Diabetes in Native Chicago: An ethnography of identity, community, and care

By

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Any errors within the following pages are mine alone.

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ABSTRACT

While diabetes has been found in human populations for several millennia, cases of type 2 diabetes were rare in American Indian populations prior to World War Two. Today American Indians have some of the highest rates of diabetes worldwide. The majority of the research on this epidemic focuses on reservation populations. While rates of diabetes climbed in reservation areas, they also grew in cities, where nearly 80 percent of Native people live today. In this dissertation, I explore experiences with, understandings of, and care for diabetes in Chicago's Native community, a community that is made up of individuals representing more than 100 tribes from across the United States and Canada. Through this exploration I illustrate that diabetes in Native Chicago is understood and organized by a local system of classification that has been shaped by what community members observe in cases of the disease among family and friends. I show that in the face of this epidemic, care for disease is woven into the everyday lives of community members. Ultimately I argue that the relationship between human culture and human biology is a reciprocal one, in which history and culture shape modern human health and human health shapes modern culture. I argue that colonialism acted on bodies and communities through intergenerational trauma, displacement, chronic poverty, and altered foodways, and that the high risk of developing diabetes is being incorporated into contemporary discussions of indigenous American identity in the urban space.

CHAPTER 1
INTRODUCTION

Introduction

As the staff meeting at the American Indian Center of Chicago concludes, Laura Cunningham suggests I head over to Tribal Hall to see if I can assist with preparations for the elder lunch.[1] Laura is the director of the center's wellness program and one of my first contacts in Chicago. I make my way from the meeting in the Little One's Room to Diane Maney Tribal Hall, passing through the front reception area where a sign hanging over the receptionist's window informs guests, "You're on Indian Land." As I enter the double doors to the hall I am overwhelmed by the magnitude of the room. Though warm sunlight shines in on this late May morning through the three tall windows flanking the south wall, the room feels cool. The hall is silent and I am seemingly alone. Tribal Hall, however, is prepared for the arrival of community members for one of the week's two elder lunches. In the center of the hall, six tables stand in two rows of three. The long and narrow tables with thin white plastic covers are surrounded by chairs upholstered in thick burnt-orange fabric. As I serve the meal an hour later, I note the necessities that each table holds for the soon-to-arrive diners: a bowl filled with red and black salt and pepper packets, a styrofoam cup with either a creamy white ranch or a syrupy magenta raspberry salad dressing, and a second bowl containing tiny brown tubs of Country Crock brand margarine.

Looking around for someone to give me a task, I note the north side of the hall where three tables stand beneath an expansive mural. This mural depicts three women, each with long dark hair and heavy mustard yellow dresses that cover their arms and reach their ankles; they

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[1] Laura Cunningham is a pseudonym.

stand behind a large shallow azure bowl holding the “three sisters” of early American Indian diets – squash, maize, and beans. One of the sisters holds the leafy stem of the climbing beans as her stern eyes meet with the viewer’s; the two other sisters are turned in towards one another, looking at something within their own landscape, beyond the sight of the observer.

Hearing a sudden clanking of a metal spoon being tapped against a stainless steel pot, I peer into the doorway to the left of this mural, and see two women inside the kitchen preparing for the 28 diners that will arrive later that day. As I draw nearer to the door, the spiced aroma of beef marinara with onions and green peppers that simmers over a gas lit stove intensifies. The women are preparing a tray of iceberg lettuce salads. I enter the kitchen to introduce myself and offer help. The women introduce themselves as regular volunteers at the center’s lunches and instruct me to pull my hair back and wash my hands before helping with anything. I help with menial tasks like ensuring the water container is full and washing dishes, while the regular volunteers make the lunch – a salad with carrots, broccoli, and croutons, a plate of spaghetti with the meat and pepper marinara and a slice of whole wheat sandwich bread, finished with a thin slice of sweet potato pie topped with pecans for dessert. I later learn that to work alongside the regular staff and volunteers in the center’s kitchen, one must first prove one’s competence through the performance of menial tasks.

This senior meal at the center foreshadowed in its very mundaneness some of the important symbolic and pragmatic issues in contemporary urban American Indian diabetes I was to learn about in subsequent years. On this first day of my research in May of 2007 I assisted with my first of nearly 100 meal preparations at the center and also began to forge relationships with members of Chicago’s Native community. This 2007 research was the first of four phases of ethnographic fieldwork aimed at studying diabetes in Chicago’s Native community. My goal was to document the experience, care, and understanding of the disease from the perspective of people living with diabetes and people providing care for diabetes. In this introductory chapter I introduce readers to the questions guiding this dissertation research and offer a brief summary of what is to come in the chapters that follow.

Native, American Indian, and indigenous: a brief note on word choice

Members of Chicago's Native community refer to themselves individually and as a community using a variety of terms – Indian, American Indian, Native, Native American, Indigenous, NDN, and most often by individual tribal affiliation. In this dissertation I refer to the people indigenous to the United States of America as Natives, American Indians, indigenous peoples, and often by tribal affiliation when speaking of an individual. I use a capital N in "Native" to mark the difference between those whose ancestors were indigenous to the Americas and those born in the United States whose ancestors arrived to this land within the past few hundred years. Throughout this dissertation I use this variety of terms interchangeably to reproduce the language used in the community.

Research questions

This dissertation explores experiences with, understandings of, and care for diabetes in an urban American Indian population. American Indian populations have some of the highest rates of type 2 diabetes (hereafter referred to as *diabetes)* worldwide and are disproportionately affected by the secondary complications when compared with other ethnic groups in the United States of America (hereafter *United States*) (Centers for Disease Control and Prevention 2003;

Centers for Disease Control and Prevention 2011). Prior to World War Two, however, cases of diabetes among individuals of American Indian heritage were rare.

Scholars have studied the diabetes epidemic in Native populations since the 1970s. Studies have investigated the history and causes of diabetes in these populations, the experiences of the disease, and local models for and challenges to diabetes care. The majority of research on the diabetes epidemic is focused on reservation populations, though nearly 80 percent of the Native population lives outside of reservation spaces today (Norris et al. 2012). This dissertation investigates the experience and care for diabetes in an urban American Indian community. The guiding questions of this research were: (1) what is the experience of diabetes in an urban Native community? and (2) through what processes is diabetes knowledge generated or altered? In the next section I describe the research site and the methods used to collect data with the aims of answering these questions.

Thesis

This dissertation is an exploration of the relationship between human culture and human biology. In the following pages I argue that there is a reciprocal relationship between human culture and biology, wherein history and culture shape modern human health and human health shapes modern culture. I show how colonialism acted on bodies and communities through intergenerational trauma, displacement, chronic poverty, and altered foodways. Anthropologists have long been aware of the devastating toll wrought on the indigenous populations of the Americas through the Columbian Exchange. As this dissertation will show, noncommunicable diseases like diabetes are thought of by some urban Natives in similar terms. While there is a long history of diabetes in human populations, the rise of diabetes in the indigenous populations of the Americas is relatively recent, and this growth in rates of diabetes is related to the long term effects of colonial practices and policies.

Further, this dissertation demonstrates that this new epidemic has influenced Native culture. I show that the diabetes, as a disease that American Indians are at risk of developing, has been adopted and incorporated into local discussions of indigenous identity in the urban space. I will show that Native identity is a contested topic in Chicago and in Native North America more broadly. Chicago's Native population is an inter-tribal one, with citizens representing more than 100 different tribes from the United States and Canada. In local discourse members of Chicago's Native community articulate a shared Native identity through a shared vulnerability to diabetes that transcends tribal differences. In theorizing how diabetes has been incorporated into these local discourses, this dissertation explores the role history and culture play in shaping modern human health and how human health shapes modern culture.

The findings of this dissertation contribute to the vast scholarship on the American Indian diabetes epidemic, and move it in a new direction. Medical anthropology studies of diabetes in North American Indians trace the high occurrence of the disease to changes in lifestyle (eg. land restriction and diet) imposed, in many cases violently, upon American Indian populations by Western colonial forces (de Cora 2001; Geishirt-Cantrell 2001; Gohdes 1986; Jackson 1993; Mihesuah 2003). In recent decades, medical anthropologists have shifted their attention to American Indian perceptions of diabetes etiology and to the formation of treatment programs based in local health and treatment models. Medical anthropologists find that the indiscriminate implementation of biomedical treatment programs is unsuccessful in multicultural healthcare settings, like those found on American Indian reservations (Evaneshko 1993; Garcia-Smith 1993; Hickey and Carter 1993; Roy 2006). While researchers find that American Indian concepts share some commonalities with those of biomedicine, they also find that American Indian models diverge from biomedical models in viewing psychological stress and spiritual wellness as two significant factors in diabetes etiology (Garro 1996; Garro 2000; Garro and Lang 1993; Lang 2006a; Lang 2006b; Olson 2001; Rock 2003; Smith-Morris 2005; Weiner 1999; Weiner 2001). Diabetes treatment programs incorporating American Indian cultural practices like talking circles, native games and traditional foods are additionally being developed, implemented, and studied (Olson 1999; Olson 2001; Smith-Morris 2006; Venkat-Narayan et al. 1998; Wilson et al. 1993).

This dissertation contributes to these studies in three ways. First, the majority of this anthropological work on the American Indian diabetes epidemic has been centered on reservation settings. This study focuses on the care and experience of diabetes in an urban setting, where the majority of indigenous Americans live today. Second, these previous studies focus on the causes of diabetes and the challenges to its care in these populations. This dissertation approaches the study of diabetes in Native communities from a new vantage point by focusing on the influence this epidemic has on contemporary discussions of indigenous identity. Lastly, this dissertation incorporates theorizations from the lifeworld concept and from the anthropology of knowledge to explore how diabetes care and understandings are developed and negotiated in this urban space.

Chapter organization

This dissertation is made up of eight chapters, including this introduction as chapter one, a methods chapter, six main findings chapters, and a brief conclusion.

In chapter two I describe the research site, the participant population, and the methods used to conduct and analyze this research. In chapter three I explore the history of diabetes from antiquity to today. In this chapter I describe and contrast past and current medical models for what diabetes is and why people develop the disease. I situate current understandings of diabetes within biomedicine, which is defined by its dependency upon technology and biology as sources of legitimization and its locating of disease at some of the smallest levels of the body (Clarke et al. 2003; Fullwiley 2011; Lock 2002; Lock and Nguyen 2010; Wendland 2010). In the latter half of this second chapter I turn to the American Indian diabetes epidemic. During the decades following World War Two, rates of diabetes in Native populations and in indigenous populations worldwide began to climb. I describe two mainstream biomedical explanations for the ultimate cause of diabetes, those focusing on genetics and environment (Hales and Barker 1992; Knowler et al. 1981; Neel 1962; Neel 1982; Szathmary and Ferrell 1990; Wiedman 2012). Medical anthropologists describe that understandings of disease, health, and bodies are deeply enmeshed in local social histories and politics (Farquhar 2002; Lock 2002; Mol 2002; O'Nell 1996). I argue that the rise in American Indian diabetes incidences is the embodiment of a long history of colonialism and forced migration on Native bodies.

In chapter four I introduce readers to Chicago's Native population. This chapter first traces the history of the relationship between American Indian Nations and the settler community and United States Federal Government before examining the history of the Federal Relocation Program. While the indigenous peoples of North America have built and lived in urban areas for millennia, in the years following World War Two, with the pressure from Federal Relocation and Termination Programs, American Indians moved to cities in greater numbers than they had in the centuries before the war (Blackhawk 1995; Forbes 1998; Jackson 2002; Sorkin 1978; Thrush

2007). Between 1952 and 1972, 100,000 American Indians relocated to cities through the federally established Relocation Program that offered housing and employment support. In this chapter I show that the Relocation Program was one piece of a larger part of history that aimed at assimilating American Indian peoples and reducing federal obligations to Native peoples and nations during the mid-twentieth century. In the latter half of this third chapter, I put these aims of assimilation in dialogue with elder's and second generation relocatees' reflections upon why they and their families migrated to cities like Chicago during the relocation era, showing that many of the people who moved to Chicago chose to move in search of life opportunities that they could not find on the reservation.

In chapter five I describe contemporary Native Chicago. Research on urban American Indian life focuses largely on the processes and effects of relocation, the maintenance of American Indian identity in the city, and the development of pan-Indian movements (Arndt 1998; Beck 2002; Intertribal Friendship House et al. 2002; Jackson 1998; Jackson 2001; Jackson 2002; Lobo 1998; Ramirez 2007; Straus 2002; Straus and Valentino 1998). This fourth chapter explores research participants' views of what it means to be Native in an urban context and the ground level politics of identity taking place in Chicago. In the first half of the chapter I focus on local identity discourses in terms of blood, race, appearance, shared history, language, and performance. In the second half of the chapter I describe Chicago's contemporary Native community, illustrating that the community is made up of a number of interconnected networks that reach beyond the city to reservation spaces. In this chapter I show that Chicago is an inter-tribal community in which individuals both follow individual tribal traditions while also fostering a shared indigenous American identity.

In chapter six, I describe diabetes in Native Chicago. I show in this chapter that rates of diabetes are high in urban spaces like Chicago and this prevalence of the disease shapes local beliefs, practices, and understandings of the condition. I build upon anthropology of knowledge studies, which show that people learn through observation and engagement with the world around them (Downey 2007; Herzfeld 2004; Ingold 2000; Ingold 2003; Lave 1990; Mall 2007; Willerslev 2007). Children in the community learn about diabetes at a young age and in relationships of care in contrast to non-Native populations, and their knowledge of the disease and its care grows with age. This sixth chapter also documents the local views about diabetes in terms of fatalism and moralization about diabetes care. In this section I demonstrate how the prevalence of diabetes in the community, in addition to public health media, influences understandings of diabetes risk for indigenous Americans – and this is an important topic that I return to in chapter seven. In the last section of this sixth chapter, I describe an emic classification system that defines diabetes on a scale from mild to full-blown to severe. This system is based in local experiences and observations of the disease, and I contrast this emic system with the biomedical or etic model for diabetes.

In chapter seven, I take a step back and look more broadly at local definitions and explanations for diabetes in the community. Scholars have found that lay understandings of health and illness are shaped by local medical models and local experiences (Garro 2000; Hunt 1998; Sahota 2012). In the first half of this seventh chapter, I explore how diabetes definitions are based within the local medical system and community experiences with the disease. In the second half I look at diabetes explanations. In this section I describe two less mainstream explanations for diabetes development that correspond to local understandings of diabetes development, stress and intergenerational trauma. Explanations for why people develop diabetes range from genes and diet to intergenerational trauma and evolution. Building upon discussions in chapters five and six on Native identity and on Native risk for developing diabetes, I show that in local discourse, a vulnerability to developing diabetes is a trait linked with indigenous identity and ancestry.

In the last chapter I explore how care for diabetes is performed in Chicago. I argue in this chapter that "care" for diabetes goes far beyond individuals' self-care in this highly affected community. In the first-third of this chapter I look at expectations for care, and then local explanations for why some people choose not to perform diabetes care tasks. In the latter two-thirds of the chapter I focus on who, when, where, and how care work is performed. Care is often associated with and performed by women (Abel 2000; Allen and Webster 2001; Aronson 1992; Buhler-Wilkerson 2007; Marks 1996). I show that both men and women, along with young children, are involved in the day-to day care of diabetes in Chicago. Scholars argue that care has to be understood in terms of local contexts – historic, economic, social, cultural, and political (Han 2011; Han 2012; Klaits 2009; Yates-Doerr 2014). In the last section of this seventh chapter, I investigate the direct and indirect acts of care being performed by men, women, and children in individual households and on the community-wide level and situate this care work within the context of the diabetes epidemic in Native Chicago.

In the conclusion, I summarize the primary findings of this study, and the contributions it offers not only to the social sciences, but also to the local community and biomedical and public health communities.

CHAPTER 2
METHODS

Introduction

After just one month of research, I was elated upon receiving an invitation to participate in a seminar on diabetes in Chicago's American Indian community. The seminar took place in Laura's office. Laura Cunningham, Rebecca Mastin (the director of the center's elder program and the only person of Native ancestry in this meeting), Wendy Abney (the center's dietician), Fred Williamson (a social work intern), and I sat around Laura's recently cleared desk to discuss a range of topics related to diabetes – prevention, symptoms, diagnosis, education, research, and care. Having not run into any significant resistance to my presence at the center up to this point, I was unprepared for what was to come in this seminar.

While discussing how aspects of Native culture and history affect diabetes treatment, trust emerged as a prominent issue. Wendy had been speaking about the frequent research surveys brought into elder lunches when Rebecca shifted the topic of discussion to the position of outside researchers: "We don't trust people that sit in the corner with notebooks." I could feel my eyes widening, jaw tightening and abdomen tensing as I realized that though Rebecca's passing statement was directed at no one in particular, I was implicated in the comment. My eyes darted from person to person, anxiously avoiding eye contact with the incriminating evidence resting on my lap. My pink and green checkered notebook had been with me at all times to jot down observations and thoughts during the past month; even at the very moment of Rebecca's remark, I was jotting down Wendy's statement about how the community had been "surveyed to death." I could feel my face reddening with the heat of embarrassment as Laura transitioned the conversation towards the types of food offered at the center's events. My mind, however, could not make such a switch. As I drove home later that afternoon I began to interrogate the goals and motivations behind my research.

Approach to research

Rebecca's comment in that 2007 meeting significantly shaped the way I approached research in the community in the years that followed. Throughout this research I continued to observe critiques of researchers and their agendas and methodologies in this community. These local critiques mirror those published by Native scholars who criticize research and suggest ways in which to decolonize research methodologies. These scholars stress the fact that researchers have responsibilities to the communities they study (Deloria 1969; Deloria 1991; King 2007; Smith 1999).

This dissertation is based upon a total of 25 months of ethnographic research conducted with Chicago's American Indian population between 2007 and 2014. In Chicago I worked with a network of American Indians who were either living with diabetes or who were involved in the care for diabetes. This research consisted of observations of wellness programs at the American Indian Center of Chicago, shadowing diabetes patients for a few hours during their typical daily routine, ethnographic and oral history interviews, and archival research. During these months of research, I also volunteered at the American Indian Center and at other community events in the city. This volunteer work ranged from working at the center's reception desk, helping prepare for and clean up after community events, entering data for the center's wellness programs, and cleaning center bathrooms and floors. This volunteer work at the center both gave me an opportunity to observe the day-to-day management of the organization and further made me visible to community members. This volunteer work, then, helped me establish relationships with community members, effectively separating me from researchers who collect data and never return.

Research site and the local community

The greater Chicagoland area is home to tens of thousands of American Indians. My research began through contacts I made at the American Indian Center of Chicago. An advisor in my Master of Arts program at Southern Illinois University in Carbondale put me in touch with the director of the American Indian Center, who then put me in touch with Laura Cunningham. Founded in 1953, the Chicago American Indian Center is the oldest urban inter-tribal American Indian center in the United States. The center today is located in the Uptown neighborhood of Chicago, a neighborhood once known to house much of the city's Native population, though this population in recent decades has begun to move to the west in search of more affordable housing, which I describe in the conclusion to chapter four. The center was organized by the Native community in the area with early support from the American Friends Service Committee, a Quaker organization concerned with righting social injustices (American Friends Service Committee 2007). This center first opened with the aim of providing a social gathering place for the community in Chicago.

The American Indian Center relies on grants and donations to fund its programs and to support the building's upkeep. Funding has been a constant challenge for the center throughout its history (Garbarino 1973). Over the course of this research, funding for the center's programs has been unstable, and center staff attributes this uncertainty of funds in part to the lingering effects of the 2008 economic crisis. In 2007, the center employed nearly two dozen people. Today, there are five center employees, who community members describe as just being able to hold the center together and keep it running at the bare minimum level. The wellness department programming, for example, once offered social services, two weekly elder meals, health screenings at these meals, and monthly wellness events developed for the whole family. In 2009 the program employed two nurses, a dietician, a social services coordinator, an exercise coordinator, an elder lunch member coordinator, and a cook. This program at the time focused on all areas of wellness – physical, emotional, mental, and spiritual. Today the program is run by one part-time employee, and offers just one elder lunch a week and limited social services. This issue of limited funding for urban Native organizations is an important topic that I return to in both chapter four and the conclusion. Throughout this dissertation I refer to this American Indian Center using both its full and abbreviated titles commonly used in the community, “the center,” “the American Indian Center,” and “the Indian center.”

There are other Native organizations in the Chicago area utilized by community members. In this dissertation, I make reference to the Kateri Center, Saint Augustine’s Center, the Mitchell Museum, American Indian Association of Illinois, California Manpower Consortium, and American Indian Health Services of Chicago. Like the American Indian Center, many of these Native organizations remain located in the Uptown area of Chicago, though gentrification has begun to push Natives further west in the city. While I attended occasional events at each of these Native centers during this research, my work was primarily centered at the American Indian Center.

Research Participants

I began my research with interviews and observations at the American Indian Center and expanded from there through contacts first made at the center. Participants for this study were recruited using the snowball method of sampling. First working with the wellness department of the American Indian Center I met several medical practitioners, diabetes patients, and caregivers. Those first interviewees introduced me to other research participants. I completed 120 interviews with 95 participants for this study. Interviewees identified themselves as citizens of American Indian Nations from across the United States and Canada, including the Apache, Akimel O'odham, Arikara, Assiniboine, Cherokee, Chippewa, Choctaw, Covelo, Dakota, Ho Chunk, Lakota, Menominee, Meskwaki, Micmac, Navajo, Odawa, Ojibwe, Omaha, Oneida, Ponca, Potawatomi, Pueblo, Sac and Fox, Seneca, Sioux, and Stockbridge Nations.

There were two types of interviews for this study, diabetes and oral history interviews. The study included 93 interviews on diabetes and 27 oral history interviews with first and second generation relocatees. Table 1 below shows information about research participants. Diabetes interviews included 46 interviews with 40 people living with diabetes (15 men and 25 women), 30 interviews with 30 family members of diabetics (13 men and 17 women), and 17 interviews with 13 medical professionals (1 man and 12 women, 5 self-identified as Native and 8 as non-Native). In 2012 I began to conduct oral history interviews to learn more about Chicago's Native community and its history. These oral history interviews were completed with 9 men and 18 women who were between the ages of 50 and 87 and who either moved or their parents moved to a city during the era of the Federal Relocation Program.

Interview Participants (Table 1) [1]

	Diabetes Interviews	Caregiver Interviews	Biomedical Provider Interviews	Oral History Interviews
	N (%)	N (%)	N (%)	N (%)
Gender				
Male	**15** (37.5%)	**13** (43.3%)	**1** (7.7%)	**9** (33.3%)
Female	**25** (62.5%)	**17** (56.7%)	**12** (92.3%)	**18** (66.7%)
Age				
18-30	**4** (10.0%)	**7** (23.3%)	**3** (23.1%)	**0** (0%)
31-45	**8** (20.0%)	**9** (30.0%)	**2** (15.4%)	**0** (0%)
46-60	**13** (32.5%)	**13** (43.3%)	**5** (38.5%)	**11** (40.7%)
61-75	**13** (32.5%)	**1** (3.3%)	**3** (23.1%)	**11** (40.7%)
76+	**2** (5.0%)	**0** (0%)	**0** (0%)	**5** (18.5%)
Has diabetes				
Yes	**40** (100%)	**0** (0%)	**3** (23.1%)	**12** (44.4%)
No	**0** (0%)	**30** (100%)	**10** (76.9%)	**15** (55.6%)
Years with diabetes				
Less than 1 year	**8** (20.0%)	-	-	-
1-2	**5** (12.5%)	-	-	-
3-5	**10** (25.0%)	-	-	-
6-10	**4** (10.0%)	-	-	-
11-15	**5** (12.5%)	-	-	-
16-20	**1** (2.5%)	-	-	-
21 or more	**7** (17.5%)	-	-	-
Type of care provider				
Physician	-	-	**1** (7.7%)	-
Dietician	-	-	**1** (7.7%)	-
Nurse	-	-	**7** (53.8%)	-
Community Health Worker	-	-	**4** (30.8%)	-
Works primarily with Native population				
Yes	-	-	**10** (76.9%)	-
No	-	-	**3** (23.1%)	-
Year moved to Chicago				
1951-1960	-	-	-	**8** (29.6%)
1961-1970	-	-	-	**4** (14.8%)
1971-1980	-	-	-	**5** (18.5%)
1981-1990	-	-	-	**2** (7.4%)
Born in Chicago	-	-	-	**8** (29.6%)

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[1] For individuals interviewed more than one time, their age and/or their number of years diabetic indicated in this table is based on the time of their most recent interview.

Table 1 does not include social and economic status of research participants, nor does it include information on health insurance status. In Cook County, the county in which Chicago and its nearest suburbs are housed, American Indians face the second highest rate of families below the poverty line, behind African American families. In 2013, 22.4% of Native families living in Cook County lived on an income below the national poverty level (United States Census Bureau 2015). In interviews I did not inquire about income or health insurance status. The participant population does include a varied range of social and economic status based on what I can infer from other aspects of their life. Several participants held full time jobs, owned homes, held insurance plans through their place of work, and drove new cars. Many others were unemployed or underemployed, lived in apartments and utilized public transportation. A few other participants were homeless at the time of our interview.

Access to professional biomedical healthcare is also varied in this population. While some people seek healthcare regularly, others choose to go to a doctor only when absolutely necessary. In Chicago, Natives have access to a variety of health care options, including private and public health centers. Natives can receive free or very low cost care from Cook County Hospital and from American Indian Health Services of Chicago. In cases where individuals do not have insurance, they can use these local resources; however, the cost of time is high to utilize some of these resources. Participants describe full days in the waiting room to get in for an appointment at Cook County Hospital, a health center southwest of the city's downtown that can take a long time to reach via public transportation from the northern side of the city where many Chicago Natives reside. Similarly, American Indian Health Services of Chicago is described as being difficult to get in for an appointment. In addition to the tight schedules at that health center and the distance to the center from homes via public transportation, participants complained of the care they received at American Indian Health Services of Chicago. Some participants thought the providers were outwardly judgmental at the center, and some were uncomfortable with the quick pace of staff turnover. Many other participants, however, utilize American Indian Health Services of Chicago, and describe it as a great benefit to the community through their ability to gain access to care at a relatively low cost. Lastly, some community members seek health care on reservations on annual or semiannual visits to their home reservation.

