture and labor of Tejana women in the context of these problematic realities in San Antonio. Mayorga describes her awareness of her co-worker’s and her agency

and intelligence: “as smart women, we could have made better choices all around”

(9). Mayorga also recognizes how “the intense pressure of time, geography, economics, and the structure of our working day often derailed our best intentions”

(9). Mayorga takes ownership of her experience, but also acknowledges a number of external pressures that are shaping it. The image of the *zapateado* dance while these statistics play in the background encapsulate Mayorga’s conundrum.

The next slide addresses an economic reality: “Texas schools generate about \$54 million a year from vending machine contracts” (65). The statistics continue with other facts such as 5% more of Hispanic children are obese than Anglo children while the audience now realizes how much money Texas schools are making vending machine contracts. The slides that follow begin to link together facts on race, place, and economics:

slide: ‘We know that the highest increase in obesity has been observed among Hispanics and African-Americans.’

slide: ‘The food industry produces roughly 3,800 calories a day for every man, woman, and child in America . . . twice what they need.’

slide: ‘Living in sprawl can increase your spread—those in compact counties weigh up to 6 pounds less.’ (66).

Race and class are relevant factors in these statistics. The issue Grise and Mayorga are describing is also known as food oppression. Andrea Freeman defines this term in her 2007 *California Law Review* essay, “Fast Food: Oppression through Poor Nutrition”:

although some social and cultural factors account for fast food's overwhelming popularity, targeted marketing, infiltration into schools, government subsidies, and federal food policy each play a significant role in denying inner-city people of color access to healthy food. The overabundance of fast food and lack of access to healthier foods, in turn, have increased African American and Latino communities' vulnerability to food-related death and disease. (2221)

Freeman's argument about "food oppression" is essential to understanding the broader context for obesity and type 2 diabetes in San Antonio. "Noticias" shows audience the impact of food oppression in a variety of statistics. Doing so, Grise and Mayorga complicate the diabetes discourse that solely focuses on individual responsibility. The next slide names diabetes specifically as a concern in this landscape, "slide: '15.7% of border residents suffer from Type 2 diabetes, compared with a national average of 13.9% in the United States and 14.9% in Mexico' (Grise et al. 66). This headline is not blameful. I read it as an invitation to the audience to ponder *why* this reality is the case. Gender is another factor that contributes to the complexity of type 2 diabetes in San Antonio, "slide: 'One in two Hispanic females born in the United States in 2000 will develop diabetes if current trends continue, according to the Centers for Disease Control and Prevention.'" (66) This sobering fact highlights the trends that Mayorga discusses in her chapter on the development of the piece. She knows that the women she is working with are smart but, as she says, "the intense pressure of time, geography, economics, and the

structure of our working day often derailed our best intentions” (9). The monologue concludes with this sobering newspaper headline in the audience’s mind, the *zapateado* dance and the Los Flacos’s music.

The main goal of this monologue is to deconstruct the bias that type 2 diabetes is the result of the moral failings of one individual. This monologue depicts a community including women and children who are affected by many overlapping factors such as restaurant choices and access to healthy foods/grocery stores. This effort is captured by Mayorga when she says:

*The Panza Monologues* attempts to show in some small measure, the conditions that manifest in our bodies come not only by way of personal choices but also by way of generations of struggle to negotiate racism and discrimination that have forced people to make choices that are driven by adaptations to survive. The high rates of obesity, diabetes, and physical maladies connected to diet that have afflicted Mexican American people must be assessed in the stead of underlying contributing factors such as these in order to be addressed in any meaningful manner. (125-126)

I wholeheartedly agree with Mayorga that in order to truly address the diabetes crisis in the United States, shaming and blaming will not save or even help anyone. As Mayorga states, it is in the broader understanding of contributing factors that we may begin to offer effective care for ourselves, our loved ones, and other bodies that are experiencing this reality. The percussive dance reveals the enormous

amount of effort going into the “dance” between survival and adaptation for these Tejanas that is playing out in the statistics displayed on the slides. “Noticias” demonstrates that a holistic approach that “incorporate[es] the impact of poverty, tradition and other important cultural factors” is needed to understand the impact of diabetes in San Antonio (Wright 1).

### **Intentional Audience Engagement**

Grise & Mayorga published a series of questions to guide reader/audience engagement before and after *The Panza Monologues*. In the second edition of the text these questions are in the section “Topics for Discussion and Activities Based on *The Panza Monologues*.” The first three questions encourage readers/audience members to examine their general beliefs about weight, size, and health. The questions are:

1. Define obesity. List all the factors that you believe can cause someone to become obese.
2. In the past twenty years there has been a dramatic increase in obesity in the United States. Why do you think this has occurred?
3. What does it mean to be healthy? What other types of health exist besides physical health? What types of health concerns affect you, your family, or your community? Do you consider yourself healthy? Why or why not? (Grise et al. 205)

These questions allow readers to examine their beliefs and assumptions. Once one to realizes they hold a belief system about these topics, then the work of deconstructing stereotypes and examining society's role begins.

Grise and Mayorga provide questions that are more specific to diabetes for after the audience sees or reads the text. Here is the second of the questions they present:

2. Read or view the monologue “My Sister’s Panza.” What types of concerns might a child with diabetes have? What types of concerns might that child’s parent/s or caregiver/s have? Have you or anyone in your family ever been diagnosed with an illness that was either life-threatening or caused major changes in your/their lifestyle? What type of impact did it have on your family? (205-206)

These questions ask an audience to connect to their own experience and their conceptions about diabetes. Rather than using diabetes as a punch line about weight, this question encourages empathy by asking what concerns a parent or caregiver might have for their child with a diabetes diagnosis.

A meaningful discussion around diabetes specific to the context is so important to the co-authors, that they encourage communities to tailor the questions to address concerns in their own city. In a sub-section, “Obesity in the United States” (207), the co-authors ask their audience to consider the following question that includes diabetes specifically:



3. Look up statistics about obesity for your city and state. We recommend starting at the Centers for Disease Control and Prevention's website, which has figures on adult obesity in the United States ([www.cdc.gov/obesity/adult/index.html](http://www.cdc.gov/obesity/adult/index.html)). Also be sure to look at the CDC's information on childhood obesity ([www.cdc.gov/obesity/data/childhood.html](http://www.cdc.gov/obesity/data/childhood.html)). With further Internet investigation, can you find what percentage of your city's residents are considered overweight or obese or have diabetes related to weight? How does your city rate nationally in terms of obesity or obesity-related illnesses? Dig further: how does the United States compare to other countries in terms of body weight or obesity? This data can be made into a pie chart or a bar graph to visually represent the statistics you've found. (207)

This action to look at one's own context also addressed in the notes for staging your own production of the show. I imagine the reason for this approach is to avoid "othering" the community in San Antonio. Tailoring the questions to your own city shows the universality of the disease. Instead of only hearing the narrative taking place "over there," they encourage creators and audience members to locate themselves and their community in the problem, and then part of the solution. These acts also ensure that audiences are thinking critically about stereotypes around weight, diabetes, and blame. They are not merely doing so in relation to

women in San Antonio, but also actively engaging their own selves and communities while unpacking the viewing/ reading of the monologues.

## **Summary**

Using the social model, Grise and Mayorga create theatrical monologues such as “My Sister’s Panza” and “Noticias” to reflect on economic, cultural, factors that impact Tejana women with type 2 diabetes. They closely examine the relationship between food, identity, and family roles in “My Sister’s Panza.” In “Noticias,” the co-authors ask the audience to see the overlapping impacts of structural entities in San Antonio and the impacts on working-class people of color. They engage the audience intellectually with statistics and materially with dance. This parallel demonstrates the “best efforts” of the intelligent, Mexican women Mayorga worked with at EPJC center, but in the face of the sobering statistics, we see the outcome. Lastly, Grise and Mayorga provide their audience with before and after questions to guide critical thinking and reflection about type 2 diabetes.

## **4.4 Conclusion**

This chapter explored two case studies that demonstrate the ways in which theater artists use the social model to explore the daily lived experience of type 1 and type 2 diabetes. In Robbie McCauley’s *Sugar*, McCauley used storytelling, embodiment, and dialogue to tell the personal-bigger story with diabetes. This

strategy invites the audience to integrate diabetes into the historical narrative of sugar as a driving force in the transatlantic slave trade and the lasting impacts of racism in the U.S. health care system. In *The Panza Monologues*, Grise & Mayorga humanize characters with type 2 diabetes by telling non-stereotyped stories and by illuminating the incredibly complex economic, historical, and cultural fabrics within which type 2 emerges. They also provide tools for a community to have a politically productive dialogue after an audience witnesses the embodied storytelling or for readers as a part of a discussion group. Together, these examples of theater encourage us to move beyond the binaries of good / bad, crisis / invisible, control / crisis when it comes to depicting life with diabetes. These binaries emerged from the medical model, and I contend that the social model gives us a broader picture.

However, there are also valid critiques of the social model, including its oversimplification of the disability experience, the logical impossibility of being a disabled person who is not oppressed, and a tendency to focus on stable, predictable impairments (Shakespeare 165; Wendell, “Unhealthy” 160). These critiques can be addressed when we consider disability as an embodied identity rather than solely as a social construction. The artists in the next chapter deconstruct the stereotype that diabetes must always be denied and distanced as a part of one’s identity, while they also reflect on the influence of society on their relationship with diabetes. They integrate diabetes into their identity through the image of an ongoing journey, revealing “the processual nature of people’s attempts to make sense of the disease” (Bock, “Grappling” 127). They create theater that gives voice to their journey and

challenges audience members to make sense of their own relationship to diabetes and health.

## CHAPTER 5

### FORMING DIABETIC AESTHETIC IN THE THEATER THROUGH COMPLEX EMBODIMENT

#### 5.1 Introduction

In the previous chapter, I argued that McCauley and Grise & Mayorga's performances explicitly address the social barriers that influence people's experiences with diabetes. In so doing, they challenge the first common narrative about diabetes, the narrative that positions diabetes, more commonly type 2, as a biological dysfunction resulting from the behavioral failings of an individual. In *Sugar*, McCauley shared many of the personal, embodied experiences she has had with her diabetes. In her efforts to communicate her experience with the audience, she utilized the metaphor of war. She took the audience responses to what they thought about the war in Afghanistan ("terrible," "endless," "relentless," and "atrocious"), and McCauley explained to the audience that she was at war with her body, and this war had the same characteristics of "terrible," "endless," "relentless," and an "atrocious." McCauley's metaphor derived from and expressed her lived experience on stage. For me as an audience member who also has type 1 diabetes, I related to her point regarding the daily, constant labor to discipline and control the naturally "recalcitrant body" (S. Williams 438). The "diabetes-as-enemy" mentality

implicit in the imagery of war is certainly one way for a person to conceive of their diabetes.

However, my research indicates that imagining one's relationship to a chronic illness in this way is not the only way; in fact, there are artists and patient advocates who would find this metaphor problematic. For example, THE BETES Organization is a group that aims to help people with chronic conditions form a flourishing relationship with their health through the performing arts. One of their guiding principles is that "illness is a teacher, not an enemy" ("About Us"). In other words, they believe that one is not "at war" with one's diabetes but, rather, one lives with, listens to, and learns from it. Approaching illness as a friend or teacher addresses the second common stereotype about diabetes which persists in theater more broadly, which is the framing of a character's diabetes as a specter that intrudes in their otherwise healthy life and ultimately leads to their death. In order to change this narrative, playwrights might wish to consider how diabetes can function as an ongoing part of a character's embodied identity. This embodied identity captures both the phenomenology of the diabetic body as well as the benefits of ownership over one's sense of self.

When I use the phrase phenomenology of the body, I mean the "[the body's] defining elasticity—not as an established fact, but rather as a mutable, temporal, 'first-person' organism" (Snyder and Mitchell 382). I am asking playwrights to reckon with the diabetic body as elastic, not as a stable thing oscillating between crisis and control. This way of thinking about diabetes is endemic even for scholars

critiquing crisis-oriented portrayals of diabetes. For example, Kevin L. Ferguson states that “the real reason [he] dislike[s] *Steel Magnolias*” is because “diabetes only appears at one excessive moment and is never otherwise a part of Shelby’s life” (189). While Ferguson critiques portrayals of diabetes that occur only as excessive moments, he also argues that the labor of diabetes management is an “utterly banal secret” (192). Ferguson reinvests in this dichotomy by characterizing diabetes management as otherwise “boring” and “banal” (192). To deconstruct this binary and explore diabetes as a partner in a life-journey rather than an enemy, I contend that we must embrace the elasticity of the body. The efforts of diabetes management, i.e. “checking blood glucose levels before and after meals, injecting insulin or taking oral medication, measuring carbohydrate intake, and planning an exercise schedule,” might instead of war, suggest an elaborate dance with one’s body and its functions (Ferguson 192). While one person may experience these behaviors and this way of being as painful and war-like, the war metaphor reinforces the idea that diabetics battle with a recalcitrant body which is “always threatening...to ‘overspill’ the culturally constituted boundaries which currently seek to ‘contain/constrain’ [it]” (S. Williams 428).

