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"DIABETES IS NOT A POOR PERSON'S AILMENT": HOW INDIVIDUALS ON THE SOUTH SIDE OF CHICAGO NEGOTIATE THE DIABETES CARE EXPERIENCE

by

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Introduction:

According to recent data published by the Centers for Disease Control and Prevention (2018), an estimated 30.3 million people in the United States had diabetes, both diagnosed and undiagnosed. Yet, the rapidly increasing burden of diabetes does not fall evenly among all groups: in the same report, the CDC noted significant differences in the age-adjusted incidence of diabetes along racial and socioeconomic lines. Indeed, non-Hispanic blacks and people of Hispanic origin had much higher incidence rates compared to non-Hispanic whites (12.7%, 12.1%, and 7.4%, respectively), and age-adjusted incidence was about twice as high for individuals with less than a high-school education in relation to individuals with greater than a high school education (The Centers for Disease Control and Prevention 2018). In addition, many studies have documented that the severity and management of diabetes are also patterned by race and class (Cowie and Eberhardt 1995; Diamant et al. 2003; Kington and Smith 1997; Phelan et al. 2004; Tang, Chen, and Krewski 2003). When considering a chronic, management-focused disease like diabetes, it is not only incidence and pure numbers of individuals diagnosed with diabetes, but also its severity and management, that matter in understanding the impact of diabetes.

Medical sociologists have long been interested in socioeconomic inequality and its role in understanding the development of health inequalities. Link and Phelan's (1995) introduction of the idea of socioeconomic status as a potential "fundamental cause" of health disparities provided a novel way of understanding how a broad characteristic can act via multiple mechanisms to create a durable, multi-faceted relationship between socioeconomic status and health. Continued research on chronic disease, and diabetes in particular, has continued to support the durable, multi-faceted relationship between diabetes and lower socioeconomic status.

Understandings of diabetes as a chronic disease controlled by behavioral interventions emphasize the importance of patient education and maintaining management routines, but highlight the continued external struggles that lower socioeconomic status individuals face with diabetes management (Queen et al. 2017; Spruijt-Metz et al. 2014; Weaver et al. 2014). Medical research shows the value of strong patient-provider interactions and exposure to medical information resources for diabetics and other individuals with chronic diseases, but there remains a gap for understanding how and why some individuals are able to effectively negotiate their healthcare and mobilize access to diabetes care resources outside of the routine clinic visit.

In this study, I leverage the sociological research on cultural health capital (Shim 2010) and social networks (Small 2006) to elucidate the mechanisms impacting how individuals with diabetes deal with their illness and navigate access to additional diabetes care resources. Drawing from ethnographic data collected during fieldwork examining diabetes healthcare resources and interviews with individuals living with diabetes on the South Side of Chicago, I examine how access to quality healthcare interacts with the daily lives and illness experiences of individuals with diabetes. Qualitative methods allow me to delve deeply into the individual experiences of respondents and identify the mechanisms by which diabetes care is negotiated. I argue that it is important to consider fundamental causes of health inequality beyond socioeconomic status, as I reveal how access to reliable and high-quality healthcare plays a fundamental role in health outcomes by impacting individuals' ability to seek and access quality care and resources through multiple mechanisms. I specifically examine these mechanisms, as I show how access to healthcare and continuity of care influences healthcare outcomes through insurance status, trust in the doctor-patient relationship, sustainable medication and management routines, and access to healthcare information networks. Ultimately, I argue that access to health insurance is

fundamental, structuring individuals' ability to develop and maintain continuous medical care and strong relationships with their doctors, impacting individuals' access to important medications and healthcare resources, ability to manage their illnesses, and overall health.

Theoretical Framework:

"Fundamental Causes" of Health Inequality

Many studies have examined the role of socioeconomic status as a causal factor in creating and maintaining health disparities. Scholars across the disciplines of sociology, public health, epidemiology, and medicine have looked at the effects of socioeconomic status on mortality, cumulative social disadvantage in creating health disparities, discussed how neighborhood socioeconomic disadvantage can structure access to healthcare, and even asserted socioeconomic status as a source of such significant resources that it can be seen as a "fundamental cause" of health outcomes (Fiscella and Sanders 2016; Kirby and Kaneda 2005; Link and Phelan 1995; Sudano and Baker 2006). When introducing the concept of fundamental cause theory, Link and Phelan (1995) question the epidemiological focus on individual risk factors as a cause of disease and seek to explicate the value of examining social factors like socioeconomic status and social support as "fundamental causes" of disease that work through multiple mechanisms. Link and Phelan argue that "a fundamental cause involves access to resources . . . thus, even if one effectively modifies intervening mechanisms or eradicates some diseases, an association between a fundamental cause and disease will reemerge" (81). For Link and Phelan, social conditions are not only "proxies" for true causes or starting points to direct to more proximal risk factors; social conditions themselves structure connections to "resources that help individuals avoid diseases and their consequences" (81).

In subsequent studies, Link and Phelan have continued to reflect on the importance of considering socioeconomic status as a fundamental cause of health disparities. Indeed, according to fundamental cause theory, socioeconomic status directly affects individuals' ability to access particular resources like knowledge, money, power, prestige, and beneficial social connections that help them obtain effective medical treatment. As Phelan, Link, and Tehranifar (2010) discuss, because these resources can be used across different contexts, they can be considered "flexible resources" (S29). In a quantitative analysis, Phelan et al. (2004) noted that socioeconomic status was less strongly associated with mortality for less preventable causes of death than for more preventable causes of death. The authors note that fundamental social conditions, like socioeconomic status, "directly shape individual health behaviors by influencing whether people know about, have access to, can afford, and are motivated to engage in health-enhancing behaviors" (267).

Research highlighting fundamental cause theory has continued to explicate the multiple mechanisms behind which socioeconomic status acts as a fundamental cause of health inequality. Lutfey and Freese's (2005) comparative ethnographic study of the routine clinic visit for patients with diabetes highlighted multiple ways in which differences in socioeconomic status impacted the healthcare experiences of diabetic patients. Lutfey and Freese's observations showed marked disparities in the healthcare experiences among lower socioeconomic status and higher socioeconomic status diabetes patients, noting differences in continuity of care, in-clinic educational resources, negative impacts on proposed diabetes treatments and management routines, and healthcare providers' biases. Fundamental cause theory suggests that socioeconomic status may be acting on multiple planes to structure disparate outcomes and healthcare experiences.

Olafsdottir's (2007) comparative study of health disparities in the United States and Iceland supported the concept of socioeconomic status as a fundamental cause of health, but complicated the perspective by showing how welfare state interventions in Iceland created a weaker correlation between health and socioeconomic status compared to that of the United States. According to Olafsdottir, as compared to the United States, with its weaker structure of a publicly-funded healthcare safety net, Iceland's comparatively stronger and more supportive welfare state interventions served to ameliorate some of the negative effects of low socioeconomic status on health. Olafsdottir's incorporation of the welfare state into fundamental cause theory provides an interesting complication of the ways in which socioeconomic status can impact individual health, suggesting not only the importance of socioeconomic status in healthcare outcomes, but also the comparatively important role of healthcare coverage and insurance access in impacting healthcare outcomes. In order to better understand how and why insurance coverage can serve to maintain and reproduce healthcare inequalities in the United States, we must look closer at its healthcare system.

The United States' healthcare safety net is not very comprehensive. Even among the select few individuals who are able to access the United States' limited public healthcare resources, underfunding and overcrowding are problems endemic to the system (Campbell 2014). Over the last fifty years, the United States has focused much of its healthcare system towards encouraging a private, employer-funded healthcare system rather than expanding its publicly-funded system, with negative consequences on health for many Americans (Hoffman 2013). Indeed, many studies highlight the importance of access to private healthcare insurance for improving individuals' healthcare utilization, access to continuity of care, and trust in their healthcare providers (Baker et al. 2001; Mewes and Giordano 2017).

By examining the framework of fundamental causality on an individual and institutional level, we can recognize that socioeconomic status works in many ways throughout individuals' lives to structure a wide variety of healthcare experiences, yet we can also begin to see that there may also be other useful explanatory factors. Olafsdottir's (2007) study highlights the importance of looking at health insurance coverage as another important mediator of health disparities, revealing that the framework of fundamental causality can and should be applied to different characteristics to best understand how health disparities are created and reproduced across different contexts. Looking forward, we should apply the lessons learned from examining socioeconomic status as a "fundamental cause" of health to examine how characteristics like healthcare access and continuity of care can also function via multiple mechanisms to produce different kinds of health inequality.