Research methods

Two primary research methods for this project were interviews and observations. Interviews took between 15 and 90 minutes to complete, with an average length of 45 minutes. In diabetes interviews, I asked participants about their understandings of diabetes, their personal experiences in caring for the disease, and the history and status of diabetes in the community. In these oral history interviews, I asked participants about their and their families' experiences moving to Chicago, their life in the city and the reservation, and the history of Chicago's Native community. Interviews were recorded and transcribed, except in cases when the interviewee did not consent to a recorded interview. In the instances where an interviewee did not consent to a recording, I hand wrote their responses during the interview. Beginning in 2010, grant funding provided monies to compensate interviewees $20 for their time and travel to the interview site. Prior to 2010 I did not compensate participants.

Observational material collected during this research complemented the material collected through interviews. In Chicago I observed the day-to-day running of the center, its programs, and larger community events, including powwows, holidays, and funerals. Through my involvement with the wellness program staff and work in the center's kitchen for community meals, the weekly elder lunches and health screenings became primary observation sites. When I first began this research in 2007, the center held an elder lunch twice each week – every Monday and Wednesday. By the end of the summer of 2010, wellness department staff was being laid off due to lack of grant resources to pay their wages. It was around this time that the frequency of elder lunches began to decline, slowly with a cancellation one week here and there. By the time I returned in 2012, there were only Wednesday elder lunches. These lunches were once prepared and served by a dedicated cook and under the advisement of a staff dietician. The lunches today are prepared by volunteers and the remaining staff members from unrelated departments at the center.

The health screenings at the center have also been affected by these changes in center funds. The voluntary health screenings were once offered by the wellness department staff and its volunteer nurses. These health screenings were offered in the hour before the elder lunch began in the Tribal Hall at a small table near the entrance. Anyone attending lunch was welcome to have their blood pressure and/or their blood glucose measured. I observed that people who took part in the screenings always had their blood pressure tested, and then either opted in or out of having their blood glucose level tested. During these observations I would sit near the nurse or intern doing the screening and help by recording the results on a sheet that the center kept for their grant writing records. When the wellness department nurses were laid off, some volunteer nurses continued to offer health screenings with donated supplies until the summer of 2012.

Since that time, American Indian Health Services of Chicago performs health screenings at the center a few times a month before the elder lunches.[2]

Informal conversations that emerged in the day-to-day interactions at the center and in the community also informed this study. Conversations about diabetes and other health concerns including cancer, heart disease, fetal alcohol syndrome, and depression, and about the community and state of the center arose in daily interactions – while taking a lunch break during the Thursday food pantry, when someone stopped by for a chat while I sat at the reception desk, as we prepared the elder lunch on Wednesdays, or in cars while stuck in Chicago traffic. I occasionally offered to drive senior community members home from center events, and from 2012 through 2014, I commuted to Chicago from my home in Northwest Indiana with a community member who also lived in Indiana. These discussions about life in Chicago, Native health, the history of the community, and Native history that cropped up in these informal conversations have supplemented the information documented through formal interviews and observations.

In 2013 I added another area of observations by shadowing ten people living with diabetes in their daily routine. These shadowings occurred in the individual's home, at the American Indian Center, at a local powwow, and around town while running errands. On one occasion I was permitted by a doctor's office to observe a medical appointment with a research participant.[3] In shadowing diabetics, I aimed to observe the daily life experiences of living with

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[2] Due to HIPAA (Health Insurance Portability and Accountability Act), I did not observe the health screenings performed by American Indian Health Services of Chicago.

[3] I had anticipated observing fifteen medical appointments with diabetes patients in Chicago, but ran into significant resistance from medical offices. The appointment I did observe was at a small private practice with one medical provider who consented to my observation of the appointment. The majority of other clinics attended by research participants in contrast, however, were part of larger medical organizations. These larger organizations required that I speak with their legal representatives about my research and gain their approval before I could move forward with

diabetes in the city. In the medical appointment, I noted the flow of the appointment, what each participant in the appointment discussed in terms of health and care, and how each person interacted with the other. For all observations and informal conversations, I recorded notes from memory upon returning home. Due to my experience on that awkward day of research in 2007, I rarely took notes while onsite at the center. I occasionally jotted notes down when something was said and I wanted to capture the exact turn of phrase used. Otherwise fieldnotes were recorded from memory once I returned home each evening.

In addition to collecting data through observations, informal conversations, and interviews, I also collected print documents and studied archived materials. I collected diabetes related literature from local community centers, pharmacies, and medical centers visited by people in the community. Notes were taken on these pamphlets and materials, noting, for instance, for whom the text was intended, the meanings and ideologies communicated through text, and how communication is accomplished through text. Archival research was done at the Newberry Library in Chicago. This archival research focused on the history of Chicago's Native community and the Federal Relocation Program. At the library I sought out documents on the relocation program, an oral history pilot project on Chicago's Native community from the 1980s,

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observations on their premises. I stopped pursuing the attainment of this type of approval and, thereby, the observations of medical appointments in May of 2013 when I discovered that my attempts to gain access to these medical locations had been and would continue to be futile. In May 2013, I contacted the legal representative for Advocate Health in Chicago, who after I explained the project and the Internal Review Board (IRB) protocol I had obtained from the University of Wisconsin, advised me to complete a protocol application with their IRB. After speaking with this representative for another ten minutes about the project, why I was in Chicago, and the fact that there is a substantial Native population in the city, she offered to email me the information for the IRB process at Advocate Health. I thanked her for help and also explained that I would not at this time apply for their IRB, as the appointment with the research participant was only a week away – not nearly enough time to write, submit, and gain IRB approval. In response, the representative then said "To be honest, I don't think it would get approved," explaining that even the staff on site has trouble obtaining IRB approval for local research projects. After this interaction and many earlier road blocks to observations in clinics, I decided to forgo the medical appointment observations for this study, and instead refocus my attention to urban Native community life.

records from Native organizations in the city, and the documents of researchers on Native life and history. These documents offer additional context to this study.

Research approval

This study was approved by the Social and Behavioral Sciences Internal Review Board of the University of Wisconsin Madison under protocol number SE-2009-0188, and then transferred and reapproved under the Minimal Risk Internal Review Board of the University of Wisconsin Madison under protocol number 2012-0345. Because the research protocol grew in the fall of 2012 to include observations of medical appointments, a new protocol on medical appointment observations was submitted to and approved by the Minimal Risk IRB. In order to reduce confusion, the entirety of this research protocol was transferred from the Social and Behavioral Sciences IRB to the Minimal Risk IRB in March of 2013. In accordance with the requirements of the IRB, throughout this work I refer to participants using pseudonyms. These pseudonyms were randomly chosen using the website fakenamegenerator.com. All tribal affiliations listed of participants are those named by the participants, using the spelling they provided. Ages listed in association with participants are their age at the time of the interview.

Analysis

I began analyzing this data during the course of the research, noting trends that emerged in the day-to-day observations and the interviews, and in the transcription process of interview material. Trends that I noted early on include, for instance, a widespread fatalistic view of the inevitability of a diabetes diagnosis and gendered divisions of diabetes care work. These trends, which I first noted in typing daily observational notes and in transcribing, provided a base set of categories for coding data using NVivo coding software. Using this software I coded electronic data sources – including observational fieldnotes, interview transcripts, notes from archival research, and analyses of diabetes texts. Coding was an iterative process that began with identifying ethnographically relevant categories and important themes relating to diabetes, Native identity, and community history. These themes were identified by looking at frequency of mention or occurrence, including for instance, how life factors influence diabetes definitions and how fatalistic views of diabetes development in this context do not necessarily hinder people from taking preventative measures – topics discussed in detail in chapters five and six.

The majority of analysis was done through analyzing textual data through coding. In two instances I use statistics to analyze participation in diabetes care. In chapter eight I compare participation in care practices of male and female participants using a two-proportion z-test, with the null hypothesis that the two groups would be equally involved in diabetes care.[4]

A brief note on subjectivity

Before moving on to the main text of this dissertation, I want to make note of how my own personal experiences with diabetes have influenced this study. I have had type 1 diabetes since adolescence, and have seen family members care for type 2 diabetes throughout my life. These personal and familial experiences with the disease have shaped this research in both known and unknown ways. First and foremost, my interest in this topic was spurred by my

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[4] $H_0: p_1 = p_2$ and $H_1: p_1 \neq p_2$ with test statistic $z = (p_1 - p_2) / \sqrt{P(1-P)\left(\frac{1}{n_1} + \frac{1}{n_2}\right)}$ and $P = \frac{x_1 + x_2}{n_1 + n_2}$

curiosity to know how culture and history shaped the experience of diabetes. My lived experience as a diabetic – particularly experiencing cases of high and low blood glucose levels, being acutely aware of my own daily carbohydrate consumption, and working with biomedical providers to develop care routines – influenced the development of the research protocol and my analysis of the data collected. For instance, while transcribing interviews during the first phase of research in 2007, I realized that one interview question was leading interviewees to a response focused on the role of diet in diabetes care. Aware of the possibility of such unintended influences since that first month of study, I have striven to mitigate this influence by reevaluating observation methods and interview questions throughout this course of this research. For example, I revised the phrasing of interview questions to ensure they are open-ended. The influence my experiences with diabetes has had was further realized in the process of analyzing this research material. For example, as I describe in chapter six, diabetes is learned about in care practices within homes and in the community. However, I did not initially recognize this as an interesting finding from this study, because I too learned about the disease through care practices within my home life. While my experiences with diabetes have required additional care in developing research methods and analysis, my status as a fellow diabetic was also beneficial in the early years of this study when I had fewer contacts in Chicago. During these early years, some community members expressed greater comfort with me as a researcher because I shared some of their experiences in managing diabetes.

CHAPTER 3
DIABETES AMONG AMERICAN INDIANS

Introduction

Old invoices, hand written notes, and crumpled paper napkins are strewn across the desk between us as Steven Barnes talks about his experiences with diabetes. Steven is a 61-year-old Seneca man who moved from the Tonawanda Reservation in upstate New York to Chicago in 1979. Today Steven is a slender man with ear-length jet black hair and glasses. While it is hard to imagine Steven at a larger size, he explains that at his diagnosis with diabetes 15 years earlier he was 75 pounds heavier than today. His weight loss helped him to take control of diabetes, a control, he explains, that requires knowledge and self-discipline. Upon his diagnosis, Steven immediately quit drinking alcohol and smoking cigarettes, and over time learned how certain foods and activities affected his blood glucose control. Half an hour into our interview Steven's wife Susan pokes her head into this office on the lower level of the American Indian Center to see if we were done, jesting that Steven likes to talk and I should stop him if he is going on too long. Steven retorts that he never gets to talk at home, and is going to use this opportunity as he pleases. After Susan leaves, laughing along with Steven and me at his reply, we return to our conversation on diabetes and its causes. While describing the factors that can lead to diabetes, Steven notes that Native Americans have particularly high rates of the disease. I ask him to elaborate on why he thinks that is the case.

> This is a personal view of mine. I think that the way that the Native American people have been susceptible - to live the white man's way, to live the way the white man lives and to eat the white man's food… 200 years ago, there was no such thing as smallpox, there was no diseases here until the white man came across this ocean and brought them with him. The Indians never had no problems

> with any of that thing or anything like that. Common colds and stuff like that maybe, but nothing as rampant as these [referring to smallpox and diabetes].

Steven describes diabetes as a disease that is rampant among Native populations today, but that did not exist in those populations prior to contact with European populations.

While diabetes appears new to some members of American Indian communities, it has a long history. Diabetes has affected humans for thousands of years (Aretæus et al. 1856; Bryan 1931; Galen 2006 [~150CE]; Henschen 1969; Hippocrates et al. 1978 [~500BCE]; Papaspyros 1964; Sanders 2002; Schneider 1972). While it was known to exist in Old World contexts for millennia, diagnoses of diabetes among the indigenous peoples of North America were rare prior to World War Two (Joslin 1940; Olson 2001; West 1974). Since that time the rate of diabetes has rapidly grown in American Indian, Alaskan Native, and First Nations populations, as it simultaneously rose in other indigenous populations worldwide (Knowler 1990; Montoya 2007; National Institutes of Health 2008; Pavkov et al. 2007; Schultz 1999; Smith-Morris 2006; Szathmary 1994; West 1974). In the United States, American Indians have the highest rates of diabetes when compared with other ethnic groups. According to the Centers for Disease Control and Prevention, 15.9 percent of American Indian adults are living with diabetes. The Centers for Disease Control and Prevention estimate that 13.2 percent of Non-Hispanic Blacks, 12.8 percent of Hispanics, 9.0 percent Asian Americans and 7.6 percent of Non-Hispanic Whites are living with diabetes. Within Native populations, the rates of diabetes vary by tribe; some Alaskan Native nations have as low as 5.5 percent of the population with diabetes, while some Southwestern American Indian nations have as high as 33.5 percent of the adult population living with diabetes (Centers for Disease Control and Prevention 2014).[1] Today American Indians not only have some of the highest rates of diabetes, but they are developing diabetes earlier in life and they suffer from higher rates of diabetes complications when compared with other ethnic populations in the United States (Centers for Disease Control and Prevention 2011).

My aim in this chapter is to provide an overview of diabetes to serve as a background for the remainder of this dissertation. I begin by looking at the history of what we now call diabetes in the human race. This history is both brief and partial, relying on extant written records of what has been interpreted as early cases of the disease. I contextualize these early accounts of diabetes by describing the features of the ancient Greco-Roman medical model under which many of these accounts were written. I include this history both to give readers a sense of the long history of diabetes in humans in contrast to the very recent development of diabetes cases in American Indian peoples, and to compare features of historical models of diabetes to contemporary biomedical understandings of the disease. While there are other accounts of diabetes in early human history in the Old World, I focus primarily on Greco-Roman accounts of diabetes in the first portion of this chapter because the contemporary biomedical model of the condition that is most often utilized by the participants of this study is built upon these accounts. After looking at the history of diabetes from antiquity through the development of insulin therapy, I turn to modern definitions of diabetes. In this section I use interview excerpts and published biomedical materials to explore the contemporary biomedical model of this disease. Finally, in the last two sections of this chapter I describe the relatively recent diabetes epidemic in American Indian populations and review biomedical explanations for why people develop diabetes, with a

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[1] Adults are defined as those over the age of 20 in these studies referenced by the Centers for Disease Control and Prevention. In a study of the Akimel O’odham Indian Tribe of the Gila River reservation, 50 percent of those over the age of 35 were living with diabetes (Knowler 1978; Knowler 1990).

particular focus on explanations for why American Indians are developing diabetes at such high rates today. I argue that the diabetes epidemic among American Indians today was engendered by colonial policies. As foreshadowed by Steven's description, there are local definitions and explanations for diabetes in Native communities that both mirror and diverge from the biomedical explanations explored in this chapter. These local understandings are the focus of chapters six and seven.

A history of diabetes in the western world

Diabetes existed in Old World contexts more than three millennia ago (Feudtner 2006; Papaspyros 1964; Sanders 2002; Schneider 1972; Schumacher 1961). While the earliest extant accounts of diabetes date back to 3500 years ago, it is likely that pre-modern hominin species experienced the condition during earlier periods in history for which we do not have written evidence. For instance, scholars have found that Neanderthals carried a gene that today is associated with the development of type two diabetes (The Sigma Type Diabetes Consortium 2014). The experience of diabetes in prehistory and antiquity would have been very different from the diabetes we know now – today physicians recognize multiple manifestations of the disease and there are therapies to manage the condition, whereas diabetes in ancient texts is described as a singular condition classified with other fatal diseases.

Medical classification systems shape the ways in which diseases are understood and treated. Geoffrey Bowker and Susan Leigh Star explain that classifying the world around us is an essential component of human life (Bowker and Star 1999). It is these classifications and organizations that influence and shape behavior (Bowker and Star 1999; Hacking 2007[1986]). Fitting a human experience of ill-health into the local taxonomic system is an important step in a medical system. In his study of Subanun disease categories, Charles Frake illustrates that diagnosing a condition is pivotal in determining the next steps that are taken for treating the condition (Frake 1961). Once an ailment is diagnosed, treatment can begin. The model of diabetes in ancient Greek and Roman medicine was shaped by the medical thought of the period. To situate understandings and classifications of diabetes in antiquity, I first describe the medical model of ancient Greece and Rome.

During the fifth and fourth centuries BCE in Greece, Hippocrates developed a school of medicine that strove to separate medical practice from religious practice. This shift was based on the view that health and disease had worldly explanations for their causes and these explanations would determine treatment (Hippocrates et al. 1978 [~500BCE]). The concepts of balance and imbalance were central to conceptualizing health, disease, and treatment during this period (Lloyd 1978). Medical anthropologist George Foster would categorize this medical system as a naturalistic one. In a naturalistic system illness is explained in terms of an imbalance in the body created by natural forces or conditions; in a personalistic system, on the other hand, illness is understood to be caused by the actions of an agent – either human or supernatural (Foster 1976). Working from the standpoint that nature sought balance, Hippocrates and his students used diet and other life activity adjustments, for instance staying in the bath longer or daily exercise, as treatment to help patients return to a balanced state (Nutton 1995a).

An understanding of the internal structures of the human form was important to the development of this medical model. The Grecian medical practices developed by Hippocrates and his students migrated to Egypt and Rome in the centuries after Hippocrates' lifetime (Lloyd 1978; Nutton 1995b; Smith 1979; Temkin and Cranefield 1973). In these Mediterranean locales, knowledge of where a disease was situated within the body helped physicians to determine treatment plans (Nutton 1995b; Temkin and Cranefield 1973). In order to understand how the body functioned and how diseases could situate themselves in bodies, dissections were performed on animals, and, on rare occasion, on humans during Hippocrates' lifetime (Nutton 1995a). By the time that physician Aulus Cornelius Celsus wrote his encyclopedic account *Of Medicine* in the first century CE, the practice of dissecting human bodies was considered a necessity for physicians (Celsus 1756 [~25CE]). In the centuries that followed his lifetime, the medical practice developed by Hippocrates and his students spread throughout the Mediterranean and continued to seek knowledge by seeking the cause for disease within human bodies.

Throughout antiquity, there was little official control of medicine or medical knowledge in Greece and Rome; medicine was diverse, people passed knowledge primarily through oral means, and the divine still held a place in the healing practices of some. In the ancient Greco-Roman world medicine began to break from the ties with religious healing practices through the efforts of physicians. These physicians emphasized the natural basis for ailments that affected the human body and rejected the notion of supernatural or divine beings interfering in human health. Medicine was a practice that sought knowledge through observation. These steps towards developing a rationalized medicine contributed to the early development of the medical model that organizes biomedicine today, as physicians began to build authority in recognizing, defining, and developing treatment and management plans for disease.

Diabetes was present in the human population while these medical practices were first developing. Medical historians identify the existence of diabetes in antiquity based upon descriptions of symptoms commonly linked to the condition – polyuria and polydipsia, or frequent urination and excessive thirst. Entries in the Papyrus Ebers, written around 1500 BCE in Egypt describe several remedies and ointments for treating polyuria (Bryan 1931; Christopoulou-

Aletra and Paparamidou 2008; Papaspyros 1964). Though Hippocrates is described as not studying diseases he could not effectively treat, there are some indirect references to what is thought to be diabetes in the Hippocratic Corpus, specifically descriptions of polyuria (Fournier 2000; Gemmill 1972; Morgan 1877; Papaspyros 1964; Schneider 1972).[2] While there are references to what medical historians believe are cases of diabetes earlier, the condition known today as diabetes was not commonly referred to using that label until the second century BCE. There is dispute over who was first to coin the term "diabetes" which in ancient Greek translates to "siphon." Some historians of the disease believe that it was Demetrius of Apamea who offered the term "diabetes" to describe the condition (Christopoulou-Aletra and Papavramidou 2008; Gemmill 1972; Schneider 1972).[3] Aretæus of Cappadocia has also been accredited with the naming of the condition "diabetes."

While Aretæus may or may not be responsible for the naming of diabetes, he is credited with having written the most complete description of the disease in antiquity (Fournier 2000; Gemmill 1972; Henschen; Papaspyros 1964; Sanders 2002; Schneider 1972; Schumacher 1961; Smith 1979). Aretæus describes the application of the term diabetes to this condition:

> It seems to me that the epithet Diabetes has been assigned from the disorder being something like passing of water by a siphon, since the liquid does not remain in the body, but makes use of the patient to escape as it would by a bridge [Aretæus 1971 [~50 CE]:6]

According to Aretæus, for those who have developed diabetes, the body acts as a bridge, channel, or ladder for water to pass through.[4] Aretæus notes the similarity of the disease to the

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[2] The Hippocratic Corpus is made up of the works of not only Hippocrates, but also his students.

[3] The original manuscripts, however, have since been lost to history and the printers who copied the manuscripts that held this information, it is believed, failed to transcribe the one paragraph in which Demetrius named the affliction "diabetes."

[4] Gemmill (1972) notes that the translation of the Greek term to ladder does not quite fit in this context, and that bridge or channel more aptly fit what he believes Aretæus was trying to describe.

effects of a bite from the dispas snake, a bite that was fabled to engender a great thirst in the person bitten.

Aretæus' description of diabetes is one focused on the outward physical effects diabetes has on the affected individual's body. In Aretæus' description, diabetes does not immediately attack and destroy the human body, but slowly establishes its presence:

> When the malady is established, it is obvious enough; while it is impending, the mouth is dry, the saliva white and frothy, as if from thirst, though as yet there really is no thirst; there is a feeling of weight in the hypochondria, a sensation of heat or cold proceeding from the stomach to the bladder, like the passage of the disease in its progress [Aretæus 1971 [~50 CE]:3]

In this account, Aretæus describes the disease as being a disorder with the bladder or kidney. As the disease progresses, the symptoms worsen:

> Life too is odious and painful, the thirst is ungovernable, and the copious potations are more than equaled by the profuse urinary discharge; for more urine flows away, and it is impossible to put any restraint to the patient's drinking or making water. For if he stop for a very brief period, and leave off drinking, the mouth becomes parched, the body dry; the bowels seem on fire, he is wretched and uneasy, and soon dies, tormented with burning thirst [Aretæus 1971 [~50 CE]:3]

As Aretæus expands on his description of the experience of diabetes:

> How indeed could the making of water be stopped, or what sense of modesty is paramount to pain? But if he continue to place restraint on himself for a short time, then loins, testicles, and ischia swell, and when he relaxes, he discharges a vastly profuse quantity of water, and the swelling subsides, for the superfluity passes by the bladder [Aretæus 1971 [~50 CE]:3]

In reading Aretæus' description of diabetes we become privy to the experience of diabetes in antiquity – dry mouth, frequent urination, and great discomfort. In creating such an account of the disease, Aretæus abides by and contributes to this ancient medical model and understanding of diabetes in three ways. First, he links the occurrence of the disease to causal factors in the natural environment – both by relating it to the effects of snake venom and considering it a disorder of the organs. Second, he locates the disease within the body by specifically noting its relationship with the kidneys and bladder. And lastly, in developing the most thorough extant account of the disease, Aretæus contributes to the already growing power of rationalized medicine by inscribing this definition of the disease that was not revised again until the eighteenth century (Gemmill 1972).

Evidence of diabetes has been found throughout the Old World in early history. In the Hindu world, a disease is described in the *Ayur-veda* as being indicated through the signs of sweet or honey urine, phlegm, and sweat (Henschen 1969). Between 1400 and 2000 years ago, Charaka, Susruta, and Vaghbata described the sweetness of urine in some individuals almost one thousand years before their European counterparts did, by noting the attraction of ants to the urine of those afflicted with this ailment (Sanders 2002; Schneider 1972).[5] In the third and fourth centuries CE China, physician Tchang-Thoug-King noted the attraction of dogs to the urine of those who had a malady of thirst (Papaspyros 1964). In the tenth century CE Arab physician Avicenna, like Aretæus, wrote a detailed account of the symptoms and progression of diabetes (Clarke and Foster 2012).

Worldwide, diabetes was an acute and fatal disease until the early twentieth century. As noted above, the definition of diabetes in western medicine did not significantly change between Aretæus' lifetime in the first century CE and the eighteenth century. During this expanse of time, treatment for the condition aimed to minimize symptoms and ease pain before death (Martin 1966; Papaspyros 1964). In the early twentieth century, the understanding of and care for diabetes transitioned with the development of insulin therapy.

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[5] The dates of Charaka's life are uncertain; he is placed sometime between 600BCE and 600CE – and has been linked to the writing some of the *Ayurvedic* texts.

Treating diabetes in the twentieth century

In 1921 diabetes shifted from an acute disease to a chronic condition with the successful extraction and purification of insulin for injection in humans (Feudtner 2006; Papaspyros 1964).[6] This extraction came after several decades of research that determined the role of insulin in living organisms. Medical historians tracing the history of diabetes highlight a few key dates and events over the past few centuries that led to the modern understanding and treatment of diabetes. The processes of the science behind this development, of course, are more complicated than this brief history shows. Science and technology studies scholars Bruno Latour, Steven Woolgar, Andrew Pickering, and Karin Knorr-Cetina show that the work done in laboratories is a long and complicated process of negotiation between scientists and their objects of study (Knorr-Cetina 1999; Latour and Woolgar 1986; Pickering 1995). In this section I highlight some of the key events, knowing that failed experiments and running into dead ends after years of research also played a significant role in shaping the biomedical model of diabetes today. To situate this history of insulin therapy development, I first describe the medical model under which it was developed – biomedicine.

As a practice, biomedicine was established as the principal medical practice in the west over the decades between the turn of the twentieth century and the end of World War Two (Clarke et al 2003). Biomedicine is not one singular practice. Rather, biomedicine is shaped by and enmeshed in the local contexts in which it is practiced (Fullwiley 2011; Livingston 2012; Lock and Nguyen 2010; Wendland 2010). Though its practice is situated within local spaces, there are features of biomedicine that bind it together across these spaces. Globally, biomedicine

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[6] In rural and impoverished locales, uncertain insulin supplies problematize the status of diabetes as a chronic condition.

is reliant upon the standardization of bodies in order to understand what constitutes disease and wellbeing. In this system, norms are created using statistical data – and scholars note that individual corporeal bodies rarely meet these expected standards (Epstein 2007; Foucault 1990; Lock and Nguyen 2010; Rose 2001; Urla and Swedlund 2004). Where Greek and Roman physicians sought to locate the causes of diseases within organs in the body, biomedicine increasingly focuses on locating disease at some of the smallest levels within the body – genes, cells, and molecules – and is dependent upon science and technology to make the interior of the human body at these levels visible (Clarke et al. 2003; Lock and Nguyen 2010; Rose 2013). Anthropologists Margaret Lock and Vinh-Kim Nguyen describe that this relationship with science, biology, and technology works to legitimate biomedicine and its use on a global scale (Lock and Nguyen 2010).