I advocate for an understanding of the body that disability studies scholar Tobin Siebers terms “complex embodiment” (“Disability and the Theory of Complex Embodiment” 326). This theory of the body welcomes its “vital and chaotic” nature (325). Siebers developed this theory from his initial observation of a contradiction: humans put a great deal of effort into both ignoring and perfecting the body (313).

He argues that this contradiction may exist because “our thinking is steeped in ideology,” which Siebers refers to as the theory of ability, otherwise known as ableism (314). Siebers draws out several core tenets of ableism and credits the disabled body’s position outside of this ideology as a good place from which to “make epistemological claims about [ableism]” (314). Though the disabled body may have insights into ableism because of its social location outside of this ideology, the fundamental problem still exists that as a society we do not trust the body as a site of knowledge (326). If human beings generally fear the body’s fragility and mortality, then it is easier to “imagine the body as a garment, vehicle, or burden,” rather than “as a complex system that defines our humanity, any knowledge that we might possess, and our individual and collective futures” (326). Disability studies scholars such as Simi Linton have long contended that we must “claim the value and variety of disability,” and Siebers describes complex embodiment as “the next step for disability studies is to ... value[] disability as a form of human variation” (“Disability and the Theory of Complex Embodiment” 316, 325).

I am particularly interested in complex embodiment as a way of theorizing the diabetic body and representing it on stage because this theory “raises awareness of the effects of disabling environments on people’s lived experience of the body, but it emphasizes as well that some factors affecting disability...derive from the body” (325). In other words, I claim that our attempts to reflect the lived experience of diabetes rather than using it as a stigmatizing mark on stage must emerge from a mutual understanding of social factors influencing the body as well as its elastic



nature. While Siebers terms this complex embodiment, other feminist and disability scholars have made similar requests for “complex understandings of the cultural history of the body” (Garland-Thomson, “Integrating Disability” 4). Sharon L. Snyder and David T. Mitchell advocate for disability studies to “re-engage the body” and Liat Ben-Moshe ask for “a new conceptualization of disability, not just as a socially excluded category, but as an embodied identity” (367; 120). I argue that artists and playwrights representing diabetes on stage can respond to these movements in disability studies by incorporating the social, cultural, historical influences that create diabetes as well as experiences that derive from the elastic body. I call this a form of diabetic aesthetic, which considers both the limits imposed by social barriers and the possibilities opened by individual embodied experience. Complex embodiment in theatrical representations can enact this new ideology for non-diabetic and diabetic audience members alike by combating stigma about diabetes at the ideological level. My proposal for this complex embodiment that I call diabetic aesthetic specifically combats the two most common stigmatizing narratives about diabetes: one’s failure at personal responsibility and the denial of diabetes as an ongoing part of oneself.

The diabetic body presents an opportunity that can lead to new knowledge about oneself and a world pervaded and shaped by ableist ideologies. When I argue for playwrights and artists to consider diabetes as a part of a person’s embodied identity, I began with the premise that “in almost every case, people with disabilities have a better chance of future happiness and health if they accept their

disability as a positive identity and benefit from the knowledge embodied in it” (Siebers, “Disability and the Theory of Complex Embodiment” 326). I advocate for an approach that allows artists to represent diabetes as a part of their identity, that accepts one’s “disability as an epistemology that . . . embraces what the body has become and will become relative to the demands on it, whether environmental, representational, or corporeal” (327). Stigmatizing narratives about impairments make embracing the body as it is extremely difficult. Yet, we know if people are to accept diabetes as a part of their identity and benefit from their embodied knowledge, we must not frame it as an undesired difference (Goffman 133). Many people living with diabetes are already doing this work, and theatrical representations need to catch up.

Marina Tsaplina and G. William Zorn are two artists who form a diabetic aesthetic by expressing a complex embodiment for their characters. They depict characters with diabetes that process grief and move towards self-acceptance, agency, and empowerment in their sense of self as people with diabetes. They challenge representations that suggest diabetes is a failure in personal responsibility with health. They depict diabetes a part of a person’s life, not merely a dramatic specter that appears suddenly and will lead to their death before the curtain goes down. In *The Invisible Elephant Project*, Marina Tsaplina performs a 25-minute one-woman show, in which she converses with her diabetes as embodied by a puppet and explores the possibility of her losing a limb from diabetes-related complications. In Zorn’s *Lucille*, the audience meets the title character in the

hospital, as she makes sense of her type 2 diabetes diagnosis. While Lucille initially believes that she is not the kind of person who would get diabetes, the play depicts her willingness to learn about diabetes management and to build a support network with her nurse, Candy, and daughter-in-law, Judy. *Lucille* portrays a character grappling with her body as a changeable entity, but ultimately presents her as a person who can incorporate this new way of being into her behavior and relationships.

### **5.1 Case Study: Marina Tsaplina and *The Invisible Elephant Project***

“It is my duty to respond to you, the society that produced me. All artists must do this.”

- Marina Tsaplina

#### **5.2.1 Performer History**

I was first introduced to Marina Tsaplina’s work through Dr. Tess Jones at the CU Anschutz Center for Bioethics and Humanities. Tsaplina is a founder of THE BETES Organization whose mission is to “employ the performing arts to help people with chronic conditions form a flourishing relationship with their health” (“About Us”). I was able to speak with Tsaplina in September 2018; I asked about her personal identity and her development as a performing artist who addresses chronic illness. Tsaplina shared that her journey to performance with puppetry started when she was in school for stop motion animation. The isolation of this work motivated Tsaplina to investigate other art forms and led to her discovery of

puppetry, which seemed to her to be an embodied form of animation. She studied puppetry at the University of Connecticut and then in Berlin for six months. When she returned to the U.S. Tsaplina “was looking for theatrical training and specifically physical theater that places the body first.”

Putting physicality and the body first is a theme in all Tsaplina’s training. Tsaplina has also pursued the Margolis Method for physical actor training, Linklater voice work, object theater workshops in Paris, puppetry intensives with Sandglass Theater, and clown work with Richard Pochinko (Tsaplina, “Interview”). While we were discussing her training, Tsaplina confirmed, “I realize this a very through answer but, it kinda all comes together because they are all placing primacy upon the body.”

In addition to discussing her training, we also talked about Tsaplina’s diabetes diagnosis and how she decided to bring together performance and her identity as a person with diabetes. Tsaplina shared that she was diagnosed with type 1 diabetes when she was two years old, but she did not consider how it shaped her until she began the transition from studying animation to live performance. Tsaplina was considering how performance can serve society when:

I found that living in my own backyard when I realized that I had been taught a mechanical relationship to my diabetes and that, that’s not the reality that I was living with my whole life. Theater is the art of staging relationship and art overall is the pursuit... of questioning ... what is real. And what is the experience of being alive, so I brought

those two together and that has really opened up the path that I have been on for the past, I think five, and a half years.

Tsaplina's journey exploring what is "real" in her relationship with diabetes has led her to depict it as a friend and teacher in performance. In live performance, Tsaplina enacts for others the relationship that she has internally with diabetes and shifts the perspective of the audience many of whom view diabetes as a biological dysfunction. In her Artistic Statement, Marina terms living with a chronic illness as "fractured embodiment." Part of her intent is to build sutures between these fractures and to reveal another way of living with them. Tsaplina's work in *The Invisible Elephant Project* acknowledges the fractures by making diabetes an embodied puppet with whom she dialogues, listens to, and learns from.

### **5.2.2 Development of the Piece**

*The Invisible Elephant Project* is a piece comprised of a twenty-minute performance followed by a facilitated discussion and exercises. The structure of the performance event was informed by the Narrative Medicine workshop model. Columbia University developed this model in 2000, which aims to increase narrative competence in medical practitioners by "fortify[ing] clinical practice with the ability to... be moved by stories of illness ("About Narrative Medicine"). This focus on story resists the "technologization" of medical care (Tsaplina et. al 2). The technologization leads those working in health care to treat "bodies-in-care and diseases [as] objects to be examined, contained, and categorized according to

insurance coding” and erases the humanity of the person receiving the care (Tsaplina et. al 2).

The Division for Narrative Medicine at Columbia recognizes that “the care of the sick unfolds in stories, and we recognize that the central event of health care is for a patient to give an account of self and a clinician to skillfully receive it” (“About Narrative Medicine”). One of the foundational ways that Columbia University suggests one can partake in narrative medicine practice is through a workshop. For a workshop, there are three important components: close reading, writing, and reflecting (“About Narrative Medicine”). The facilitator presents a piece of art such as a “poem, prose piece, painting, photograph, comic, or song,” and then invites the audience to observe and comment. The facilitator offers a prompt for the participants to write about in the “shadow” of the art (“About Narrative Medicine”). The development of *The Invisible Elephant Project* reflects the influence of the narrative medicine model through its structure, content, and post-performance exercises.

As for the content of the piece, The BETES Organization provides additional context by explaining their methodology for collecting stories on their website. They gathered almost 1,000 responses from people with type 1 and type 2 diabetes ranging from ages 17-75 on their “their experience, thoughts and feelings around diabetes complications” (“Our Work”). They also conducted 26 phone interviews, and their website describes the research shaping the project as “ongoing” (“Our Work”).

### **5.2.3 Data Analysis: Video and script of *The Invisible Elephant* performance by Marina Tsaplina on April 3<sup>rd</sup>, 2018 at the University of North Carolina**

#### **Overview**

The performance I analyzed was filmed on April 3, 2018 at the University of North Carolina. In the video capture, Marina Tsaplina introduced a theatrical event from behind a podium by addressing the questions, intentions, and context that have guided her work. In the twenty minutes that follow, Marina shared an internal monologue with the audience; it focused on her thinking through and imagining her own possible encounter with diabetes-related complications such as a leg amputation. She moved from direct address with the audience and put a puppet on her lap to continue a dialogue with the puppet. After the performance with the puppet, Tsaplina led the audience in a free-write response exercise.

#### **Inclusion of Social Context**

The video of Tsaplina's performance began with her standing at a music stand.



Fig. 7: Marina Tsaplina performing *The Invisible Elephant Project* at the University of North Carolina. Screen shot of video courtesy of Marina Tsaplina.

Tsaplina played an audio clip of the James Baldwin's talk "The Artists' Struggle for Integrity." Tsaplina framed her performance through Baldwin's story about people asking him what he does. Baldwin noted that when he told people that he was a writer, they would often persist with "but what do you *do*?" After establishing this confusion about what artists *do*, Baldwin expressed his hope that his audience will proceed to discuss the importance of artists and poets to a society. Tsaplina picked up her story with the audience:



Just like James Baldwin in 1963, what we are attempting to do is very difficult. What I must do for you is to try to articulate why the type of report that only an artist can make is being called upon by medicine.

(“The Invisible Elephant Project” 00:00:45-00:01:08)

Tsaplina is referring to The American Association of Medical Colleges’ announcement for the need for arts and humanities in medical education (Mann). The announcement and Tsaplina’s mention of it demonstrate the reflexive relationship between embodiment and social context. The social context of medicine has primarily understood illness as a biological dysfunction, but in the 21<sup>st</sup> century there is a “growing recognition that studying the arts and humanities may help learners develop qualities such as professionalism, self-awareness, and communication skills that are increasingly important for physicians” (Mann). Through her performance, Tsaplina will contextualize her body and experience of diabetes within this social context. Tsaplina laments “the deafening silence and inability to allow oneself to fully see and feel what it means to live in a body that before the 20<sup>th</sup> century would have perished (“The Invisible Elephant Project” 00:02:14-00:02:24). In her words, Tsaplina is lamenting the prevalence of the medical model which taught her to view her own diabetes through a mechanical lens. Using performance, she aims to more fully express the emotional experience connected to her body. This type of effort is a form of complex embodiment, which views “the economy between social representations and the body not as unidirectional as in the social model, or non-existent as in the medical model, but as

reciprocal (Siebers, “Disability and the Theory of Complex Embodiment” 325).

Tsaplina goes on to describe her performance as a response to a society that produced her body. When Tsaplina says that society produced her body, she is referring to invention of insulin as a creation of modern medicine and the “transmutation [of type 1 diabetes] from an acute to a chronic condition” (Feudtner 17). While the society that invented insulin allows people with diabetes to live longer, Tsaplina calls attention to the inexplicable rise in the cost of insulin prices. She even discusses physicians aiming to help people with diabetes as are doing so under the shadow of:

an industry that dares to raise the price of this drug, without which I die, from \$20.82 in 1996 and in 2016 was \$255, an increase of 1124% in 20 years, and is now currently over \$300 dollars. I go through three of these a month. (“The Invisible Elephant Project” 00:02:28-00:02:54)

Tsaplina highlighted one of the most urgent, systemic barriers that people with diabetes have in 2018. The rising costs of insulin is so extreme that “the American Diabetes Association note[d] that between 2002 and 2013, the average price of insulin nearly tripled” (“Opening Statement”). This vital dynamic between the experience of diabetes and the extreme cost of necessary medical supplies goes totally unacknowledged in examples from Chapter 3, which stigmatize and narrowly focus on a person’s deserved shame and blame.