The Case of Diabetes

Medical, public health, epidemiological, and sociological research has followed similar lines when considering diabetes, affirming the importance of considering socioeconomic status while studying diabetes incidence and management. For many years, international, national and state-level studies have correlated socioeconomic status with diabetes incidence, functional status, and management (Cowie and Eberhardt 1995; Diamant et al. 2003; Phelan et al. 2004; Tang, Chen, and Krewski 2003). Kington and Smith (1997) found that socioeconomic status can essentially explain racial and ethnic differences in functional status and management of chronic diseases, including diabetes. Socioeconomic inequality, measured through poverty income ratio, is more strongly associated with type 2 diabetes than with education or occupational status (Robbins et al. 2001). Others note that many different facets of socioeconomic position and the health of diabetic individuals, including access to care, processes of care, healthcare systems, and

communities and neighborhoods, can have a broad influence on the health disparities witnessed with diabetes outcomes (Brown et al. 2004). Lutfey and Freese's (2005) comparative ethnographic study of diabetes clinics highlighted the many mechanisms behind which socioeconomic status worked as a fundamental cause of disparate healthcare outcomes among diabetics, including clinical structures and resources, provider bias, and patient ability. Cox et al. (2007) discuss the association of the geographical distribution of diabetes along lines of socioeconomic status, describing higher diabetes incidence in areas surrounded by more deprived areas and lower diabetes incidence in areas surrounded by less deprived areas, suggesting a kind of "pull-up, pull-down" hypothesis in the geographic effects of socioeconomic status on health.

Epidemiological and medical research on the disease process of type 2 diabetes reveals that its incidence and management can often be linked to lifestyle behaviors like dietary intake, exercise, sedentariness, and stress (Spruijt-Metz et al. 2014). Yet, the capability to adapt lifestyle behaviors to become more concordant with diabetes disease management is yet again linked to socioeconomic status and available resources. Queen et al. (2017) noted that young adults with Type 1 diabetes who lived in more disordered neighborhoods were at higher risk for poorer glycemic control. Individuals with low socioeconomic status and less access to economic, social, and cultural resources experience greater barriers and less ability to modify lifestyle behaviors and pursue healthy diets to manage diabetes, whereas individuals with higher socioeconomic are were able to marshal the most resources to maintain a healthy diet (Weaver et al. 2014).

In the United States, structural barriers that accompany low socioeconomic status, like the geographical segregation of urban neighborhoods and the inequitable distribution of health centers, mean that millions of Americans are left unable to access quality and affordable healthcare services. Given that access to quality and consistent healthcare services are crucial in

managing diabetes and its many complications, low socioeconomic status can have particularly serious effects on individuals with diabetes. When Rhee et al. (2005) examined the impact of healthcare access on glycemic control in a low-income, urban, African-American population, the authors observed that the most important factors associated with diabetes management, measured through HbA1c levels, were related to healthcare access. The strongest relationships to higher HbA1c levels were seen among individuals who reported a history of having trouble obtaining medical services, defined as individuals who did not have a regular source of care, using primarily an acute care facility or no regular care facility (Rhee et al. 2005). Heisler et al. (2003) noted that better patient self-management was significantly associated with the receipt of diabetes services, leading to lower HbA1c levels. Patients who experienced higher standards of care and increased monitoring of health factors were much more likely to have better-controlled metabolic outcomes, including blood glucose levels and LDL-C < 130 mg/dL (Persell et al. 2004). The research clearly shows that healthcare access plays an important role in mediating the severity of diabetes.

Yet, it is not enough to understand that increased access to healthcare resources improves diabetes outcomes. We must understand how individuals become aware of and access the healthcare resources that may be available to them. Without knowledge of how individuals discover and use healthcare resources, empirical improvements in access to healthcare resources will not matter. Research has shown that a lack of access to healthcare resources has radiating effects on disease management and health outcomes, which has motivated new research programs and policy interventions targeted towards creating new community and health system partnerships in the hopes of reducing disparities (Peek, Cargill, and Huang 2007), but it is also important to consider how access to these new health partnerships is mediated. In pursuit of this

goal, I bridge two different theories of cultural health capital and social network theory to better understand how individuals achieve access to healthcare resources through multiple pathways.

Patient-Provider Interactions and Cultural Health Capital

For many years, patient-provider interactions have been an important research topic for medical sociologists. Indeed, much classic work in medical sociology has emphasized the importance of patient-provider interactions in encouraging utilization of medical services and adherence to medical recommendations and treatment (Freidson 1988; Waitzkin 1991). As time has passed, medical sociologists continue to document the importance of patient-provider interactions. Over the past 50 years, patient-provider relationships have continued to become more pivotal to health outcomes. The doctor's paternalistic, "expert" role has been challenged as patients become increasingly knowledgeable with the rise of the internet, patient-provider communication, and the standardization of healthcare (Boyer and Lutfey 2010). Yet, strong doctor-patient relationships do not emerge for all individuals, leading to significant disparities in perceived quality, patient satisfaction, and medical service provision (Smedley, Stith, and Nelson 2003)

Shim's (2010) theory of cultural health capital (CHC) helps to elucidate some of the mechanisms behind which social inequalities operate in patient-provider interactions and healthcare experiences. Shim's concept of cultural health capital finds its basis in Bourdieu's (1986) theories and notions of cultural capital. According to Bourdieu, capital, as accumulated labor with a social force, can accumulate and distribute in different types and quantities in such a way that it constrains individual possibilities. In particular, Shim focuses on Bourdieu's concept of cultural capital, which identifies cultural practices and products as forms of capital which, in their unequal and difference distribution, link to social stratification and the maintenance of

class-based hierarchies. By modifying the Bourdieusian framework of cultural capital to apply specifically to medical interactions, Shim seeks to adapt cultural capital to the unique field of health care experiences, conceptualizing "cultural health capital" as a "specialized form of cultural capital that can be leveraged in health care contexts to effectively engage with medical providers" (Shim 2010: 3). Shim describes cultural health capital as "the particular repertoire of cultural skills, verbal and nonverbal competencies, and interactional styles that can influence healthcare interactions at a given historical moment" (2). According to Shim, particular characteristics find increased value in clinical interactions and serve as resources that individuals can leverage to build stronger relationships with health care professionals. Cultural health capital, like cultural capital, accumulates as individuals increase their exposure to the cultural context. While continued systematic inequalities in how cultural capital is both amassed and employed for advantage maintain systems of structural inequality in the healthcare system, the ability of individuals to amass cultural health capital through exposure to the medical context suggests an important avenue for understanding how and why some individuals are able to effectively cultivate and marshal cultural health capital.

Social Networks and Resource Access

Shim's (2010) explication of cultural health capital can help elucidate some differences in how individuals respond to and access high-quality medical care and additional diabetes care resources, yet it is important to also realize that not all people are exposed to the conditions necessary to develop the cultural health capital to engage effectively with their medical providers. Due to structural and bureaucratic constraints, some individuals cannot access the clinical setting regularly enough, or comfortably enough, to develop and accumulate cultural health capital. As such, we must look at ways of gaining access to information about healthcare

resources beyond the doctor's office. By examining research on social network theory and health, we can better conceptualize how some individuals manage to negotiate access to external healthcare resources.

Social networks and their relationship to health have long been studied by public health researchers and sociologists. The study of the effects of social networks on health began in the 1970s, as researchers theorized and demonstrated that social networks could affect mortality (Cassel 1976; Cobb 1976). Now, researchers recognize that social networks impact individual and population health through multiple mechanisms, including the provision of social support, social norms and control, social engagement, and access to resources (Berkman and Glass 2000; Smith and Christakis 2008). While social networks do not completely counteract the negative effects of poverty on health and wellbeing, they can have a protective effect on health (Cattell 2001). Social network studies have identified that social relationships can influence external behaviors that can influence positive effects on health, like triggering weight-loss among friends and encouraging individuals to undergo mammography (Gorin et al. 2005; Murabito et al. 2001; Wing and Jeffery 1999). Following from this research, it is important to look at and understand how social relationships may be capable of helping individuals develop healthy habits and techniques for managing their diabetes.

At the same time, not all individuals can gather useful healthcare information and healthy habits from their immediate social networks. In this case, it is useful to conceptualize of access to resources as mediated by intermediaries like "resource brokers" (Small 2006). Small introduces the idea of "resource brokers," defining them as interorganizationally networked neighborhood institutions that serve to connect individuals of lower SES living in poorer neighborhoods with valuable resources, including healthcare resources. While Small focuses on childcare centers as a

kind of resource broker, he also mentions how other forms of neighborhood organizations, like community centers, can similarly function as sites of social interaction where individuals and organizations can exchange valuable resources and information with one another. Resource brokers, as community entities well-connected to valuable information and resources, help to connect individuals to healthcare information networks, especially those who do not have the cultural health capital necessary to negotiate access to healthcare resources on their own. By extending the theory of resource brokers to healthcare information networks, we can conceptualize how individuals, even those without access to other sources of healthcare information, can find out about important external healthcare resources.