Understandings of diabetes transitioned along with the changes in the medical system. In antiquity, the patient's symptoms were central to the definition of diabetes and it was thought to be located in the bladder or kidneys. By the late nineteenth century, scientists began to look deeper within the human body to understand the cause of the disease. In the nineteenth century French scientists Joseph Freiherr von Mering and Oscar Minkowski learned that removing the pancreas of a dog resulted in the dog displaying diabetes symptoms. Eugene Opie found in 1901 that the pancreas' islet cells, cells first noted and described by Paul Langerhans in the nineteenth century, showed lesions in patients with diabetes. By 1913 Sir Edward Albert Sharpey-Schäfer and Jean de Meyer had independently referred to the hormone secreted by the islets of Langerhans as "insuline." Each hypothesized that a disturbance in the production of this hormone would lead to diabetes (Papaspyros 1964; Rosenfeld 2002). In 1916 Sharpey-Schäfer suggested that the islets of the β-cells in the pancreas secrete insulin (Papaspyros 1964). By

1916, then, scientists aimed to find a way to reintroduce insulin to the diabetic patient as a possible means of managing diabetes (Papaspyros 1964; Rosenfeld 2002). In the early years of biomedicine's development, the definition of diabetes shifted and scientists narrowed down the location of the disease. Diabetes was no longer being defined primarily by the symptoms of polyuria and polydipsia. Scientists had located the cause of diabetes not merely in the pancreas, but in the islets of β-cells within the pancreas, reducing the condition to smaller levels within the body.

Finding a way to reintroduce insulin into the diabetes patient was a long process of trial and error.[7] Fredrick Grant Banting and John James Rickard Macleod, along with their student assistants Charles Herbert Best and James Bertram Collip first successfully extracted insulin for use in lowering the blood glucose of a person with diabetes in 1921. Banting and Macleod won the 1923 Nobel Prize in Physiology or Medicine for their work on insulin and each shared half of their prize monies with their student assistants, Best and Collip (Papaspyros 1964; Rosenfeld 2002). In the 1920s, pharmaceutical company Eli Lilly and the University of Ontario took up role of the mass producers of insulin which in its early years was extracted from pigs and cattle.[8]

Understandings of diabetes today are built upon this history of diabetes in human populations, forming a palimpsest over the descriptions of Aretæus and the studies of Sharpey-Schäfer. In the next section I look at contemporary definitions of the disease offered in biomedical publications and from biomedically trained research participants, and show how this development of insulin therapy spurred further refinements and divisions in the biomedical model of diabetes.

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[7] See Rosenfeld 2002 for a description of the scientific history, partnership, and later rivalry of Fredrick Banting and John James Rickard Macleod in this process.

[8] Today most insulin in the United States is recombinant human insulin.

Defining diabetes today

A mesh hamper filled with cicadas rests on the long buffet table in Laura's office, their song providing a backdrop to our discussion. Having worked as a nurse in Chicago's Native community for more than a decade, Laura Cunningham is involved in a wide range of projects in the community – from planting a Native food and medicine garden and hosting traditional healers and spiritual leaders for weekend events to helping members of the community manage chronic condition care, and later this afternoon teaching youth at the American Indian Center about the seventeen-year-life-cycle of cicadas. After two weeks of shadowing Laura in her daily routine during my first stint of research in 2007, we sit down to discuss diabetes care in the community. Laura earned a bachelor's degree in nursing in the late 1990s after working as a registered nurse since 1980. In addition to her training in the biomedical field of nursing, Laura has also taken courses in in Ayurvedic and Chinese medicine and worked with Native American medicine men from across the Midwestern United States. In response to my question "what is diabetes," Laura defines diabetes by describing its physiological traits, noting that it can lead to additional health concerns, and seriously considering local explanations for its cause in Native populations.

> We call diabetes, whether it's type one or type two, we still call it diabetes but they're two very, very different things. They happen to both end up with high blood sugar and they both happen to, can lead to a lot of the same chronic illnesses such as kidney failure, and high blood pressure, and eye problems and that kind of thing. But I think that they're two different things. So there is that, physiological part. But I once met a Ho-Chunk man who felt that diabetes was a conspiracy by the US government. He was very serious about this. He felt that the government had poisoned his people a long time ago and it was now coming out. And I have to say I didn't totally disagree with him.

I learned within a few short weeks of beginning this research in the summer of 2007 that interviewees found this question, "What is diabetes?" far more difficult to answer than I had anticipated. Participants with and without biomedical training had a hard time developing and organizing a description of what they knew as diabetes. Laura's definition stands out from other definitions offered by biomedical providers I spoke with and from those found in biomedical publications in her inclusion of this idea that diabetes in Native populations is a conspiracy of the United States Government. In chapter seven, local explanations for diabetes development will be discussed in detail.

> The American Diabetes Association defines diabetes as:
>
> A group of metabolic diseases characterized by hyperglycemia resulting from defects in insulin secretion, insulin action, or both. The chronic hyperglycemia of diabetes is associated with long-term damage, dysfunction, and failure of different organs, especially the eyes, kidneys, nerves, heart, and blood vessel. [American Diabetes Association 2014:581]

Of the 13 biomedical providers I spoke with, 11 providers' definitions of the condition factored hyperglycemia, or high blood glucose levels, into their definition. In addition to defining diabetes in terms of elevated glucose levels, biomedical providers focused on diabetes as a failure, inability, or malfunction in the body's capability to break down and metabolize food:

> Laura Cunningham: The body's endocrine system does not *function* in the appropriate manner to keep, in particular, blood sugars in a normal range. [55-year-old non-Native nurse]

> Janice Block: Diabetes I would have to say it's the inability of the body to… metabolize glucose levels. It's when the blood sugars in the body are, are elevated than normal. [30-year-old Ojibwe nurse]

Providers describe diabetes as an insufficient amount of insulin, referring specifically to the endocrine system and metabolism. According to this biomedical model, as we eat, food is broken down into glucose; this glucose makes its way into our cells as sources of energy. In order for the glucose to enter cells, insulin is necessary. Insulin is described by biomedical providers as the key that opens the pathway allowing glucose to enter the cell. For someone with diabetes then, his/her insulin is not working the way that the biomedical model expects it should – it is not opening that cell or the individual is not producing enough insulin. In these descriptions, we can see that there is an expectation for how the body should function and that with diabetes the body is not doing what is expected of it. The result of this lack of proper functioning or reduced amount of insulin is hyperglycemia. This model of diabetes frames the disease around the metaphor of the body as a machine or factory of machines, in which the piece responsible for insulin production or the cells that should be responsive to insulin are defective. This body as machine metaphor is common in biomedical models of the body today (Martin 1997; Scheper-Hughes and Lock 1987).

While this biomedical definition of diabetes strives to describe the physiological factors behind diabetes, it does not get at the experience of diabetes for those living with the disease in the same way that Aretæus was able to in the first century CE. Since that time, a great separation has occurred in biomedicine, whereby the patient and his/her experience of disease have been removed from definitions of disease and findings based in the bio-technological sciences have taken the place of the patient and his/her bodily experience.

In recent decades, biomedical technologies have increasingly affected the human-body experience. Rayna Rapp describes how ultrasound technology altered the ways in which women experience pregnancy (Rapp 1999). Through ultrasound technology, the health of the fetus that was once only known through the mother's experiences can now be viewed through the technology; ultrasound, as Rapp explains, gives doctors a window into the womb and shifts the experience of pregnancy from an individual mother's experience to a communal one. This shift in bodily health experience is also noted in the work of Margaret Lock (2002) and Annemarie

Mol (2002), where the severity of brain death and atherosclerosis is defined through expert interpretation of high-tech images. In the case of atherosclerosis, the person's experience of his/her own body is shaped by these expert interpretations (Mol 2002). Medical technologies are increasingly making their way into individual homes, and this migration of medical technologies into the home is especially true for diabetes management. In her study of blood-glucose monitoring devices in the Netherlands, Annemarie Mol shows that through the increase in at-home glucose monitoring, the sensations of hyperglycemia in diabetes patients are no longer trustworthy; these sensations take a back seat to the numbers that appear on the screen (Mol 2000). In chapter eight I discuss how some research participants with diabetes explain that they do not always feel any symptoms of the disease and are reliant upon these blood glucose monitoring devices to tell them if their blood glucose levels are in the range their physicians would like them to be. Technologies, then, not only shift views of the body, but can challenge and alter one's body experience.

Biomedical technologies, in addition to shaping the personal experiences of disease, shape medical classification systems. As a medical technology, insulin shifted the experience of those living with diabetes. People with diabetes now lived for decades after diagnosis and this increased lifespan of a person with diabetes led to further refinements in the biomedical model of diabetes. In the mid-twentieth century biomedical researchers began to record diabetes related complications: renal disease, retinopathy, cardiovascular disease, and neuropathy. By the 1970s, research studies began to associate long-term hyperglycemia with the development of these complications (Clarke and Foster 2012). During this post-insulin therapy period, diabetes not only grew to include the possible development of future complications, but it also was re-defined by researchers to include multiple forms of the condition. Until the 1950s, biomedicine recognized diabetes as a single disease. By the end of that decade, researchers had noted variation in amounts of extractable insulin in diabetic patients through post-mortem autopsies that suggested differing degrees of diabetes severity. By the 1980s, it was well recognized that there are multiple forms of diabetes, forms that are continuing to expand today (American Diabetes Association 2014; Martin 1966; Neel 1982). Over the course of 60 years, then, diabetes transitioned through insulin therapy from a fatal disease to a set of diseases that share hyperglycemia as a defining feature and that can lead to complications if not under control.

The three most common forms of diabetes are type 2, type 1, and gestational diabetes. According to the biomedical model, type 2 diabetes occurs in individuals who are insulin resistant. Often in the early stages of type 2 diabetes, insulin is over produced and the individual builds up a resistance to insulin. In the past, type 2 diabetes was often referred to as adult-onset diabetes, because people typically developed the disease in mid to late adulthood. Today more and more people are developing diabetes at a younger age, and American Indians have the highest rate of adolescent and childhood type 2 diabetes cases in the United States (Centers for Disease Control and Prevention 2011; Fagot-Campagna et al. 2001). Two less common types of diabetes are type 1 and gestational diabetes. According to the biomedical model, type 1 diabetes occurs in individuals whose immune system destroyed the insulin producing cells of the pancreas and gestational diabetes occurs when pregnancy induces a state of insulin resistance. In gestational diabetes, once the woman has given birth, her blood glucose returns to normal levels, however, both the mother and the child are considered to be at a heightened risk for developing type 2 diabetes later in life (Hales and Barker 1992; Vaag et al. 2012). There are additional forms of diabetes that are brought on by disease and surgery that occur less frequently, and there are multiple divisions within type 2 and type 1 diabetes being defined and elaborated upon each year by national and international diabetes organizations (for examples see American Diabetes Association 2014).

To summarize, biomedicine defines diabetes as a chronic condition characterized by elevated levels of blood glucose due to either insulin deficiency or insulin resistance that can lead to complications if not controlled. What biomedicine is still striving to answer is what the ultimate causes of diabetes are – why do some people become insulin resistant? And why do others lose their insulin producing cells? Before discussing hypotheses for type 2 diabetes etiology, I describe the recent history of diabetes in American Indian populations.

The American Indian diabetes epidemic

While there is ample evidence of diabetes in human populations throughout the past 3500 years, diabetes was rare in American Indian peoples prior to World War Two. The earliest recorded case of diabetes in a Native person is found in the medical notes of Doctor W.K. Callahan who treated an Akimel O'odham woman for diabetes in 1902 (documented in Hrdlička 1908).[9] The next recorded case of diabetes is found in diabetes specialist Elliot P. Joslin's 1940 article "The Universality of Diabetes," in which he describes how diabetes is found among members of an Arizona Navajo population noting one diabetic Navajo male in the article (Joslin 1940). Based upon military records, Kelly M. West finds no recorded cases of diabetes prior to 1939 among American Indian peoples living in Oklahoma (West 1974).[10] Both West's study and Dennis Wiedman's more recent study of Federal Indian Agents' records from the mid-nineteenth century on three southwestern tribes describe finding no cases of diabetes in Native populations in the nineteenth century (West 1974; Wiedman 2012). Based on their archival work, I surmise

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[9] The Akimel O'odham people are popularly referred to as the Pima Indians in most research literature.

[10] West notes a possible case of diabetes in 1936 according to an interview he conducted, but he did not find further evidence to support the existence of this case and kept his first recorded date as 1939 (West 1974).

that diabetes had not gone undocumented in earlier Native populations, but that it was very rare if present prior to the late nineteenth century in these populations. In the 1950s, diabetes did not factor into the top ten causes of death for American Indians based on Indian Health Service records (Indian Health Services 2007). During that time Indian Health Services programs were aimed towards the treatment and prevention of communicable disease, like tuberculosis. By the late 1990s, however, diabetes was the fourth leading cause of death for American Indians, listed behind heart disease, cancer, and accidents (Indian Health Services 2007).

Today American Indian populations have some of the highest rates of diabetes worldwide (Barnes et al. 2010; Bruce 2000; Centers for Disease Control and Prevention 2011; Duffie 2001; Gallo et al. 2005; Gilliland 1997; Gohdes 1986; Knowler et al. 1978; Knowler 1990; Kramer 1992; Pavkov et al. 2007; Pettitt et al. 1982; Rhoades et al. 2004; Rith-Najarian et al. 1993; West 1974; Young 1993). Growing rates of diabetes in indigenous populations is a worldwide trend, particularly in the Pacific Islands. On the small island of Nauru, nearly 40 percent of the adult population has diabetes (Ezeamama et al. 2006; Lewis 1998; Parry 2010). The majority of diabetes research and rates are based upon Indian Health Services studies conducted in reservation clinics. Though there is less data on the diagnosis rates of diabetes in urban settings, it is prevalent in urban American Indian populations where studies have been completed; 19.8 percent of those over the age of 45 in Los Angeles and 21 percent of those over the age of 50 in Seattle have been diagnosed with the disease (Kramer 1992; Rhoades et al. 2004). I found in my own study that no published rates of diabetes for Chicago's Native population exist, and the feasibility of accurately estimating rates in the city is complicated by the fact that Chicago Natives utilize a wide variety of health care providers both in the city and on reservations.[11]

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[11] Interview participants visit health service providers on their tribe's reservation, both near and far, from central Wisconsin to upstate New York. While American Indians can utilize the services of American Indian Health

Through interviews I learned that community health workers in Chicago hold widely varying estimates for diabetes in the community – one nurse estimated that as few as 10 percent of the population had diabetes, while another estimated that it was nearly 80 percent. In chapter six I discuss community member estimates of the disease in Chicago's Native population.

Rates of diabetes in American Indian populations have grown drastically over the past 60 years and are estimated by the Centers for Disease Control and Prevention to be higher than the rates of diabetes in other ethnic populations (Centers for Disease Control and Prevention 2011). However, while talking about diabetes in the community during an unrecorded interview, an employee of American Indian Health Services of Chicago posed a question to me – are rates of diabetes in Native peoples that much higher than the rates in other populations, or are the rates similar but only seen as higher in American Indian populations because of the higher level of reports on Native health statuses through Indian Health Services? This individual had stated earlier in our conversation that diabetes is one of the leading causes of death in American Indians, but he further believed cases of diabetes in other ethnic populations are equally high. This man's question raises an important point – American Indian bodies have been, as Michel Foucault might say, under surveillance since the eighteenth century (Foucault 1990). Is it the case that rates of diabetes are similar to other populations, but appear higher in Native populations because of this surveillance? I do not have an answer to this question, but it deserves serious consideration.

Ethnographers have documented how published health and disease data are shaped by local history, culture, and politics. In the United States, Roy Grinker asks if there are really more

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Services of Chicago in the city for a minimal fee, some Chicago Natives returned to their reservations one or more times throughout the year for health care services because their tribe had more services available than AIHSC and/or because their tribe would mail prescription needs free of charge to their Chicago home if they had an annual checkup at the reservation clinic.

cases of autism spectrum disorder in recent years or if the number of cases remains unchanged, but the disorder itself is more visible through the increased number services available (Grinker 2007). Ian Whitmarsh's study of asthma in Barbados illustrates the role society and history play in the diagnosis of a chronic condition. The West Indian island of Barbados has a high occurrence of asthma, with up to 20 percent of its population being affected by the disease. Barbados has a national contract with a biomedical research team from the United States; because of this agreement, Whitmarsh questions whether there are really comparatively more cases of asthma in Barbados as the statistics suggest, or if it is the result of greater awareness due to this research relationship (Whitmarsh 2008). Steve Ferzacca's ethnography on health in modern Indonesia illustrates how Suharto's New Order regime strove to demonstrate the modernity and the *pembangunan* (development) of Indonesia by citing increasing national rates of chronic conditions like heart disease, hypertension, and diabetes. At the same time, however, doctors in the Javanese city where Ferzacca worked describe that 50 percent of the cases they regularly encountered were cases of infectious diseases like dengue fever, malaria, and tuberculosis (Ferzacca 2001). Based on the findings of Ferzacca, Whitmarsh, and Grinkler, the question posed by the staff member at American Indian Health Services of Chicago on the difference in rates of diabetes by ethnicity deserves attention that is outside the scope of this dissertation.

Explaining the recent rise

In populations that had comparatively low rates of diabetes sixty years ago, why has the disease become an epidemic over the course of a few decades? In the remainder of this chapter, I engage with literature from the biological sciences that has aimed to answer this question and suggest how social science perspectives contribute to these discussions. In this section I focus on the two mainstream biomedical explanations for diabetes development – genetic and phenotypic features and environmental factors. In chapter seven, two less commonly accepted etiological explanations will be discussed in sections of that chapter that correspond with local explanations for diabetes development – stress and intergenerational trauma. I argue that people studying the recent diabetes epidemic in American Indian populations must take colonial history and policies into account.

Thrifty genotypes and phenotypes

In 1962 geneticist James Neel postulated the existence of a thrifty genotype. As Neel hypothesizes, the thrifty genotype helped earlier humans to survive a turbulent history by allowing for the storage of excess fat during periods of feast to live off of in times of famine. While this genotype was beneficial in the past, it has become detrimental in an era of constant food supply (Neel 1962; Neel 1982; Neel 1999). Neel did not initially link his thrifty genotype hypothesis to American Indian populations, but the researchers behind a longitudinal study of diabetes among the Akimel O’odham believed that the thrifty genotype adequately answered their questions for the recent epidemic rise in the number of diabetes cases among American Indian groups (Knowler et al. 1981; Knowler et al. 1983; Pettitt et al. 1982; Wendorf 1989). Later in his career, Neel agreed with these researchers, applying his thrifty genotype hypothesis to the indigenous populations of North and South America (Neel 1999).

More than three decades after Neel’s first publication of the hypothesis, biological anthropologists John Allen and Susan Cheer describe Neel’s hypothesis as ethnocentric, arguing that Neel’s model describes the thrifty genotype as the derived trait rather than the ancestral one, meaning that Neel hypothesized that earlier humans shared a non-thrifty genotype and later humans developed a thrifty genotype (Allen and Cheer 1996). Allen and Cheer argue that it was more likely that all human ancestors shared the thrifty genotype as a primitive trait and the non-thrifty genotype later developed in contexts with more reliable food supplies. There have been further critiques of Neel from the biological sciences. A primary critique is the lack of genetic evidence to support the thrifty genotype hypothesis (Ozanne and Hales 1998; Southam et al. 2009). This lack of evidence for a thrifty genotype does not dispute some genetic basis for type 2 diabetes. Current genetic research has identified 11 gene loci related to type 2 diabetes (Frayling 2007).

Thirty years after Neel's first publication on the thrifty genotype hypothesis, biochemist C. Nicholas Hales and physician epidemiologist David Barker posited that rather than a thrifty genotype, a thrifty phenotype was a more feasible model for understanding diabetes etiology. According to the thrifty phenotype hypothesis, humans are predisposed to diabetes not by genes, but by development in early stages of life. Hales and Barker contend, "Poor nutrition of the fetus and infant leads to permanent changes of the structure and function of certain organs and tissues… we suggest that poor early development of islets of Langerhans and β cells is a major factor in the aetiology of Type 2 diabetes" (Hales and Barker 1992:597). The thrifty phenotype hypothesis argues that the rapid shift from low birth weight and poor fetal nutrition to over-nutrition in early life may lead to glucose intolerance later in life. They further note that this thrifty phenotype hypothesis does not remove genes entirely from the diabetes etiology picture, finding that the genes involved in fetal development may play a significant role in diabetes development. While Neel's thrifty genotype hypothesis has lost popular support in the past few decades, Hale and Barker's thrifty phenotype hypothesis continues to hold support today in the biomedical research community (Benyshek et al. 2013; Casazza 2011; Corbett et al. 2009; Vaag et al. 2012). In chapter seven I will look at local conceptions of the role of genes and heredity in diabetes etiology.

Both the thrifty genotype and the thrifty phenotype hypotheses consider biological makeup one piece in the puzzle of diabetes etiology. For many researchers, diabetes is a biocultural condition, a disease to which one is predisposed by biological factors and that is then triggered by a cultural environment (Allen and Cheer 1996; Birnbaum 2005; Eisenmann 2003; Gilliland 1997; Justice 1993; Knowler et al. 1981; Knowler et al. 1983; Muir and Zegarac 2001; Pettitt et al. 1982; Szathmary 1994; Szathmary and Ferrell 1990; Young 1993; Weiss 1984; Wiedman 2010; Wiedman 2012; Wirsing 1985).

Environment and life conditions

Biomedical providers interviewed in this study held varied views of what causes diabetes. Some argued for both a genetic and environmental component, while others focused entirely on environment – citing diet, obesity, work life, low physical activity, poverty, food deserts, lack of education, stress, and intergenerational trauma. Many biological studies argue that a decrease in physical activity plays a significant role in the development of diabetes, and that diets high in fat and refined carbohydrates are behind the diabetes epidemic in American Indian populations (Buchanan 2007; Fretts et al. 2009; Gallo and Schell 2005; Hamilton et al. 2007; Jeffery and Harnack 2007; Knowler et al. 1981; Knowler et al. 1983; Kriska 2003; Pettitt et al. 1982). In Leslie Schulz' comparative study of diabetes rates in two related Native populations living on different sides of the United States-Mexico border, Schultz found that the Akimel O'odham living a more “traditional lifestyle” in Mexico, eating foods higher in fiber and being more physically active, prevented the emergence of diabetes in that population (Schultz 1999). Schultz here uses the term “lifestyle,” which is commonly used in literature theorizing the cause for diabetes development. This use of lifestyle, particularly in relation to the American Indian diabetes epidemic is problematic. Susan Reynolds Whyte challenges the use of the term “lifestyle” when speaking of non-communicable chronic diseases. She argues that the use of the term “lifestyle” glosses over political and social situations, in which many of these so-called lifestyle factors are not by choice, but due to circumstances outside the control of individuals developing these non-communicable chronic conditions. Whyte proposes using the term “life conditions” instead of “lifestyle” (Whyte 2014).

I take a biocultural approach to understanding the recent rise of diabetes in the indigenous populations of the Americas. Human history, politics, and society play a role in shaping human biology and health. For American Indian populations, colonial history and policies have played a significant role in shaping contemporary American Indian health. Diseases and epidemics of disease are situated within local political, social histories. (Fullwiley 2011; Livingston 2012; Mitchell 2002). Anthropologists Mariana K. Leal Ferreira, Gretchen Chesley Lang, and Nancy Scheper-Hughes argue that biological studies and theorizations, like the thrifty genotype hypothesis, depoliticize the colonial histories of forced movement that led to the disease; as these medical anthropologists argue, the shift in American Indian diabetes cases is largely related to life changes imposed upon American Indian peoples by Western colonial forces (Ferreira and Lang 2006; Scheper-Hughes 2006). The critique Scheper-Hughes and Ferreria and Lang level at these biological scientists is supported by researchers studying the effect of colonialism on the bodies of the indigenous peoples of the Americas.

Forced changes in life conditions led to the diabetes epidemic among American Indians today (de Cora 2001). Rates of diabetes in Native populations saw a turning point in the years following World War Two. During the post-World War Two era, the diet of all Americans was forever altered by the shifts that had taken place in the agricultural and food production industries during the war. In the decades following World War Two, American diets saw an increase in the amount of processed foods, dairy, meat, fats, and sugar, while the use of fresh fruits and vegetables and grains decreased (Page and Friend 1978). While the diet of all Americans shifted toward the consumption of more processed foods and fats in the post-World War Two era, this shift alone cannot account for the increased rates of diabetes in American Indian populations.

According to Winnebago scholar Lorelei de Cora, the United States Federal Government holds a large portion of the responsibility for the high occurrence of the disease among American Indian populations; through the restriction on land area, de Cora describes that American Indian peoples became dependent upon federally allocated food supplies – supplies that consisted of foods lacking nutritional value and containing high levels of fat and simple carbohydrates. Yvonne Jackson describes the change in the general diet of American Indians since colonization and forced relocation: “The diets today are high in refined carbohydrates, fat, and sodium, and are low in meats, eggs, cheese, milk, vegetables, and fruits. Many dishes are combinations of meat and starch, and many foods are fried” (Jackson 1993:388). In addition to changes in diet, de Cora describes how the land restriction greatly decreased the amount of physical activity that individuals performed on a daily basis. According to Betty Geishirt-Cantrell, the Sioux diet based on the local agriculture and strenuous labor was replaced during the period of relocation to reservations with a diet high in white flour, sugar, and lard (Geishirt-Cantrell 2001). James

Justice adds to de Cora's, Jackson's, and Geishirt-Cantrell's arguments by indicating that these changes in diet are largely associated with socioeconomic standing; the movement to reservations had forced American Indians into a socioeconomic position where they became dependent financially on the Federal Government for food provisions (Justice 1993). As these scholars illustrate, diabetes in American Indian populations is the embodiment of the structural violence brought on by colonialism in the centuries following European-American contact with the indigenous populations of North America.