Fig. 8: Marina Tsaplina performing *The Invisible Elephant Project* at the University of North Carolina. Screen shot of video courtesy of Marina Tsaplina.

Tsaplina expressed to her audience that without insulin “I die,” but additionally uncontrolled diabetes can lead to complications such as, “vision problems, nerve damage, kidney failure, heart disease, stroke, and ultimately death.” (“Opening Statement”). The transmutation of diabetes from an acute to chronic condition has in fact produced her body which “enables people to live longer, allowing another disease to rise to prominence, substituting for the diminished disease” (Feudtner 21). Tsaplina contends with living in a body produced by medical advancements that is expensive to maintain: the high cost of insulin is a prohibitive barrier for

some and leads to dire consequences. This addition of social context allows for a fuller representation of Tsaplina's daily lived experience with diabetes. Tsaplina made a powerful remark that, "It is my duty to respond to you, the society that produced me. All artists must do this" ("The Invisible Elephant Project" 00:002:57-00:003:10). Tsaplina will perform the elasticity of her body within this troubling broader context.

Another way in which Tsaplina called attention to her body's elasticity occurred when she tested her blood sugar before continuing in the performance.

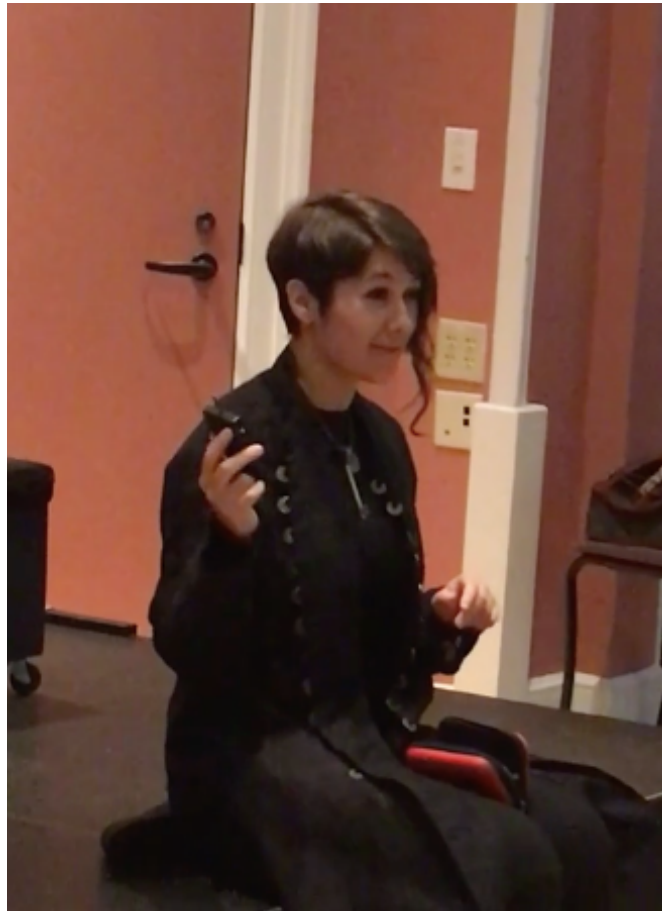


Fig. 9: Marina Tsaplina performing *The Invisible Elephant Project* at the University of North Carolina. Screen shot of video courtesy of Marina Tsaplina.

After the introduction, Tsaplina stepped away from the lectern and told the audience:

I am going to check my sugar since I have lived with type 1 diabetes since I was two years old, and for the sake of my sanity and my body before every performance I really should know where I am at. So of course, the question is, did the performance already begin? (00:005:40-00:06:23)

Tsaplina pricks her finger and shows the audience her blood. She puts the blood on a test strip, and then licks the blood off her finger.



Fig. 10: Marina Tsaplina performing *The Invisible Elephant Project* at the University of North Carolina. Screen shot of video courtesy of Marina Tsaplina.

Tsaplina's interaction with her own blood, displaying her blood for the audience, and then licking the blood off her finger is a visceral demonstration of the ebb and flow of Tsaplina's body. Tsaplina revealed the need to know her blood sugar levels before going further into the performance, as they influence her mind and body during her work. Tsaplina cannot separate her physical and mental well-being from her presence during the performance. With this gesture, Tsaplina invited the audience to witness the porous boundaries of her body near the troubling social context around insulin costs that poses a barrier for people with diabetes.

### **Forming Complex Embodiment through Puppetry**

One of the most striking aspects *The Invisible Elephant Project* is Tsaplina's use of a puppet to enact and embody her internal dialogue about diabetes-related complications for her audience. In her Artist Statement, Tsaplina explains why she uses a puppet in this performance:

I work with puppetry and live performance because a puppet is a material site of pure imagination. An object of paper, cloth, leather, papier-mache, wood, and urethane combines into a form that enchants you into believing it is alive. In the puppet, the physical material and the imagination unite. Puppets also hold the ability to jump from the literal to the metaphoric in an instant. In my work, puppet theater serves to reveal the consciousness that is held in the stories of

fractured embodiment, transformed and revealed by the materiality of the puppet and the physicality of the actor.

Revealing the non-visible consciousness of living with diabetes is vital. This act empowers those with diabetes to give voice to their experience and be understood as more than mere stereotypes. It also counters the ableist notion that one must deny and hide any part of themselves that does not conform to a societal norm. The goal of complex embodiment is to empower a person with a disability to value their body as a site of knowledge (Siebers, “Disability and the Theory of Complex Embodiment” 313). As Tsaplina enacts her relationship to diabetes as a puppet and depicts herself as a puppet going through the process of losing her limb, she challenges core tenets of ability theory such as “the lesser the ability, the lesser the human being” and “ability is the supreme indicator of value when judging human actions, conditions, thoughts, goals, intentions, and desires” (315). The narrative that diabetes is a specter relies on crisis and disruption of the narrative, while this processing of life with diabetes is neither an actual nor a disruptive event. It is the internal dialogue that a person with diabetes has with themselves, contemplating the experience of loss that they will possibly encounter one day as a result of living with diabetes for so many years. Tsaplina’s work with the puppet in *The Invisible Elephant Project* highlighted the processual nature of diabetes, where those living with diabetes do not make sense of it in one event, but over time and through repeated “attempts to make sense of this disease” (Bock, “Grappling” 127). As communities process and make sense of this disease, there is a need to make the processing visible (Bock,

“Grappling” 127). Tsaplina made her processing visible through her interactions with the puppet, and so forms a diabetic aesthetic that engages grief and loss with gentleness and courage.

Tsaplina introduced the puppet in the performance by first taking off a black sheet from its body. She lifted the puppet from the hold in the back, gripped another handle for the left arm, and was able to control the puppets feet with wooden bars between her toes.



Fig. 11: Marina Tsaplina performing *The Invisible Elephant Project* at the University of North Carolina. Screen shot of video courtesy of Marina Tsaplina.

As a scene transition, music started in the background, almost like ringing bells.

Tsaplina sat on a box with wheels on the bottom. In the script that Tsaplina shared with me, the puppet was named “P” while Tsaplina was referred to as “M.” As



Tsaplina sat on the box, Tsaplina (M) used her feet to turn around and the puppet (P) began to walk and look up and around. The puppet's feet mirrored her movements, and P looks out and around at the audience. The puppet's feet step forward, and Tsaplina shakes the puppet's head. P looked up and around. The puppet rested on Tsaplina's knee. Tsaplina uses a higher tone for P's voice, and a lower register to represent M speaking. The dialogue between M and P enact the internal concerns M has about her diabetes, and the loneliness and frustration she feels discussing the topic with only herself. For example, M tells P that she can talk to M about the weight she is carrying, and P responds: "P. Yes, and that's almost like I'm speaking with myself. M. Well, yes." (Tsaplina and Kaufman 2). P's face looks back at M and asks, "Well, what good does that do?" (Tsaplina and Kaufman 2).



Fig. 12: Marina Tsaplina performing *The Invisible Elephant Project* at the University of North Carolina. Screen shot of video courtesy of Marina Tsaplina.

This gesture acknowledges the frustration and fruitlessness of not having a network of support and only leaning on yourself to carry the burden of illness. P and M look at each other and then out and around to the audience. The stage direction reads that the “head of puppet + Marina look opposite directions, creating a mirror illusion” (Tsaplina and Kaufman 2).

Tsaplina returns to the engagement of the audience’s imagination and communal processing of possible loss. M asks what *it* is like, and P answers:

It is an elephant with a thousand faces! But one face in particular keeps haunting me... it keeps coming closer and closer. And I-

M. - I !

P. -want to try to come to know it. Before it comes to me, if it comes. It might, it might not. But if it does, will it be like I have crossed to the other side?

M. the other side of what?

P. that thin line between...What if it comes to *me*? I might become partly invisible. I could lose a part of myself. Like... my leg. (Tsaplina and Kaufman 3)

At the end of this interaction, Tsaplina will remove the leg of the puppet. The stage directions read:

*(At this moment, Marina has involuntary sharp intake of breath.*

*Puppet sits on Marina's leg. M looks at puppet--M takes off P's leg quietly, moves leg to the side.*

*P stands up --loses balance to right side where leg missing, struggles to regain balance by leaning head left, overcompensates to left and falls on right M to balance, then sits on M knee, huffing.)* (Tsaplina and Kaufman 3)

Here Tsaplina vividly engages the audience in her own imagination of losing a limb from diabetes complications. Tsaplina performs the loss, and interrogates the emotions she might experience if she were to endure such a loss:

M.: Is that what you wanted?

P. What did you do?

M. You wanted to see what would happen!

P. Why are you doing this to me?

M. You said you wanted to know it, to know what it was like to become partly invisible! Wasn't that it?

P. Am I invisible?

M. No, you're still here. I'm so sorry I did this to you. (Tsaplina and Kaufman 3-4)

In this interaction, M confronts the belief that to lose a limb would make her invisible, essentially devaluing her as a person, which is a core tenet of the theory of ability (Siebers, "Disability and the Theory of Complex Embodiment" 315). M

apologizes to P and depicts P as the partner in the ebb and flow of M's body. In this way, the body is not "a garment, vehicle, or burden" that one must contain, control, and discipline when it dysfunctions (Siebers, "Disability and the Theory of Complex Embodiment" 326). Rather, M's apology to P depicts a mutual relationship where, however non-visible P is as an illness, as a puppet, P is material and present to the audience as well as to M.

M and P address the role of denial as a part of diabetes. M asks P, "M. Why did you do this to me?" and P responds, "*(P cradles M head and pulls it over to look directly into hers; both P and M faces profile to audience, looking at each other.)* P. Because you weren't really listening to *you*" (Tsaplina and Kaufman 4). This moment is a vital expression of complex embodiment where the materiality of the puppet shows an audience a person listening to the embodiment of their chronic illness. In re-shaping illness as a material puppet, P and M can enact the teaching and benefitting from the knowledge illness holds. M demonstrates this listening through dialogue with P. For example, M explains why she didn't "listen" to P earlier on in their relationship. After M has detached a leg from P, M explains her emotional reaction to the imagined loss:

*P stands up with one leg*

P: How do you feel now?

M. Sad. Betrayed. We have no control over *it*. Its wildness-

P. -will not be tamed. But the thousand faces of shame, anger, and despair can.

M. How do I tame the face of loss?

*P places her right hand on M's stomach.*

P. Touch the stability within you M. *inhales, exhales*

*(P stands up, on one leg, facing stage left)* (Tsaplina and Kaufman 5)

Again, Tsaplina confronts the belief that this loss will be the end of her value as a human. Tsaplina directly confronts the fear of loss and grief, but through engaging her diabetes. There is pain in this confrontation, and P expresses the sentiment:

P. Do you remember when someone told you, 'Complications are battle scars, the result of living the life of a warrior.' *(gestures to leg)* Our scars hold our history. And the elephant can wound...

M. I didn't want to know.

P. History cannot be cured. Listen. (Tsaplina and Kaufman 5)

The mention of a cure and history that cannot be cured is a response to the medical model, and to a perspective that many people with diabetes cherish--the hope of a cure for diabetes. To remark that history cannot be cured brings forth a diabetic aesthetic, an embodied reality of a person living with diabetes. Rather than entertain the fantasy that disability is not real, a person with diabetes needs to hold on to the hope of a cure and wait patiently (Siebers, "Disability and the Theory of Complex Embodiment" 316).

M and P facilitate grieving through song. M and P begin to sing together: "P: Breathing in.. M: Breathing out.." Eventually P's detached leg falls on the ground. Tsaplina's own leg stepped in place of P's wooden leg.



Fig. 13: Marina Tsaplina performing *The Invisible Elephant Project* at the University of North Carolina. Screen shot of video courtesy of Marina Tsaplina.