Methods:

This thesis is based on an ethnography of diabetes education on the South Side of Chicago. I chose to focus my study specifically on individuals with Type 2 diabetes due to Type 2 diabetes's particular nature as a chronic illness and as a "behavioral" disease, wherein much of the responsibility for disease management is placed on individual behavior modifications. Many studies have proven the value of access to educational resources and diabetes self-management training in improving disease outcomes (Diabetes Prevention Program Research Group 2009; Glasgow and Anderson 1999; Norris, Engelgau, and Narayan 2001; Peek et al. 2007; Persell et al. 2004). At the same time, studies do not address the socioeconomic and cultural factors that influence an individual's ability to access and engage in these resources. I rely on qualitative methods of in-depth interviewing and ethnographic observation in order to better explicate the answers to these questions from an individualized perspective.

I began my study with ethnographic observation at a local weekly farmers market's diabetes education class on the South Side of Chicago complete with a healthy cooking

demonstration, a nutrition-focused educational farmers market tour, and a $7 incentive of market money distributed after the completion of the tour. The market tour, organized by a local university's medical system, was completely free-of-charge and open to the public, regardless of disease status. I chose to observe this educational resource because it was one of only few publicly advertised diabetes care resources on the South Side of Chicago. At the same time, the resource provides only a very particular understanding, analysis, and exposure to diabetes resources on the South Side of Chicago. The location was relatively limited in outreach, primarily serving a small group of 10-15 regularly-attending individuals living in the surrounding neighborhood, many of whom were not even diagnosed with diabetes. Nevertheless, the resource's rhetoric provided a valuable opportunity to observe the messaging provided by outreach opportunities and observe how individuals respond to and understand that messaging.

To complement my understanding of the messaging of diabetes care resources, I conducted in-depth, semi-structured interviews to better understand how individuals interact with the medical establishment, manage their diabetes, and mobilize access to diabetes care resources. Interview data was collected during 15 interviews with 14 individuals who live with diabetes on the South Side of Chicago. Interviews varied in length, from 29 minutes to 106 minutes in length, with the average interview lasting approximately 52 minutes. Informed consent was obtained verbally and with the approval of the institutional review board at the University of Chicago. In order to protect the privacy of respondents, all names of respondents and places mentioned in quotations have been replaced with pseudonyms. While I did not make any specific requirements or restrictions on age, race, or gender during recruitment, all of my respondents were Black men or women over the age of 50 who had been living with Type 2 Diabetes for over 2 years. Given the demographics of the South Side of Chicago on the whole and the fact that

Type 2 Diabetes generally affects an older population, the age and racial characteristics of my sample provide a valuable population of interest for my study.

Table of Respondents:

Respondent	Interview Length	Current Insurance	Regular Healthcare Provider
Andrea	98 minutes	Medicare and Medicaid	Doctor's Office in large healthcare system
Angela	47 minutes	Medicaid	Low-income Federally Qualified Health Center (FQHC)
Renee	37 minutes	Employer-Funded	Doctor's Office in large healthcare system
Alisha	51 minutes	Medicaid	Low-income Federally Qualified Health Center (FQHC)
Diana	68 minutes	Medicare	Medicare-specific primary care clinic
Jerrold	54 minutes	Veteran's Affairs	Veteran's Affairs Clinic
Judy	35 minutes	Uninsured	Low-income Federally Qualified Health Center (FQHC)
Charlene	39 minutes	Medicare, Employer-funded	Doctor's Office in large healthcare system
Rita	52 minutes	Medicare	Solo Practitioner Doctor's Office
Tyrone	29 minutes	Medicare	Medicare-specific primary care clinic
Francine	57 minutes	Medicare	In-home care
Marianne	32 minutes	Medicare	In-home care
Janine	32 minutes	Medicaid	Doctor's Office
George	103 minutes	Medicare	Medicare-specific primary care clinic

I primarily engaged respondents through targeted recruitment efforts focused on diabetes outreach and education resources located on the South Side of Chicago, including the weekly

farmers market tour and a monthly food pantry; however, I also asked participants to pass along flyers and my information to anyone they knew who they thought might be eligible and interested in the study. Four of my fourteen participants were referred to me by others familiar with the study. Given these recruitment efforts, I largely spoke with respondents who had accessed diabetes educational resources. Considering the limited availability of resources on the South Side, I caution that the sample of individuals I spoke with is not a representative sample of all individuals with diabetes living on the South Side of Chicago. Given their exposure to external educational resources, my respondents may have a comparatively different illness experience than individuals who do not access these resources. While this may skew my data towards individuals who are more proactive in their healthcare experience and comparatively better-informed about healthcare resources in the area, it does not prevent me from gaining insight into how individuals mobilize and find access to healthcare resources. Because I am interested in understanding individuals' illness experiences within the context of their access to resources and their relationship to their doctors, I believe that my respondents' exposure to diabetes care resources provides a valuable data source for exploring and answering this question. Ultimately, even given my relatively small sample size and focused recruitment efforts, I found that my interviewees had widely varying healthcare experiences that created meaningful and measurable differences in their networks of available resources and their experiences with the healthcare system and disease maintenance.

Analytic Plan:

Findings emerged from analysis of ethnographic field notes and transcribed interview data. Quick "jottings" of field notes were taken whilst in the field and expanded upon once I returned home, in order to maintain my complete presence whilst in the field and ensure that my

observation did not change the natural workings of the space (Weiss 1995). Interviews were semi-structured, conducted using a basic interview guide focused on understanding participants' experiences with their diabetes, illness management strategies, relationship with doctors, and access and understanding of local community healthcare resources for individuals with diabetes. Interviews were recorded with participant's consent using the iPhone's Voice Memos app, given its high audio quality and less obtrusive nature. Interviews were transcribed by the author using a combination of the online automated transcription service Temi and personal listening and transcription, used to correct mis-transcriptions and add in data about tones and non-verbal communication techniques. The combination of transcription methodologies allowed for increased efficiency in transcription without sacrificing quality of transcription.

To discern patterns in the data, I used the framework of abductive analysis, a combination of inductive and deductive coding schemes, to code my data. Field notes and transcribed interview data were imported into the NVivo 12 qualitative coding software, where I coded my data using the framework of abductive analysis (Timmermans and Tavory 2012). I do not argue that I analyzed my data free from influence of pre-existing theoretical frameworks; instead I argue that the framework of abductive analysis allowed me to build off of pre-existing ideas to find unique, surprising tendencies in the data in order to recognize patterns in how individuals cope with their diabetes experience and access healthcare resources.

Results:

In this section, I will discuss how access to quality and continuous healthcare acts as an important mediating factor in individuals' diabetes experiences. Building upon Link and Phelan's (1995) explication of fundamental causes of health inequality, I introduce healthcare access and continuity of care as a kind of fundamental cause of health outcomes. I look

specifically at the case of individuals living with diabetes on the South Side of Chicago in order to show how access to quality healthcare acts in fundamental ways to impact individuals' ability to effectively manage a chronic disease like diabetes. I will specifically focus on the role that access to healthcare plays in influencing continuity of care and the doctor-patient relationship, developing sustainable medication and management routines, and structuring access to healthcare information networks. Instabilities of health insurance coverage interrupt individuals' ability to maintain continuous medical care, working against their ability and desire to develop strong, trusting relationships with their doctors, disrupting their access to important medications, external healthcare resources, and, ultimately, negatively impacting the management of their diabetes and overall health.

In the first section, I will look at the critical role of healthcare insurance in structuring individual ability to access quality and continuous healthcare and diabetes management. In the next section, I delve deeper into the impacts of continuity of care on my respondents' perceptions of the doctor-patient relationship, as I argue that my respondents' divergent experiences of trust in their medical providers is rooted in their differing experiences along the continuum of continuity of care. Then, I will explore how continuity of care influences my respondents' ability to build cultural health capital and negotiate and create sustainable and effective medical management routines for their diabetes. Finally, I will explore my respondents' divergent networks for accessing healthcare information, showing how differences in continuity of care and stability of access to healthcare influence how individuals discover and mobilize access to diabetes informational resources.

The Effect of Insurance on Patients

For many of my respondents, insurance was a key mediating factor throughout their narratives of their diabetes illness experience. While my respondents represented a wide variety of current insurance situations, ranging from being uninsured to possessing private, employer-funded health insurance, none could discuss the doctor-patient relationship or their healthcare experience without mention of health insurance coverage. Stories of fluctuating insurance coverage and appreciation of more comprehensive healthcare coverage were frequent, especially among respondents who had been diagnosed with diabetes for an extended period of time. Their ability to compare experiences of uninsurance to times of stability, achieved through Medicare or employer-funded health insurance, reflect the real, multi-faceted effects that health insurance has on individual lives. Respondents described how their insurance coverage enabled them to access the healthcare they needed to manage their diabetes. With good insurance, they could continue seeing the same doctors, pay for the right medications, and even access valuable additional diabetes-specific healthcare resources.