Conclusion

The scholarship on the diabetes epidemic from both cultural and biological standpoints is significant, but this scholarship is greatly lacking in two important areas. First, as I have described, the majority of biological studies on the factors behind diabetes in American Indian populations tends to focus on the individual bodies – on their genotypes, phenotypes, individual activity level and diet. What these studies do not consider is the role of history in shaping these bodies and the role of colonialism behind this epidemic. Social scientists and Native scholars have brought to light the central role colonialism has played in the recent diabetes epidemic in Native populations. These factors are important to diabetes research. As I will show in chapter six, it affects the ways in which people think about diabetes and subsequently treat it. Second, the majority of the research has focused on reservation populations. While rates of diabetes climbed in reservation areas, they also grew in cities, where nearly 80 percent of American Indian peoples live today. In the next chapter, I describe the history of American Indian relocation and what motivated participants in this study to move to cities during the decades following World War Two. This study of urban Indian migration is an important history that factors into later discussions of Native identity and diabetes understandings, experiences, and care in the city space.

As this review of the scholarship has shown, it is difficult to tease out distinct etiological factors for diabetes. In the remainder of this dissertation, therefore, I will provisionally consider the emergence of diabetes in Native populations as a collective of material and socio-historical factors. In the latter half of this dissertation, I expand upon the theorization of the relationship of human biology and human culture. I demonstrate that while colonial history has greatly contributed to the diabetes epidemic in Native populations, the diabetes epidemic today is being incorporated into local discussions of ethnic identity in Native Chicago, where a vulnerability to the development of diabetes is described as a distinctly Native trait.

CHAPTER 4
THE BUILDING OF CHICAGO'S CONTEMPORARY AMERICAN INDIAN POPULATION: RELOCATION AND THE AIMS OF ASSIMILATION

Introduction

Sunlight illuminated and warmed the west office space on the first floor of the American Indian Center where Elmer Pierson and I met to talk about his life and history in the greater Chicago area. Elmer, a 77-year-old member of the Bad River Band Chippewa – a group that he took care to remind me was not a rock band – was born during his parents' journey from their northern Wisconsin reservation to the Chicago area in the late 1940s. In our conversation about his early life in Elgin, Illinois, Elmer elaborated on his view of the American Indian Relocation Program that began several years after his parents migrated to the Chicago region:

> Now with the urban Indian relocation, yes and that was a disaster, I saw Indians relocated even out in Elgin and just it was such a disaster. And the old grandmother was arrested for shoplifting and her kids… these people were uprooted and transplanted without any fertilizer, well even any ground, just transplanted on the rocks out there and it was a disaster… they finally ended up shipping these people back or getting out or bringing them to Chicago where they died. It was almost like their continuation of genocide. Unjust. Unjust.

The program Elmer describes as the United States' continuation of genocide is the Relocation Program run by the Bureau of Indian Affairs (BIA) from the 1950s to 1970s. Discussing the program elicits mixed responses from Chicago's Native community members. While the program assisted Natives in moving away from the poverty and high unemployment rates of the reservation, the primary aim of the program was to assimilate Native peoples into the broader American society and to reduce federal obligations to American Indian nations. In subsequent conversations with Elmer, he referred to Native peoples as cultures of survival. He explained that despite federal policies and programs aimed at assimilation, Native cultures continue to survive both in cities and on reservations. While the Relocation Program's aim of assimilation was not met, it was successful in moving hundreds of thousands of Native peoples from reservations to cities during the latter half of the twentieth century.

The Chicagoland area is currently home to tens of thousands American Indians. An accurate estimate of the city's and of the larger area's Native population is a contested topic in the community.[1] Community organizers argue that the United States Census Bureau grossly undercounts the city's Native population.[2] The American Indian Center of Chicago estimates a population of 44 thousand Natives in this greater Chicago area, while the United States Census Bureau estimates just over 14 thousand within the city-limits (United States Census Bureau 2012a). Until the 1980s, Chicago led the nation as the city with the largest American Indian population in the country (Chicago American Indian Oral History Project 1982-1985).[3] While Chicago's contemporary American Indian population is in large part the result of the Federal Relocation Program, the Chicagoland area was once inhabited by members of the Mesquaki, Illinois, Kickapoo and Mascouten, Miami, Piankeshaw, Potawatomi, Sauk, Shawnee, and Winnebago nations (Vogel 1962).[4] In 1832 and 1833 representatives of American Indian tribes in Illinois ceded territory to the state of Illinois; the Native peoples of Illinois moved to

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[1] The Chicago Native community is made up of individuals who come from both within the city limits and from the suburbs surrounding the city.

[2] This undercounting of American Indian populations has also been documented in other urban contexts (Ramirez 2007).

[3] Based on census data, Chicago currently ranks eighth in the United States for largest American Indian population; New York now holds the number one spot with nearly 156,000 American Indian inhabitants making up 0.8 percent of the city's population (Norris et al. 2012; United States Census Bureau 2012b).

[4] Like many geographical sites in the northern Midwest region of the United States, the city's name can trace its roots back to an American Indian term. Virgil Vogel traces the etymology of Chicago to the Miami term for wild garlic, leek, or onion as documented in the journal of Henri Joutel of LaSalle's expedition and in the Illinois-French dictionary written by Joseph Ignatius Le Boulanger. Vogel additionally notes that the term Chicago is similar to the Illinois term for stinking beast, which may be the cause for why some believe the city name to mean "skunk place" (Swenson 1991; Vogel 1962).

reservations outside the state, while the Chicago region was inhabited by settlers (Beck 1988). In the years following World War Two, the Native population grew and is now made up of individuals representing more than 100 tribes from across the United States and Canada.

In this chapter I utilize interview material, archival material, and primary and secondary sources to meet three aims. First, I provide a brief history of the relationship between American Indian peoples and the United States Federal Government beginning with the arrival of European settlers to the Americas. Second, I describe the aims of United States politicians and legislators in the post-World War Two era to reduce federal obligations to American Indian nations and to assimilate Native peoples through a series of policies and programs. Third, I provide accounts from members of Chicago's Native community on what brought them to the city. Ultimately, my aim in this chapter is to introduce readers to the history of urban American Indian communities by looking at both the goals of the United States Federal Government to get out of the Indian business through the policies and programs of the 1950s, while also exploring the motivations behind the migration of Native individuals and families to cities. This chapter moreover begins to introduce readers to Chicago's Native community.

Domestic dependent nations: sovereign states within the United States

In the first several centuries after settler arrival in the "New World" – or the world new to those settlers – colonial populations were dependent upon American Indians for survival and success in the unfamiliar landscape of North America.[5] Settlers depended upon American Indian peoples for food and other resources, for knowledge of the North American landscape, and even

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[5] A note before I begin - the experience of American Indian communities in relation to settler communities and the United States Federal Government is far from being a homogenous or simple one. What I describe is but a generalization of some of the larger historic events that do not completely describe the specific histories of any one group.

for assistance in wars with opposing settler groups (Cattelino 2008; Levinson 1976; McNickle 1975; McNickle 1988; Ricciardelli 1963; Ritzenthaler 1950; Sider 1987; Thornton 1990; Wilkinson and Briggs 1977; Wolf 1983). As Steven Barnes, a 61-year-old Seneca man explained in an interview:

> If it wasn't for them [the Native population of the region], the people that came to Virginia, they would have never made it because the Indians got them through that first winter, you know. And they had a big heart and stuff. We got all this land, you know, and they did, they gave them land and they fed them and stuff. And these Indians, they had a green thumb or something because they always had a bunch of corn and everything, and they were excellent hunters.

Steven explains that the indigenous population was adept in making a living in the North American landscape and that they assisted the newcomers in surviving in this New World. As Steven's description foreshadows, though the Europeans were first dependent upon the Natives they encountered for survival, this relationship soon shifted.

After their success in the Revolutionary War, the American settler community began to gain its footing in North America, while the diseases introduced into the Americas by settlers continued to decimate the indigenous population (Thornton 1990). Russell Thornton finds that smallpox, typhus, measles, and tuberculosis were the most detrimental of the introduced diseases; over the course of a few centuries, Thornton estimates significant fall in population numbers (Thornton 1990).[6] Estimates of pre-contact American Indian population vary widely and range from 900 thousand to 18 million (Shoemaker 1999; Snipp 1992).[7] By 1900 the American Indian population reached its lowest point since contact; there were 237 thousand

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[6] Bioarchaeologist Clark Spencer Larsen argues that the Americas were not free of disease prior to contact, citing osteological evidence of both tuberculosis and treponematosis particularly in more densely populated areas where people practiced agriculture (Larsen 1994).

[7] The Native population of the United States has recovered since 1900. 5.2 million people self-identified as American Indian in the 2010 census (Norris et al. 2012).

American Indians living in the United States at that time (Shoemaker 1999). During the post-Revolutionary War era, the relationship between the settler and American Indian communities began to shift; in many instances the relationship grew hostile as the new nation's desires to spread further westward into Indian Country increased.[8] The settler community was less dependent upon American Indians for survival, and in some cases American Indians were growing dependent upon settler resources (Cave 1999; Pearson 2003; Thornton 1990).[9] Since the shift in power several centuries ago, the United States has vacillated between policies promoting the assimilation of American Indian peoples and policies supporting American Indian sovereignty (Burt 1982; Deloria and Lytle 1984).

In the United States, American Indian tribal entities formed in relation to treaties and agreements with the Federal Government. Prior to the arrival of European settlers, American Indian communities did not define themselves in terms of bounded tribal entities; rather, group membership was more fluid, and based upon a number of factors, including kinship and shared myth and ritual (Churchill 2001; Goldberg-Ambrose 1994; Iverson 1998; Maybury-Lewis 1997; Straus and Valentino 1998). In a 1970 publication, Africanist anthropologist Aiden Southall challenges the continued use of the term "tribe" in contexts around the world. The term traditionally referred a group of people who were politically autonomous and self-sufficient, who used simple technology, who were not literate, and who had a distinct culture, language, sense of identity, and religion. Southall argues that few groups meet this traditional definition of "tribe." To further support his critique of the contemporary use of the term, Southall outlines how tribes were named in relation to other groups in the area and shaped by the colonial state (Southall

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[8] In the 1763 Royal Proclamation of Britain, Indian Country was defined as the land west of the Appalachian Mountains to the Mississippi River (Clinton 1989).

[9] For instance, American Indians turned to settler vaccines to combat the diseases brought from Europe (Pearson 2003).

1970).[10] Today American Indian nations still use the terminology of “tribe,” as do members of Chicago’s Native community. Tribes today represent both ethnic and political groups; however, American Indian tribes are neither representative of traditional conceptions of group identity, nor do they necessarily represent a cohesive group of peoples (Goldberg-Ambrose 1994). I will discuss contemporary concepts and enactments of American Indian individual and group identity in the following chapter.

While the relations between the Federal Government and American Indian peoples of North America played a role in the development of tribal entities, the legal and political status of American Indian tribes has been and continues to be an ambiguous one in federal policies and laws. This ambiguous relationship between the Federal Government and American Indian tribes began with the United States Constitution in 1789 and was further cemented in conflict and confusion through the three Supreme Court Rulings known more popularly in American Indian Studies as the Marshall Trilogy.[11] The United States Constitution declares that: “Congress shall have the power… to regulate Commerce with foreign Nations, and among the several States, and with the Indian Tribes” (US Constitution Article 1, Section 8, Clause 3). In the Constitution, American Indian tribes hold a unique position; they stand as political entities alongside states and foreign nations, but yet, as indicated in their separate naming in the document, tribes are distinct from states and from foreign nations. In the sixth article of the document, the men drafting the Constitution define American Indian tribes to be in a relationship with the Federal Government and not with state governments (US Constitution Article 6, Clause 2): “All treaties made, or which shall be made, under the authority of the United States shall be the supreme law of the

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[10] For example, the Tsistsistas are popularly recognized by the name Cheyenne, which is taken from the Sioux term meaning “red talkers,” indicating for the Sioux a group of people who spoke a language they did not understand. Members of this group refer to themselves as Tsistsistas, which means “people” (Grinnell 1972).

[11] Robert Clinton describes how the relationship between the Federal Government and the American Indian tribes was both based in and bound to the 1763 British Royal Proclamation (Clinton 1989).

land, and judges in every state shall be bound thereby." In the United States Constitution, early policy makers defined American Indian tribes as political entities that are distinct from states and from foreign nations, and that are in a relationship with the Federal Government.

During the 1820s and 1830s, a series of Supreme Court cases under Chief Justice John Marshall further defined the United States-American Indian tribal relationship and the Federal Government's position on the sovereign status of tribes. In the 1823 case *Johnson v. McIntosh*, the Court denied the claim made by the descendants of Thomas Johnson over the right to land purchased from the Piankeshaw Tribe in the late eighteenth century; the Court denied this claim based upon the ruling that Indians could not sell land to private individuals. The Court ruled that only the Federal Government could purchase land from the American Indian tribes. In the 1831 case *Cherokee Nation v. Georgia,* the Cherokee Nation attempted to bring a case against the state of Georgia to the Supreme Court as a foreign nation. While the Court determined that the state of Georgia does not have jurisdiction over the Cherokee Nation, the Court denied the Cherokee Nation's claims of being a foreign state. The 1831 *Cherokee Nation v. Georgia* Ruling in effect defined American Indian tribes as domestic dependent nations in a ward-guardian relationship with the Federal Government. In the third case in this trilogy, *Worcester v. Georgia,* the Court further stressed that states do not have jurisdiction in Indian affairs when missionary Samuel Worcester refused to obtain a state license for entering Cherokee land. As seen in the progression across these three cases, the sovereignty of American Indian tribes as autonomous nations was challenged under the Supreme Court's rulings. The Marshall Trilogy solidified the status of American Indian tribes as wards of the United States Federal Government, both nations not permitted to sell their land, while yet independent of state laws (Deloria and Lytle 1984). This ward-guardian relationship between the Federal Government and tribes is defined by a trust obligation, whereby the Federal Government has the duty to protect American Indian tribes; this trust obligation obstructs complete American Indian tribal autonomy (McCarthy 2004).

Since its founding, the United States Federal Government has neither solely focused on the assimilation of American Indian peoples nor defended and upheld American Indian sovereignty. Around the time that these Supreme Court Cases were being adjudicated, representatives of American Indian tribes were signing treaties that in some cases led to the forced removal of American Indian peoples from their homelands to reservations (Goldberg-Ambrose 1994; Sturm 2002; Trafzer 2000). The reservation policy was not intended to go on indefinitely; the Federal Government expected American Indian peoples to assimilate over time into American society (Neils 1971).

There were a number of programs put in place or supported by the Federal Government that promoted Indian assimilation during the nineteenth and early twentieth century (Burt 1982; Cowger 1999; Lewis 1993; Lomawaima 1993; Snipp 1992; Wilkinson and Briggs 1977). The General Allotment Act, also known as the Dawes Act, passed in 1887, divided up reservation lands into family plots, which American Indians could sell after a period of time. The goal of allotment was to divide up American Indian peoples and break down their communities (Clark 1994; Trafzer 2000). The tribal rolls that are a product of this allotment play an important role in tribal enrollment, which will be discussed in the next chapter. A second program promoting assimilation that has had a lasting effect on Native culture and life are boarding schools. Boarding schools removed American Indian children from their homes. In the schools children were restricted from using their Native language, taught English, and encouraged to join "American society." Indian boarding schools have a long documented history of abuse, abuse that members of Chicago's Native community recalled and reflected on in interviews today

(Churchill 2004; Lomawaima 1993; Chicago American Indian Oral History Pilot Project 1983-1985). This history of treatment and ideologies spread through the boarding school system appear in the following chapters in discussions of a shared history of oppression, language loss, and intergenerational trauma.

The status of American Indian tribes as domestic dependent nations survived each of these attempts, and contributed to the continuing and growing tensions between American Indian tribes, state governments, and the Federal Government (Cattelino 2008; Goldberg-Ambrose 1994; Jarding 2004; Rand and Light 1998). In the decades following World War One, the tide turned towards supporting American Indian sovereignty. Developed out of the findings of the 1928 Meriam Report that described the living conditions of reservations as deplorable, the Indian Reorganization Act was passed in 1934 with the aim of Indian tribes becoming self-governing nations.[12] In the years following World War Two, just over a decade after the Indian Reorganization Act was passed, the United States policies and programs were again re-aimed in the direction of American Indian assimilation into the broader American society.

Post-World War Two era: relocation and aims of assimilation

Beginning in the 1940s, the United States Federal Government policies began to shift toward the promotion of American Indian assimilation with the aims of reducing federal obligations to American Indian tribes. The Federal Relocation Program that supported the migration of American Indians from reservations to cities is one program among several during that era that were directed towards American Indian assimilation. The Indian Claims Commission and the Zimmerman Plan emerged in the late 1940s, both aimed towards the end of

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[12] 191 American Indian tribes adopted the Indian Reorganization Act, and 71 refused to adopt it (Trafzer 2000).

federal obligations to American Indian tribes (Fixico 1986; Iverson 1998). The Indian Claims Commission of 1946 was developed for tribes to bring past grievances to Federal Courts and to be compensated for past offenses against the tribe. Geographer Elaine M. Neils explains that the underlying goal of the commission was for the government to end all claims on its services by adjudication through the courts (Neils 1971). Between 1946 and 1978, American Indian tribes won 58 percent of the cases brought to the commission; these tribes were awarded a total of $818 million through 546 claims cases (Lewis 1993). The acceptance of federal reimbursement, however, threatened tribal sovereign status (Fixico 1986; Iverson 1998; Neils 1971).

In the year after the origin of the Indian Claims Commission, acting Indian Commissioner William Zimmerman sorted tribes into four categories, ordering tribes by what Zimmerman thought was their level of preparedness for the withdrawal of federal services; this sorting is known as the Zimmerman Plan (Cowger 1999; Fixico 1986; Iverson 1998). Historian Peter Iverson explains that Zimmerman's sorting was the result of his being put on the spot in a Senate Committee hearing and torn between the Senate's desire to scale back funding for the BIA and his knowledge of the varied range of needs on American Indian reservations. The ramifications of Zimmerman's sorting, however, were great for the tribes he described as prepared for the reduction of federal services; these tribes, including for instance the Menominee and Klamath Nations, were among the first tribes to be terminated in the 1950s (Iverson 1998).[13] Fixico refers to the Indian Claims Commission and the Zimmerman Plan as the "germs of termination," because both of these programs were precursors to the Termination and Relocation Programs of the 1950s – the Zimmerman Plan identified which tribes were prepared for

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[13] Through termination policy, the United States Federal Government terminated its recognition of an American Indian nation's sovereign status.

assimilation and termination and the Indian Claims Commission threatened tribal sovereignty upon the acceptance of claims payments (Fixico 1986).

In the early 1950s, policies and congressional resolutions continued to support American Indian assimilation. In 1950, President Harry Truman appointed Dillon Myer to the position of Commissioner of Indian Affairs. During the war, Myer had directed the Japanese-American relocation to internment camps. As commissioner of Indian Affairs, Myer launched efforts towards the development of American Indian Relocation Programs in 1952 (Bennett et al. 1986; Burt 1982). While Myer was launching these Relocation Programs, in 1953 the Eighty-Third Congress passed House Concurrent Resolution 108, laying the foundation for the termination of tribal sovereign status (Fixico 1986). The Resolution states:

> It is declared to be the sense of Congress that, at the earliest possible time, all of the Indian tribes [listed on the resolution] and the individual members thereof… should be freed from federal supervision and control from all disabilities and limitations specifically applicable to Indians (House Concurrent Resolution 108:615).

In framing the termination of tribal status as “freeing” individuals from supervision and control, the authors of this resolution gloss over the termination of tribal status in favor of highlighting the freedom it will bring individual members of tribes.[14] On August 15, 1953 Public Law 280 was passed with no debate in Congress, effectively reducing federal involvement in American Indian tribal concerns (Burt 1982). This law turned criminal and civil jurisdiction of Indian tribes in six states and territories over to the state governments.[15] Even as power changed hands

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[14] Between 1945 and 1960, a total of 109 American Indian tribes were terminated across the United States under House Concurrent Resolution 108. The termination of these tribes eliminated sovereign status and terminated the trust relationship between the Federal Government and the tribes (Cowger 1999; Fixico 1986). Some of the terminated tribes have regained their former status, including both the Menominee and Klamath tribes.

[15] The mandatory states and territories include California, Minnesota, Oregon, Nebraska, Wisconsin and the Alaskan territory.

in Washington, the policies favoring American Indian assimilation in this postwar era did not shift. According to historian Larry Burt, Glenn Emmons, the Commissioner of Indian Affairs under President Dwight Eisenhower, had developed an agenda for the gradual termination of all American Indian tribes by the bicentennial of the United States – July 4, 1976 (Burt 1982). The plans and actions of the Commissioners of Indian Affairs and the laws and resolutions that passed through Congress in the decade following World War Two show a general tendency favoring the termination of the trust obligation between the Federal Government and American Indian tribes; in place of this trust obligation, plans and programs oriented towards the assimilation of American Indian peoples were cultivated.

The Relocation Program, then, was one among several policies and programs during the postwar era that favored American Indian assimilation. The indigenous peoples of the Americas have built and lived in urban centers for millennia prior to the development of this relocation program (Forbes 1998; Rosenthal 2012; Thrush 2007). In the decades before the development of the Relocation Program, American Indians migrated to cities in search of work (Jackson 2002; Miller 2013; Rosenthal 2012). During the war, American Indians moved from reservations to cities both to work in factories supporting the war effort and to be in a central transportation hub if a family service member had leave time (Chicago American Indian Oral History Pilot Project 1982-1985; Garcia 2002). 30 thousand, or 32 percent, of all eligible American Indian men served in World War Two as members of the armed forces (Deloria and Lytle 1984; Levinson 1976; Neils 1971; Sorkin 1978).[16] American Indian men and women voluntarily enlisted in the United States Armed Forces; according to participants in the Chicago American Indian Oral History Pilot Project, American Indians joined the war as a means of following their people's tradition of

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[16] American Indians in both the past and in the present serve in the United States Armed Forces in greater proportions than any other ethnicity in the United States (Watkins and Sherk 2008).

warriors in a contemporary context (Chicago American Indian Oral History Pilot Project 1982-1985).[17]

Based upon Dillon Myer's plans, the BIA began to offer services to tribal members interested in relocating to urban areas in the mid-1950s; the BIA initially offered financial assistance for housing, and employment officers who helped relocatees find work (Fixico 1986; Intertribal Friendship House et al. 2002). Rosenthal describes that the idea for the Relocation Program originated in 1948 when the BIA assisted Navajo and Hopi men find work off the reservation after a rough winter limited their subsistence and work on the reservation land (Rosenthal 2012). In 1952 Congress appropriated $579,600 for the opening of field relocation offices in Los Angeles, Denver, and Chicago. This early start of the BIA program offered relocating American Indians transportation to their urban destination, employment placement services in the city, financial assistance for subsistence needs before individuals received their first paycheck, and what Elaine Neils describes as "some guidance in community adjustment" (Neils 1971:58).[18] The amount of money spent on each client who joined the Relocation Program increased over the several decades that the program was in place; the program on average spent $410 per client in 1955, $710 in 1960, $1,750 in 1965, and $2,270 in 1970 (Neils 1971).

In order to relocate American Indians to cities, the BIA set up field offices in large cities as well as field offices near reservations around the country to encourage and recruit individuals to relocate (Jackson 2001). In the early 1950s, these agency offices collected materials

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[17] The Chicago American Indian Oral History Pilot Project took place in the early 1980s, directed by Herbert Hoover, David R. Miller of the D'Arcy McNickle Center at the Newberry Library, and Dorene Weise. The project consisted of 23 interviews with American Indians about the history of Chicago's American Indian community and personal experiences in the city; these interviews touch on the topics of education, health, alcoholism, housing, and employment. From these interviews, the project drafted a manuscript "Native Voices in the City," available, along with 12 of the 23 interview transcripts, in the Ayer Collection at the Newberry Library.

[18] Nicolas Rosenthal's chapter on relocation in *Reimagining Indian Country* provides a detailed history of the relocation process from filling out paperwork to advising women how to be better homemakers to fit into their new neighborhoods (Rosenthal 2012).

documenting American Indian life on reservations; these files include typed notes on housing, education, religion, employment, and health status of individuals on reservations as well as photographic documentation of reservation life and struggles (United States Bureau of Indian Affairs 1975b). The BIA agents who authored these documents strove to make relocation sound necessary while the situation on the reservation without hope of recovery. The agency offices' findings on the status of American Indian reservation life are summed up in the conclusion to the "Great Lakes Agency's Brief History:"

> The conclusion which must be drawn then, is that many of the people do not have adequate opportunities on the reservations and the surrounding areas, and from this standpoint it is felt that the program of relocation services is indeed a boon to this needy group. [United States Bureau of Indian Affairs 1975a:2]

As the brief history explained earlier in the document:

> The relocation division's basic objective is to facilitate the voluntary relocation of Indians who are unemployed or underemployed, to areas where there is steady employment and they have a chance to become self-supporting on a standard of living compatible with health and decency and to become part of the normal social and economic life of the nation. [United States Bureau of Indian Affairs 1975a:1]

The agency offices across the Midwest and Northern Plains described the situation on reservations as bleak. Despite the similarities between the 1928 Meriam Report and the BIA field office reservation area reports, the responses differed greatly. The 1928 Meriam Report led to the 1934 Indian Reorganization Act supporting Indian self-administration, while these 1950s findings supported the BIA view that relocation was the best solution for the issues of poverty and unemployment faced by American Indians living on reservations. It is clear in the Great Lake Agency's documentation of its own history that the aims of relocation were to assimilate American Indians into American society, or what they termed "normal social and economic life"

(United States Bureau of Indian Affairs 1975a:1). As the group wielding more power, the BIA and policy makers in Washington perceived their own way of life to be “normal” and anything not mirroring their lifestyle was marked as “abnormal” social life. The Relocation Program gained support from the agency offices’ reports, which gave a figurative green light and provided a moral justification for a program aimed at the assimilation of American Indian peoples into American society.