Tsaplina eventually placed P back on the stand. After gathering up P's detached legs, Tsaplina invited the audience to join her in song. With her hand up to her ear and drawing the song out of her audience, they sing, "Breathing in / breathing out / I am here / I am wounded / yet whole" (00:22:09-00:23:29). This behavior from the audience demonstrates the acknowledgement of the lived experience that has taken place. When the audience to joins Marina in singing, she is not alone with her experience and they support her performance.

### **Challenging the Theory of Ability with the Audience**

Tsaplina follows the performance with P with a facilitated discussion and free-write exercises as recommended by the Narrative Medicine workshop structure. This workshop structure requires audience members to participate and reflect after they witness the piece of art. The goal of the narrative medicine model is to develop “close attention skills, which are directly transferable to clinical practice,” and to allow for the audience to “pause and reflect on their lives and their work” (“About Narrative Medicine”). While Tsaplina’s use of the narrative medicine model was apparent during the talkback session, where she asks her audience to free write a response to her performance with the prompt: “Write about what you didn’t want to know” (“The Invisible Elephant Project” 00:25:10-00:25:25). Through this interaction, Tsaplina invites the audience to engage their own areas of struggle. I argue that in inviting an audience response, she deconstructs theories of ability that demand that us to move away from and otherize anything conceived as disability.

Tsaplina’s interaction with the audience after the performance directly challenges aspects of the theory of ability outlined by Tobin Siebers. One tenet of the theory of ability is that “Disability is always individual, a property of one body, not a feature common to all human beings, while ability defines a feature essential to the human species” (Siebers, “Disability and the Theory of Complex Embodiment” 316). Tsaplina challenges this notion from within the creative process by identifying the elephant in the room. During the performance, she asks P, “What

are you looking for?” and P answers, “Do you see it? It’s here.” This comment initiates a conversation:

P. Oh, well I don’t want to worry you.

M. Hmmm... now I am worried.

P. The... elephant.

M. What elephant?

P. It’s always here.

M. Always?

P. Yes.

M. Even now

P. Yes. I can feel it. Can’t you?

M. Have you told others?

P. They (*the puppet sits down on Marina’s knee and gestures toward the audience*) They are uncomfortable when I speak of it with them.

(Tsaplina and Kaufman 1)

During my interview with Tsaplina, I asked if the “elephant” of *The Invisible Elephant Project* was specifically diabetes complications and thinking about having complications, or if the “elephant” represented the difficulty of having the conversation about complications with others. Tsaplina shared with me that:

I don’t think art, art is not messaging or dogma. Never in the piece does it say what the elephant is. And the elephant is whatever, whatever you perceive it to be. I don’t think it’s, it’s for me for a piece



of art to tell anyone, um, what the elephant is for them. It just helps them realize what it is for them. Uh, and to, to simply help to say something that they didn't want to say, or they couldn't say. Um, and yet that's the single task of art, um, but I certainly won't, um, won't give a definition of what the elephant is or isn't.

In fact, Tsaplina was quite intentional to never explicitly name the elephant, but rather to keep asking and going deeper and deeper with the question “without ever putting a definitive frame and closing the questions, uh, and making it something truly known.”

Tsaplina also sent me writing samples that audience members had left behind after the performance from the free write exercise. Tsaplina shared seven writing samples with me, and these are quotes pulled from those writings: Out of seven reflection writing samples, each mentioned the performance as confusing or uncomfortable. The open and vague nature of the performance struck several of the audience members:

In our small, four-person group, each one of us interpreted it completely differently. Hannah thought the puppet symbolized the ‘true self’ of someone with chronic illness, which is better known through suffering. Maleeha initially understood it to be about the burden placed on others when you are vulnerable with them about your suffering. Personally, I figured the puppet represented her diabetes and showed that it is beneficial to truly realize and accept

your illness for what it is, because it as much alive and real as we are – and for a diagnosis like diabetes, it’s not going anywhere, it is a part of you.

This reflection represents the openness of the elephant as Marina conceived of it. One respondent connected “Marina’s honesty and openness with her fear of losing a limb really helped me understand why my mom (a type II diabetic) often changes the subject when it come up.” Later in the same response, the author wrote:

After the performance, Marina asked “what did you not want to know?” I took that prompt personally, and immediately thought of alcoholism, which runs in my family and has caused me a lot of grief and fear of becoming an alcoholic myself.

The open prompt causes audience members to confront their feelings of confusing and discomfort. Some respondents connected with their own personal “elephant,” while others observed what is was like for them to hold someone else’s experience of chronic illness.

Tsaplina framed the sharing, “the prompt is a response that performance allows people to hone in a certain on a certain piece of their, of their own response. You see as many elephants in people’s writing as, as people in the room you know?” These excerpts from writing samples prove that indeed there were many “betes” in the room. The writing exercise challenges the ideology of ability which contends that “overcoming a disability is an event to be celebrated. It is an ability in itself to be able to overcome disability” (Siebers, “Disability and the Theory of Complex

Embodiment” 316). Tsaplina interacts with the audiences as they contemplate their own stories of what they did not want to know; she thereby encourages others to own their stories rather than to distance and deny them. Tsaplina brought this point up again that there were many versions of elephants in the room. She notes that she created the piece around diabetes, but that it transcends that specific experience. Ultimately, the piece is “really addressing the space of loss, or the possibility of loss and at least in part, and um, letting go” (“Interview”). For Tsaplina, the writing confirmed that diabetes pointed a light beam towards this topic, but “you will see that in people’s responses in their writing, uh, which again is I think the power of artistic work, artistic inquiry” (“Interview”).

I shared that from my own perspective, I had become quite focused on how theater can communicate about diabetes, and Tsaplina shared with me that having performed the piece in front of several types of audiences, from health care providers to patients to general audiences, that the work translated. She observed “the potential for universality in all of our struggles, while at the same time retaining the specific history of the suffering of a community and that history matters. That that history is not isolated from struggles of other communities.” By gathering responses from the audience, she guided others to work towards a deeper understanding of the experiences they may not have wanted to know but had experienced as a part of their own story.

## **Summary**

In the close reading of Tsaplina's performance, I mapped out the diabetic aesthetic she formed through complex embodiment and in effect acknowledged her daily lived experience with type 1 diabetes. Tsaplina began the performance by informing the audience of social realities that impact her body and her experience with type 1 diabetes, particularly the rising cost of insulin. She enacted a dialogue with her illness through the materiality of the puppet, P. Lastly, she challenged dominant notions of ability that demand we avoid disability at all costs by inviting the audience to ponder what they themselves wish not to confront (Siebers, "Disability and the Theory of Complex Embodiment" 315-315). Tsaplina welcomes diabetes as a part of her identity, as a friend and teacher, and shapes a new diabetic aesthetic that does the same.

## **5.2 Case Study: G. William Zorn and *Lucille* of The Sugar Plays**

### **5.2.1 Playwright History**

G. William Zorn is an "actor, director, playwright, dramaturgy, educator" and self-described "evil-genius" ("GWiZ"). In his Artistic Statement, he explains his interest "to illuminate the darkest corners of human relationships and behavior." He writes that he especially enjoys exploring familial relationships, the use of music is a staple in his work, and the paranormal is a common facet in his playwrighting. He describes his style as:

humor mixed with pathos and punctuated with witty, incisive dialogue; a style that is character-driven and relies on language and negotiation. My characters are minutely and accurately drawn and the story lines are at once familiar yet unpredictable. ("Artistic Statement")

My first encounter with G. William Zorn's playwriting was through a one-act play titled *Lucille*. *Lucille* is one of three plays in a series available online titled, *The Sugar Plays*.

### **5.2.2 Development of the Piece**

In 2007, Ohio University commissioned theatre students from its MFA in Playwrighting program to write one-acts plays about people living with diabetes in the Appalachian region. This series of plays was a part of a diabetes education initiative designed for people living with diabetes in the Appalachian region. The School of Nursing at Ohio collaborated with the School of Theatre to select three playwrights for the project. These playwrights were given the constraints that the play must be approximately 20 minutes and have five or less character (Denham 2). G. William Zorn was selected as one of the three playwrights to have his one-act workshopped (Wright xv). After the playwrights were selected, there were staged readings and feedback for play development (Wright xv-xvii). Kallia O. Wright notes in her dissertation on *The Sugar Plays* project that after the playwright selection, the subject matter became even more personal for G. William Zorn. Zorn was

himself diagnosed with type 2 diabetes during the winter break of the 07-08 academic year (xvi). Many of the details Zorn presents about the character Lucille's experience are from his own time getting hospitalized from and diagnosed with type 2 diabetes (xvii).

### **5.3.3 Data Analysis: Close Reading of *Lucille* and The Study Guide**

#### **Overview**

The script for *Lucille* begins with a 70-year-old widow, Lucille, waiting in a hospital room. A 20-something-year-old nurse, Candy, comes in to talk Lucille through diabetes management at home. Lucille initially disbelieves her new diabetes diagnosis. Her tone with Candy is sarcastic and ornery, but Candy can match wits with her. Candy teaches Lucille about carbohydrate counting for meals and blood sugar testing. Candy encourages Lucille to share her story with her family and build a support network. Candy learns that the closest family Lucille has is a “bony-butt, holier-than-thou wallet-chaser” daughter-in-law, Judy, whom Lucille claims to loathe (Zorn, “Lucille” 8). Thanksgiving is coming up, and Candy suggests that Lucille teach Judy a beloved family recipe and try out a deeper conversation with her about diabetes. When Candy exits the hospital room, Lucille can hear Judy coming down the hospital hallway, singing.

#### **Inclusion of Social Context**

These characters reflect and critique the social environment that influences the complex embodiment of the character Lucille. One of the ways this reflection and critique occurs is through Lucille's relationships with the primary physician in the hospital and her transition nurse, Candy. Consider the claim, "Medicine in the United States is in crisis" (Tsaplina et al. 1). Scholars in the health humanities are delineating this crisis from several perspectives: one, the high rates of physician burn out; two, the "entrenched racial, gender, and economic inequity," and with "race-associated differences in health outcomes" as a function of institutionalized racism in American health care (Tsaplina et al. 1; Jones 1212). And thirdly, "the for-profit healthcare industry reduces human beings to biological entities, legal liabilities, dollar signs, and administrative burdens" (Tsaplina et al. 3). While this highly medicalized approach to impairments in the body may appear to emphasize embodiment, what also occurs is that "physicians sometimes lack the capacities to recognize the plights of their patients, to extend empathy toward those who suffer, and to join honestly and courageously with patients in their illnesses" (Charon 1897). This dehumanization in the health care system justifies the need for the narrative medicine approach, but it also reflects the dominant construct of U.S. health care that Lucille is located within during the play.

*Lucille* reflects this dynamic from the opening scene. Candy enters Lucille's hospital room and Lucille says, "If you've come for more blood, I'm all out. Empty. Caput. The tank is on E and I'm runnin' on fumes" (Zorn, "Lucille" 3). This line shows Lucille's resistance to the dehumanization that can occur by being treated as

an object “to be examined, contained, and categorized” (Tsaplina et al. 1). Candy introduces herself as the “transition nurse,” and explains she is there to help Lucille with the transition back home after the diagnosis. Candy is surprised to hear that she is going home the next day, and sarcastically comments on feeling like she is not told what is going on around her (Zorn, “Lucille” 3-4). The disconnect between Lucille and her primary physician becomes clearer when Candy says:

CANDY: Now. Your doctor told me how important it is for you to get home in time for Thanksgiving.

LUCILLE. I never said that.

CANDY. Oh. It isn't true?

LUCILLE. Yes. I would like to be home for Thanksgiving, but I never told him that and he didn't ask me either. (5-6)

Lucille's remarks reveal the lack of connection between her and her primary physician. This is not surprising to learn when “Physicians, despite their ‘top of the food chain’ status, have become figureheads, their agency constrained by bureaucracy and the ‘technologization’ of medicine’s delivery” (Tsaplina et al. 2). While Lucille shares that the doctor did not ask if she wanted to be home by Thanksgiving, perhaps he too is operating within a systemic construction of medicine that does not allow for a compassionate approach to his patient. Later in the play, Candy asks Lucille, “So, what has your doctor told you so far?” to which Lucille reveals, “Not a lick. He'd rather talk to someone nearer his own age, I guess. I've seen him for all of five minutes since I been here” (Zorn, “Lucille” 8). This



comment is indicative of the larger systemic problem in American healthcare: the lack of dialogue with a healthcare provider, doctor only having a few minutes with a patient, and the lack of information that can leave a patient in this vulnerable state without the knowledge to be empowered. The U.S. healthcare system has a social structure which may produce problems by treating human in this mechanical way, which is not how type 2 diabetes is typically framed as an issue of moral failing. This result is ironic as the very system whose goals are treat and cure health problems may be unintentionally creating barriers to improved health.