Andrea, who relied on Medicare and Medicaid for her healthcare coverage, highlighted the importance of her health insurance for her diabetes management. Indeed, for Andrea, access to quality healthcare coverage contributed just as much, if not more, to her disease management than her income level:

> Diabetes is not a poor person's ailment or disease. It can be anybody's disease, but it's particularly hard on someone with a limited income. Uh, you know, you don't have to be dirt poor to, you know, to have the problem, but if you have a limited income and only a relatively good insurance, then you have a problem. I do not know what I would do if I didn't have Medicare and Medicaid. I do not know what I would do if Northlakes didn't keep me on the rolls with my Medicare and Medicare and Medicaid. I don't know what I would do if the Part D didn't pay for my medication because I don't pay for the metformin.

While Andrea pronounces that "diabetes is not a poor person's ailment or disease" as she describes the difficulties of managing diabetes at a "limited income", she actually prioritizes the importance of her health insurance over that of her income when she describes how she "[does] not know what [she] would do" if her medical providers stopped taking her insurance, or if her insurance stopped paying for her medication. With these statements, Andrea describes her insurance as her main link to healthcare, implying a kind of helplessness that would emerge without insurance. With this implication of there being nowhere to turn to if she "didn't have Medicare and Medicaid," Andrea highlights the crucial role of health insurance in her care. Yet, it is also important to note that Andrea focuses on dual impacts of her health insurance on her healthcare experience. She describes the importance of Northlakes "[keeping her] on the rolls" with her insurance, highlighting the value of insurance in maintaining stable doctor-patient relationships and establishing continuity of care, while she also mentions the importance of her insurance paying for her medication, describing how, without coverage, she would not be able to pay for her care.

Given the critical importance of health insurance in affording medication and management routines, it follows that instability in insurance coverage could also have important negative impacts on medication management routines. Andrea described the struggle of finding appropriate and effective methods for her disease management given the constraints of public health insurance and its limited coverage:

> It took me a while to get my Medicare and Medicaid . . . Stabilization of the diabetes medication and who will pay for it and how much I get of it, was, for, about, I would say six or seven years, was fluctuating. Glucotrol was effective, but I was, but they stopped covering the Glucotrol. They wouldn't give me the Medicare Part D, and they wouldn't approve the Glucotrol. So, we went to Glipizide. I do not feel that Glipizide is, that it has ever been, that the Glipizide has ever been as effective, because the Glipizide, like a brand, is like a generic thing that you can use that is cheaper, and has never been as effective as that first prescription that I had.

For Andrea, the main barrier to successful management of her diabetes was the structural, bureaucratic barrier of medical insurance and payment for her medications. Due to her fluctuating and inconsistent healthcare coverage, Andrea's medication did not stay constant and her diabetes management suffered. Andrea's experience mirrors that of many others relying on publicly-funded health insurance like Medicaid and Medicare who struggle with regular patterns of desired interventions not being covered and constant streams of rejection and denial. These inconsistencies in coverage thwarted Andrea's ability to choose her own care, and, as a result, she still feels as though she does not have the same ability to manage her diabetes.

Often, income and employment instability contributed to insurance instability which meant that respondents lost access to valuable healthcare resources and found themselves increasingly alone with regards to diabetes management. Indeed, as Alisha, a 49-year-old Medicaid recipient, described, her healthcare benefits had dramatically changed throughout her illness experience because of her insurance coverage:

> When I first became a diabetic, they seemed to be real, real helpful. Then they, I don't know if it was due to the insurance, but they just gradually took those things away... Because I had a dietitian, she went away, you know, and it was like, "Oh, you could call me any day or night." Right. Yeah, right. . .I don't know . . . Maybe because of insurance . . . Because I remember, when I had better insurance, that they, everything was being coordinated somehow, you know, and I didn't have to worry about a lot of things. Now it's like I got be on -- you know, where's, when am I going to get my eyes and when am I gonna get this, and I have to do that.

Alisha's story of diabetes management is one of loss of resources, which she attributes to the loss of private, employer-provided healthcare after the loss of her job. Alisha can remember a time when she had "better insurance" and her care was "coordinated," eliminating much of her worry and insecurity in her healthcare experience. Healthcare insurance is a significant and powerful tool to receiving quality healthcare and access to necessary educational resources. When Alisha

was first diagnosed with diabetes, she had high-quality insurance which connected her to valuable educational resources like dieticians and specialty care providers. But, now, without the benefits of private insurance, Alisha feels like the help that she used to rely on has disappeared. She has to "worry about a lot of things" and "be on" in order to make sure that she receives the care that she knows that she needs. Without the support provided by private insurance, Alisha struggles with uncertainty around her access to additional healthcare resources and information.

Yet, even when respondents were able to maintain some healthcare coverage through Medicaid, they could not always maintain access to the same healthcare providers. Diana describes losing her access to healthcare resources and healthcare information when her Medicaid wouldn't cover her previous provider, forcing her to move to a different clinic: "I was with University Friends Health Service right there on Garden Plains, but my insurance wouldn't pay for that, so that means that I had to go to an insurance where, that would pay, but I really liked it, that place, because they had so many…opportunities." Even though Diana had really enjoyed her experience at University Friends Health Service, she could not stay at the clinic because of the instability provided by her health insurance. Her insurance served as a barrier to her continuity of care and limited her ability to access additional resources by forcing her to find a new healthcare provider and leave the "opportunities" available to her at University Friends.

In contrast with Diana and Alisha's experiences of a loss of "opportunities" due to their changing or inadequate insurance coverage, respondents with comprehensive medical coverage were able to mobilize their healthcare to learn about diabetes management and educational resources from their doctors and medical systems. Individuals received referrals from their doctors to dieticians and diabetes support groups, who helped them rethink their diets and improved their diabetes management. Jerrold, a veteran who received services from the VA,

described how he mobilized access to healthcare resources because of the centralized medical center at the Veteran's Administration:

> The VA also has a lot of stuff . . . They got all kinds of machines over at the VA, and they got all kinds of programs . . . We are really strongly encouraged to participate in anything that have to do with the diabetics. It does not matter. And also, they have groups. The people that have diabetic, they want you to join the groups

Jerrold's experience of constant access to diabetes support groups and education classes provided him with the ability to search for new methods of care and opportunities to educate himself in the self-management that is so important for diabetics. The distinctive nature of healthcare coverage by the Veterans Administration affords Jerrold with a unique access to all-inclusive, high-quality, and continuous care that provides him with more support to better manage his diabetes. Unlike Alisha and Diana who noticed significant uncertainty in their access to healthcare resources, Jerrold had a myriad of opportunities for education, exercise, and support to improve his diabetes at his fingertips. Using Alisha, Diana, and Jerrold's experiences to understand the continuum of insurance coverage, we can see how differences in insurance drastically change individuals' sources of healthcare, subsequently impacting their access to healthcare information networks and additional diabetes care resources. Health insurance serves as a powerful force throughout individuals' healthcare experiences, structuring individual abilities to access and maintain stable access to healthcare.

The Consequences of Continuity of Care on Trust

For many of my respondents, positive relationships with their doctors were linked to high levels of continuity of care. Continuity of care, which is defined as a continued relationship between doctor and patient, has long been considered to be an important factor in patients' ongoing utilization of medical services and adherence to medical recommendations, and the situation is no different when analyzing the case of diabetes (Freidson 1988; Lutfey and Freese

2005; Waitzkin 1991). Indeed, from observing how my respondents built trusting relationships with their doctors, I noticed that continuity of care was a necessary condition for my interviewees to build positive, trusting relationships with their doctors. My respondents, who covered the continuum of healthcare options, ranging from private insurance and consistent doctors for over 10 years to Medicaid and a rotating cast of doctors at the local federally-qualified health clinic, also spanned a similar continuum of trust in their doctors.