The official goal of the Bureau of Indian Affairs was to send people who would be most able to survive in urban areas. Kurt Dreifuss, director of the Chicago BIA office, explained the program to the Chicago Daily Tribune in a 1957 article reporting that “tribal families like suburban life:”

> All who come here under the program make application before they leave the reservation and have assurances of jobs and housing. Upon arrival they are advised how to shop, health service is provided, and they receive a grant for initial purchases of food, housewares, and clothing. [Chicago Daily Tribune 1957]

While the official line of the BIA was that they supported the relocation of those who were most prepared to relocate, the reality was that the agency offices would send anyone willing to move to the city. An interviewee in the Chicago American Indian Oral History Project describes how he was asked one day if he would like to move to a city and found himself on a train to Chicago just a few days after this passing conversation with an agency officer (Chicago American Indian Oral History Project 1982-1985). Peter Iverson describes that among the Navajo who relocated in the 1950s, those least familiar with Anglo culture and language moved to cities (Iverson 1988). Though the BIA promoted their Relocation Program as screening and preparing Natives to migrate to American cities, in reality, anyone willing to relocate did (Burt 1982; Chicago American Indian Oral History Project 1982-1985; Iverson 1988).

Today, some members of Chicago's Native community reflect on the aims of the program with indignation. Elmer Pierson, quoted at the fore of this chapter, uses the strongest language of those I spoke with in reflecting upon the aims of relocation. From what he witnessed as a child during the early years of the program, Elmer today characterizes the policy as a form of genocide – by moving Natives to cities where, in his view, the death of large numbers of Native peoples went unnoticed. Harriet McClean, a second generation Ojibwe relocatee describes the program as an involuntary one that attempted to spilt up her family. Harriet, now 50 years old, retold the experience of her grandmother being forced into the program on the Lac du Flambeau Reservation:

> Well my mother, my grandmother who lived on a reservation in Wisconsin, she was brought here by the Relocation Act. And then her kids were put in foster homes on the reservation, until they all snuck away and they made their way here to Chicago to find their mother… She [her grandmother] was forced here. She was forced off the reservation.

Rosenthal documents that pregnant women and single women with children were not typically accepted into the Relocation Program, and in the cases where single women with children joined the program, they were required to leave their children behind (Rosenthal 2012). Some contemporary Chicago Natives like Harriet and Elmer describe the Relocation Program as forced migration that divided families, and aimed not only at assimilation, but possibly genocide. The program was openly aimed at assimilating Native peoples into American society. Though people are resoundingly angry about the underlying aims of assimilation, not everyone reflects on the program with the same anger as do Harriet and Elmer. Many first generation migrants describe the program as a boon to them and their families during that era. In the next section I look at what motivated people to move to Chicago and in chapter five I describe how urban Natives define and maintain Native identity in the city space.

During the post-World War Two era, the United States Federal Government turned towards the assimilation of American Indians into American society through a succession of federal policies and programs, including the Indian Claims Commission, the Zimmerman Plan, House Concurrent Resolution 108, Public Law 280, the Termination Program, and the Relocation Program. The Relocation Program was successful in relocating a significant portion of the American Indian population from reservation areas to cities. Between 1952 and 1972, 100 thousand American Indians relocated to urban cities from rural areas and reservations through the federally established program (Snipp 1992; Sorkin 1978). The BIA assisted in the relocation of American Indians to Chicago, Cleveland, Dallas, Denver, Los Angeles, San Francisco, and San Jose during the early years of the plan and extended the locations to Tulsa and Oklahoma City by 1968 (Sorkin 1978). According to 2010 census data, nearly 80 percent of American Indians live in urban areas (Norris et al. 2012). In the next section I look at what motivated people to move to Chicago.

Moving to the city

Frances Archer and her late husband, both citizens of the Sisseton Wahpeton Sioux, moved from the Lake Traverse Reservation in South Dakota, to Chicago in 1958. Now at the age of 84 having raised her 11 children and worked for 45 years in Chicago, Frances describes why she and her husband chose to move through the Relocation Program:

> Oh we came on the relocation. They placed us here. We had a choice between Chicago and Los Angeles, but we took Chicago because you know it's closer to home, you can travel home and the other way would be too far and stuff, yeah…I thought it was good. Because that's the way you can learn to what trade they give you, schooling that you have to go take up some kind of trade or something you know, that's one good thing. That's what my husband went under. He went, became a barber, he went to barber school. Yeah they offer you jobs and stuff,

> school, training, training. That was good, I don't mind it. Otherwise we could have been living all the old ways yet. We came a long time ago when nothing was good over there [the reservation] yet, but now it is. Everything's all up to date like at home [the reservation].

Frances and her then small family moved to Chicago through the Relocation Program which provided assistance to set up her family in the city. In their decision to move to Chicago, the Archers sought a locale close to their home – which Frances continues to visit each year – in addition to opportunities for a better quality of life.

American Indians did not migrate merely because there were programs prepared to help them relocate; rather, those who came to cities did so for a variety of reasons. In this section I utilize oral history interview material in concert with archival material and secondary publications to show that individuals who chose to move and to stay in cities considered multiple and overlapping factors into their decisions. While the Federal Relocation Program assisted some in their migration to Chicago, many more American Indians moved to the city on their own. Of the 27 oral history interview participants in this study, 3 moved to Chicago through the Relocation Program, 17 moved to Chicago on their own, and 7 were born in the city. Of those born in Chicago, 5 were in Chicago because their parents or grandparents moved to Chicago through the program, and 2 because their parents moved there on their own. The majority of participants in the 1980s Chicago American Indian Oral History Pilot Project described choosing to move to Chicago in search of better opportunities (Chicago American Indian Oral History Pilot Project 1983-1985). In speaking of what led them to move to Chicago, they described how the opportunities on the reservations were scarce while the city had ample job opportunities. Participant responses in this contemporary study mirror those of the 1980s pilot project.

Opportunities in the city appeared to far exceed those on the reservation, and drew many families to cities like Chicago.

American Indians had been migrating to cities in large numbers since the 1940s. In the context of the harsh poverty of reservation life, which had grown out of over a century of policies and programs supported by the Federal Government, many American Indians opted to relocate to urban areas in search of stability and employment (Arndt 2002b; Jackson 2001; Miller 2013). Deborah Davis Jackson's account of Indian life in a mid-size Midwestern city shows that many of those who moved to the pseudonymously named city of Riverton did so for the opportunity of employment in the booming automobile industry of the 1940s (Jackson 2002). Historian Douglas K. Miller likewise demonstrates that many Natives moved to cities like Chicago both before and during the era of the Federal Relocation Program for employment opportunities (Miller 2013). During the war, 46 thousand American Indians left reservations for war-time work in cities (Sorkin 1978). The Federal Relocation Program that began in 1952 only increased the rate of American Indian relocation (Fixico 2006). Though this program was supposed to be "completely voluntary" (Sorkin 1978:27), in that no one was forced against their will to relocate, it was also involuntary in the sense that economic help on reservations was greatly scaled back during this period; the Federal Government was offering more services in the designated relocation cities while reducing programming on reservations. The BIA agents at reservation field offices presented to reservation Natives images of city life that appeared desirable in contrast to reservation life. In the reservation field offices posters, informational handouts, and advertisements portrayed cities as welcoming American Indians and offering opportunities for training, employment, housing, family life, and financial security (Arndt 2002b; United States Bureau of Indian Affairs 1975b).

As Frances Archer described in her statement above, there were fewer employment opportunities on her reservation in South Dakota in the late 1950s, and the same was true for many reservations across the United States at that time. Alan Sorkin describes the economic situation of reservations in the mid-1960s as one of abject poverty (Sorkin 1971:8). Sorkin explains that the median income on all reservations was below and the unemployment rates higher than the median income and unemployment rates of the rest of the nation. Almeda Cortez is a 77-year-old Choctaw woman. She moved to Chicago in 1961, having followed her then boyfriend and future husband to the city. Almeda describes the hardship she faced on the Mississippi Choctaw Reservation near Philadelphia, Mississippi, though, like the Lake Traverse Reservation described by Frances Archer, the situation on her reservation has greatly improved in recent years:

> I think it [the Relocation Program] did a lot of good for a lot of people, because it was, you know Philadelphia, Mississippi is such a small town, and it's not that many jobs at that time. Now the, our tribe has two casinos down there and the school is bigger than when I was going there and the tribes take care of that.

The job scarcity and low employment rates Frances and Almeda saw on their reservations during the 1950s and 1960s were two of many issues faced by Natives living on reservations; other problems include poor housing conditions, low quality food, limited access to higher quality foods and medical care, and high rates of alcoholism. As described in the previous chapter, the commodity food supplies provided by the United States government has played a significant role in the growing rates of diabetes and obesity among American Indian peoples today (de Cora 2001; Jackson 1993; Mihesuah 2003). While since the mid-twentieth century, the economic situation on many reservations has improved, for much of the second half of the twentieth century, the living conditions on the reservation were poor. During the second half of the twentieth century, American Indians moving to cities were actively engaged in life choices aimed at survival.

There were other difficulties beyond unemployment on reservations that prompted individuals to relocate to cities. Two interviewees in this study spoke of distancing themselves from physically and emotionally abusive family relations on the reservation. The decision to move to escape abuse was also reported by participants in the 1980s Oral History Pilot Project (Chicago American Indian Oral History Pilot Project 1983-1985). High rates of alcoholism are another aspect of reservation life that some families hoped to leave behind in migrating to a city. Sandra Harrell, a 61-year-old San Carlos Apache woman, described how her father participated in the Relocation Program in 1954 as a means of moving his family away from what she described as a dangerous environment for her mother who was then battling alcoholism:

> My father came out of the service and then he wanted to move to the c-, get away from the reservation because it was too many drinking going on. He tried to get my mother away from there so we moved to Phoenix, but it didn't work, so he took a part in the Relocation Act and they asked him what city would he like to go to, and he had his choice of cities that he can go to. So he chose Chicago, and then we all came on a train over here. And the Bureau of Indian Affairs helped us get situated by finding my dad a job and food, furniture, clothing, and whatever necessities we needed, they helped. And then we were here, my father and my family had to be on our own after that.

Unfortunately for Sandra's family, moving to Chicago did not resolve her mother's addiction to alcohol.[19] Sandra described how she dropped out of high school to take on the role of homemaker, raising her younger siblings and cooking for her family, while her dad worked the third shift and her mother continued to struggle with alcoholism. Alcoholism has been and continues to be a significant social and health concern in urban Native communities (Rosenthal

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[19] I asked interviewees about what the most pressing health and social concerns were for Chicago's Native population. Diabetes, alcoholism, poor dental health, and unemployment were the four most frequently named concerns.

2012; Snipp 1992). In Chicago, research participants describe how neighborhoods where Natives lived there were "bars galore" and that some establishments in those areas came to be known as "Indian bars." Bars were a primary place for socialization in those early decades. One research participant, added too that not only did American Indians seek socialization in bars, but also in all Native churches that sprang up in cites across the United States. Life on the reservation during the postwar era is described by many participants as difficult and riddled with economic and social problems that people aimed to escape by migrating to cities like Chicago, though in cases like Sandra's, not all problems were left on the reservation.

While the 27 oral history interviewees had multiple reasons for moving to Chicago, finding employment was a primary factor for 17 interviewees. In contrast to employment opportunities on reservations, jobs in Chicago during the era of the Relocation Program were abundant, and people did not have to move through the program itself to find work in cities like Chicago. Agnes Harrison, an 82-year-old Odawa woman, moved to Chicago for work in 1958. Though Agnes worked at only two places during her 41 years of working life in Chicago, she described how easy it was to find work when she first moved to the city:

> I just wanted to move on. So I came here. Oh jobs were so plentiful… You could work at one job and if you didn't like it, walk out and you'd have another one tomorrow. But I stayed with mine.

Agnes worked in two factories for her entire career-life in Chicago. The oral history interview participants worked a variety of jobs with widely different training and educational requirements. Those I spoke with worked as factory workers, truck drivers, daily pay employees, office workers, pharmacy technicians, nurses, employment officers, police dispatchers, customer service representatives, and employees of Native organizations in the city, including the

American Indian Center of Chicago and ANAWIM (now known as the Kateri Center of Chicago).

The high demand for workers that Agnes describes continued for those who migrated to Chicago throughout the early 1980s. In describing how she and her husband moved to Chicago in 1979, Susan Barnes, a 58-year-old Seneca woman explained how they had intended move to Texas where her husband Steven could find work as a welder on an oil rig.

> Actually we were on our way to Texas. We were going to go because they needed welders down there and that's what he did. I was working in, at Fisher Price in New York when we left. I quit my job and packed up and we were on our way there but then we had a, one of his cousins lived here and she's like well just stay for the weekend and then this, the job came up for the construction job came up for him and they hired him like the next Tuesday, so, and we've been here ever since.

The abundance of jobs in Chicago from the Second World War to the early 1980s stood in stark contrast to the lack of job opportunities found on many reservations during the same period. This abundance of job opportunities drew many Natives to Chicago during the decades following World War Two. According to local employment officers from the Chicago branch of California Manpower Consortium, however, Natives currently face high rates of unemployment in the city.

American Indians migrating to cities during the post-World War Two era came through the program and on their own, sought better life opportunities than what was available on the reservation and found jobs fairly easy to attain in the city. Additional factors contributed to people's motivations beyond these listed, including interest in nearness to family, American Indian activism, as well as chance opportunity. Consideration of distance from family and home reservations was an important factor for those who migrated to Chicago. While some intentionally moved far away from family, as noted above in cases of abuse, others like Susan

Barnes and Almeda Cortez first came to Chicago to see or to be near family. Sylvia Kistler, a 69-year-old woman who was born on the Leech Lake Chippewa Reservation in Minnesota described how she and all of her family slowly migrated to Chicago with the enticement of being nearer to family:

> My sister was living here and, and one by one we were leaving for the city and my sister finally came and she said come on home with me, come back to Chicago with me, and I said well I, I said that's too big of a city. (laughs)... She said come on! She coaxed me, so I said okay I'll go with you. Then my [other] sister came, then my brother, my sister and brother were already here. So well most of us were here by then. Then my mother came last.

Sylvia still lives in Chicago today with, as she put it, more grandchildren than she can count, after first arriving in the city in 1959. For many relocatees, being near the home reservation and family also factors into the city choice in relocating – as seen in Frances Archer's description of how she and her husband chose Chicago over Los Angeles. Many first generation relocatees visit their home reservation one or more times a year to see family, seek medical care, and participate in their nation's cultural and political activities. They pass this practice of visiting onto younger generations who first join their parents on visits in childhood, and then begin to visit the reservation on their own and with their families as they grow older. The mobility of urban Natives and their relationship with the reservation communities today will be discussed in detail in chapter five.

Employment and proximity to family and home reservation were important factors for those who migrated to cities, but the initial move could be sparked by a wide variety of individual interests and experiences. In the 1970s, Randall Leary was drawn to Chicago after having read about his cousin's involvement in the Chicago Indian Village – an act of protest against the poor housing conditions many Native people of Chicago faced during that time (LaGrand 2002;

Wilson 2002). Now at the age of 68, Randall was almost 30 years old when he moved to Chicago from the Menominee Reservation in 1974:

> I saw on the news, I think it was in the paper, a cousin of mine was demonstrating outside of Wrigley Field, and I wanted to come down here to see what was going on.

While Randall did not actively take part in the Chicago Indian Village protests after migrating to Chicago, he did continue to live in the city after finding work. In a 2010 conversation Tammy Lowe mentioned that she had moved to Chicago on a dare. Tammy is a 68-year-old woman who moved from the Oneida reservation outside of Green Bay, Wisconsin to Chicago in1961. She elaborated upon this event in an interview we completed in December 2012:

> I was 21 when I first came here and what brought it down here bunch of us kids out joyriding. They went back the next day. I was only one out of six of them that stayed – from Green Bay… I stayed and the other ones went home

Like others describe, Tammy had no trouble finding work once she arrived in Chicago and she chose to stay in the city until she passed away in 2013.

Not everyone who relocated chose to remain in the city. Alfred Stewart is an 87-year-old Turtle Mountain Chippewa man who was born in North Dakota. Alfred moved to Chicago on his own in 1953 after hearing from his brother in the city about the work there. Alfred's future wife and brother moved to Chicago through the Relocation Program, and he described the program as beneficial for a lot of American Indians that moved through its assistance. While Alfred lived in Chicago for 60 years before our interview, he described how another of his brothers did not adjust to city life and returned to their reservation in North Dakota:

> A lot of Indians went back, a lot of them… My brother from Belcourt they sent him to California. And that's what they promised him. He had 4 kids. Finding those jobs, find you a job, you get a check, you pay for your bills, but [after] the

> first paycheck, you're on your own. So he stayed there one year… [He said] I get my check, I pay the rent, I pay for this, [and] there's nothing to even feed my family. He said to hell with that, so he came home.

Alfred's brother's experience in California was not unlike many others. According to correspondence sent by Gerard Littman to Father Peter Powell – the Father at St. Augustine's Center for the American Indian who has dedicated his life running this religious organization from the mid-1950s to today – in the early 1960s there were 9 thousand American Indians settled in Chicago, while between 14 thousand and 16 thousand were in the city at some point during the year, with as many as 40 percent returning home after attempting city life for a year or less (St. Augustine's Center for American Indians 1961-2006).

There were more challenges beyond financial ones that Natives faced after relocating to cities. One significant challenge was that of loneliness in the city space. While loneliness prompted many relocatees to return to the reservation, it also led to the development of Native community centers (Arndt 2002b; Bennett et al. 1986; Blackhawk 1995; Chicago American Indian Oral History Pilot Project 1982-1985; Intertribal Friendship House et al. 2002; Snyder 1973). Participants in this study describe that both bars and churches also served as sites for socializing. Natives also faced bias in job placement and job training. The BIA sponsored training for blue collar work, but not for college education or white collar employment (Blackhawk 1995; Intertribal Friendship House et al. 2002; Rosenthal 2012). While the Relocation Program was aimed at the assimilation of American Indians into American society, the BIA did not strive to assimilate American Indians into middle class white American society.

Finding clean affordable housing was a further challenge. The BIA's aim was to scatter American Indians around urban areas, but the housing situation in cities thwarted the BIA from achieving this goal (Sorkin 1978). In cities along the West Coast of the United States, the BIA had planned to disperse American Indians around the city by housing them in apartments far from one another; the BIA had hoped to prevent tribal contact and promote assimilation through this plan. However, due to limited budgets, the BIA could barely afford to house American Indians in apartments, let alone separate apartment buildings around the city. In the end, the BIA created all Indian apartment complexes, thereby failing to meet their original intent (Eagle 1997; Willard 1994). In Chicago, BIA agents found housing for Natives in the Uptown neighborhood. By the 1970s, Uptown was well known as the "Indian neighborhood" of Chicago (Chicago American Indian Oral History Pilot Project 1982-1985; Neils 1971).[20] Those who relocated faced problems with the houses and apartments themselves, ranging from unclean homes with broken windows, mold, and roach infestations to homes that were too small to fit large families (Chicago American Indian Oral History Pilot Project 1982-1985). This experience was not an uncommon one; rather, many found that through participating in Relocation Programs, they had traded rural poverty for urban slums (Bennett et al. 1986; Fixico 1986). This poor housing situation prompted a group of American Indians to protest against living conditions in Chicago's north-side Wrigleyville neighborhood in the 1970s (Garcia 2002; LaGrand 2002; Wilson 2002). Housing discrimination is still a concern today. In the early 2000s a landlord in the northwest side of the city told Tammy Lowe that by policy he does not rent his properties out to Native Americans.

Though Alfred Stewart's brother chose to move back home upon finding it nearly impossible to maintain his family on his city income, many others who migrated from the reservation to the city and back to the reservation did so multiple times. Joshua Parker first moved to Chicago in his thirties for work, but he was no stranger to living in an urban area.

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[20] Uptown is a community area on the northeast side of Chicago, bordering Lake Michigan

Joshua, 64 at the time of our interview, moved with his family in and out of the White Earth Chippewa Reservation in Minnesota multiple times in his childhood:

> I grew up many places. I grew up on the White Earth Reservation ‘til I was about seven or eight and then we moved through Indian Relocation Act, which is a government policy to, to assimilate Native Americans and moved to urban Indian areas where the Bureau of Indian Affairs would place my father into a job and get us an apartment and then after a couple months, we’d be on our own. So we moved to Minneapolis, things didn’t work out. We went back to the reservation. Then we moved to Los Angeles. Things didn’t work out there, so we came from California back to Billings, Montana where my other uncle had obtained a job in construction and offered to see if he could get my dad a job in construction, and he, they did. So we lived in Billings, Montana for a year after Los Angeles, and then we moved from there back to Minnesota and then we moved to Milwaukee. And then I went through high school and college in Milwaukee.

Experiences like Joshua’s were not uncommon. Orlando Garcia describes that many who migrated to the Chicago area during the era of the Relocation Program moved multiple times (Garcia 2002). While some scholars describe this trend of multiple movements to be based upon the failure of the BIA to adequately prepare people to move to the city (Arndt 2002a; Burt 1982), it may be more complicated than these explanations assume. Instead of considering this as a failing system of relocation, it might also be looked at as Native peoples seeking out the opportunities that best met their own desires and needs – whether these needs and desires are to be nearer to family, to be nearer to their reservation, to be able to find work, to gain an education in a specific field, or to be closer to a vibrant and active multi-tribal Native community.

While a great number of Native people migrated with the assistance provided by the Federal Relocation Program, many others made their way to the city on their own. Reasons for the move ranged from wanting to get away from problems on the reservation, greater employment opportunities in cities in contrast to reservations, the desire to be near family members who were already in cities, and supporting American Indian activism. While second generation relocatee Harriet McClean describes her family's relocation as one of forced movement, nearly all first generation relocatees describe a more agentive role in moving to the city to survive and find work. This survival, of course, was survival from the detrimental policies that led to extreme unemployment and harsh living conditions on reservations. The choice to remain in the city is influenced by employment opportunities, family relationships, and having activities to do in the city promoted and enabled the long term residence of many Chicago Natives.

Conclusion

The greater Chicagoland area is home to a large American Indian population today. According to the American Indian Center, this population includes individuals representing more than 100 tribes. The participants of this study represent a small sample of this population. These participants self-identified as citizens from 26 tribes across the United States and Canada, including Apache, Akimel O'odham, Arikara, Assiniboine, Cherokee, Chippewa, Choctaw, Covelo, Dakota, Ho Chunk, Lakota, Menominee, Meskwaki, Micmac, Navajo, Odawa, Ojibwe, Omaha, Oneida, Ponca, Potawatomi, Pueblo, Sac and Fox, Seneca, Sioux, and Stockbridge. Participants agree that the Native population of Chicago has decreased over the last few decades, citing that some are moving further into the suburbs, some are dying, and others are moving back to reservations. Uptown is no longer the Indian neighborhood it once was in the 1970s. Today Natives live throughout the city and its surrounding areas. The American Indian Center found through census and demographic research that a significant majority of the city's Natives live in the Irving Park and Portage Park neighborhoods, just a few miles west of the Uptown neighborhood. Though many first and second generation relocatees in this study continue to refer to the reservation as home, some Chicago Natives describe the city as their home. Steven Barnes, a 61-year-old Seneca man who moved to Chicago in 1979, describes his bond with the city:

> To me, it's my life, you know. Like I told you, I built this city, you know what I mean. To me it's got, means more than just being in the city. I can look at something and I know how that thing started and I know how it was built and or even like I said I can take the grandchildren and show them the Shedd Aquarium and we reconstructed Lake Shore drive… I had the chance to do stuff like this and this is stuff that I'll remember forever, and even, even I've passed it onto my grandchildren. My grandchildren are proud to say hey my grandfather did you know this and this and built this and that you know what I mean. It's, that's why I love this city so much you know, cause to me it's like in my blood, you know.

The programs and policies of the United States Federal Government from the nineteenth century to the post-World War Two era played a significant role in motivating the migration of American Indians from across the United States and Canada to Chicago. The urban experience that American Indians faced upon arrival through the BIA Relocation Programs proved to be a harsh and alienating encounter with the society into which the Federal Government hoped American Indians would assimilate. In reality, American Indians who relocated to cities did not passively assimilate into American city life as policy makers in Washington, DC had hoped; they participated in inter-tribal alliances and activities and maintained tribal contacts, effectively reasserting Native identity in an urban context and making a home in the city. In the next chapter I utilize interview materials, along with findings from archival research and secondary sources to discuss contemporary American Indian identity and community in Chicago.

CHAPTER 5
NATIVE CHICAGO

Introduction

Rosanna Poni and I sit on each end of a turquoise velvet couch in the Little Ones Room of the American Indian Center. I ask Rosanna, a 28-year-old Oneida woman what it means to be Native in a city like Chicago. A few weeks earlier the Lakota Grandmother Truth Tour, a group of Lakota citizens and documentary filmmakers from the Pine Ridge Reservation had come to the center to screen the poignant documentary *Red Cry*.[1] The film documents the history of colonialism and the detrimental effects it continues to have on the Lakota of Pine Ridge today. More than 40 Chicago Natives attended the screening and discussion that Friday night. The atmosphere shifted over the course of the evening, moving from excitement for the event, to grief upon hearing about the past and the current situation on Pine Ridge, and finally to anger and unease when the reservation Natives in the film and in the conversation that followed described urban Natives as having lost their culture in the city space. Within five days of the film screening, the center held a healing circle to resolve the issues brought up that Friday evening. [2] In the interim conversations in-person and on the online social media site Facebook arose in which Chicago Natives voiced their anger over the way in which the film and the Truth Tour representatives spoke of urban Natives. In response to my question on Native identity in the city,

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[1] This film is available to view on the video sharing website www.youtube.com.

[2] A healing circle is a gathering in which community members share their feelings about a particular topic or event in the aim of coming to terms with and/or letting go of the issues that are bothering them. Some features of a healing circle include a sage smudging, the sharing and consumption of cedar tea, and forming a circle and having the opportunity to share what one is feeling about the topic of the event. After the healing circle, what has been said during the course of the event is supposed to remain in that circle.

Rosanna voices her own disagreement with the views expressed by the visitors to the center that April evening:

> Other people might think we're assimilated, we don't know our culture, we don't know about being Native, but since, I mean, I don't think that's ever been true. I think people struggle with that a lot, but I think no matter what, we still have different worldviews and ways of relating to the world no matter where we are… Our original medicines still come through the cracks of pavements, so like we, our animal and plant relatives are here with us, like we're not devoid of that. It's always been here.

Urban Natives stand in a unique position. They are, as Rosanna describes, enmeshed in city life while also embodying and enacting Native identity in an urban space. Rosanna's response challenges the notion that urban Natives have assimilated as the designers of the Relocation Program had intended or as some reservation Natives believe they have. Rather, urban Natives enact and cultivate their culture and traditions in individual households and as part of larger tribal and inter-tribal networks.