Health care reformers propose “narrative competence” as an alternative to this dynamic (Charon 1997). Narrative competence suggests that health care providers have the “ability to acknowledge, absorb, interpret, and act on the stories and plights of others” (Charon 1997). In *Lucille*, the character Candy is the transition nurse displays narrative competence. Candy is able to “to extend empathy toward those who suffer, and to join honestly and courageously with patients in their illnesses” (Charon 1997). The relationship between Candy and Lucille also reflects the direction of the field of medicine to incorporate narrative competence as well as arts and humanities as a part of the education of medical professionals (Charon 1997; Mann). This topic emerges from Lucille’s former position as an English teacher:

CANDY. That’s right. You used to be an English teacher.

LUCILLE. Retired now, yes. How do you know—?

CANDY. Let’s see.

*(Reciting.)*

A wise man should consider that health is the greatest of human blessings, and learn how by his own thought to derive benefit from his illnesses. (Zorn, “Lucille” 4)

The two go back and forth quoting Mark Twain, Plutarch, Pluto, and Shakespeare. Lucille's diabetes is not presented in isolation. Instead, audience members witness the importance of her connection with nurse, Candy, and the possibility of a support network with Judy.

### **Forming Complex Embodiment with Sense-of-Self Transformation**

After Lucille and Candy have met and sparred with famous literary quotes, Candy attempts to begin explaining what diabetes management will look like at home for Lucille. This scene between the two reveals Lucille's preconceived notions about what kind of person gets diabetes. Lucille interrupts Candy and informs her of pieces of her life story:

LUCILLE. I was born in the middle of the depression, number seven of fourteen kids. I've lived to see a half dozen wars. I was a riveter in dubya-dubya two. A damn good one, too. The Japs never sank one of my ships. I married my Alvin in forty-seven, ran a household, raised two boys, taught English to children who would rather read comic books and I've been president of the Elks Club Lady's Auxiliary twice.

(6)

Lucille asks Candy a series of questions that culminate with her challenging the diagnosis:

LUCILLE. Does that sound like somebody you can run roughshod over?

CANDY. No—

LUCILLE. Does that sound like someone who doesn't deserve to be addressed directly?

CANDY. No—

LUCILLE. Does that sound like someone who can't take care of herself?

CANDY. No, ma'am.

LUCILLE. Does that sound like a woman with diabetes?

CANDY Well, yes. To be honest. Anyone can— (6-7)

Lucille's initial perspective demonstrates some the fears that emerge in a culture saturated with ableism.

A complex embodiment acknowledges that the body is elastic, vital and chaotic, not one stable entity that our efforts can control. Theories of ability suggest we may convince of our relationship to the body as "a garment, vehicle, or burden" more easily than as a "complex system that defines our humanity, any knowledge that we might possess, and our individual and collective futures" (Siebers, "Disability and the Theory of Complex Embodiment" 326). Lucille poses a belief that

the body is impervious to the change news of which the nurse is communicating to her. Initially, Lucille challenges the diagnosis:

LUCILLE. Oh, bull pucky. There is no diabetes in my family history.

CANDY. Well, Mrs. Myers, we're finding out more and more about this disease everyday—

LUCILLE. Then maybe they'll find out I don't actually have it.

CANDY. Mrs. Myers, normal blood sugar tops out at about 120. Do you know what your blood sugar was when you were admitted to the emergency room?

LUCILLE. They told me it was high.

CANDY. It was 982. You were essentially in pancreatic failure. (Zorn, "Lucille" 7)

Lucille cannot return to her former way of being. Lucille must find a "different conception of [her]self, one based not on the past but on the present and the future" (Siebers, "Disability and the Theory of Complex Embodiment" 326). Her sense of self must shift to incorporate this new body function and change her behavior to manage it. However, the truth of the body is that it is always changing. Moreover, medical advancements of the 20<sup>th</sup> century have changed the demographics of the U.S. population, causing people to live longer (Feudtner 19). Joslin was aware of the demographic effects of insulin elongating the lives of diabetics. As he noted in 1924:

we are to dwell more and more with the old. A generation ago the average expectation of life was thirty-eight year and now it is fifty-seven... although we as a nation want to live to be old, we do not want to be old too soon. (Feudtner 20-21).

Lucille now has diabetes as a part of her aging body. She must confront the reality of “waking up one morning having become the person...whom [she] hated the day before” (Siebers, “Disability and the Theory of Complex Embodiment” 326).

However, rather than sinking into self-loathing and denial of the diabetes, Lucille enacts complex embodiment. Complex embodiment in this case views the body as changing and changeable, and is aware that “some factors affecting disability, such as chronic pain, secondary health effects, and aging, derive from the body” (325). In fact:

these last disabilities are neither less significant than disabilities caused by the environment nor to be considered defects or deviations merely because they are resistant to change. Rather, they belong to the spectrum of human variation, conceived both as variability between individuals and as variability within an individual’s life cycle and they need to be considered in tandem with social forces affecting disability (325)

The variability of Lucille’s life has impacted her changing body. What must change is Lucille concept of herself as a person who cannot get diabetes. As Candy explains the processes of managing diabetes at home, Lucille engages the tutorial with

messiness and humor. In this scene, where Lucille refuses to use Candy's medical jargon to describe the lancet device:

CANDY. (*Takes our lancet device.*) Now this is the lancet device.

LUCILLE. Stabber.

CANDY. Lancet device—

LUCILLE. Stabber.

CANDY. Now Lucille—

LUCILLE. Stabber. It's a stabber. Call it what it is. It stabs.

CANDY. Alright, then. If you want to get technical about it, this is just the stabber-holder. You have to insert the stabber into the end like this. (Zorn, "Lucille" 16)

In this interaction, Lucille takes the medical jargon, "lancet," and insists on a more colloquial version, "stabber" (16). Through this act, Lucille engages rather than resists diabetes management. She brings forth her own personality by renaming the device with informal, personal terms. This act of agency illustrates Lucille's engagement with the training and her ownership of the new role "stabbers" will play in her life.

Lucille's complex embodiment of diabetes also emerges as she and Candy discuss the realities of her aging. Lucille describes how she doesn't like the sight of blood, and recalls her deceased husband distracting her if she poked her finger while sewing. Lucille is suddenly overcome with tears:

CANDY. I'm so sorry.

LUCILLE. Oh, don't be. We had our time together. I have no regrets. Ain't nothin' to be sorry for. He was a good man and I miss him. And here I am, crying in front of someone I barely know. That's prob'ly how I got this. You cook for two for so many years, when you forget to hate to see it go to waste. It'd be admittin' somethin'. (18)

Lucille shares that the loss of her husband and grieving may have had an impact on her body and insinuates that the loss relates to her diabetes diagnosis. Later when Candy is training Lucille to use a syringe and to give herself insulin, Lucille makes a grim remark about diabetes as "the beginning of the end" (23). They compare insulin to the poison from *Romeo and Juliet*:

*(LUCILLE picks up the insulin syringe.)*

LUCILLE (Reciting.) *I sell thee poison; thou hast sold me none. Farewell. Buy food and get thyself in flesh.*

CANDY (Reciting.) *Come, Cordial and not poison, go with me to Juliet's grave; for there I must use thee.* (23)

After Candy's retort, she challenges Lucille's use of a quote at this point, "I know what you're doing, Lucille. That is not poison and this is not the end of your life" (23). Lucille responds, "Maybe not. But it's the beginning of the end, isn't it? (23). As Lucille's body has changed with diabetes becoming a part of her life, she also is reckoning with her mortality. However, Candy encourages her to wrestle with loss by passing on knowledge to her family, such as the sacred Thanksgiving stuffing

recipe (24). Candy goes even further to suggest that Lucille could look to her daughter-in-law as a support to her diabetes management:

CANDY. Well, we see a lot of patients become lax in their efforts to keep up with their blood sugar readings or they might start to forget their insulin. But, those that have support from their families always do much better. (18)

Diabetes is becoming an ongoing part of Lucille's life as she shares her story and ongoing needs with her family.

By the final moments of the play, Zorn suggests that Lucille has moved from denial to acceptance and ownership of her health care. The stage direction reads, "*CANDY exits. LUCILLE puts on her reading glasses and picks up the needlepoint. After a moment, she stops and picks up the insulin syringe*" (25). While examining the syringe, Lucille says, "There are worse things, I suppose" (25). This act suggests that she will take up the ownership of the ongoing management. Zorn also makes a humorous and hopeful allusion to a transformation in her relationship with Judy. In the final words of the play, Judy can be heard singing while walking down the hallway towards Lucille's hospital room, and Lucille prays, "Lord, gimme strength" (25-26). The ending suggests that Lucille is at least open to connecting with Judy and working on the next phase of their relationship.

### **Challenging the Theory of Ability with the Audience**



Alongside with the scripts, Ohio University and the Diabetes: A Family Matter Program also published discussion guides for a community to have a dialogue about the characters and themes after a performance. Dr. Sharon Denham, who developed the guide, specifically suggests that the guide may be useful for a talkback (2). These guides were meant to offer “suggestions and ideas for ways to guide discussion with persons with diabetes, family members, friends, and other community persons” (Denham 1). This effort by Ohio University and the Diabetes: A Family Matter Program captures their understanding that communities that are deconstructing stigma around diabetes may begin the conversation through theater, but dialogue after a reading or viewing of the plays is also incredibly valuable. Like the questions and prompts offered by Virginia Grise & Irma Mayorga for communities processing *The Panza Monologues*, these questions allow for an audience to critically engage with the piece and encourages audience members to examine their own internalized beliefs about health and diabetes.

The Discussion Guide begins with a plot re-cap of the play and a set of general questions that might open discussion amongst members of the audience. Some of these questions are:

- What were the best things about this play? Why did you like it? Things you dislike?
- Was the story interesting to you? Why?
- So, which of the characters in this play did you enjoy the most? What was it about this character that you most related? (Denham 6)

Following these questions, the guide encourages an audience member to consider the playwright's intentions, "What kinds of things do you think the playwright was trying to make us think about?" (Denham 6). The questions ask the audience member to begin thinking about their own family and more personal experiences with diabetes through the questions, "In what ways did this play remind you about your family?" and "Was the way you experience being diagnosed with diabetes conveyed clearly in this play? Were there things that did not ring true?" (6). Some of the questions in the guide encourage audience members to think about diabetes within a larger social construct such as the U.S. health care system, "What are the things about health care encounters that you find the most challenging? For example, visits with your doctor or hospitalization?" (7). These questions also take the text and ask the audience to find a personal connection or reflection on the story, for example, "How does your family learn about the things you need do to best manage your diabetes? What do they need to know? How can you better communicate your needs to those that care about you?" (7). These questions ultimately challenge the ideology of ableism that frames diabetes as a thing that communities should ignore and fear.

## **Summary**

*Lucille* represents another way that a person might engage with their diabetes through complex embodiment. The character Lucille contends with the social structures of the hospital and U.S. health care and while gaining a new

understanding of the reality of her changing and aging body. Zorn wrote this play based on his own experience with a type 2 diabetes diagnosis. This play demonstrates that “many embodiments are each crucial to the understanding of humanity and its variations, whether physical, mental, social, or historical” (Siebers, “Disability and the Theory of Complex Embodiment” 315). A character with diabetes who is complexly embodied rather than stigmatized can show an audience human variation, as well as the management and sense of self that can shift with this new way of being.

#### **5.4 Conclusion**

Marina Tsaplina’s *The Invisible Elephant Project* and W. William Zorn’s *Lucille* are two examples of theater that represent a way for characters to complexly embody their diabetes. These artists present diabetes on stage by incorporating an understanding of the social forces acting on and producing the diabetic bodies, as well as investigating the body’s natural elasticity. This perspective, grounded in the theory of complex embodiment, is what I call diabetic aesthetic. The diabetic aesthetic on stage means an acknowledgment of the social forces acting on the diabetic character, an understanding of diabetes as an ongoing part of the character’s life, and an incorporation of the elasticity of the body. This aesthetic can reflect the lived experience in a more powerful way than stigmatizing narratives based on ableism and insufficient understandings of the medical model. Disability can be understood as human variation which may require a range of medicine,

social justice, or acceptance of the “vital and chaotic” body (Siebers “Disability and the Theory of Complex Embodiment” 325). As Siebers argues and I agree:

Some disabilities can be approached by demanding changes in how people with disabilities are perceived, others- by changes in the built environment. Some can be treated through medical care. Other disabilities cannot be approached by changes in either the environment or the body. In almost every case, however, people with disabilities have a better chance of future happiness and health if they accept their disability as a positive identity and benefit from the knowledge embodied in it. (326)

This argument is especially relevant for people living with diabetes. I argue that a combination of medical treatment, changes in the social construction, as well as an acceptance of diabetes as human variation (rather than as a signifier of deep moral failing) may help people with diabetes live happier and healthier lives.

Both artists in this chapter have diabetes themselves, which demonstrates the need for the voices of people living with diabetes in creating theater about it. These authors reveal the elasticity of the body in their character’s interactions with it and the inner emotions expressed by their characters. Their experiences as people are a valuable source of knowledge for their characters, as well as for audience members who witness these stories. Changing the narratives on stage about diabetes has the power to normalize people with diabetes and to show them flourishing in relationship to their illness. Theater gives us a new vision of what is

possible. These artists intentionally reach into audiences and communities to continue dialogues that push back against stigma, stereotypes, and the entrenched ideology of ableism.