While examining the experiences of my respondents who were unable to build trusting relationships with their doctors, many of the reasons behind their difficult relationships with their doctors were based in structural and bureaucratic barriers to continuity of care because of the kinds of healthcare they could access. As low-income individuals without private health insurance, some of my respondents turned to publicly-funded sources of healthcare, like Medicaid and federally-qualified health centers. Yet, by relying on those forms of healthcare, my respondents were unable to build long-term, continuous relationships with their doctors. Respondents noted how frequently changing doctors made it more difficult to trust their doctors, speak honestly with them, and stay consistent with their management routines. Diana details her difficulty in establishing a rapport with her new doctor:

> I feel trust is that I'm paying attention and I'm looking at you like you're looking at me, and I feel that if you treat me in a different way, I can see it, you know? . . . So yes, I trusted him, I trusted him then. But this little girl that I got, I think she only about 25 or 26 years old. . . She can't really look at me. We haven't, like I said, I think I've only been to her one time, and we never have eye contact, you know, she's always writing something and then there's another young lady that's dictating what we say and stuff like that. . . I mean, like I said, I don't know, I haven't been with her long.

Diana, who had previously built a trusting relationship with her doctor of many years, struggles to trust and relate to her new doctor not only because of the newness of their relationship, but also because of the bureaucratic structure of the clinic. She recognizes that after only going to

her new doctor once, she has not "been with her long" and cannot expect the same levels of trust that she had established over time with her previous doctor. At the same time, the bureaucratic structure of the clinic impedes her ability to trust her doctor. She describes how she and her doctor "never have eye contact" because "she's always writing something." Diana, for whom trust is established by "paying attention" and interconnection, perceives this focus on note-taking as an affront to her way of establishing trust in relationship; yet, it is a bureaucratic cornerstone of the clinic's operations that continues to perpetuate the structural differences between the continuity of care provided by healthcare systems and federally-qualified health centers.

Judy, who attended a federally-qualified health center for her regular care, similarly recognized clinical structures as a key reason behind her inability to confide in her doctor:

> I hate going to the doctor's. I try to comply to what they tell me, you know, to uh, every three months and take your A1C levels and it's supposed to be at a certain level . . . Doctors don't have that kind of time to sit there, and you got 30 more patients or whatever. . . I've had so many of them, you know, because you have interns that come in and out, so I can't really say. My doctor is pretty much always changing.

Judy's experience of constantly changing doctors is a key representation of the lack of continuity of care that individuals relying on publicly-funded clinics face. Judy details how her "doctor is pretty much always changing," hindering her ability to talk to her doctors and building her hesitance to listen to the doctor's recommendations. The reliance on "interns" and medical residents means that doctors "come in and out" and only stay at clinics for at most a few years, making it difficult for patients like Judy to build long-term relationships with their doctors. As a result, patients do not have communicative, trusting relationships with their healthcare providers. Because she has had "so many" doctors, the doctor's office is not place where Judy feels comfortable expressing herself and bringing up concerns about her health. At the same time, it is not only the constantly revolving nature of doctors that inhibits Judy's ability to relate to her

doctors, but also the clinic's overcrowded and busy nature that negatively impact Judy's healthcare experience. Given the clinical structure of the federally-qualified health center, Judy recognizes that her doctors "don't have that kind of time" to talk to her. Instead, Judy experiences the doctor's office as a place of impersonal authority, where the doctors check her body and tell her what to do, but do not take the time to discuss her personal situation, ultimately building her distrust in her medical providers.

For many of my respondents, continuity of care was simply not available given their financial situation: unstable health insurance and low income meant that individuals needed to rely on publicly-funded clinics and Medicaid for care. The structures of these healthcare resources meant that many of my respondents could not develop strong relationships with their doctors, as Renee attests. Renee was one of the lucky respondents who moved up in her healthcare access status, yet her experiences at the Thomas Clinic are an important reflection of how instability of care can hinder the development of effective doctor-patient relationships. Renee described how different she felt when she relied on a sliding-scale fee clinic for care:

> When I was going to Thomas Clinic, I didn't feel like my doctors were listening to me. Yeah, and I'm not blaming them. I understand that it's a revolving door of people all the time. But when doctors I think are working in that kind of environment, I think it's hard to develop caring, I think it's hard to develop relationships with people. You're just trying to get them in and out, get them in and out, but I don't feel that way with these doctors, and I think that's the benefit of having a private health insurance.

Renee is a particularly valuable source to understand the ways in which structural factors influence the doctor-patient relationship, because she experienced both extremes of the healthcare continuum and could explain the difference she felt. Indeed, Renee explicitly expresses the ways in which the structures of the Thomas Clinic impeded her ability to build a strong, trusting doctor-patient relationship, as she describes how the "revolving door" of people in the clinic made it "hard to develop relationships." The constant busyness of the clinic, which

Renee describes as doctors trying to "get [people] in and out," meant that Renee did not feel like her doctors were listening to her, which was a necessary precondition for her to trust her doctors. The lack of trust present in Renee's relationship with the doctors at the Thomas Clinic served as a barrier to developing their relationship and accessing better treatment, a barrier that Renee no longer experiences due to her private insurance. Renee directly contrasts her past experience at the Thomas Clinic with her current experiences of private insurance, attributing her improved doctor-patient relationship to her healthcare coverage. Renee's experiences are an important example of the necessity of stable doctor patient relationships in developing trust: the high-volume structure of the Thomas Clinic prevented her from spending time with her healthcare provider and trusting her provider, but her subsequent change to stable, high-quality, private health insurance enabled her to experience the continuity of care that helps individuals develop trusting doctor-patient relationships.

As Renee's experience begins to explicate, several of my interviewees were able to develop strong, trusting relationships with their doctors once they secured stable insurance and continued seeing their doctors for an extended period of time. Respondents described how their relationships with their doctors gradually grew in strength, as they began to trust their doctors after years of continuous treatment. Charlene, who had been with her current doctors for over ten years, discussed the development and changes in her relationship with her doctors, explaining:

> At first I was scared to open up and did not tell them everything, but the less you tell them, the worse you are . . . [They] ask me questions and let me say how I feel. Now, I feel comfortable talking to them. They used to be, well, I didn't feel comfortable talking to a doctor. Like my primary doctor, I used to – thought, I thought I didn't like her, put it like that. But, I really love her because if it weren't for her diagnosis and sending me to the endocrinologist and all of that. She knows what she's doing. That's the way I see it.

Charlene's relationship with her doctors is a story of transformation from fear, hesitance, and dislike to one of mutual trust and honest communication. At the beginning of her relationship

with her doctor, Charlene admits that she was "scared to open up" and hid her true feelings, reflecting that trust in the doctor-patient relationship is not inherent. Now, after many years of continuous care from her doctors, Charlene illustrates her trust in her doctors as she describes how she feels "comfortable" speaking to them. For Charlene, the fact that her doctors "ask [her] questions and let [her] say how [she feels]" is critical in developing a sense of "comfort" and trust in the doctor-patient relationship. These questions communicate to Charlene that her doctor values her own input and perspective, helping to build her ability to engage with the medical establishment and effectively building her "cultural health capital" (Shim 2010). Her doctor works to create an open and trusting line of communication, encourages Charlene to make herself increasingly vulnerable and open to her doctor, and establishes a context where Charlene develops the cultural health capital to become "comfortable" with talking to her doctors. Clearly, this trusting relationship did not arise out of nowhere. Charlene and her doctor built this mutual relationship out of caring and communication established during years of continuous care. Unlike others who experienced structural and bureaucratic barriers to honest, in-depth conversations with their doctors, Charlene's constant, employer-provided health insurance enabled her to continue working with the same doctor, build a strong, trusting relationship with her doctor, and develop cultural health capital.

The Consequences of Continuity of Care on Individualized Management Routines:

Diabetes management is highly individualized, varying according to individual behavior, choices, and providers' discretion. When asked how they managed their diabetes, respondents typically described trying many different types of medication, diet adjustments, and other techniques to better control their blood sugar. Yet, not all of my respondents felt equally able to express themselves in order to negotiate the best form of management for their bodies. Some

individuals were hindered by structural barriers to care, like health insurance and clinical structures, whereas others were able to capitalize on their collaborative relationships with their doctors to advocate for more individualized treatment and the care they felt they needed.

Alisha, who had struggled to maintain health coverage through Medicaid and switched doctors numerous times before ending up at the local health center, described how she struggled to maintain agency over her own diabetes management plan:

> Well, I switched doctors numerous times. This one doctor, I mean, she's actually a nurse practitioner. She's, I guess she's pretty good, but she, she, I'm not, I don't know how to describe it. She decides to switch me from insulin with the needle to the pen, and she, she didn't say, "well, I'm switching you to the pens." I just go to the drugstore and they're giving me pens. I don't know how to use these. And then they didn't give me the needle, the tips to go on that. And they wouldn't let me buy any. I had to call her and get a special prescription... And then you call her office, and it's like, you're on hold forever. So I don't know if they're just, forgot, or occupied with other stuff or... Because I mean she could have said, "well, come on, let's do this together. I'm gonna switch you to the pens. They're so much easier." But I just show up, and I get pens instead of a vial.