Chicago's contemporary American Indian population is diverse; it is multigenerational, multi-tribal, made up of individuals whose ancestors originated in distant geographic locations, and it consists of diverse range of economic and class standings. As listed in the conclusion of the previous chapter, participants in this study self-identified as citizens of 26 tribes. These participants are one small sample of the greater Chicagoland Native population, which is estimated to represent more than 100 tribes from across the United States. In this chapter I describe Chicago's Native community. First, I explore concepts and enactments of Native identity in the city space. As reflected in the description of the film screening at the American Indian Center, there is significant pressure on the city population to identify as Indian. This pressure comes not only from the reservation Native population, but also from both Natives and non-Natives in the city space. Engaging with anthropological and sociological scholarship, I demonstrate that history, politics, and interactions with non-Natives inform and contribute to concepts of Native identity in Chicago. In the last section of this chapter I describe Chicago's Native community, illustrating that the community is made up of a number of interconnected networks that reach beyond the city to reservation spaces. While the community pulls together in times of need, there are also periods of division and in-fighting. My aim in this chapter is to introduce readers to Chicago's contemporary Native community and how its members situate their identity within this city space.

Politics, history, and blood

The space was cool and dimly lit in the conference room at Barry Dahms' place of work. We sat at one end of a large conference table, on wheeled black pleather chairs that appeared and felt as though they were fresh from a warehouse. An hour into our interview, Barry abruptly left the room, returning moments later with his two tribal identification cards from his office. He brought them back to this conference space, stating as he showed them to me that he was proud to be a "card-carrying Indian." Barry, a 68-year-old Choctaw man who has lived in several cities around the United States, juxtaposed his pride with the people he describes as saying with scorn "I'm not a card-carrying Indian." Barry and I had deviated from our interview on diabetes and had been talking about the Affordable Care Act and the effect it would have on programs like Indian Health Services, which led us into a discussion of how Chicago's American Indian Health Services requires that people to bring in a tribal identification card for services. As Barry explained, he was able to prove his ancestry and obtain a card, whereas those other people he mentions have not done the work to show that they are Native.

I had learned in the summer of 2012, a year before this interview with Barry, the importance people place in obtaining tribal identification cards in Chicago’s Native community. Early that summer, Rebecca Mastin gave special attention to instructing me on where to direct people with questions on how to trace Native lineages, while preparing me how to respond to phone calls and emails while I volunteered at the American Indian Center reception desk. The center, I soon learned, is contacted several times each week by individuals around the city who are trying to either trace their ancestry or to gather documentation in order to enroll as a citizen of a tribe. Rebecca explained that the person will first need to have some idea of what nation they descend from, and then learn the process of locating ancestry for that tribe. For most tribes that the center receives calls about, she explained, citizenship can be proven by locating an ancestor on a Dawes Roll.[3, 4] For this reason, Rebecca explained that the center directs individuals with these questions either to the tribe directly or to the Newberry Library which houses copies of some of these documents and can better assist those tracing their ancestry. Chicago Natives who know their ancestry enroll their children in their tribes often within a short period after birth, and this practice has been in place in Chicago for several decades (Straus and Valentino 1998).

Federally recognized tribes determine their own rules for citizenship. The rules and requirements of enrolling as a citizen vary by tribe. As historian Melissa Meyer explains, in setting the standard for enrollment, selection of “[The] variables that are ultimately employed is an arbitrary decision, but the implications for American Indians can be enormous” (Meyer 1999:234). Most tribes require ¼ blood quantum, meaning that, for instance, an individual must

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[3] Dawes Rolls were created in the decade before and after the turn of the twentieth century. Dawes Rolls list tribal citizens, and at the time of their creation, the rolls were used to assign allotments of Native land under the General Allotment Act of 1887.

[4] The method described by Rebecca is one reflecting the requirements of only some tribes, including the Cherokee, a tribe the center receives many inquiries about.

have one grandparent who is a full-blooded tribal member to enroll as a citizen in the tribe (Garroutte 2001; Harmon 2001; Meyer 1999; Tallbear 2003; Tallbear 2013). Eva Garroutte and Kimberly Tallbear explain that while the European concepts of race and blood were first introduced within just the past few centuries, they permeate discussions of Native citizenship today (Garroutte 2001; Tallbear 2003). Prior to contact with Europeans, indigenous Americans had their own systems for categorizing and marking the differences between groups of people. Nancy Shoemaker analyzes events from the eighteenth century to demonstrate that Native American groups of the southeastern United States categorized white, black, and Indian people as distinctly different groups of people. For some groups, these divisions of human groups were rooted in origin stories (Shoemaker 1997). In terms of blood and tribal citizenship, Kimberly Tallbear explains that while the Federal Government does not require federally recognized tribes to use blood quantum as a factor in the enrollment of citizens, the BIA offers information to tribes on how to determine blood quantum (Tallbear 2003).

As Rebecca Mastin explained, the process of proving blood quantum often rests upon locating ancestors on a Dawes Roll. Historian Alexandra Harmon demonstrates that studies on American Indian citizenship policies would greatly benefit from investigation of how tribes and federal agents determined who could and could not be included in a tribe’s roll. In her study of the Coleville Roll, Harmon shows a discursive back and forth between federal agents’ definitions of tribal membership and American Indian definitions – where federal agents focused on descent-based membership and tribal members considered kinship, residence, and behavior as important factors for inclusion (Harmon 2001). Blood, then, in this context is complicated and more studies on the process of the creation of Dawes Rolls would be beneficial. As anthropologist and science and technology studies scholar Kimberly Tallbear describes, though blood and forms of genetic evidence are shaped by and deeply enmeshed in social and political histories, the history of their making has been fetishized and many American Indian tribes and individuals incorporate these concepts of blood – and more recently genetic evidence – into their definitions of identity and citizenship (Tallbear 2013). While blood is recognized by Harmon and Tallbear to be a dubious marker of identity due to this social and political history, it is not often challenged or questioned within in Native communities like Chicago. In Chicago, blood is referenced in discussions of Native identity, while genes are not. Blood is considered a substance directly through which identity is passed, and I discuss this relationship of blood and identity in detail below. In chapter seven, I show that both blood and genetics are discussed in terms of diabetes inheritance, and further argue that diabetes is incorporated into contemporary discussions of Native identity, thus indirectly entangling genetic inheritance with contemporary definitions of Native identity in Chicago.

While American Indian nations hold significant power today in determining who can and cannot enroll as tribal citizens, the United States Federal Government wields significant power in determining which groups it recognizes as tribes. Professor of social work Hilary Weaver explains that Native identity is defined in three ways – by the self, by the community, and by external identification. This external identification, she continues, is a form of power and exclusion (Weaver 2001). In the previous chapter I described how American Indian Tribes were defined as political entities in the colonial context. Today the Federal Government plays a primary role in defining which groups are federally recognized as tribes. Historian James Clifford elaborates on the role the United States Government plays in his discussion of the 1977 *Mashpee Tribe v. New Seabury et al.* case (Clifford 1988). In this trial, the Mashpee sought recognition of their ownership of land based on the 1790 Non-Intercourse Act which required

Congressional approval for any transfer of land from Indian to non-Indian holders. As Clifford demonstrates, the trial was more about the negotiation of Mashpee indigenous identity than about the land dispute with the Seabury Company, which was reaping a substantial profit from its development of Cape Cod. In describing the efforts of the Mashpee, who lost this battle and their first appeal, Clifford explains that the court played the role of philosopher, defining who Indians are by interrogating contemporary Mashpee performances of indigeneity by the yardstick of the past (Clifford 1988). The power of the United States Federal Government in this context is an example of identity politics. Jonathan Hill and Thomas Wilson theorize the relationship between politics and identity in their definition of identity politics and politics of identity:

> ‘Identity politics’ refers mainly to the ‘top down’ processes whereby various political, economic, and other social entities attempt to mold collective identities, based on ethnicity, race, language and place, into relatively fixed and ‘naturalized’ frames for understanding political action and the body politic. ‘Politics of identity’ refers to a more ‘bottom up’ process through which local people challenge, subvert, or negotiate culture and identity and contest structures of power and wealth that constrain their social lives. [Hill and Wilson 2003:2]

Both identity politics and politics of identity are at play in definitions of Native identity in Chicago, however, the politics of identity on the ground are fraught with more disagreement than Hill and Wilson’s definition implies. Whether one is Native or not can be challenged by other members of the community. After one senior lunch, a newcomer to the center spoke with several regulars about Native items he had an interest in selling. One Native elder who overheard this man’s conversation, walked past him and muttered under her breath “You’re no Indian.” The on the ground politics of identity are full of internal challenges like this event, wherein pressure from inside the community is present. I will expand upon these internal pressures in later section of this chapter.

In these discussions, blood and appearance are important factors in some definitions of Native identity despite the fact that blood in this context has a complicated social and political history (Harmon 2001; Tallbear 2013). Lisa Oritz' early twenty-first century survey of Chicago Natives' perception of identity found that for both "full-" and "mixed-blooded" Indians, blood and appearance are considered significant factors in determining whether or not one is Native (Oritz 2002). In this study I found that blood and appearance continue to be important factors today. Several people describe a sense of pride in their status as full-blooded members of a single tribe, while others expressed concern for the future due to genetic admixture of Native and non-Native peoples. Pauline Massey, a 57-year-old Lakota woman, has lived her entire life in cities and explains that it was important for both her and her mother to marry within the Native community, and expresses concern over younger generations that are not doing the same. For Pauline, the Relocation Program's aims of assimilation were in a sense met by moving Natives to cities where they would begin to partner with non-Natives:

> Well I think they did their job. Their job was to break us up and to get us assimilated into you know a different culture and to probably make us extinct, and I think you know they're on their way. We, see like me and my sisters and my brother, we all have Indian kids, but their kids are half, so it's like, you know.

Earlier in our conversation, Pauline describes that for her own family she sees Native physical features fading away in younger generations:

> I kind of had that mindset too that I was going to marry a Native and nobody else, so he's Menominee. So he's Menominee, so my kids are Indian. You know, you know, so okay, so they're not half or whatever, so but my daughter, my middle one, her husband is white, I mean, so my granddaughter who's my granddaughter, you wouldn't even know she was mine. But no, she has blonde hair and the bluest eyes you've ever seen. Right and then the other one, she looks like you [fair skin, dark hair, green eyes], so, so you know she's darker than the other one is, but the other one's blonde haired and I mean the most beautiful blue eyes you've ever seen. And the other one has your color eyes and your color hair, maybe a little

> lighter, and they used to think that my daughter was their nanny. Nanny? That's her kids, her biological kids. But so then I got this one here is my youngest one and you can tell, she's African American, so you know I can't say anything because my kids, I do not have, I don't consider, I don't have any Native American looking grandkids…

For Pauline, relationships producing children with less Native blood and mixing physical features of Natives with non-Natives are a physical marker of assimilation. Circe Sturm describes that views like Pauline's are shared on reservations, where on the Cherokee Reservation genetic mixing was seen as contributing to cultural loss (Sturm 2002). In Chicago, Natives marry fellow citizens of their own tribe, citizens of other Native nations, and non-Natives. There are challenges that come from inter-marriage, for instance it becomes more difficult to enroll a child born in the inter-marriage relationships. However, marriages outside one's group can be beneficial in other ways, for instance in the promotion of inter-tribal understanding, which is discussed in the last section of this chapter. Blood and physical inheritance are important factors in definitions of Native identity in Chicago today. However, definitions of Native identity in the city and on reservations are fluid and they incorporate many factors beyond blood and appearance. Additional considerations include kinship, spiritual practices, knowledge and ability to speak Native languages, behavior, and shared history, values, and symbols (Cattelino 2008; Garbarino 1984; Goldberg-Ambrose 1994; Gonzales 1998; Lobo 1998; Sturm 2002).

Identity as shared history and experience

Group membership can be defined by the sharing of features – for instance, sharing a language, a cosmology, a set of ancestors, or an experience. The history of oppression throughout the past several centuries represents a set of shared experiences binding Native

Chicagoans together. While today parents teach their children about Native culture and history, this teaching was not always done openly or in many cases at all. Community members attribute this history of not passing on traditions to the experiences their parents and grandparents faced in boarding schools, where children were punished for speaking their Native languages and practicing their traditions. Larry Hood, a 53-year-old member of the Covelo Tribe, explains how this situation of passing on knowledge and traditions has shifted in recent years:

> When I grew up because of the, the Indian school structure, the elders back then and my parents did not want their kids to be raised Native because they all had horrible experiences with it. So my generation had to find kind of its own way, and we had to reinvent. So it's nice to see some of the elders that are still around finally realizing I can't die without passing on my knowledge. So there's been a big explosion here I think in culture that I haven't seen before. And there's been some political strengthening of the group.

As Larry describes, a history of oppression led to a fear for survival. Several elders spoke of not teaching or learning Native culture or tradition in the city or on the reservation. Alfred Steward, an 87-year-old member of the Turtle Mountain Chippewa, explains that he and his wife did not raise their children in their Native ways or to engage them with other Natives in the Chicago area:

> My kids they're here. I didn't raise mine Indian. I didn't raise my kids with Indian people until lately… They don't understand Indian. They don't speak my language, all English. That's terrible. Nobody thought to. Raise them like white kids.

Now later in life, Alfred expresses regret for not having taught his children his language and postponing involvement with the inter-tribal community of Chicago earlier in life.

This practice of not teaching Native traditions to children was common on reservations during that period in time as well. Randall Leary, a 68-year-old Menominee man, explained that the younger generations did not participate in ceremonies and traditional practices on his reservation, and as a consequence he could not learn pieces of his culture until later in life:

> Well as a younger child when I was growing up I would go, our parents would take us to reservation where they had powwows and they, they weren't really, we weren't really allowed to go to such things. The elder people would go, but they didn't want to teach the younger people, somehow they weren't allowed to let us practice our culture. I learned that stuff when I came down here after I recovered from alcohol. I had to learn about my own culture and other cultures… I'd often wonder as I was growing up why just my parents went to the powwow, not me, I wanted to learn the stuff when I was a kid, but I wasn't allowed to participate. Today I can, we can all, I'm not the only one that went through stuff like this; other Native Americans, depends on what tribe you were from or something. My tribe was, we weren't allowed to practice our traditions with our kids. Today I think it's a little bit different. The regalia people wear today is all new, I mean it's, the old days just parents were involved. Today it's everybody's involved. When I go to a powwow here, sometimes you see the tiny tots when they go, a special dance for them. I wish I would have learned it a long time ago.

As Randall explains, the situation has greatly changed in recent history.

History plays a large role in the constitution of individual, ethnic, and collective identities, but not only through the top-down identity politics. People employ their history to define identity and group membership today in a form of politics of identity (Connerton 1989; Hill and Wilson 2003). There are different ways in which groups use their history to exert the collective identities of the present. Chicago Natives reflect upon this history of oppression and today see it as a piece of their Native identity. A shared history of oppression, scholars have found, can play a significant role in modern understandings of group membership and identity. In Venezuela, David Guss found that Afro-Venezuelans in contemporary festivals, ceremonies, and celebrations highlight the parallels of their modern life experience with those of their Cimarron ancestors. In these events they focus on the tradition of dignified resistance to oppression, creating an unbroken link to the past (Guss 1993; Guss 1996). Histories of oppression are re-conceptualized in the present. Scott Simon describes how Formosans who lived under Chinese

Nationalists marshal law for 40 years grew to look fondly upon the Japanese colonial rule of the island that existed prior to this Chinese Nationalist rule. As Simon demonstrates, people re-define histories of oppression in contemporary circumstances (Simon 2003). Scholars of identity demonstrate that histories of oppression play an important role in the makeup of present identities.

The experience of oppression suffered by American Indian peoples through relations with the United States Federal Government, state governments, and individual cases of discrimination is a history that Natives index today in speaking about identity. In a discussion of Native poet Laura Tohe's work, linguistic anthropologist Anthony Webster describes how Tohe indexes her Indian identity through the use of terms commonly associated with boarding school experiences (Webster 2008). In using the terms "Cats" and "Stomps," Tohe indexes her membership in the boarding school generation. Just as the experience of attending a boarding school is a way in which one can index their Indian experience and identity, for American Indians living in cities, shared experiences in urban life contribute to one's sense of identity. In Deborah Davis Jackson's work in the pseudonymously named town of Riverton, Michigan, American Indian identity is in great part about the lived experience of being Indian in the city. As Jackson explains, the urban elders faced racism, discrimination, and alcoholism in cities and while they do not outwardly display their Native heritage, they are Native because they have lived it:

> Elder generation Anishinaabe people – those who grew up in the home communities of the early twentieth century – do not often seek their Indianness, nor do they usually express it in self-conscious ways. What they do – daily, subtly, with grace and gentle humor – is live it [Jackson 2002:166]

Supporting Jackson, Susan Lobo and Kurt Peters explain that for San Francisco Bay Area Natives, identity is about a shared history and shared values (Lobo 1998; Lobo and Peters 2001).

The history that Jackson describes for urban Natives in Michigan is similar to the experiences of Natives in Chicago, where racial discrimination against Natives in the workplace, in schools, and in neighborhoods was common (Chicago American Indian Oral History Pilot Project 1983-1985). Younger generations whose parents faced discrimination both on the reservation and in cities feel they have to work harder to get involved in their Native traditions to enact their identity than someone born on the reservation. These younger generations explain that those born on a reservation are ascribed Native identity, while the urban Natives have to achieve Native identity through study and performance. These younger urban Natives must strive to learn about tribal culture, history, and language on their own and through participation in American Indian organizations in the city because, as Alfred and Randall describe, it is not always taught by the elders due to the discrimination and oppression they faced in the past.

In the 1960s and 1970s there was a resurgence in American Indian identification; between 1970 and 1980, there was a 72 percent increase in the number of individuals who identified as American Indian on the United States census (Cerulo 1997; Gonzales 1998; Nagel 1995). C. Matthew Snipp claims that this increase in population is due to the political mobilization through acts of self-determination during this period, which promote tribal culture and resurgence in American Indian ancestry through pan-Indian movements in urban areas (Snipp 1992). Deborah Davis Jackson describes a second possible factor in the increase in American Indian identifications on census forms; Jackson worked with the second generation of American Indians living in a pseudonymously named Midwestern city, many of whom had not known of their Indian identity for a significant majority of their childhood (Jackson 1998). According to Jackson's description of four accounts from second generation American Indians living in Riverton*,* the parents of these individuals faced high levels of discrimination in the workplace, being called names like "Indian Joe" or "Chief." While their parents had varied responses to these forms of workplace discrimination and varied ways of speaking about American Indian identity, each of the four individuals Jackson worked with in this paper show that during the 1950s to be Indian in the city was to be discriminated against.

The experience of being Native, as Jackson puts it – having lived it – and being able to index that experience of shared history, often of shared oppression, plays into urban Native identity today. People like Larry Hood and Randall Leary speak of the oppression their parents and grandparents endured and how that plays a role in shaping their worldview and experience in the world. Younger generations in Chicago consider this history their parents lived as part of their identity and experience today, particularly for those who have had to strike out on their own later in life to learn more about their culture and traditions. In chapter seven I return to this discussion of a shared history and the development of an inter-tribal indigenous identity when speaking about explanations for diabetes in Native populations.

Maintaining ties with reservation communities

In 1971 Anthony Paredes suggested considering urban Native communities as part of a larger system with reservations. Renya Ramirez further developed and theorized a concept of this system in her 2007 work *Native Hubs.* In her work, Ramirez explains that urban Native communities, like the Santa Clara Valley Native community with which she worked, are the central hubs of this system Paredes suggested. From this center, Natives travel in and out of the hub, from cities to reservations and the reverse. In the process, inter-tribal alliances are made, information is shared, and a network is formed. Ramirez further describes that this form of transnationalism – living in a United States city while continuing contact with home tribes – keeps urban Natives connected with their individual tribes and creates a sense of cultural identity for urban Natives.

Transnationalism is practiced in other ethnic populations within the United States. Edna Viruell-Fuentes describes the different ways in which multiple generations of female Mexican immigrants practice transnationalism while living in Detroit, Michigan. First generation females maintain contact with their family through monthly or bimonthly phone calls, by sending materials to their family in Mexico, and by purchasing homes in Mexico. Viruell-Fuentes explains that for these first generation immigrants, the phone calls are the primary source of support that helps the women to feel a sense of belonging in the United States, while the women know that there are people at home in Mexico thinking about them. For the second generation, women gained a sense of pride in their history and a stronger sense of identity through the experiences they gained through trips to Mexico learning about their heritage and identity (Viruell-Fuentes 2006). Contact with home communities is significant in developing a sense of identity for many cultures living away from their extended families. As I noted in the previous chapter, many Chicago Natives visit their reservation one or more times each year. Some go to visit family, while others go to participate in ceremonies, vote in political elections, and/or fish, hunt, and gather foods on traditional tribal lands. In these trips from Chicago to reservations, people often go along with friends from other tribes and learn about and participate in the tribal ceremonies and events of other American Indian tribes than their own. Members of this community also live for portions of their life on a reservation, and not necessarily on a reservation of which they are a tribal citizen. Some return to the city, and others do not.

Often on visits, Chicago Natives will bring Native items for consumption back to share in Chicago. Consumption has long been recognized as a feature of identity performance (Bourdieu 2005; Caplan 1997; Douglas 1997; Messer 1984; Miller 2000; Mintz 1996; Roy 2006; Sutton 2001). Consuming certain types of food is a way of identifying who you are, and who you are not; culinary choices mark ethnicity and create distinctions between self and other (Caplan 1997; Sutton 2001). In Native Chicago, community members bring food from reservations and from the city that contributes to Native identity. At the senior lunches I observed between 2007 and 2014, the meals that incorporated Native foods, such as venison, bison, squash, beans, corn, hominy, walleye, berries and wild rice, along with fry bread were highly praised by seniors.[5] Food is a cultural connector in this context. In the case of those attending senior lunches, the meals featuring Native food items that were not part of their own ancestors' diets are still seen as connecting them to their indigenous American ancestry. Consuming the traditional foods of a tribe that is not one's own not only serves to connect an individual to their indigenous American ancestry, but it further binds individuals of a diverse set of American Indian tribes together in Chicago as a community.

In addition to obtaining Native foods from the reservations for community meals, Chicago Native community members bring plants and Native medicines for use in the city space. Cedar is brought for tea, sage for smudging, and plant seeds and saplings from reservation lands

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[5] Fry bread is considered by community members as a Native food, but not a traditional Native food. Fry bread is looked upon as a form of ingenuity and creativity during a period of oppression. In this case, Natives found a way to make bread using what resources they had from the commodity program. Today, however, fry bread is also considered a food that is not healthy in the context of the high rates of diabetes, heart disease, and obesity in the community.

are brought to grow in Chicago soil – Native plants then are not only growing between the cracks of the pavement as Rosanna described, but also planted and cultivated in dedicated city spaces for Native gardens and tended to by community members.

The road between the reservation and the city is travelled both ways. Some tribes also bring services to the city. In Chicago, a direct and constant relationship with the reservation is seen in the relations between the Chicago Ho-Chunk and the Wisconsin Ho-Chunk government. The Ho-Chunk Nation of Wisconsin set up an office in Chicago in 1993, the Ho-Chunk Nation Urban Branch Office (Arndt 2002b; Straus and Valentino 1998). This office provides Ho-Chunk members with government services, such as tribal loans for housing and education, as well as health and social services. The goal of this urban office is to strengthen the link between the Wisconsin tribe and their relatives in Chicago. Each month there is a meeting, where the tribal legislators and Chicago Ho-Chunk share a prayer and a meal, as well as discuss new legislation and events happening in the Ho-Chunk government. This opening of the Ho-Chunk office shows the importance of the associations being maintained between urban and reservation tribal members (Arndt 2002b). The American Indian Center maintains a close relationship with several of the local tribes, including the Menominee and the Potawatomie tribes that offer both financial and personnel support for some of the center's programming. The relationship between the city and the reservation is one that is actively maintained by both urban Indians and their reservation relatives and governments.

Performance

I had been volunteering daily at the American Indian Center for six months, answering phones in reception, working with the weekly food pantry, assisting in the cooking and serving of the senior lunch, and helping with preparations for the center's 59th annual Chicago Powwow, when I poked my head into Rebecca Mastin's office to tell her I was on the way home for the day and said "goodbye." With exasperation Rebecca stopped me as I began to turn to leave, saying: "Meg, we do not say goodbye, we say see you." Rebecca explained that "goodbye" implies finality, and that even when someone passes away, it is customary to say "see you" rather than "goodbye." After all of these months, I had not consciously observed the absence of this expression. On my drive home that night I recounted conversations I had had with Rebecca and with others over the past few months, noting that those conversations typically concluded with "see you tomorrow" or "talk to you later," and rarely ended with "goodbye." Through calling my attention to daily faux pas after these months of volunteering at the center, Rebecca was inviting me to become more involved in the community as an insider rather than an outsider. One of the many ways in which people identify themselves as members of a group is through performance.

According to anthropologist and sociologist Edward H. Spicer, Native identity is a flexible category, not merely based upon an association with land or the practice of tradition so much as it is about the ideas and feelings about the various events that people have shared together and lived through:

> Being an Indian means participating in the Indian realm of meaning regarding these events which both Indians and whites have experienced… meanings which make the real difference between Indians and others. [Spicer 1975:47]

In Native Chicago, beyond blood and shared history, and some contact with the reservation communities, speaking a Native language and participating in rituals and other events are performances of Native identity.

Language is considered an important feature of Native identity. Jessica Cattelino explains that members of the Seminole Nation see the loss of language as equating to a loss of culture (Cattelino 2008). Ability to speak Native languages was a primary aspect in which the film *Red Cry* turned to in describing urban Natives as not knowing their culture, equating language with culture. Rebecca Mastin, a 53-year-old Omaha/Odawa woman, describes how in the past, Chicago community members would continue to use their Native languages in conversation. However, Rebecca explains that parents, as also described by Alfred Stewart earlier in this chapter, did not pass Native languages down to their children, fearing that their children would be taken away:

> My dad would talk, there were several people in the community that would talk, Agnes Harrison, and some of the other ones that he would, Arlene Hunter's mom, she said oh we all used to speak Ojibwe with your dad and we'd all be laughing. They said that's when we would really get to speak our language was when we all got together was when they were all at the Indian Center. So I never realized that. I knew when we went back home to Canada that everybody up there that was the first language. And they'd use English occasionally. But he said he didn't want me to learn because everyone, it seemed like everyone was scared they were going to take the kids away and make us all go to boarding school.