## CHAPTER 6

### CONCLUSION

“One in five Americans identifies as having a disability, and performers with cognitive, mobile, and physical disabilities span all ethnic groups, gender identifications, and age groups. So where are their stories, and who gets to perform them onstage?”

-Allison Considine

#### 6.1 Findings

When I began this research, my intent was to locate and analyze representations of diabetes in the theater. My hypothesis was that these representations were often stigmatizing; the few I knew of before collecting and examining the data had shown me as much. The research began with a focus on eight plays that I categorized by the two common narratives stigmatizing diabetes. The first narrative is rooted in the medical model, which identifies disabilities as biological defects to be cured and frames people with diabetes as failing to control their biology. The second narrative, also established by the medical model, depicts characters with diabetes as hiding and denying their diabetes until it emerges suddenly in the plot and leads to a character's death. In these plays, characters with diabetes distance themselves from their condition and it emerges in their lives as a specter. Scholars like Kevin L. Ferguson have referred to this as the “Jekyll-and-

Hyde” characterization of diabetes (184). I find this metaphor useful to describe how playwrights frame diabetes to evoke horror. The data revealed many playwrights used diabetes as a stigmatizing mark—or an incidental plot device—rather than exploring it as an ongoing, daily lived experience.

Further research revealed that not all theater artists depicted diabetes this way. Other artists approached diabetes from the perspective of the social model of disability that looks at systemic barriers for people with impairments to understand their lived experiences. Robbie McCauley, for example, connected her experience as a person with type 1 diabetes and disparities in the U.S. health care system to the historical legacy of the transatlantic slave trade through her “personal bigger story” (McCauley, “Interview”). McCauley integrated her experiences with diabetes into her performance, notably using her body to visually connect the history of the slave trade with the current problems in the U.S. health care system and food deserts. McCauley dialogued with her audience, asking them to understand her chronic illness, which she likened to warfare.

Virginia Grise & Irma Mayorga created *The Panza Monologues* to reflect on the experience of “activists, artists, friends, and neighbors with whom they worked, played, and broke bread in San Antonio, Texas” (López xi). In two specific monologues, “My Sister’s Panza” and “Noticias,” they examine the impact of diabetes on their community. In “My Sister’s Panza,” a type 2 diabetes diagnosis upends the family. The speaker addresses how food, culture, and grief impact the families experience with diabetes as opposed to a character’s failure to uphold

personal responsibility and maintain control. In fact, when the sister loses her husband and significant weight, her diabetes control gets much worse (Grise et al. 64). In “Noticias,” Grise & Mayorga employ the social model to examine the structural inequalities of San Antonio alongside data related to type 2 diabetes in the city. They quote statistics from the *San Antonio Express-News* on “the health conditions of Mexican Americans in San Antonio—named one of America’s ‘Fattest Cities,’” by playing them on an upstage screen. Statistics about Mexican Americans in San Antonio are situated next to statistics revealing economic disparities in the structure of city (65). While these facts are presented on a screen, a *Tejana* dancer performs a traditional “zapateado,” a Mexican tapping that dance that portrays the physicality of the culture and the labor that Mexican and Mexican-American people offer to San Antonio, in contrast with the economic injustice that produces type 2 diabetes. In the published edition of the script that I analyzed, Mayorga & Grise provide discussion questions for audience members to deconstruct assumptions around health and diabetes. In this way the community can participate through dialogue after a viewing or reading of the *Monologues*.

Tobin Siebers’ theory of complex embodiment suggests another important way to represent diabetes on stage, by bringing together an understanding of the social forces acting on and producing the diabetic bodies, as well as investigating the body’s natural elasticity. Diabetic aesthetic occurs when diabetes is complexly embodied on stage. The artists in Chapter 5 consider the social conditions that influence how their characters behave. They allow diabetes to change them as a



part of the understanding that their bodies are elastic. They can live with, rather than war against, this new reality. In her performance piece *The Invisible Elephant Project*, Marina Tsaplina complexly embodies diabetes for her audience. She opened her performance by outlining the social barriers to managing her diabetes like the increasing cost of insulin. Next, the character she depicted, M, interacted with a puppet, P. The two discuss M's fear that she will one day lose a limb from diabetes-related complications, which embodies a listening to one's illness. After the performance, Tsaplina challenged the foundational tenets of ableism by asking her audience to free-write about what they did not want to know. In G. William Zorn's play *Lucille*, the characters and plot of the play result from Zorn's own experience of being diagnosed with type 2 diabetes (Wright xvi). *Lucille* is a character who initially expresses resistance to the diabetes diagnosis but utilizes her sense of humor and grit to incorporate diabetes into her new sense of self. The play comes with a study guide that encourages audience members/readers to critically engage their preconceived notions of health and the body.

The findings from this study reveal new ways for artists to depict diabetes on stage without relying on the common stigmatizing narratives. Diabetes is not a monolithic category and neither are the experiences of people living with diabetes. Many of the artists in this study created their work about diabetes with specific communities in mind. This awareness is in step with physicians who advocate for a better understanding of systemic factors that lead diabetes to impact historically marginalized groups at higher rates in the U.S. population (Black 543). In order to

understand this situation, an intersectional understanding of diabetes is indispensable in U.S. society. For example, Melanie Rock advocates for such an intersectional understanding of diabetes in the medical community:

Can we imagine social inequalities so powerful that the effects of drugs might vary across socioeconomic strata? Inequalities so powerful that they affect people's blood glucose levels, irrespective of how much they eat, what they eat, or how physically fit they are? The type 2 diabetes epidemic demands that we do, and yet these questions remain marginal to research on diabetes. (484)

Rock calls upon our imagination for new solutions. The artists that I study in this dissertation help us see these inequities in new ways and assist us to dialogue about new solutions as well.

## 6.2 Significance of Project

I believe that this research has a great deal to offer the world of commercial theater. There is abundant evidence that commercial theater in the U.S. in 2019 is more open than ever for diverse, authentic, and honest conversations about a wide range of health issues. For example, consider the immense success of the 2009 rock musical *Next to Normal*, which won the 2010 Pulitzer Prize for exploring how “one suburban household copes with crisis and mental illness” (“Next to Normal”). Another example is *The Curious Incident of the Dog in the Night-Time*, which won the 2015 Tony Award for Best New Play and was heralded by critics for its

innovative approach to telling the story of a young boy who has autism spectrum disorder. In 2015, Deaf West revived the musical *Spring Awakening* while incorporating deaf and hearing actors. This production also featured Ali Stroker, the first performer who uses a wheelchair for mobility to perform on a Broadway stage. In 2018 the play *Cost of Living* won the Pulitzer Prize for exploring the relationship of two separate couples: John, who has cerebral palsy, and his caregiver, Jess, as well as Eddie and Ani, a couple who recently divorced after Ani became quadriplegic in an accident. The Broadway production featured the actors Gregg Mozgala as John and Katy Sullivan as Ani. Both actors possess in their off-stage lives the disabilities that they portrayed on stage. What these shows have in common is not only that they address real health issues that many people in the audience may connect with, but they also touch on broader truths about the human experience. Take, for example, the 2018 revival of *Angels in America*. Marianne Elliott's production won the 2018 Tony Award for Best Revival of a Play. Oskar Eustis said of Tony Kushner's work in *Angels in America*; "Tony is tackling nothing less than the relationship between freedom and responsibility in the American character," but the play would not explore that larger themes without its connection to the U.S. HIV/AIDS epidemic (Schulman, "*Angels Rises Again*").

I argue that U.S. theater finds itself at an exciting moment full of potential to bring stories about specific health issues to a broad audience. For example, the production history of *Sugar*, which began as a solo-performance at the University of Ohio in 2006 but had a run at a commercial venue in New York in 2018, reveals

that artists can develop work about diabetes in and for specific communities that also can work in commercial venues for broad, general audiences. Marina Tsaplina is another artist who makes the case that theater about diabetes transcends this specific health concern. During our interview I asked if the “invisible elephant” in her work was diabetes, or complications, or the fear of talking about complications, and she reminded me that “art is not messaging or dogma” and “the elephant is whatever...you perceive it to be.” She granted that while “the work was created around diabetes... it far transcends that... It’s really addressing the space of loss.” I agree with Tsaplina that there are broad connections that a general audience can make from work that begins around diabetes. My hope is that artistic explorations of illness in commercial theater can include diabetes through complex embodiment and move away from the common stigmatizing narratives.

This dissertation also contributes to the evolving conversation around chronic illnesses and representation in the field of disability studies. While scholars such as Susan Wendell, Diane Driedger, and Michelle Owen have drawn our attention to chronic illnesses as a site of analysis and understanding, the nuances of diabetes and its representations remain overlooked. In Wendell’s pioneering essay “Unhealthy Disabled: Treating Chronic Illness as Disabilities,” she mentions diabetes only twice. First while defining a chronic illnesses, Wendell writes “lupus or diabetes are known to by typically chronic” and in the same paragraph says “many [chronic diseases], such as diabetes, are expected to kill the patient eventually, either by wearing down the patient's health or by creating severe, life-

threatening episodes of illness” (20). While this description may be factually accurate, it does little to convey the lived experience the way artists like McCauley or Tsaplina do. In the entire text of Driedger and Owen’s *Dissonant Disabilities: Women with Chronic Illnesses Explore Their Lives*, the total collection of essays only mention diabetes five times, though it is mostly within the context of a larger list. In one instance, they clarify the merits of the project because people are living longer with “all kinds of mobility disabilities, spinal cord injuries, premature babies, those with diabetes, those with heart problems, those with HIV/AIDS” (5). This is another example of authors grouping diabetes with a broad selection of impairments, and in so doing, do not examine the specific nuances of the lived experience. These emergent conversations in disability studies around chronic illnesses would benefit from a concentrated study on representations of diabetes, an illness which currently impacts 30.3 million people, or 9.4% of the U.S. population (“National Diabetes Statistics Report”).

The fields of intersectional feminism and gender studies also benefit from the research of this project. These fields are invested in the presentation of intersectional stories on stage because this act affirms the value of those stories. When artists make diabetes the subject of art, they introduce it into public discourse, which then has the effect of valuing their experiences and shifting the predominate narratives. This work is important because like the category of “women,” “people with diabetes” is also not a monolithic term or experience. The

stories of “people with diabetes” are also varied, many, and intersectional in their nature. Various stories are needed on stage to add nuance to the public discourse.

One surprising area where this project contributes is the field of health care reform. In this field, the goal is to “control costs and improve quality by increasing access to preventive services, wellness programs and continuous medical care” (Stanhope and Henwood 656). Theatrical performances such as McCauley’s, Tsaplina’s, Grise & Mayorga’s, and Zorn’s decrease stigma and cultivate dialogue in their audiences. When artists ask communities to think about diabetes through creative modalities, they can shift the shame that is attached to it and operates as a barrier to people getting the care they need managing their illness.

### **6.3 Limitations**

There were several limitations on the scope and findings of this research project. The database of dramatic literature that I used, the Chadwyck-Healey Literature Collections, did not provide examples from contemporary musicals and plays. The Collection’s Twentieth-Century Drama database limited me to dramatic literature that was published before 2008, though, from additional research, I discovered plays and musicals written after 2008 that mention diabetes. The plays and artists that I looked at beyond those sources were from word of mouth and e-mail requests through the Literary Managers and Dramaturgs of the Americas (LMDA) listserv. This limitation became more and more evident as examples of diabetes in contemporary musical and plays were revealed from my own casual

viewing of musicals and plays. For example, in the winter of 2018 I saw the musical *Waitress* on Broadway, which contained one line about diabetes and donuts, which had not come up in the Chadwyck-Healey database. I was able to see the CU department's production of the 2009 rock musical *Next to Normal* in which one character tells another, "You have a chronic illness. Like diabetes, or hypertension. If you leave it untreated, it could be catastrophic" (Yorkey and Kitt 84). The mention of diabetes in this musical did not come up in my database searches because of the publication date. I believe that there are many more lines and references to diabetes in plays and musicals published after 2008 that my initial research for this project did not uncover.

Another limitation writing this study and advocating for those with diabetes is that I do not have type 2 diabetes. I believe that there are many experiences about having type 1 diabetes that a general audience is unaware of, and I may be blind to some of the experiences of a person with type 2 diabetes. I confess that even in my frustration experiencing type 1 diabetes as so misunderstood, I have trafficked in stigmatizing type 2. I have separated myself from "them" as people worthy of blame, and it was not until I undertook this project that I examined my own biases, assumptions, and misunderstandings about people with type 2 diabetes.

One final limitation to consider was access to performances. Theater and solo performance work are ephemeral, and I was only about to write about shows when I had material evidence of the performance. I primarily worked with scripts, video recordings, and viewings of productions, which means I was unable to write about

pieces that I was unable to access a script, recording, or performance. For example, I was aware of James Luna's 1996 solo performance piece "In My Dreams: A Surreal, Post-Indian, Subterranean Blues Experience" as it was analyzed in Jane Blocker's book *Seeing Witness: Visuality and the Ethics of Testimony*. However, I was unable to get a video or script of the performance and thus I was unable to include it in this study.