The bureaucratic structures of the medical system divorced Alisha from her agency in participating in decisions about her diabetes management. Stretched for time and unaware of Alisha's need for more information, Alisha's nurse practitioner made the quick move to change Alisha's insulin administration method from injections with a needle and vial to injections with an insulin pen. While Alisha admitted to me that she would not have been opposed to switching her insulin routine had she discussed the change with her provider, she was shocked and confused when her nurse practitioner changed her routine without notifying her first. Instead, because of her provider's lack of oversight and communication, Alisha felt as though her care was out of her control, and she struggled with her ability to find agency within the system. This action, while simple for the nurse practitioner, caused Alisha significant frustration while she was forced to negotiate with the pharmacy and her doctor's office to gain access to the new treatment that she had not even chosen for herself. Due to lack of communication and the

overcrowded nature of the clinic, Alisha's access to insulin was delayed while she was "on hold forever," as she attempted to reach her overworked provider. The bureaucracy and clinical structure of the clinic meant that Alisha struggled with ways to engage in her own disease management and was unable to feel satisfied with her methods of disease management.

Similarly, Judy, who relied on a publicly-funded Federally-Qualified Health Center for her medical treatment, expressed frustration at the way her doctors approached her treatment:

> [Doctors] don't have to keep pushing it and telling me, "okay, you got this, you better do this, you'd better do that." Or, "we're gonna have to go on insulin" or "you have to get on dialysis." You know, sometimes I think it's a scare tactic or whatever. Give a person time. It didn't, it didn't happen overnight. You know, some people's body takes a little bit longer for it to do, to try to change to, to what it should be, you know, don't be so quick in a hurry. You know, next month your level could be down to six or it could be up to 13. You don't know what that person had been going through. Whatever the first thing you're like, "oh, he ain't doing what you're supposed to do." You don't know my body, you don't know what I was doing. They [doctors] need to be more supportive.

Judy's experiences represent a breakdown in patient-provider communication and a struggle to relate to her doctors. Due to her lower socioeconomic status and apparent issues with controlling her diabetes, Judy's doctors assume that she is unable to manage her diabetes and resort to "scare tactics" in their attempts to communicate with her. In addition to feeling that her doctors were not being "supportive" enough of her individual situation, Judy perceived that her doctors ignored her wishes and perspective when prescribing treatment and management techniques for her diabetes.

Unlike Alisha who has recently started with her nurse practitioner and Judy, who experiences a rotating cast of providers, Charlene, after over 10 years spent with her endocrinologist, identifies that she has a "good rapport" with her doctor. Yet, even though she identifies that she has "all the confidence in the world" in her endocrinologist, she is not a perfectly compliant patient, because she feels as though she has the right to control her body and

her treatment. As Charlene admits, there are times when she stops taking her medications or modifies her medication routine:

> When I did take [metformin],[1] I wouldn't take it like I was supposed to. I cut it in half . . . When I went to the endocrinologist, she said, "that's a time release capsule. You can't cut it in half." And I said, "well, you know what? My behind is raw.[2] I can't take this. I can't take metformin. It's not working." And she just switched me right away. She listened to me.

Charlene's experiences with her endocrinologist highlight the ways in which continuity of care, built through long-term doctor-patient relationships, can benefit diabetes patients by empowering them to contribute to the development of their own management routines. After over ten years with her endocrinologist, Charlene feels comfortable enough to speak frankly about her situation and disclose her non-adherence to her medication regimen. While Charlene had taken matters into her own hands and wasn't taking the metformin as prescribed because of the negative side effects she was experiencing, she did not hide her choices from her endocrinologist. After 10 years of continued care with her doctor, Charlene has accrued a tacit understanding of and comfort with medical communication, having developed valuable "cultural health capital" to communicate purposefully with her doctor (Shim 2010). Charlene is forthright and honest as she tells her doctor quite frankly that she "can't take metformin" and does not believe that the medication is working. Because Charlene had built a positive relationship of mutual respect with her doctors, she feels comfortable disclosing her "medical misdeeds" of improper medication usage in order to advocate for a different form of treatment (Bergen and Stivers 2013). Her doctor listens to her complaints and takes her off of metformin, switching her to another medication "right away." In this moment, Charlene places herself evenly with her endocrinologist, granting her knowledge of her body priority over her doctor's orders, upending

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[1] An oral diabetes medication used to control blood sugar before patients are placed on insulin
[2] Common side effects of metformin include stomach upset and diarrhea

the typical power dynamic that places doctor at the top and patients at the bottom. This honest, frank communication is distinct from Alisha and Judy's experiences of detached, didactic medical care because, after years of continuous care, Charlene has developed valuable cultural health capital. With cultural health capital, accrued through continuous exposure to the medical system as a result of her continuity of care with her doctor, Charlene established a relationship of mutual understanding with her endocrinologist, enabling her to develop a program of individualized and specific diabetes care together with her endocrinologist.

Reliance on Informal Social Networks:

While this study highlights the fundamental role of high-quality healthcare in enabling individuals to achieve effective disease management, not all of my respondents experienced the same exposure to high-quality healthcare that motivated access and information to external diabetes care resources. At the same time, a select few still managed to find ways to navigate access to community healthcare resources. By examining the experiences of these few individuals, I argue that, without reliable, high-quality, healthcare, some motivated individuals rely on a structure of informal social networks and connected "resource brokers" to gain access to resources.

In the absence of strong, trusting relationships with their doctors, respondents were often forced to rely on informal social networks and "word of mouth" to find out about new diabetes care resources. Without insurance and relying on irregular appointments at the local federally qualified health center, Judy could not rely on her doctors to provide information about external healthcare resources, and instead relied on her informal social networks to provide her with information:

> You know, you go to the doctors and . . . they tell you what you need to do, but where's the resources? Where's the help? . . . I don't find out about things from my doctors, just

> on my own. . . The word of mouth, by other people saying, hey, you know, they're having a class here, or they're giving out some free food, vegetables and fruits. That's how I learned about certain things and I pass it onto other people because I know that they don't know.

For Judy, "word of mouth" is the only way to learn about things like monthly diabetes outreach classes and food pantry demonstrations. Her healthcare situation, highlighted by instability and insecurity, structures her experience such that she does not build productive, informative relationships with her doctor. This lack of medical support highlights the creation of informal social support networks, the mechanism for how individuals navigate access to healthcare resources, in the absence of institutional support from doctors and healthcare networks. Judy recognizes the lack of information from healthcare providers as a systematic issue amongst her family and friends, as she described why she passes information onto other people "because [she knows] that they don't know." In this way, Judy acts as part of an important kind of informal support network to continue to build access to external resources even when institutional structures fail to make the connections necessary.

Without friends and family serving as informal support networks to encourage healthy practices, others were often divorced from information until exposure to local "resource brokers" enabled them to tap into valuable community resource networks. Angela, who lost her primary care provider several years ago and hasn't had a consistent doctor since, described how she had a very difficult time accessing the information she needs to manage her diabetes. As she relayed to me, she only learned about healthy eating and nutrition from chance exposure to a diabetes outreach program at the local community center's monthly food pantry:

> I was dumbfounded on what I was supposed to eat and stuff. I thought that I could eat everything but just not a lot of it, that it wouldn't mess with my sugar, but I was wrong. . . I need to know all that. What I can't eat, what kind of foods you can't eat, what kind of foods you can eat. Because I was going, thinking I'm eating fruit. I was doing all right, that you could do that. I was eating watermelon, cantaloupe, all that. The lady here told

> me, "Oh no, them is high in sugar," so I was doing all that thinking I'm doing the right thing, and that wasn't even what I was supposed to be doing.

Here, I argue that the local community center served as a kind of resource broker (Small 2006). As a resource broker, the community center, with its ties to larger organizations like the local food bank and a nearby elite university medical center, exposed Angela to critically important diabetes educational resources and knowledge. Without regular medical care, Angela had no source of information about diabetes and its management; yet, because of her exposure to the community center, Angela was able to gain access to additional diabetes educational resources and build the knowledge she needed to better manage her diabetes. Unlike patients with continuity of care, who martialed cultural health capital and felt ready and able to mobilize access to educational resources and speak candidly with their doctors, individuals like Angela, who experienced healthcare insecurity, were often uncertain and unaware of critical knowledge about their diabetes management. At a loss for where to turn next, they searched for external resources as a stopgap measure for the education they needed to manage their disease progression. Luckily, some respondents like Angela were able to utilize connections to local resource brokers, like the community center, to gain education and access to valuable healthcare resources. Yet, even resource brokers could not be consistently counted on to provide information to all individuals divorced from healthcare information networks, highlighting the reliance of individuals upon their local communities of family and friends for information.