The history of boarding schools and the institutionalized suppression of Native culture and language have deeply affected Native identity today. Today the majority of Chicago Natives primarily speak English. Native languages are known by community members. Participants in this study described having knowledge of or having a family member with knowledge of Diné, Choctaw, Lakota, and several dialects of Ojibwe and Pueblo languages. Many participants knew only a few words of these languages, while few could claim fluency. Within the larger Chicago Native community, there are relatively few fluent speakers of Native languages today in contrast to language speakers on reservations. Some reservations have dedicated Native language classes and schools that have no counterpart in the city. There are groups meeting in the city that work towards language learning, and the youth program at the American Indian Center strives to teach some Native words to younger generations. In January 2015, an Ojibwe language class began in Chicago. As described to me by one participant in this class, the students in this course include not only members of Ojibwe-speaking-Nations, but other unrelated tribes. Similar to the consumption of Native foods described above, there is a great interest in learning about and participating in Native cultural traditions and activities in the city space as a way not only of connecting with one’s own ancestry, but with engaging in the inter-tribal community and indigenous American culture more broadly.

Participation in spiritual and ritual events constitutes a performance of Native identity. Based upon his ethnographic and survey research, Chicago Native anthropologist Eli Suzukovich finds that Chicago Natives participate in a wide range of religious practices and belief systems in the city, including Traditional beliefs (Tribal belief systems, Native American Church, Midewiwin, Big Drum, and Longhouse), Christian beliefs (Catholic, Protestant, Episcopalian, Born Again Christian, and Seventh Day Adventist), and in mixed religions practices that combine these Traditional and Christian systems. Spiritual events are common in the city and include sweat lodges, morning prayers, naming ceremonies, healing ceremonies, pipe ceremonies, drum feasts, sunrise ceremonies, wakes, funeral celebrations, and Sunday masses. However, as Suzukovich explains, many of these practices are unseen (Suzukovich 2011).

These events are often done within homes and are announced via word of mouth. Identities are negotiated through discursive interactions. One may perform an identity, but this identity relies upon the acknowledgement of one's interlocutors (Kiesling 2001; West and Zimmerman 1987). In the summer 2013 after a senior lunch, Roy Nieves stopped by the table where other volunteers and I were eating to chat for a few minutes when he noticed a flyer inviting people to attend a sweat lodge in one of the northwestern suburbs. He commented that this flyer was not right, adding that the traditional way was to spread news of the event via word of mouth. Participation in the event, then, is not the only performance of identity, but so too is the way in which the news is spread. In this situation, Roy contests and challenges this sweat lodge host's performance of Native identity. There is pressure in the city to enact Native identity in a certain way. Roy is doing boundary maintenance just as the elder woman was doing after that senior lunch when she challenged the newcomer's claim to Native heritage.

Other performances of Native identity in Chicago include participating in powwows, dancing, drumming, storytelling and behaving in what is described as Native ways. Powwows are a significant aspect of urban Native life. Members of Chicago's Native community not only host several powwows throughout the year, but some also follow the powwow trail – attending, dancing, drumming, and selling food and crafts in powwows across the United States and Canada. Telling stories to children is another activity Chicago Natives described as a way of enacting their Native identity and passing culture and tradition on to their children. Lastly, behaving in a Native way was described as important to Native identity. Behaviors commonly referred to as tied to Native traditions included sharing what you have with others, respecting women, and having a reverence for the earth. Rosanna Poni described holding a worldview that is distinctly Native. This worldview she references is made up of each of these factors – from carrying the knowledge of a shared history of oppression to showing reverence and respect for the earth and for one another.

Being Native in the city space

Natives living in cities like Chicago are performing and negotiating their Native identity in a space surrounded by people representing a diverse array of cultural and ethnic backgrounds. Living in this space, people learn to balance their identity. Urban Indians adopt cultural items and values of city life while retaining Native values and cultural ways. Roy Nieves, a 35-year-old Oglala Sioux/Navajo man, described what it was like growing up Native in the city:

> Roy: Different from other, different in a sense from, from an outsider, from well, two perspective. One perspective inside, one outside. So more of perspective from the inside, so just trying to balance city life and sort of Indian life if you may.
>
> Meg: So, what exactly does that mean?
>
> Roy: Well I mean like being a part of I would say mainstream in a sense. And then be more of underground with what I've been taught in a sense from my tribal culture, 'cause it's there are, there are differences, and there are similarities, so just trying to find a balance between both mainstream and my tribal cultures if you may.

Roy speaks of managing his identity, aiming to strike a balance between his Native identity and his urban life. Elders of the community are concerned that the younger generations are not learning from the elder generations. In many contexts worldwide older generations see change as culture loss. Michael Herzfeld finds in his work with artisan apprentices in Greece that older generations view taking up aspects of modern life as losing one's cultural identity (Herzfeld 2004). The younger generations, of which Roy is a part, explain that they do follow their Native traditions, but they incorporate some of the urban life into their individual identities. Roy, for instance, drums, participates in powwows and traditional ceremonies, visits and has lived on reservations, but is also an avid member of online communities, plays video games, and enjoys watching Hollywood blockbusters. Urban Natives are involved in a variety of communities outside of Native life, including work, school, volunteer organizations, neighborhoods, churches, and sports. In the city space people adopt cultural items and values from these non-Native spheres of life while retaining Native values and cultural ways (Fixico 2006; Lobo 1998).

Concepts of identity change over time (Ramirez 2007). As James Clifford argues in his discussion of the Mashpee court case, all cultures change – no one group is static for all of time, and this fact is especially true for cultures that are changing in the context of domination (Clifford 1988). Larry Nesper's work *Walleye War* highlights how the Lac du Flambeau Ojibwe incorporated violating – or hunting and fishing off-reservation illegally – in their definition of Ojibwe identity before the 1983 court decision to uphold Ojibwe treaty rights to fish off reservation (Nesper 2002). In the context of communities that are separate from their homeland, identities can be flexible and overlapping. Dalia Abdelhady's work describes the different ways in which Lebanese immigrants in Montreal, Paris and New York belong to three separate communities. These three types of membership include one to their host country, one to the disasporic community within their host country, and one to the Lebanese immigrant communities throughout the world. Abdelhady shows that immigrants do not have one singular membership to any one community, but rather, there are ways of participating in multiple separate and fragmented communities, and yet retaining dedication to Lebanese autonomy (Abdelhady 2006).

Like the Lebanese in Abdelhady's discussion, Chicago Natives are managing their Native identity in a diverse locale through balance. New cultural forms are adapted to urban life, as the traditional practices may not function in the urban setting as it would on a reservation. Traditions and identities evolve with time and in place and younger generations of Chicago Natives are developing and negotiating their own ways of managing their Native identity in the urban space.

Relationships with non-Natives

Part of the balance that Roy speaks of achieving is done within interactions with non-Natives. In an interview, Mary Bey, a 57-year-old Menominee woman, describes being dismayed by an acquaintance's assumptions after telling this person about a planned trip to the Menominee reservation:

> She's like oh, the reservation, are there teepees on there? I'm like Alice, are you talking to me or what? I had to laugh, I'm like, I told Alice later I was going to say I can't believe you asked me that question when you're like a smart person. Of course there's no fucking teepees on there. It's like small town living I told her, kind of like towns gathered together around the lake, it's not, there's no teepees unless you make a fake one in your driveway or something. Yes, really? So I mean sometimes that surprises me and then she, I think when she said it she was embarrassed, I said Alice that would be like me thinking oh you're Mexican, do you have like a dirt floor house, or what. She was like, oh yeah. So I didn't, I did answer her and I showed her pictures you know where my mom lives and then around the lake and everything and how beautiful it is and it's all just small town living. I said you wouldn't be able to survive there unless you have a car you know or a good truck in the winter. So I think that's a challenge because I really, it's a stereotype kind of thing and it, it happened to me a lot when I was a nurse, a manager too.

What occurred in Mary's interaction is not uncommon. In the week before the American Indian Center's 61st annual powwow, community members were excited for publicity for the event that was made possible by the local news channel WGN picking up the story and inviting dancers and drummers to perform for a segment of their morning broadcast. In this segment that aired on September 10, 2014, one newscaster described the event as the community honoring the Relocation Act of the 1950s and another newscaster later referred to Chicago Natives as though they were all members of a single tribe. These occasions of misunderstanding represent pressures from non-Natives on contemporary definitions of Native identity. These types of misunderstandings and interactions are spaces in which Chicago Natives choose to either ignore or push back against stereotypes and define Native culture, traditions, history, and identity in the contemporary context.

People develop and negotiate their identities in conversation with individuals and other groups of people (Barth 1969; Cameron 2001; Fuller 2007; West and Zimmerman 1987). In *Indians in Unexpected Places* Philip Deloria describes how many non-Native Americans do not expect to find American Indians living in urban centers. Deloria explains that this is because urban Indians do not match up with the expectations non-Natives have for who American Indian peoples are (Deloria 2004). In the collective consciousness of the majority of the United States, Native Americans are not thought of as an urban populace, but as members of a reservation community. Oftentimes, non-Natives are not aware of the large Native population in Chicago. Community organizers see this as one of the largest challenges faced by the Native community. This invisibility of the community hinders their ability to gain access to financial resources to support community programs. Joshua Parker, a community organizer, explains in an interview:

> We’re just an invisible part of Chicago’s community, and we need to become more visible. And I think one of the sayings that the organization that I belong to is making the invisible visible… I think that the mayor’s office needs to do something to recognize Indian people. I think Indian people need to make them more aware of us by having a big powwow downtown in Grant Park or something, just to show we’re here.

Two weeks later at a meeting of the Coalition of Chicago American Indian Community Organizations – the group Joshua spoke of – organizers described the frustrations they faced as not-for-profit organizations seeking funding. One member of this meeting described how in a rejection explanation from a grant application her organization received, the funder noted that they had already supported a Native program located in the Southwestern United States. The organizer asked those of us in attendance at the meeting to consider whether any funder would offer this same explanation to an African American or a Hispanic organization. Invisibility of urban Native populations to non-Natives is widespread, despite the fact that nearly 80 percent of American Indians reside in urban areas – this invisibility is experienced throughout urban Native communities around the United States (Danziger 1991; Deloria 2004; Intertribal Friendship House et al. 2002; Weibel-Orlando 1991).

My point here is not to essentialize all non-Natives as though they are unaware of the Native population of the city and have no clue about Native history or contemporary Native culture, but to note that the majority of Chicago's inhabitants are unaware that the city is home to the eighth largest Native population in the United States and many Natives feel they have to educate those they encounter in the city who hold stereotypes of Natives. Both Mary's interaction with her friend Alice and the coalition's discussion of trying to increase the visibility of the community demonstrate the ways in which Chicago Natives perform acts of politics of identity, challenging widely held stereotypes about who and where Native people are today.

As referenced by Pauline above, many Natives in the city are also marrying non-Natives in the city space. From Pauline's view, this occurrence can result in the reduction of Native identity. For those I knew in the city who were part Native and part non-Native, they were equally interested in the cultures of their ancestors, participating in events at the center and also being involved in their other ethnic communities in the city. All of the non-Native spouses I knew also became active members in Chicago's Native community, wherein some volunteered and participated in events at the center.

A community of survival

At the annual American Indian Center Giving Thanks Feast in November of 2013, a founding member of the center led the community in prayer before the meal began. In her welcoming address, she stated that she was thankful for the survival of Native communities – from surviving the first Thanksgiving through surviving as an urban Native community today. This elder's sentiments, Rosanna Poni's statement quoted in the introduction to this chapter, and the comments of Elmer Pierson on Native peoples representing cultures of survival described in the previous chapter are examples of how multiple generations of Chicago Natives take pride in their and their ancestors' accomplishments in being able to survive centuries of struggles against colonialism, oppression, and attempts of assimilation.

Chicago's Native community today is not a cohesive singular group, but rather a set of overlapping networks, wherein individual membership is multiple and fluid. Chicago's community is made up of individuals representing more than 100 tribes from across the United States and Canada. As described above, maintaining individual tribal identities and contact with tribes is important to Chicago Natives, and the relationship between the city and the reservation is one that is actively maintained by both the urban and reservation Natives. One of the largest support systems for Natives in Chicago is the network of relationships between Natives in the city, supported in great part by organizations supporting inter-tribal Native community and traditions. Native organizations in the city include the American Indian Center of Chicago, Kateri Center (a now Catholic organization, formerly known as ANAWIM), Saint Augustine's Center, the Mitchell Museum, American Indian Association of Illinois, California Manpower Consortium, and American Indian Health Services of Chicago.

The American Indian Center of Chicago is described by many members of the community as the flagship Native institution, because most people, both Native and non-Native, first come across the center when searching out Natives in the city. The Chicago American Indian Center is the oldest center of its kind in the nation. As described in the introductory chapter, in 1953 community members, some of whom had been involved in developing previous organizations in Chicago and others who were new to the city, established the All Tribes American Indian Center, with an emphasis on the first two words in the name. Although supported by the BIA, the center from its early years was an Indian-run organization. It began as a social gathering place. Over the years it developed a social service function and became central to the identity of the Chicago Indian community (Beck 2002). Participants in the 1980s Chicago American Indian Oral History Pilot Project explained in their interviews that they likely would have left the city had they not found the center due to the loneliness they faced in the city (Chicago American Indian Oral History Pilot Project 1982-1985). Inter-tribal alliances in cities across the United States first developed to combat loneliness in the cities (Ono 2011; Snipp 1992). Natives living in Chicago, as well as in Rochester and the California Bay area, explain that it is easier to maintain Native identity through participation in inter-tribal Native organizations in the city because they promote cultural values and traditions (Krouse 2001; Suzukovich 2011).

The American Indian Center is central to many peoples stories about their lives growing up in Native Chicago. While some people intermittently visit the center on holidays, for powwows, and for ceremonies, others Natives are involved in the day-to-day programs of the center. Rebecca Mastin is a self-proclaimed “center baby.” Her parents met at the center, held their wedding reception and her baby shower there, and Rebecca has been involved in the center for most of her life. She recalls going to powwows at two of the center's three locations while growing up in one of the city's suburbs:

> I don't remember the first center. I remember the second one over on Sheridan Road and going upstairs and they had big powwows when we had monthly powwows, there were like 8, 9 drums set up. We had the Chippewa Drum and Menomonie Drum and Winnebago Drum, Family Drums, Sioux Drum, Southern Style Wipponka Drum, and a lot of people danced. It was, the rooms were just full.

The center brought people from tribes across the United States together, and was a place where community members now in their middle age recall growing up. Arlene Hunter, a 63-year-old Ojibwe/Odawa woman who grew up in the city, recalls going to each of the locales the center has stood in over the past 60 years:

> My mom used to bring us to powwows. I went, I remember going to powwows on LaSalle. Now that was a long time ago. That was in the '50s and I remember going up there, my mom used to take us. That was a long time ago. But I remember going there. It was, I think that was the first Indian Center that was in Chicago. They moved from LaSalle to I think the next one was on Sheridan and Broadway. It was on the corner there. No, it was on Sheridan and Broadway. There was an Indian Center there. It's gone now. There's a gas station there now. But there was another, there was an Indian Center there, and then from there I think they moved over here.

Arlene grew up at the center, as she describes. She went to powwows as a child, "hung out" at the center as a teen, met her ex-husband in those teenage years, and now volunteers at the center each week.

Through these inter-tribal networks, many Natives met future spouses from other tribes. Gerard Paul, a 44-year-old Choctaw/Navajo man, laughingly spoke of how he has to often explain his mixed-Native ancestry to people:

> My mom's from Mississippi, Choctaw and my dad's from New Mexico and they came here through the relocation, brought them to Chicago. They were both placed, I always get this, you know they're like the people who know tribes and the geographical regions of the tribes and they're like how did you become Choctaw Navajo, they're two different parts of the country, it's because of relocation and because my parents were placed in the same neighborhood.

The relocation program brought Natives from across the United States together. Not only did people partner with citizens of other tribes, but they also shared traditions and practices in the urban space, as is also occurring in the Santa Clara Valley (Ramirez 2007). Diane Bauman, who is a 27-year-old Arikara/Omaha/Odawa woman, explains that one of the great things about Native life in a city is that they learn about other Native cultures:

> Growing up, one advantage is here in the city is you learn not only your ways, is you learn a whole bunch of tribes' ways, like I know a lot of Navajo ways or Ho Chunk ways, or Potawatomi, Menominee ways that I know there's a lot of different ways to do things, so I've learned some of the different, so if I go to travel to different areas, I kind of know what you can and can't do when you're over there.

For Diane, knowing different ways has been useful as she and her family travel the powwow trail each summer, visiting different locales around the United States and Canada, feeling more prepared to participate in events at each site than she would only knowing her own tribes' cultures.

Though the name has changed, the center activities reflect its initial name, All-Indian. Steven Barnes explained in an interview on what it meant to be Native in Chicago:

> In Chicago, is that you're, you're not just from your tribe, there's so many different tribes here in the city that you're not, it doesn't matter what tribe you are. You're still an Indian. Once you come to the center, we're all Indians here and it doesn't matter what Indian you are or what you are. We're all united as the Indians in Chicago, you know what I mean, it's, we're all one type of Indian. Where you can't say oh well I belong to this tribe, I belong to that tribe.

Steven’s sentiments are not shared by everyone. There are members of some of the older generations who chose not participate in the center because they did not feel that the people they could meet at the center were their people. The Native community of Chicago is not one single community that exists without dispute. However, Veronica Hanover explains that the community comes together when it is needed:

> It’s just that when things occur to us, we try to pull together as a community or as a group, or as a family to help each other out. Like if someone’s gets, one time there was somebody that had a fire in their apartment, so we were going around getting things that they needed to set up and somebody was helping them find an apartment. You know we try to be there to help when we know somebody is in trouble or needs some kind of assistance. We try to be there and do what we can. Sometimes if it’s not physically possible, at least we try to encourage them to, to hang in there until times get better. And of course you know we have our, when someone dies in the community, we have their memorial service.

While people like Steven and Veronica both speak of coming together, there are many instances where divisions can be seen. Chicago’s organizations are trying to work together today to find more funding to support community program, but in-fighting in recent years has detracted from their ability to do so. Larry Hood, a leader of one organization explains:

> They’re not united. They’re going through a process now with a lot of the agencies of uniting and being a united front politically. There’s been a whole strategic planning over the last year. They’ve gotten further along with that than they ever have, which is a great sign, so I think a lot of it is newer people coming on board that are leaders, wanting to change. You still have some in-fighting.

Chicago’s Native community is an inter-tribal one that is made up of smaller networks of people. There are disputes from time to time, but the community does pull together in times of need, as they did for the healing circle that followed the Truth Tour event in April of 2013.

Conclusion

Members of Chicago's Native community articulate a story of survival when reflecting upon the Relocation Program and on the longer history of Natives in relation to European powers. Native identity in the city is deeply rooted in history and politics, while performed and negotiated in the present. Chicago Natives factor blood, history of oppression, contact with reservation communities, language, food, religious beliefs, behaviors, and relationships with non-Natives into their concepts of identity. A central finding of this dissertation is the ways in which discourses of diabetes play into these discussions of Native identity in the city space. In chapter seven, I describe how local explanations for why people develop diabetes pertain to these discussions of shared history in Native identity.

Today, Chicago's Native community does not represent a cohesive singular unit, but a network of people who at times are at odds with one another, and at other times come together. Urban Natives identify both with individual tribes, and as members of an inter-tribal indigenous community in which members practice traditions, learn languages, and eat foods that historically belonged to a variety of tribes. This sharing of Native traditions in the urban space not only works to bind the community together as an ethnic enclave in the city space, but it further works to connect individuals to a broader indigenous American history and identity. Now that I have briefly sketched out Chicago's Native community, in the next chapter I begin to describe diabetes in Chicago's Native community, showing that the high rate of diabetes in the community shapes local beliefs, practices, and understandings of the condition.

CHAPTER 6
DIABETES IN NATIVE CHICAGO

Introduction

The receptionist’s bold and authoritative voice travels through the ceiling and into the background of our conversation as Idella Chaisson and I speak in a basement office at the American Indian Center. We had tried to escape the heat of this July afternoon by moving to a basement office, but there was little relief to be found in this humid space. Idella is a 35-year-old Potawatomi/Puerto Rican woman. She was diagnosed with type 2 diabetes just one month prior to our interview. Wearing an oversized navy blue Cubs t-shirt with black ankle length leggings, Idella rests her arms on the table between us as she describes of the effect diabetes has had on her family. She lists family members living with the disease, naming her grandmother, mother, aunts, and uncles. Later in our conversation, Idella relates her now growing concern for her teenage daughter who is beginning to display dark patches of skin on the back of her neck – a sign many mothers in the community regard as an early symptom of diabetes in children.[1] Idella and I speak about her care routine and adjustments she has made since her own diagnosis. In response to one of the last questions – what she wants to see for her future and for the community’s future – Idella returns to her concern over the high rates of diabetes in her family and in the community:

> Honestly, like all the people that I know that are Native American and that are family, everybody has it. It’s just something, I don’t know if it’s in our blood, from our generations, but everybody that I know family wise or friends that are Native American all have diabetes… for us it’s like in our blood I think and it’s passed down from generation to generation, cause you know my mom passed it

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[1] These dark patches of skin on the neck and/or underarm are known as acanthosis nigricans in the biomedical community – described in that context as an early sign of insulin resistance (Hearst et al. 2011).

> down to me and I kind of passed it down to my older daughter and now I'm scared because if she don't lose the weight, she's going to be with diabetes.

In chapter three I described the recent history of the diabetes epidemic in American Indian peoples. While there are no published statistics on rates of diabetes in Chicago's Native population, accounts like Idella's attest to the high prevalence of diabetes in the community today. From Idella's vantage point, everybody has it.

Through oral history interviews and archival research I found that diabetes has been in Chicago's Native community since the beginning of the Relocation Program era in the 1950s. By the 1980s, diabetes was a pressing health concern in Native Chicago. Ada Powers, a participant in the 1980s Chicago American Indian Oral History Pilot Project described in a 1983 interview how nearly all Chicago Natives are affected by diabetes:

> To me it seems like all the Indians are crippled or diabetics. I'm one of them. If it's just the Indian himself or their diets or what, but all those old Indians you talk to, they're diabetic… No matter who you talk to, they got diabetes [Chicago American Indian Oral History Pilot Project 1983-1985, Ada Powers interview, folder 012, page 15]

While Idella's statement mirrors that of Ada Powers from nearly 30 years earlier, Idella also speaks to the now growing occurrence of diabetes in younger generations. Children as young as 11 years old are being diagnosed as prediabetic, making diabetes a significant health concern for Chicago Natives of all ages.

My aim in this chapter is to introduce diabetes in Native Chicago. I show that the prevalence of diabetes in Chicago's Native community shapes local beliefs, practices, and understandings of the condition. I first look at how community members learn about diabetes in childhood. I then show that the prevalence of the disease in conjunction with public health media foster the idea of heightened risk of diabetes in Native populations and that this labelling of Natives as at risk for diabetes can lead to fatalistic views about its development. In the third section I describe the moralization of diabetes care practices and diabetes management. In the last section I look at a local taxonomy of diabetes severity, demonstrating that the classification of diabetes forms is situated within local experiences with the disease.

Developing an awareness of diabetes in childhood

In July 2009, wellness staff at the American Indian Center chose diabetes as their monthly health topic. Over the course of the month, members of the wellness staff would provide information via lectures, handouts, and demonstrations on a health topic to senior lunch attendees. Topics in the past included cancer, heart disease, and men's and women's health. The aim of these monthly health topics was to educate seniors about common health concerns in the community. There were more than 50 people in attendance at the elder lunch when Wendy Abney presented on diet and diabetes. During her presentation she asked those in attendance – a mix of both seniors and youth and of Natives and non-Natives – to raise their hands if they had an immediate family member with diabetes. Nearly every person in Tribal Hall raised a hand.

This banquet room full of lunch attendees raising their hands illustrates what Idella and Ada Powers describe. There is a high rate of diabetes in Chicago's Native community, and not only are adults aware of this prevalence, but so too are the children attending the summer youth program. In contrast to the non-Native medical providers I spoke with, Native medical providers along with Native diabetics and lay caregivers were often conscious of what diabetes was from childhood. Where non-Natives first learned of the disease in school, Native participants often recall seeing a relative inject themselves with insulin, test their blood glucose levels, watch the foods they eat, and/or contend with diabetes complications, which can include the loss of limbs and eyesight.

For Chicago Native youths, diabetes is ever present in their lifeworld, which stands in stark contrast to the lifeworld of Native peoples 70 years ago when diabetes was rare (Habermas 1987; Jackson 1998; Schutz 1962). Alfred Schutz describes the lifeworld as the intersubjective world of everyday life. This lifeworld is the day-to-day space and time in which an individual lives; this daily life puts people, phenomena, objects, concepts, stories, history, et cetera within the subject's reach (Schutz 1962). Kenneth George builds upon Schutz when he describes a lifeworld as:

> The ongoing circumstances in which we find ourselves, culturally, politically, historically, and experientially. Each of us is thrown, with others, into a lifeworld through which we must find our way, refashioning its horizons as imaginatively and as pragmatically as we can. [George 2010:4]

Lifeworld theorists explain that the world is both intersubjective and always in motion (Habermas 1987; Jackson 1998; Moore 1987; Rosaldo 1993; Williams 1977). In contemporary Native Chicago, diabetes often factors into individual lifeworlds. I argue that in Chicago, Natives learn about diabetes through relationships of care within their families and often at a comparatively young age when contrasted with non-Natives who work in diabetes care.

Adults in the community recall their first awareness of diabetes through witnessing either the care or the complications of the disease in their family. Diane Bauman remembers growing up around diabetes:

> My aunt had diabetes, and that was my mom's best friend, my dad's sister. I remember she always used to give herself insulin shots and so we al-, I mean she'd kind of, we knew she had diabetes, I mean she had to take insulin shots. We

> knew that’s all we seen, that’s all we knew about it when I was little… I learned more about it as I got older, like I’d ask questions.