#### **6.4 Areas for Future Study**

After this study concludes, there are several venues for me to continue investigating how artists can acknowledge the daily, lived experience of people with diabetes through performance. In a future research project, I would like to engage more performance studies scholars such as Peggy Phelan's work on the unmarked and Butler's work on performativity to examine the intersection of social media and self-representation. These platforms allow people with diabetes to create community and self-represent on a regular basis, though often they are choosing to mark and perform their non-visible illness. I would like to conduct a study of the performativity of people with diabetes as they utilize visual image and language in public, digital spaces.

Secondly, one model that I looked at during this work was the Chronic Care Model (CCM) as a method of care for people with chronic illnesses. This model suggests community interventions and social connection as a part of wellness and health for people with chronic illness. In this project I was not able to do a systemic



study of the effectiveness of theater about diabetes for communities. An extension of this research would be to conduct surveys and interviews after performances that aim to create a dialogue about diabetes in a community. In that way, I could learn more about how people respond to this form of representation.

Lastly, I am excited about the possibilities of artists with disabilities engaging with campuses where biology students, medical students, medical ethics are discussing disease from the perspective of medical model. Marina Tsaplina's work and the health humanities are already working extensively with medical students to incorporate the arts and bring about a more full, whole, and human understanding of illness. Pre-med programs are inviting more arts and humanities experiences into the education of these future medical practitioners. I would like to conduct research in order to understand how live performance that represents the complex embodiment of diabetes might change the biases in these medical students.

## 6.5 Conclusion

“Becoming disabled means moving from isolation to community,  
from ignorance to knowledge about who we are, from exclusion to access,  
and from shame to pride.”

- Rosemarie Garland-Thomson, “Becoming Disabled”

As I complete this project, I cannot help but think of Georgina Kleege. As a scholar of visual studies, Kleege wrote in her book *Sight Unseen* of the difference between “medical low vision and blindness as a cultural identity by observing that,

‘Writing this book made me blind,’ a process she calls gaining blindness rather than losing sight.” (Garland-Thomson, “Becoming Disabled” 7). Can I say that writing this dissertation made me diabetic? By which I mean, embarking on this project has changed me, my relationship to my diabetes, and my relationship to the social world that shapes the experience of diabetes through its rhetoric about it. I have gained a sense of cultural identity and participation in a community that is much more diverse, wise and complicated than I knew of through my own isolated lifetime with type 1 diabetes. Rosemarie Garland-Thomson calls this type of transformation one of disability consciousness (“Becoming Disabled” 7). In terms of my own diabetic consciousness, I have spent much of my lifetime passing for able-bodied and wrestling with non-visible impairments that make me feel at times like a fraud and at others an imposition. This project has revealed more clearly than ever before that “disabled people who pass for able-bodied are neither cowards, cheats, nor con artists but skillful interpreters of the world from whom we all might learn” (Siebers, “Disability and the Theory of Complex Embodiment” 324). I have learned much from the artists and communities who expressed their experiences through theater.

Garland-Thomson argues that a disability consciousness “demands learning how to live effectively as a person with disabilities, not just living as a disabled person trying to become nondisabled” (“Becoming Disabled” 9). For me, this means advocating for new representations of diabetes in the theater instead of remaining quiet and frustrated as the art form I love perpetuates unjust and inaccurate stereotypes about diabetes. The goal that Garland-Thomson outlined for people with

disabilities to develop a sense of consciousness and pride that allows them to advocate for themselves also “demands the awareness and cooperation of others who don’t experience these challenges” (“Becoming Disabled 9). This observation is striking to me when so often as I described this project to a casual inquirer, I was told that the topic was incredibly narrow and that a non-diabetic person is not really thinking about diabetes that often. While that may be true, I agree with Garland-Thomson that the awareness and cooperation of non-diabetic people must increase as systemic injustices and stigma harm their friends, family, and perhaps even themselves at a later point in time.

I have certainly gained new compassion for the complexity of type 2 diabetes, as well as the pervasiveness of damaging stereotypes about it in U.S. culture. I have a new appreciation for the stakes and the historical inequities that have created the situation people with diabetes find themselves burdened by. Theater has a role to play shifting ideology about diabetes in the U.S. This stigma and shame result in poor diabetes management, and the results of poorly managed chronic conditions harm U.S. society at large (Stanhope and Henwood 656). If U.S. society could see people with diabetes improve their management, it would mean:

fewer medical costs, lower rates of complications, and greatly reduced mortality as a result of the disease. It has been noted that a reduction of just 10% in the average blood glucose levels of all diabetics would result in a 40% decrease in the rate of diabetic complications and associated health care costs. (Black 546)

Black cautions her reader though that many of the changes for better diabetes management are not individual ones, but systemic shifts based in the implementation of better clinical practices (546). Black argues for the role clinical practice can play in attaining these benefits at the institutional level, but I believe we must also engage the arts to shift U.S. ideology and increase understanding and compassion for those living with diabetes.

This project recognizes that theater can play a role in achieving these benefits in three main ways. First, theater can engage audiences in a meaningful dialogue. Second, theater can educate audiences beyond these stereotypes. Third, theater can humanize the incredibly common and complex chronic illness that is diabetes. I invite you, reader, to join me committing to this work and this group of people. In so doing, we may all become more connected and see more justice in our communities and go further along the path of restoration and wholeness.

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## APPENDIX A

*E-mail Interview with Ken Weitzman*  
*Conducted by Bianca Frazer*  
*July 25<sup>th</sup>, 2018*

**Interviewer:** How did you come about to writing this play? I read that it is was inspired by true events, and I am curious if there was any particular inspiration behind the character of Sid?

**Weitzman:** The play is indeed inspired by a true story – two men both claiming to have caught Barry Bonds single-season record breaking home run. The previous record-breaking home run (hit by Mark McGwire) sold for 3 million at auction. The two men ended up in a lawsuit and the play is about that, about their respective lives and families, and about the dual-edge of American optimism.

In terms of Sid: dramaturgically, Sid is there as a foil to Gary. Gary lives in the lottery economy world. The dot com in which any moment one might strike it rich. (The play takes place in 2001 – in the dotcom bubble and burst). Sid thinks Gary's strike-it-rich attempts are nonsense. Sid lived his life with a steady job, saved little by little, bought a modest house, etc. In terms of his diabetes, it was important Sid have some needs and vulnerabilities and that despite his disdain of Gary, he still needs him. The idea for Sid's burns came from my Grandfather who actually did suffer an accident in a hotel shower, in which the hot water came on suddenly - he slipped and fell, and over 70% of his body was burned. He nearly didn't survive. It was a hotel not too far from Woodstock, in fact, right around the time of Woodstock. It was difficult for the ambulance to make its way to him which didn't help matters. The choice of the shower accident relates to Gary and Sid's competing world views as well. Really, the hotel should have had safeguards – a rail, a temperature gauge, etc. So Sid really could have sued, except that Sid disdains the litigious society, finds it nonsense and belonging to the world of Gary in which people try to game the system instead of work hard and save. Later Sid admits he really had a right to sue and probably should have. Once I made the choice of the shower accident, I discovered one of the results of that kind of burn in the development of diabetes. This added complications to Sid's character and the relationship with his son. It made sense to give Sid a sweet tooth and be a danger to himself. It allowed a character contradiction, something less disciplined about Sid. Gary knows this and shops for healthy food tailored to Sid's diabetes which makes Sid crazy and makes him feel like he's not in control. Ultimately a major plot point comes when Sid binges on red vines and nearly sends himself into a coma. I should mention, my

grandmother had diabetes and as she got older slowly lost pieces of herself – her toes turned gangrenous and some were amputated. Eventually she lost both legs below the knee. The fear of that, of what could be coming also haunts Sid, though he denies it. My grandmother had a hell of a sweet tooth too.

“Stress-induced diabetes, with hyperglycemia and IR, during acute hospitalization is a hallmark of severely burned patients” NIH

**Interviewer:** What drew you to using the subject of diabetes on stage?

**Weitzman:** Hopefully the above answers this question. I didn’t start with it but it was rich material once I engaged with it.

**Interviewer:** Did you do any research in your writing about diabetes in this play?

**Weitzman:** I did a lot of research. Of course, it’s been a while and I don’t remember all of it but for anything I put in a play it’s incumbent on me to make sure I’m accurate. I read, spoke to people, delved back into my grandmother’s self care or lack thereof as related to her diabetes.

**Interviewer:** Can you talk about any conversations that were had with directors or actors about dealing with this subject, either in tone or staging?

**Weitzman:** Often the conversations I want to have is for the actors/director not to make assumptions. They do need to educate themselves (if they haven’t) but that no two cases, no two people are the same. What does it mean for *this* character to have diabetes, for this character not to take care of himself the way he should, etc. The character certainly has blindspots and a certain amount of magical thinking when it comes to his condition, that he won’t suffer the consequences of his actions. The burns and the resulting diabetes was of interest to the actor – how that happens, what it is like to suddenly be faced with that diagnosis, what should he do to take care of himself that he doesn’t, etc. etc. So yes, the actor wanted as much information as possible so he could make character choices that fit the truth, but from the perspective of this particular man. He was very interested, as well, in the physical life of the character, particularly when he binges and almost puts himself into a coma. What does that look like? What happens physically? How does he portray that onstage?

## APPENDIX B

*Telephone Interview with Marina Tsaplina  
Conducted by Bianca Frazer  
September 27<sup>th</sup>, 2018*

**Interviewer:** Hi is this Marina?

**Tsaplina:** This is.

**Interviewer:** Hi, how are you doing?

**Tsaplina:** I am well, how are you?

**Interviewer:** I am well. Thank you so much for taking the time to chat with me today. Congrats on all your recent work in Canada. Are you, you're back in New York for awhile?

**Tsaplina:** Oh, I am. I am. I'm back for... I have to take off to Texas next week but um... I am here now and enjoying actually some bright sunshine. It is a beautiful day, um, maybe a little bit too beautiful for the end of September, but [laughter], um, yea. I'm kinda happy for a breather for a little bit. How about you? Have you had a chance to travel or have you been in Colorado?

**Interviewer:** I, I have been in Colorado, most of the summer I have been trying to write this dissertation, and.

**Tsaplina:** Yes! [laughter]

**Interviewer:** That has been so exciting, because I am so delighted to be writing about you, and your work with the Invisible Elephant Project. I'm so grateful you shared the video and the script. That was all so, so helpful.

**Tsaplina:** Oh I'm glad to hear that because it's always, I think about the nature of writing and how do you, how do you have enough context to frame something, you know? Um.. I always tend to air on the side of more context than less [laughter].

**Interviewer:** Right, I care about that so much. Representing something as faithfully, um, as I can which is why I am so glad that you would chat with me today. Do you mind if I record our conversation so I can recall all the details?

**Tsaplina:** Absolutely, absolutely fine.

**Interviewer:** Thank you so much. Uh, this is for my records, and something else I wanted to ask, uh, your title. So I know I see in your email that you are an “Artist. Founder. Patient Advocate. Associate at the Trent Center at Duke University, and uh, a Kline Scholar at Penn State, and the Founder of The BETES Organization. Is there anything else that you want me to include in how I identify you in the project?

**Tsaplina:** It’s quite a lengthy identification once you use all of it. I think a shorthand is I’m an interdisciplinary performing artist and a scholar in the medical / health humanities.

**Interviewer:** That is perfect. That [laughter] that works just great.

**Tsaplina:** [laughter].A little bit less of a mouthful.

**Interviewer:** You are so accomplished, its which amazing thing to choose from, but that is a good shorthand the interdisciplinary artist. So the questions that I wanted to ask you, um, hopefully I believe I sent you them but if its ok hopefully I can just ask you them and if anything is unclear I can re-frame it or if you don’t want to answer anything that is totally, fine with me, um, so would you mind, the first question I that I had was just about your story, and your training. When did you get into performance, and if you’re willing to talk about when you got diagnosed with diabetes, and how, like, when did those two things comes together?

**Tsaplina:** Sure. And just to make sure can you hear me ok because I have you on speakerphone.

**Interviewer:** Yeah, this is great. I can hear you, perfectly.

**Tsaplina:** Ok.

**Interviewer:** Um, so I uh I started um I realized I was a performed after I was in school for animation. Uh film animation I love working in stop motion animation and I just wasn’t, I wasn’t happy being alone in a room and I went to the school library and looked up puppetry books and found theater puppetry books and puppetry was referred to stage puppetry was referred to animation and I said oh gosh maybe I am just in the wrong kind of animation and so that was in my, how old was I think I was twenty three, twenty four um and I after that I, I moved to do some programs kind of picking up I did a semester at the university of Connecticut which has a puppetry Master’s Program and then I gathered grants to do puppetry in Berlin for six months



um and then I came back to the United States and looking for theatrical training and specifically physical theater, uh, that places the body first. In it's approach to the training of the actor and uh so what I found was the Margolis Method for physical actor training. And then I spent years, years, going to study with Kerry Margolis who is a master teacher so that really the um, that's one of the biggest foundation blocks of my performance training. Following that, I've done Linklater voice work, object theater workshops in Paris, and then I just recently there is also, there's a prominent theater company called Sandglass, uh, Puppetry company called Sandglass Theater and they have a puppetry training intensive. So I realize this a very through answer but, um, it's kinda of it all comes together um because there are all placing primacy upon the body. So, yes and a little bit of clown. Pachinko clown Richard Pachinko clown [laughter] yeah.