Discussion:

Diabetes in the United States is a rapidly growing healthcare issue. Millions of Americans are affected by the disease, yet the burden of this chronic disease rests inequitably on low-income, minority populations. Medical, epidemiological, and public health researchers identify the problem and highlight methods for improving individual management of the disease.

Often, medical research focuses on increasing patient exposure and access to quality healthcare and health education, but few studies examine the forces that enable individual access to these resources. Even fewer studies look qualitatively at individual experience in order to understand how health care experiences and access are intertwined with the illness experience. In this study, I build upon Link and Phelan's (1995) theory of fundamental causes of health inequality to ask the question, how fundamental is consistent access to the same doctor and healthcare?

In order to answer this question, I examined the role of health insurance and access to healthcare on patients, highlighting the ways that health insurance structures individuals' abilities to access healthcare. Fundamental causality makes the case that socioeconomic status acts through a variety of mechanisms to produce health disparities; however, it also highlights the power of access to doctors in enabling individuals to effectively manage their diseases and achieve good health outcomes. While one cannot deny the importance of socioeconomic status in health outcomes, I reveal the importance of considering health insurance access as a kind of fundamental cause, showing how it acts through multiple mechanisms to produce different healthcare experiences by affecting individuals' ability to trust in the doctor-patient relationship, achieve sustainable medication and management routines, and access healthcare information networks.

Using a comparative analysis of individuals who experience stable access to health insurance and continuity of care with individuals who experience a dual instability in their access to health insurance and consistent medical providers, I reveal that the ability to achieve successful diabetes management often begins with stable access to health insurance. With continuous, stable health insurance access, individuals are able to build consistent relationships with their healthcare provider and build their ability to accumulate cultural health capital. Using

Shim's (2010) theory of cultural health capital, I argue that cultural health capital acts in important ways to counteract the deterministic aspects of socioeconomic status on health. With continuity of care, individuals, regardless of their socioeconomic status, are able to accumulate cultural health capital and take a more active role in their own medical care, helping to build sustainable management routines that they want to follow. Improved disease management is facilitated by cultural health capital and assisted by access to healthcare resource networks negotiated through comprehensive healthcare systems. In the absence of these healthcare systems, individuals become reliant on their communities, using informal social networks to inconsistently acquire knowledge and resources helpful for disease management.

This study has valuable implications for the field of medical sociology. Using the framework of fundamental causality, this study builds upon the importance of socioeconomic status in not only structuring individual health and healthcare outcomes, but also in the ways in which patients relate to and navigate interactions with medical providers. By using a qualitative perspective to reach an underserved population of individuals with a high disease burden, this study explicates important factors at work in understanding how individuals negotiate access to important healthcare information networks. This study explicates the mechanisms acting behind differing health outcomes and experiences, showing how health disparities can occur even among individuals of a similar socioeconomic status because of the critical importance of continuity of care in developing individual cultural health capital. In its unique goal to understand individuals' illness experiences, this study highlights the continuing and growing importance of continuity of care given its impacts on patient-provider communication. With continuity of care, low-income individuals can build trusting, meaningful relationships with their healthcare providers, enabling them to access critical healthcare information and resources. For

individuals with lower socioeconomic status, the doctor's office becomes one of the only places to accumulate cultural health capital and gain access to important healthcare information.

This study also has important implications for social policy. By revealing the fundamental importance of continuity of care and the critical role that health insurance plays in negotiating access to continuous healthcare, this study highlights the importance in improving the United States' public healthcare system. As Olafsdottir (2007) noted in her comparative study of the United States and Iceland, the welfare state does not completely erase the fundamental impacts of socioeconomic status on health, but it does serve to mediate its effects and improve the health of lower-income individuals. This study's qualitative approach reveals firsthand the dichotomous experiences of healthcare access among those with continuous access to medical insurance and without stable healthcare insurance, highlighting the value of a universal publicly-funded health insurance program for improving the health of the United States population. The United States' more comprehensive public health insurance programs like Medicare and the Veterans' Administration worked to help some of my respondents navigate improved access to healthcare and better health outcomes, while other individuals faced a dual insecurity in healthcare access created by gaps in employer-provided insurance and the public healthcare safety net. As this study shows, insecurity in healthcare access leads to less continuity of care, worse medication and management routines, and less access to external healthcare resources. The path forward for health policy is clear – expanding a basic, universal healthcare coverage will enable more individuals to improve their health and disease management.

Despite this study's contributions, this study does have its methodological limitations. As a small-sample study of a particular population of black, low-income individuals living with diabetes on the South Side of Chicago, this study was well-positioned to examine the situation of

low-income individuals living with diabetes, but likely cannot be extended to understand the situation of higher-income individuals living with diabetes. There are still many mechanisms which must be examined in order to understand how and why health inequality amongst other populations emerges. Additionally, this study was particularly focused on the small population of individuals who did find themselves able to access external diabetes care resources. I caution that this study's primary population of interest is likely not representative of the broader population of people living with diabetes, and even probably not representative of the whole population of individuals living with diabetes on the South Side of Chicago. Nevertheless, I believe that this particular population was especially valuable for examining the question of how certain, seemingly similar, individuals navigate access to quality healthcare and healthcare resources, a particularly important and under-studied aspect of medical sociological and healthcare research.

Building upon these limitations, further investigation should be made towards understanding the experience of individuals living with diabetes. While this research focuses specifically on a population of low-income, Black Americans, qualitative studies need to examine the experiences of other under-studied minority and vulnerable populations, like Latinx populations, Native American, Asian American populations. Beyond diabetes-specific research, it continues to be of importance to research what factors influence the take-up and access of healthcare resources, which is why I propose that future research continue to examine the question in different urban and rural areas with more diverse groups of respondents. This study also highlights the importance of looking at the United States welfare programs and social security net. Healthcare access continues to be challenging for many Americans, and it is important to look deeper at how bureaucratic hurdles and institutions can influence the ever-important access to healthcare resources. After the Affordable Care Act and Medicaid expansion,

the changing, different contexts of healthcare coverage from state-to-state should be examined. Comparative studies of individuals in states with the Medicaid expansion and those in states without the Medicaid expansion would further clarify the ways in which insurance access contributes to health outcomes. These are just some of the many future paths that we need to examine more closely in the future.

In the United States, growing numbers of individuals are living with diabetes, and racial and socioeconomic disparities amongst disease prevalence, severity, and management continue to expand. Yet, most research fails to explore mechanisms beyond socioeconomic status in order to explain the differences amongst groups. I fill this gap by leveraging a case study of diabetes on the South Side of Chicago, highlighting the fundamental role that access to the same doctor and continuity of care play in managing a chronic illness like diabetes. Using the framework of fundamental cause theory, I establish how access to quality and continuous healthcare works through multiple mechanisms to develop distinctly different healthcare outcomes among individuals explicate how and why certain individuals are able to mobilize access to healthcare information networks and diabetes care resources outside of the doctor's office.

Works Cited:

Baker, David W., Joseph J. Sudano, Jeffrey M. Albert, Elaine A. Borawski, and Avi Dor. 2001. "Lack of Health Insurance and Decline in Overall Health in Late Middle Age." *The New England Journal of Medicine* 345(15):1106–12.

Bergen, Clara and Tanya Stivers. 2013. "Patient Disclosure of Medical Misdeeds." *Journal of Health and Social Behavior* 54(2):221–40.

Berkman, Lisa F. and Thomas A. Glass. 2000. "Social Integration, Social Networks, Social Support, and Health." Pp. 137–73 in *Social Epidemiology*. Oxford: Oxford University Press.

Bourdieu, Pierre. 1986. "The Forms of Capital." Pp. 241–58 in *Handbook of Theory and Research for the Sociology of Education*, edited by J. G. Richardson. New York: Greenwood Press.

Boyer, Carol A. and Karen E. Lutfey. 2010. "Examining Critical Health Policy Issues within and beyond the Clinical Encounter: Patient-Provider Relationships and Help-Seeking Behaviors." *Journal of Health and Social Behavior* 51(1_suppl):S80–93.

Brown, Arleen F., Susan L. Ettner, John Piette, Morris Weinberger, Edward Gregg, Martin F. Shapiro, Andrew J. Karter, Monika Safford, Beth Waitzfelder, Patricia A. Prata, and Gloria L. Beckles. 2004. "Socioeconomic Position and Health among Persons with Diabetes Mellitus: A Conceptual Framework and Review of the Literature." *Epidemiologic Reviews* 26:63–77.

Campbell, Andrea Louise. 2014. *Trapped in America's Safety Net: One Family's Struggle*. Chicago: University of Chicago Press.

Cassel, John. 1976. "Contribution of Social-Environment to Host-Resistance - 4th Wade Hampton Frost Lecture." *American Journal of Epidemiology* 104(2):107–23.

Cattell, Vicky. 2001. "Poor People, Poor Places, and Poor Health: The Mediating Role of Social Networks and Social Capital." *Social Science & Medicine* 52(10):1501–16.

Cobb, Sidney. 1976. "Social Support as a Moderator of Life Stress." *Psychosomatic Medicine* 38(5):300–314.

Cox, Matthew, Paul J. Boyle, Peter G. Davey, Zhiqiang Feng, and Andrew D. Morris. 2007. "Locality Deprivation and Type 2 Diabetes Incidence: A Local Test of Relative Inequalities." *Social Science & Medicine* 65(9):1953–64.

Diabetes Prevention Program Research Group. 2009. "10-Year Follow-up of Diabetes Incidence and Weight Loss in the Diabetes Prevention Program Outcomes Study." *The Lancet* 374(9702):1677–86.

Fiscella, Kevin and Mechelle R. Sanders. 2016. "Racial and Ethnic Disparities in the Quality of Health Care." *Http://Dx.Doi.Org/10.1146/Annurev-Publhealth-032315-021439*. Retrieved April 11, 2018 (https://www.annualreviews.org/abs/doi/10.1146/annurev-publhealth-032315-021439?intcmp=trendmd).

Freidson, Eliot. 1988. *Profession of Medicine: A Study of the Sociology of Applied Knowledge*. University of Chicago Press.

Glasgow, Russell. E. and Robert M. Anderson. 1999. "In Diabetes Care, Moving from Compliance to Adherence Is Not Enough. Something Entirely Different Is Needed." *Diabetes Care* 22(12):2090–92.

Gorin, Amy, Suzanne Phelan, Deborah Tate, Nancy Sherwood, Robert Jeffery, and Rena Wing. 2005. "Involving Support Partners in Obesity Treatment." *Journal of Consulting and Clinical Psychology* 73(2):341–43.

Heisler, Michele, Dylan M. Smith, Rodney A. Hayward, Sarah L. Krein, and Eve A. Kerr. 2003. "How Well Do Patients' Assessments of Their Diabetes Self-Management Correlate With Actual Glycemic Control and Receipt of Recommended Diabetes Services?" *Diabetes Care* 26(3):738–43.

Hoffman, Beatrix. 2013. *Health Care for Some*. Chicago: University of Chicago Press.

Kington, Raynard S. and James P. Smith. 1997. "Socioeconomic Status and Racial and Ethnic Differences in Functional Status Associated with Chronic Diseases." *American Journal of Public Health* 87(5):805–10.

Kirby, James B. and Toshiko Kaneda. 2005. "Neighborhood Socioeconomic Disadvantage and Access to Health Care." *Journal of Health and Social Behavior* 46(1):15–31.

Link, Bruce G. and Jo Phelan. 1995. "Social Conditions as Fundamental Causes of Disease." *Journal of Health and Social Behavior* Spec No:80–94.

Lutfey, Karen and Jeremy Freese. 2005. "Toward Some Fundamentals of Fundamental Causality: Socioeconomic Status and Health in the Routine Clinic Visit for Diabetes." *American Journal of Sociology* 110(5):1326–72.

Mewes, Jan and Giuseppe Nicola Giordano. 2017. "Self-Rated Health, Generalized Trust, and the Affordable Care Act: A US Panel Study, 2006–2014." *Social Science & Medicine* 190:48–56.

Murabito, Joanne M., Jane C. Evans, Martin G. Larson, Bernard E. Kreger, Greta L. Splansky, Karen M. Freund, Mark A. Moskowitz, and Peter W. F. Wilson. 2001. "Family Breast Cancer History and Mammography: Framingham Offspring Study." *American Journal of Epidemiology* 154(10):916–23.

Norris, Susan L., Michael M. Engelgau, and K. M. Venkat Narayan. 2001. "Effectiveness of Self-Management Training in Type 2 Diabetes: A Systematic Review of Randomized Controlled Trials." *Diabetes Care* 24(3):561–87.

Olafsdottir, Sigrun. 2007. "Fundamental Causes of Health Disparities: Stratification, the Welfare State, and Health in the United States and Iceland." *Journal of Health and Social Behavior* 48(3):239–53.

Peek, Monica E., Algernon Cargill, and Elbert S. Huang. 2007. "Diabetes Health Disparities: A Systematic Review of Health Care Interventions." *Medical Care Research and Review: MCRR* 64(5 Suppl):101S-56S.

Persell, Stephen D., Nancy L. Keating, Mary Beth Landrum, Bruce E. Landon, John Z. Ayanian, Catherine Borbas, and Edward Guadagnoli. 2004. "Relationship of Diabetes-Specific Knowledge to Self-Management Activities, Ambulatory Preventive Care, and Metabolic Outcomes." *Preventive Medicine* 39(4):746–52.

Phelan, Jo C., Bruce G. Link, Ana Diez-Roux, Ichiro Kawachi, and Bruce Levin. 2004. "'Fundamental Causes' of Social Inequalities in Mortality: A Test of the Theory." *Journal of Health and Social Behavior* 45(3):265–85.

Phelan, Jo C., Bruce G. Link, and Parisa Tehranifar. 2010. "Social Conditions as Fundamental Causes of Health Inequalities: Theory, Evidence, and Policy Implications:" *Journal of Health and Social Behavior*.

Queen, Tara L., Katherine J. W. Baucom, Ashley C. Baker, Daniel Mello, Cynthia A. Berg, and Deborah J. Wiebe. 2017. "Neighborhood Disorder and Glycemic Control in Late Adolescents with Type 1 Diabetes." *Social Science & Medicine* 183:126–29.

Rhee, Mary K., Curtiss B. Cook, Virginia G. Dunbar, Rita M. Panayioto, Kathy J. Berkowitz, Barbara Boyd, Christopher D. George, Robert H. Lyles, Imad M. El-Kebbi, and Lawrence S. Phillips. 2005. "Limited Health Care Access Impairs Glycemic Control in Low Income Urban African Americans With Type 2 Diabetes." *Journal of Health Care for the Poor and Underserved* 16(4):734–46.

Shim, Janet K. 2010. "Cultural Health Capital: A Theoretical Approach to Understanding Health Care Interactions and the Dynamics of Unequal Treatment." *Journal of Health and Social Behavior* 51(1):1–15.

Small, Mario Luis. 2006. "Neighborhood Institutions as Resource Brokers: Childcare Centers, Interorganizational Ties, and Resource Access among the Poor." *Social Problems* 53(2):274–92.

Smedley, Brian D., Adrienne Y. Stith, and Alan R. Nelson. 2003. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC, US: National Academies Press.

Smith, Kirsten P. and Nicholas A. Christakis. 2008. "Social Networks and Health." *Annual Review of Sociology* 34(1):405–29.

Spruijt-Metz, Donna, Gillian A. O'Reilly, Lauren Cook, Kathleen A. Page, and Charlene Quinn. 2014. "Behavioral Contributions to the Pathogenesis of Type 2 Diabetes." *Current Diabetes Reports* 14(4):475.

Sudano, Joseph J. and David W. Baker. 2006. "Explaining US Racial/Ethnic Disparities in Health Declines and Mortality in Late Middle Age: The Roles of Socioeconomic Status, Health Behaviors, and Health Insurance." *Social Science & Medicine* 62(4):909–22.

Tang, Mei, Yue Chen, and Daniel Krewski. 2003. "Gender-Related Differences in the Association between Socioeconomic Status and Self-Reported Diabetes." *International Journal of Epidemiology* 32(3):381–85.

The Centers for Disease Control and Prevention. 2018. "National Diabetes Statistics Report 2017." Retrieved May 8, 2018 (https://www.cdc.gov/diabetes/data/statistics/statistics-report.html).

Timmermans, Stefan and Iddo Tavory. 2012. "Theory Construction in Qualitative Research: From Grounded Theory to Abductive Analysis." *Sociological Theory* 30(3):167–86.

Waitzkin, Howard. 1991. *The Politics of Medical Encounters: How Patients and Doctors Deal with Social Problems*. New Haven: Yale University Press.

Weaver, Robert R., Manon Lemonde, Naghmeh Payman, and William M. Goodman. 2014. "Health Capabilities and Diabetes Self-Management: The Impact of Economic, Social, and Cultural Resources." *Social Science & Medicine* 102:58–68.

Weiss, Robert S. 1995. *Learning From Strangers: The Art and Method of Qualitative Interview Studies*. Simon and Schuster.

Wing, Rena R. and Robert W. Jeffery. 1999. "Benefits of Recruiting Participants with Friends and Increasing Social Support for Weight Loss and Maintenance." *Journal of Consulting and Clinical Psychology* 67(1):132–38.