**Interviewer:** I love all those details that I...

**Tsaplina:** Sorry, and I the second half of your question I was diagnosed when I was two years old, but I only, when I realized that I was moving away from film making and animation into theater I was never interested in really pursuing commercial theater I was also interested in bringing the power of live performance into a place within our society that it can serve and I found that living in my own backyard when I realized that I had been taught a mechanical relationship to my diabetes and that, that's not the reality that I was living with my whole life. Um, and that theater is the art of staging relationship and art overall is the pursuit of, of questioning what is, what is real. And what is the experience of being alive, so, I brought those two together and that's really opened up the path that I have been on for the past I think five and a half years.

**Interviewer:** That, and so, that's just a interesting, just to clarify when you said that "mechanical" relationship to diabetes, um, could you say more about what you mean with that word?

**Tsaplina:** Certainly, so um, and this is diving directly into the scholarship and the work of the health humanities, um, but so you know the medical model approach is a largely approaches the body from a mechanical, um, machine like perspective. Um thinking that you can kind of break apart the human body into all the parts, fix a little part of it, um, and sort of just put it back and there you have it, you're done. So, what that translated as in terms of the relationship that many of us are being taught to our health and chronic health conditions is that in diabetes ok well so now here's your uh blood sugar kit here's your insulin um that's the number this is the number you do in return, and that's it, that's, there you are. Um, and uh so as if it is a calculator that can be programmed and once you get the right programing

um the story is over. Um, and uh so it teaches a biological materiality um, and rightfully so it must approach health and illness in this way, um, but I was interested in understanding the way that illness affects the whole human being. The questions that illness brings to the surface of, of a life. And of my life and the lives of others, and also what is the beauty within it? So the kind of word I am playing around with now is “poetic materiality,” and how art and theater and puppetry helps to manifest that in the experience of illness.

**Interviewer:** Thank you so much for sharing all that. I am, for me, I am like processing this with two minds. Like the scholar mind and then the personal like, yes that is my experience with diabetes. That’s so interesting to think about the kinda mechanical perspective versus the you said the “poetic materiality,” or materiality, I like that so much. Um. So, with the *Invisible Elephant Project* specifically, could you talk about how that project came about. How did that get started?

**Tsaplina:** Sure, so that was the second exploration for me about my own personal journey with diabetes. The second artistic piece. Which also for me as an artist and a human it means I could go further and I still what it what my question was how do I go inside my own fear of losing a physical part of myself to my diabetes. By doing that on stage help others through that process too and through that journey as well. And also to make manifest the sort of presence of this unspoken, this unspoken imprint of the possibility of loss that chronic illness carries. That is always the artistic question. What would happen if I went inside you know one of my own worst nightmares. And then also what we did was we gathered responses from the online diabetes patient community and gathered close to a thousand patent responses from type 1 and people with type 2 diabetes. And asking them about their experience and perception of the topic of complications, which also has a lot of taboo and blame around it. Um, and what we got back was an overwhelming response and just how present and prevalent the emotional, intellectual, and spiritual impact of the possibility of the presence of complications are, and we used a little bit of that in the piece though I think the video that I sent you was largely, largely what we wrote up by the [unclear] of that large response pool. So I’m sure certainly somehow incorporated into it, but not directly, but I based it, I was, the reason that we did that we wanted to know ok like I knew what my imaginative face was, and my perception was, but I wanted to, I wanted to get uh a broader sense of how others, how this is for others and after the survey we also did full interviews with twenty-six people, about 45 mins to an hour long with twenty-six individuals from across the country, and actually one woman from Israel. So, again to understand the, as much as we could, the full dynamic and perception of this topic, or of this experience.

**Interviewer:** Ok, so I, I just want to double check I am making the right connection that the elephant is the complications, thinking about having complications. It's not necessarily the burden or like the fear of speaking about to others about it? The elephant is the, that the "elephant" in the *Invisible Elephant Project* is just the awareness and presence that complications might happen, and that is nightmarish.

**Tsaplina:** I don't think art, art is not messaging or dogma. Never in the piece does it say what the elephant is. And the elephant is whatever, whatever you perceive it to be. Um, I don't think it's, it's for me for a piece of art to tell anyone what the elephant is for them. It just helps them realize what it is for them. Uh, and to, to simply help to say something that they didn't want to say, or they couldn't say. Um, and yet that's the single task of art, but I certainly won't give a definition of what the elephant is or isn't.

**Interviewer:** Yea I, I totally appreciate that. That's very limiting to say, "it is this!" when it can be many things.

**Tsaplina:** Because I think the question that is really interesting is the question of what *is* it. That's a perpetual asking of that. You know, and, and, and going deeper and deeper into that question without ever putting a definitive frame and closing the questions and making it something truly known.

**Interviewer:** Hmm re-asking the question. I like that. You mentioned asking people to think about what it is that they didn't want to know and that was kinda of like the third questions that I had was about the video you sent me of the April 3<sup>rd</sup> performance, the video ends when you are beginning to lead the talkback after you've give the writing prompt. And I was wondering if you could characterize how that went or what people shared when they responded to uh the prompt what they didn't want to know.

**Tsaplina:** Sure. So again just for a little bit of context, so the way that we developed this programming is that there is this theater show followed always by a workshop, to basically continue opening up uh the questions and the experiences that the theatrical experience opened the room to. We typically open it with a writing prompt and that was actually the first, that was the first writing prompt for the *Invisible Elephant* that I was satisfied with. I tried many different ones and uh, I don't think the prompt was, the writing prompt was quite correct until this one. So, if you want I can actually send you the responses because we usually ask for people to leave their index cards behind following the show if they choose to for their own future publication and actually current publication so people who elect to write to leave their index cards on what they wrote their responses, so I think my

sending that to you might just be easier I have to admit I don't fully remember because it was back in April...

**Interviewer:** Right [laughter] that would be wonderful if you wouldn't mind sharing that and I can look at, I don't have to have names attached to any of that or...

**Tsaplina:** It's all anonymous. There are no identifiers that we can know, um and there's also it kind of references back to your questions about you know about what is, what is the elephant, because as you see in the response, the prompt is a response that performance allows people to hone in a certain on a certain piece of their, of their own response. You see as many elephants in people's writing as, as people in the room you know? So, yea, I would be totally happy to share that it is all anonymous.

**Interviewer:** Well, that would be wonderful if you don't mind sharing that with me. I know when I watched the video the first time, I took some time to respond and write to the prompt after seeing the performance and it was, so interesting to be alone at my own desk and to just free writing for quite some time on what I don't want to know.

**Tsaplina:** Oh that's so cool!

**Interviewer:** Oh my gosh

**Tsaplina:** I love that!

**Interviewer:** What?

**Tsaplina:** That you did that! That's awesome.

**Interviewer:** I had to participate as much as everyone else and it was just so interesting because after doing the writing exercise I wanted to connect and go in deeper thinking about my own experience and thinking about the stories that were coming to mind for me about what I didn't want to know I would've, I can just totally see the value of being in a room with other people and then kind of connecting after that writing experience. Um, I should send that to you in exchange.

**Tsaplina:** Oh I just absolutely love that you did that just even through watching it that makes me really happy. I'm so glad that it served you too.

**Interviewer:** Yes, it, it absolutely did. Those are the only questions I had about the

project. Is there anything else that, um, you feel I should know about this project or the work is there anything you want to clarify or add?

**Tsaplina:** Well I don't think so, but about the *Invisible Elephant*

Specifically, I yea that is it actually, it's, though I have, the work was created around diabetes, it far transcends that. It transcends the [use] of spaces [unclear] its really addressing the space of loss. Or the possibility of loss and so at least in part and letting go. I guess to say that it's only about diabetes is not quite it. It's sort of pointing the light beam towards, through diabetes we get to many other things, you know, and again you will see that in people's responses in their writing, uh, which again is I think the power of artistic work, artistic inquiry. Um, yea.

**Interviewer:** Well, I appreciate that. I appreciate that invitation to like lift my head and look up a little bit because I am so focused on how theater can communicate about diabetes, and about um, like the lived experience rather than just stereotypes and stigma that gets attached to diabetes and I think that seems like part of how the stigma gets undone is realizing the connection to many other areas and experiences and that's neat that the work invites that.

**Tsaplina:** Yes, absolutely I mean that is absolutely you know its important to be specific and to know where, where, where you are focusing. So I by no means, I am not questioning your thesis, I am, just speaking to the experience of having performed this to a lot of different audiences some of which were diabetes audiences, some were health care provider audiences, some were general audiences that the work translates, you know? So, there is the potential for universality in all of our struggles, while at the same times retaining the specific history of the suffering of a community and that history matters. That that history is not isolated from struggles of other communities.

**Interviewer:** Well I appreciate that so much in both like validating the suffering of The community as you said, and then, always being invited to lift my head and to see connections to other communities, I appreciate that. Well, do you have to when you head out over to Texas?

**Tsaplina:** You might actually be interested in this., I was invited to participate in a focus group on, uh, there's a three-year research project on arts and public health and they are having a focus group gathering artists from across the country who are working towards and within the health sector. Again, to amplify the work and get some funding and change policies and elevate the field. So it's part this national organization for arts and health. They have a conference this is their second conference and so the focus group is within

that, is within that, but if you look at the, there is an arts and medicine program at the University of Florida. They are the leads of the project. So [unclear] there. If it interests you. And they have a bunch of good research and publication on the impact of arts on public health. And arts and health and stuff so it's a good resource if that's one of the channels you are looking at for your thesis.

**Interviewer:** Oh I appreciate that so much and this past summer I was at this yearly, annual conference ATHE, the Association for Theater in Higher Education and the theme was "revolution" and on this panel of how, what is an area of revolution that you think this field is headed in, and someone brought up the medical humanities and the connection with arts and public health and how that was what their work was and it was really interesting to see in this really like import--, well not important, but like this major conference on this public stage scholars that I see as the top of the field say this is an important direction that we are seeing revolution. I just, and I thought of you and I thought of how awesome that was.

**Tsaplina:** It's amazing to hear that um its exiting that that's being picked up because I don't even think that was the case five years ago. So, yay! [laughter] we are pushing a boulder and its starting to roll!

**Interviewer:** It's happening! Well thank you so much for taking the time I imagine you are just so busy and traveling and doing so much. I am just so grateful that you would chat with me.

**Tsaplina:** No and thank you for just thank you for the work you are doing I am really as I said before and I'll say it again that if there is any support that I can ever provide as you pursue the noble task of your dissertation just reach out. Any resources that I might be able to point you to or anything just know that I am here, and I think what you are doing is really important.

**Interviewer:** Well I absolutely think that of you as well. I love your um artistic practice and the impact you are having is so amazing the impact report from your time at Duke, that was incredible, you were with medical, or pre-med, medical students, right?

**Tsaplina:** Pre-med. Pre-med. The culture of medicine is so toxic we realize we have to start in pre-med. [laughter]

**Interviewer:** Yes! What an important intervention.

**Tsaplina:** Yea, yeah and Tess knows a lot about this pre-health phase, because you know he health humanities are growing in that space.

**Interviewer:** Yes that I got the impression of who she works with and who she teaches are like, medical students and how important to like being in literature and the arts and looking at films and working with medical students is so, yea I need to reconnect with Tess I haven't chatted with her in a while but I'd like to reach out to her soon.

**Tsaplina:** Yeah, for sure, for sure she is a rock star and you know if you would end up being interesting in publishing, I don't know a piece or a paper through that so much impossible to thin about even to test some ideas, I don't know if you are allowed to take a chunk of your dissertation and publish it in the medical humanities journal of what you're finding or early findings from the research that you're doing I would think there would be interest in that so again she is sort of the one of the rock stars of the health humanities field. Keep her close [laughter] She's fabulous so!

**Interviewer:** Will do, and she's in Colorado so it's such an incredible resource.

**Tsaplina:** Yeah, absolutely, um absolutely. Ok my dear well if you ever come to New York, give a hoot.

**Interviewer:** Yes I absolutely will. I hope you have a great rest of your day thanks for chatting with me I will be in touch over e-mail with any other follow-up questions or um yea requests for resource. I always love being pointed in directions and articles I appreciate it so much.

**Tsaplina:** Yeah you bet and I am gonna, I will, send you some the writing right now before I forget.

**Interviewer:** Yes, thank you so much

**Tsaplina:** Be well, Bianca.

**Interviewer:** Bye Marina. I will talk to you later.

**Tsaplina:** Bye!