Diane’s description of observing her aunt take shots mirrors the experience of others who also sought further information as they grew older. Diabetes was not only seen in households, but also in the community. Those who did not have family members with the disease recollect first learning of the condition through friends and community members. Debbie Hardin recalls having a young friend with diabetes:

> A young man, a Native man many years ago, his name was Alan, a young man Alan, everybody knows him. He had it. And that’s how I really knew what the heck was going on because then I found out it was really bad because he started losing his limbs. He went blind, and he started, that’s the first time I ever knew about it and I was 20 something years ago.

This presence of the disease in individual homes and in the community reduces the age at which members of this community are introduced to the disease.

Combining lifeworld perspectives with theories from the anthropology of knowledge is fruitful when analyzing how children in a community like Native Chicago incorporate understandings and care practices into their lives. Theorists of knowledge show that children develop their understanding of the world through childhood experiences and interactions. In childhood, sensory relationships with the world are developed and trained; children learn to imitate and copy their elders (Geurts 2002; Hendon 2006; Maynard et al. 1999; Mead 2001[1928]). Scholars argue that knowledge is more often gained through practice and engagement than through verbalized training. Jean Lave illustrates this point with the example of tailors, showing how they learn by doing work and comparing the products of their labor with that of others. Once the initial stage of learning is complete, where tailors have gained the basics, novice tailors begin to play with the set of knowledge skills they have gained to innovate and acquire new skills (Lave 1990). Scholars of knowledge do not deny that people do learn and share knowledge via verbal transmission, but instead they argue that knowledge is often grasped more readily through engaged practice (Downey 2007; Herzfeld 2004; Ingold 2000; Ingold 2003; Lave 1990; Mall 2007; Willerslev 2007). Knowledge, no matter the method of acquirement, is situated (Haraway1988). As Donna Haraway argues, there are no value-free accounts of the world. Rather, all knowledge is influenced by social worlds and grounded in individual perspectives (Haraway 1988).

For members of Chicago's Native community, learning about diabetes in childhood shapes the ways in which they understand, and in some cases care for diabetes later in life. In chapter eight I show that children are involved in some of the day-to-day care work for diabetes. This care work shapes how people think about diabetes. For many members of Chicago's Native community, then, the process of learning about diabetes is embedded in relationships of caring for kin. This process of learning through kin and care relationships is distinctly different from many of the biomedically trained caregivers seen by diabetes patients in the community, who often learn about this disease first through studying its pathologies in school, and later building upon this knowledge through the practice of applying their medical knowledge to patient care. Helena Edmonds, a 68-year-old Apache woman living with diabetes today, explained that she first learned of the disease and of disease care through helping others in her youth and that this trained and prepared her for caring for diabetes later in life:

> You get more the severeness of the diabetes in one respect [from doctors]. Family you get the real stuff. You get what you can have, what it's about [from doctors], but with family you get what it is. There's that difference, another interpretation. You know because if your mom had it, and I took care of her, and then I've took care of my mother-in-law with great care when she had, she didn't have diabetes, but she had a form of muscle spasms and MS and she also had Parkinson disease too. So I know what diseases can do and I know what the doctors say but you try

to work it [out].

Throughout her life, Helena has learned about diabetes from multiple sources – from popular media, from biomedical encounters, from pamphlets and informational brochures, from friends, and from family. As Helena explains, her family's experiences with diabetes and its care inform and shape her care practices today.

The experience of Native participants stands in stark contrast to the few non-Natives I spoke with in this study. In each of these cases, the non-Native medical providers described having first learned of diabetes in school, either at the secondary school level, or during their biomedical training. For Native Chicagoans, diabetes is part of their lifeworld; it is often encountered first in childhood as they observe and participate in the care routines of diabetic family and community members.

Diabetes risk and fatalistic views

Pine-scented floor cleaner permeates the air on a warm June 2009 morning as staff and community members of Chicago's American Indian Center gather in Tribal Hall for one of the center's biweekly elder lunches. The table for health screenings stands at the back of this expansive space and is ready for business with medical supplies neatly arranged for use. Violet Post and I sit at this table; Violet is a retired registered nurse who volunteers for the center's wellness department, providing health screenings for any member or visitor interested in having their blood pressure and/or blood glucose measured. Just before lunch begins, a middle-aged Native woman takes the seat to Violet's left. After checking her blood pressure, Violet asks if she would like to have her blood glucose measured. The woman responds in the negative, stating “I don’t have diabetes, thank god.” After a brief pause the woman finishes her statement with a decisive “yet.” I quickly scribbled down the woman’s words, and found myself pondering the meaning behind this woman’s “yet” upon my return home that evening. Does she believe that it is inevitable that she will develop the disease? And what has lead to such an outlook?

In the years that followed, I continued to hear similar statements from people of all ages. Chris Cooper, a 45-year-old Potawatomi/Puerto Rican man, described how all but one of his siblings had developed diabetes by their early forties, and that it was only a matter of time before that last sibling developed it. James Bey, an employee at the American Indian Center in his late twenties, would occasionally stop by the health screening table to test his blood glucose levels. James frequently had low readings – indicating hypoglycemia, the reverse of the characteristic trait of diabetes, hyperglycemia. After several weeks of his stopping by the health screening table, I asked James why he frequently checked his blood glucose and if he had diabetes. Without hesitation, James replied that he did not have diabetes, but was sure that he would have it by the age of 35, and left the table to find some juice to correct his low-blood glucose. The sentiments expressed by James, Chris, and the woman at the health screening table demonstrate the conception of a high diabetes risk in the community.

This conception of risk is not only perpetuated by the ubiquity of diabetes in Chicago’s Native community, but is further heightened and shaped by public health campaigns. In the first few years of this study, when the American Indian Center employed a wellness department with nurses and dieticians, there were multiple informational sheets, pamphlets, and posters around the common areas of the center for community members to take home with them. Pamphlets like these factor greatly into the knowledge base of community members, who describe family experience, biomedical encounters, and literature as being among their top resources for diabetes knowledge. The majority of the health-related media focused on the topics of heart disease and diabetes. The diabetes media offered information on controlling and preventing the disease. Pamphlets from the American Diabetes Association and the National Diabetes Education Program offered hope for prevention with statements like "You can prevent and control diabetes," "But you can stay healthy and have fun by keeping active," and "We must take charge of diabetes – for future generations." While each of these pamphlets and posters with hopeful messages support ideas of control and prevention, these message of hope and support were preceded by descriptions of American Indians as being at high risk for diabetes. This media states that "Type 2 diabetes is more common than ever in young American Indians and Native Alaskans" and "Diabetes is a growing problem for Native Americans. Many Native Americans have Type II diabetes." Informational pamphlets provide risk factors for readers to reflect upon and calculate individual risk. People who have diabetic family members, who are overweight, and who are over the age of 30 are described in this informational pamphlet as being at heightened risk. These pamphlets, then, reinforce notions of diabetes risk in Native peoples.

In the world of modern epidemiology, everyone is at risk (Klawiter 2006; Petersen and Lupton 1996; Sunder-Rajan 2006). Robert Castel defines the modern concept of risk to be the combination of abstract factors that may result in some undesirable behavior or outcome (Castel 1991). According to Alan Petersen and Deborah Lupton, "Risks are sociocultural constructs; are always political in their construction, use and effects; and inevitably include moral judgments of blame" (Petersen and Lupton 1996:18). As Petersen and Lupton argue, people's life experiences are then shaped by epidemiologists and clinicians' understandings of risk. In contemporary times, Nikolas Rose explains, the responsibility has shifted to the individual to care for and manage risk in the growing world of chronic disease (Rose 2001). As these theorists demonstrate, in modern epidemiology, everyone is at risk and is responsible for managing their individual levels of risk.

American Indians have been defined and labeled as a group at risk of developing diabetes, and this labelling of American Indian peoples as a group susceptible to diabetes in effect alters Native perspectives of the world. There are no biologically distinct races of the human species (American Anthropological Association 1998; American Association of Physical Anthropologists 1996; Caspari 2003; Jablonski and Chaplin 2000; Templeton 1998). This socially constructed categorization, however, was a prominent category in medical models and research in the twentieth century (Epstein 2007; Krieger 2005; Reardon 2005; Root 2003; Tallbear 2013). While the use of race in science has since lost its footing, the division of human groups by race, and more recently by ethnicity, continues to factor prominently in contemporary models of disease risk. In his article on bioethnic conscription, Michael Montoya describes how not only are Native Americans, but also people with Mexican, African, Chinese, and Pacific Islander backgrounds are defined as high risk for diabetes development (Montoya 2007).

This labelling of groups of people as “at risk,” has a lasting effect on the groups identified as such. In Puneet Chawla Sahota’s study on a southwestern reservation, she found that in a community where the thrifty genotype hypothesis in relation to Native diabetes development is commonly cited as a cause for diabetes, 22 percent of the 53 people she interviewed held fatalistic views about diabetes development (Sahota 2012). The thrifty genotype hypothesis was not cited by Chicago Natives in their explanations for diabetes, a topic I discuss in detail in the following chapter. I argue here, however, that pamphlets with covers asking readers: “Diabetes and American Indians: Are you at risk?” contribute to local conception of diabetes risk and fatalistic views. In the following chapter, I demonstrate that Native community members in Chicago have adopted and transformed this labelling of American Indians as at risk for developing diabetes in contemporary discussions of indigenous identity – to be an indigenous American entails being at risk for developing diabetes.

Donna Haraway describes how contemporary biomedicine does the work of making of bodies through its definitions and practices (Haraway 1991). Labelling in particular, as Ian Hacking argues, shapes individual actions (Hacking 2007[1986]). As is evident in the statements from James Bey, Chris Cooper, and the woman at the health screening table, fatalistic views of diabetes development are common in Native Chicago. While high rates of the disease contribute to this fatalism, so too do public health media that label American Indian population as at heightened risk for developing the disease.

Holding a fatalistic view is often linked to inaction, but this is not the case for fatalistic views about diabetes development in Native Chicago. In a discussion of East Asian fatalistic beliefs, Arthur Niehoff defines fatalism as the view that an event is fated to happen and that nothing can be done to alter or prevent this fated future (Niehoff 1966). In *Tuhami* Vincent Crapanzano describes his close informant Tuhami's fatalistic view of life (Crapanzano 1980). Tuhami believed that his destiny in love was entirely left up to Allah and the saints. This view frustrated Crapanzano, who wanted to see this close informant married. Crapanzano describes his realization of Tuhami's passive submission to this belief in fated futures, predetermined and arranged by higher powers, as a turning point in his fieldwork toward a more therapeutic relationship with this informant. In the case of Tuhami, a fatalistic view resulted in a passive stance in life. In Chicago's Native community, there is a mix of responses to fatalistic conceptions of diabetes. There are people who believe they will develop diabetes and do not take action to change their lives to prevent it. There are also people who believe they will develop diabetes, but adjust their lifestyle by eating what they consider healthier foods and increasing physical activity to prolong the time between the present and developing the disease. And though fatalistic views are widespread in this community, there are others who make life adjustments with the expectation that they can and will prevent the development of diabetes altogether. Virginia Hall, a 31-year-old Navajo woman with a family history of diabetes, aims to avoid diabetes. She has made life changes in hopes of preventing the disease. The changes she has made include being physically active on a regular basis, eating whole grain foods, cooking with olive oil, and even making fry bread with whole wheat flour in place of white. So while fatalistic views about the disease are prevalent in Native Chicago, many people are actively engaging in lifestyle activities that they intend to either prevent the disease entirely or to extend the time before its development.

Stigma and moralizing discourse of care

The response to disease is situated within time and space. Ruth Benedict's 1934 essay on the "Anthropology of the Abnormal" describes the role played by cultural models of understanding in determining whether a mental state or a behavioral pattern is normal or is not – an argument highlighting the Boasian notion of cultural relativism and a theme that continues to underlie contemporary disability studies (Benedict 1934; Kudlick 2003). As Benedict demonstrates, a person experiencing seizures and trance may be defined as severely ill in one society, while taking on the role of a shaman in another society. The experience and response to human states of health and illness are dependent upon location and time. Being diagnosed with a condition like leprosy or stumbling disease can be stigmatizing in one social context and not in the next (Boutté 1987; Desjarlais, et al. 1995; Janzen 1978; Waxler 1981). The development of diabetes is increasingly becoming stigmatized in different regions of the world. People view diabetes as a preventable disease and the blame is often placed on individual life choices like diet (Broom and Whittaker 2004). In the context of Native Chicago, the development of diabetes does not hold a social stigma in the same way as is seen outside of the Native community. Forty-one-year-old Oneida citizen and Chicago community health worker Dacia Rice explains:

> Diabetes has some social stigmas outside of Native community, I think. Type 2 diabetes, definitely, there's social stigmas. In the Native communities, not so much.

With high rates of diabetes in the community, there is no stigma associated with developing the disease. While there is no diabetes stigma, there is a heightened level of criticism for those who are viewed by other community members as not taking care of the disease. This criticism is found in the local discourse that moralizes the behaviors of people known to be living with diabetes. People are most critical of the consumption choices that known diabetics make. Agnes Harrison, who has been diabetic since the 1970s, offers a review of how one of her friends cares for the disease:

> Agnes: My friend Sarah was diabetic. She was a diabetic too. But we used to have fun. I would go all the way to Flint, Michigan to visit her from here on weekends. She was so nice. But diabetes is nothing to play with. Some people think just because they're taking pills or taking shots they can eat anything, which they shouldn't. I tell myself that. Just because you're taking pills doesn't mean you can eat anything. Because it's still in your blood. Your, your blood sugar goes up 3-, in the 300s, not mine, these are other people now. They take their blood sugar and it's, sometimes it's 400. That one, the one I'm talking about, she's in South Dakota right now. She comes around here, when she comes back she'll come around again. Hers is real bad.
>
> Meg: And is it because she just eats what she wants?
>
> Agnes: Eats what she wants

Meg: Yeah.

Agnes: Oh and she always has a bottle of soft drinks, one of the quarts

Meg: But not diet, regular?

Agnes: No not diet, regular. She has candy, cookies, and she eats anything.

Agnes here is critical of her friend's consumption of foods that diabetics are typically forewarned against eating, and of her blood glucose levels. With several decades of experience managing her own diabetes, Agnes describes the actions of her friend Sarah as a failure to care for diabetes. This was the most common critique people used when speaking of those who do not take care of diabetes – they are consuming foods that the speaker does not think they should. The practice of moralizing about food consumption in the United States has been described in other contexts, particularly in contexts pertaining to women's bodies (Bordo 1993; Counihan 1999). In Chicago, many community members – both those living with and not living with diabetes – describe situations where they comment on or "nag" those with diabetes whom they see eating foods they believe are bad for them.

The expectation in the community is that people learn how to care for the disease and follow the steps to do so. Overhearing a conversation I was having with a former American Indian Center employee about the plans I had for attending a training session offered by Rush University Medical Center to learn about the Stanford University course "Take Charge of Your Diabetes," which aims to provide general diabetes information while promoting individual care, Chris Cooper stopped in his tracks as he was passing through the center's kitchen to join in our conversation. Chris offered his opinion, stating that people who have diabetes should already know everything about how to treat and care for it, implying the course would really not be of need. In chapter eight I look more closely at diabetes care and hindrances to care. Moralizing discourse about diabetes care is found in other contexts, in which diabetes patients describe themselves as not fulfilling their patient duties by complying with doctor's orders (Broom and Whittaker 2004; Ferzacca 2000). In Native Chicago, not only are diabetes patients and medical providers discussing diabetes care and compliance in moralizing terms, but so too are non-diabetic community members when speaking about their friends and family members' care practices. There is an expectation that people with diabetes learn how to care for the disease and follow the treatment regimen that they are given by doctors. While there is little social stigma around having diabetes, there is moral judgment in terms of whether or not one is viewed as taking care of the condition.

A local model of categorizing diabetes

I spoke with Charles Mattes, an active member of the center, on a great number of occasions about diabetes, diabetes prevention, and healthy eating. Charles is a proponent of eating the diet of one's ancestors, and in his case as a 31-year-old Sioux man, he had been experimenting with a low-carbohydrate and high-lean-protein diet. In our formal interview, Charles begins to describe his role in his partner's diabetes care when he brings up a term for diabetes with which I was unfamiliar:

> Charles: Well I know Aria, the mother of my son, she's already diabetic, type 2 diabetes, but she's already on, on the path to being full blown diabetic. She's having to take insulin now…
>
> Meg: Can I ask what you mean by full blown diabetic?
>
> Charles: I would say somebody that has to take, where their pancreas is ready to shut down. I don't know if that's how it would be defined or what. I mean I'm not even sure. The, I feel like the term diabetes is very ambiguous and it, there should be more defined terminology besides type 1 diabetes, type 2 diabetes, and

> whatever else… The way I view it is that there is a whole spectrum of sensitivity towards these foods. Some people are more sensitive than others obviously. Some people are more sensitive to other things as well.

Charles' description of diabetes as being organized less by distinct types and more along a spectrum represents one aspect of the local classification system of diabetes in Native Chicago. Based on descriptions from individuals living with diabetes or individuals who have diabetes in their family, I describe the local classification system of diabetes, which looks at the disease as falling along a spectrum, moving from mild cases to more severe. In chapter three I described how the biomedical diabetes classification system has mushroomed over the past century since the development of insulin therapy for diabetes patients – distinguishing manifestations of diabetes by distinctive types. Local diabetes classifications differ from those of published biomedical materials. This local classification system is organized by care needs and the effect diabetes has on life rather than by the biomedical model's system of organization.

Local categories of diabetes are shaped by what people observe in the community, and these categories, in turn, shape action. This local diabetes classification system resonates with theorizations on human knowledge and cognition. Organization of human thought is shaped by local environments. Harold Conklin, for instance, explains that color perceptions are influenced by one's environment. Conklin finds that the Hanunoo have multiple levels of color classifications that are shaped by their engagements with the local environment (Conklin 1955). In her work half a century later, Anna Tsing demonstrates that nature knowledge is produced through specific forms of engagement with the surrounding world. As she argues, there is no pure or distinct natural environment; human knowledge of natural landscapes develops through practices of engagement and experience within it. In her ethnography, Tsing illustrates that humans approach and engage with nature in multiple ways. In the Meratus landscapes, the capitalist planners see a strict boundary between a forest and a field; “From this snapshot perspective, the difference between a neatly cultivated field and a wild forest is visually sharp. Everything between is matter out of place” (Tsing 2005:193). Those living in the Meratus landscapes, however, see multiple levels between the planners’ bounded entities through their everyday engagement with their surroundings; women and children study and utilize the plant-life growing in the “wild” swiddens. In their study of the International Classification of Diseases, Geoffrey Bowker and Susan Leigh Star build upon these descriptions of human cognitive organization to show that the processes of defining classifications can be invisible (Bowker and Star 1999). Humans classify the world around them, and these processes of classifications are not always overt.

While classifications are based upon engagement, human action is organized by classification systems. In his study of Nuer and Tikopea classification systems for twins, animals, birds, and vegetables, Raymond Firth explains that classification systems influence human action and relationships with objects in their environment (Firth 1966). Ian Hacking demonstrates that the things that people do are intimately tied to the descriptive categories of society; the categories that a society has to describe ways of being, in effect, make up people. Hacking argues that these categories of being have their own history of coming into creation that is tightly bound to society, politics, and environment (Hacking 2007 [1986]). While there are material and “natural” limitations to the emergence categories, the categories come to gain meaning through the processes of naming. For Hacking, new categories make up people through creating new possibilities for ways of being. Hacking offers the example that George Washington could never have been a pervert, because the category of perversion did not exist in the late eighteenth century (Hacking 2007 [1986]). Human classification systems, then, are built upon human engagement with their local environs, and these classification systems, in turn, play a role in shaping human behavior.

Classifications shape human understandings of disease and human health care practices. Charles Frake describes the diagnosis of an ailment among the Subanun as a pivotal step in the medical process; once the diagnosis is made, treatment can be determined and implemented (Frake 1961). In a study of healthcare in an institutionalized medical setting, Linda Hunt and Nedal Arar describe how medical providers and patients have differing understandings of disease. As they explain, while doctors acquire of knowledge of the chronic condition experience through tests, relying upon technology, patients gain knowledge through their constant interaction living with the disease (Hunt and Arar 2001). In their study of medical classifications of health and disease, Bowker and Star note that there is not a great divide between folk and scientific classifications of disease, and there is some fluidity and movement between the two (Bowker and Star 1999). Local understandings of diabetes are informed by and differ from biomedical understandings of the condition. In the next chapter, I focus on differing definitions and explanations for diabetes. Here I describe that the emic classification of diabetes forms differs from etic, biomedical classifications.[2] While the etic model in table 2 predominates in biomedical literature today, in some clinical encounters a model of diabetes more resembling the emic model described below is used in working with diabetic patients, (personal communication with Alexandra Adams, December 15, 2014). The local system is contrasted with the biomedical system in tables 1 and 2 below.

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[2] For non-anthropologists, emic refers to the perspective of a member of a culture, while etic refers to the outside or observer perspective.

Emic Classifications (table 1)

Referred to as:	Includes:
Borderline	At high risk of developing diabetes, but not diagnosed with diabetes. No pharmaceutical intervention necessary. Some people attempt to stop the diseases progression
Mild or not bad	Diagnosed with diabetes. Treated with diet and/or exercise alone
Diabetes	Diagnosed with diabetes. Treated with prescribed oral medications, along with diet and/or exercise
Full-blown or bad	Diagnosed with diabetes. Treated with insulin injections, along with prescribed oral medication, diet, and/or exercise
Severe	Diagnosed with diabetes. Treated with insulin, prescribed oral medications, diet, and/or exercise. Developed diabetes complications (e.g. toe or limb amputated, lost eyesight, or on dialysis due to kidney failure)

Etic Classifications (table 2)

Referred to as:	Includes:
Borderline or Prediabetes	Slightly elevated glucose levels, but not high enough to be classified as diabetes (to be diagnosed with diabetes, one must have an A1C ≥ 6.5 or a fasting plasma glucose ≥ 126) Physicians recommend weight loss, exercise, and diet to prevent the transition of a borderline case into type 2 diabetes. In some circumstances, oral medications are prescribed, though this practice is controversial in the United States.
Type 2	Insulin resistant Treatment is determined based on individual needs; this treatment can include diet, exercise, oral medications, and/or insulin injections
Type 1	Insulin levels are low or absent Requires insulin injections for survival. Treatment additionally includes diet and exercise, and can include oral medications in later life

The two most prominent differences between the emic model of diabetes and the etic model are first that the emic model is focused on distinguishing different forms of diabetes that would all fit within what are designated as type 2 and borderline diabetes in the etic model. Second, this emic classification is organized around treatment needs – the more invasive the treatment, the more severe the case of diabetes – while the etic system is organized around the body's insulin production and reception capabilities in addition to treatment needs. In this section I show that this emic model is based upon local engagements with diabetes experience and care in the community, and this classification system is both developed and maintained through local discourse about diabetes care and experiences in the community.

In table 1, borderline diabetes is defined as a case of diabetes not requiring medical intervention. Ruby Wade, a 64-year-old Menominee woman with diabetes, explains why the biomedical diagnosis of diabetes as borderline yet requiring medical intervention does not make sense:

> Well they say it was borderline diabetes, but I take a pill… But I figure once borderline, you are or you're not. If you're taking the pill you are, you know. That's how I figure… why am I taking a pill if I'm borderline?

As seen in table 2, pharmaceutical intervention for borderline cases of diabetes is controversial in the biomedical world, but it does happen. Meta Kreiner and Linda Hunt describe that this conflation of risk with disease is growingly common in biomedical contexts; in these contexts, physicians turn to aggressive treatment rather than preventative measures (Kreiner and Hunt 2014). In Chicago's Native community, borderline diabetes is described as being at high risk, but not having diabetes. Prescribed medication indicates a real shift from not having diabetes and having diabetes. Individual responses to having borderline diabetes vary. After her 11-year-old daughter was diagnosed as being on the borderline of diabetes, Tiffany Galvan changed her daughter's diet to both help her lose weight and prevent her from developing diabetes. In contrast, Joan Burdett was diagnosed as borderline diabetic, and while she changed her eating habits for a brief period of time, she explains that she eventually returned to her old habits of having a candy bar now and then. A year after her borderline diagnosis, Joan was diagnosed with diabetes, and attributes this shift in her health status to her eating habits over that year.

In this emic classification system, a mild case of diabetes is one in which one does not have to take any medication, oral or injections, and relies instead upon diet and other lifestyle changes. Carmen Bertsch, a 69-year-old Oneida woman who has been living with diabetes for 15 years, explains how if you work early on at diabetes care through lifestyle changes, it is not as severe of a case:

> If you follow good eating habits, you know actually if you're not real, real bad in diabetics, you can, well you can't get rid of it, but you can get it where you don't have to take medication.

Now more than 30 years since her diagnosis, Tammy Lowe describes that earlier in her life with diabetes, she was able to manage the disease the diet alone. She describes that her diabetes was so completely under control through this diet, that she for a time forgot that she had diabetes. It was only when she was prescribed steroids for an unrelated health concern that her memory of having diabetes was roused. Tammy had not informed this prescribing doctor that she had diabetes. Steroids increase blood glucose levels; when Tammy took the steroids to reduce inflammation, her blood glucose levels rose so considerably that she was hospitalized for a few days.

Moving from mild cases, diabetes gets classified as progressively worse with the more invasive treatment. A case requiring oral medication is not labelled with a distinctive classification name, and the need for insulin is described as "full blown" or "bad" cases of diabetes. Phillip Golden, a 52-year-old Micmac man who was diagnosed with diabetes, explains that his wife who takes insulin has a case of what he terms “full blown” diabetes:

> And plus, you become a full, full, full blown diabetics at any moment. That happened to my wife also, you know, so now she got to get up every morning and shot in her stomach with a needle you know, and I’m trying to avoid that myself, you know.

From full blown, cases become more severe when someone has a physical limitation brought on by the disease. Virginia Hall and Hilda Thomas both describe diabetes cases that are severe:

> Virginia Hall: I saw people with diabetes going into eye clinic who had cataracts, who had glaucoma, and I would see the patches on their eyes, I would see them with canes, I just never thought these were other people that I saw, it wasn’t until it got to my dad and my grandparents and, that I realized how bad it can become. I had a grandfather on my mother’s side and he, I know he had missing fingers he had I think it was his whole right, his left hand where all of his fingers were gone. I just knew that as a kid growing up, I didn’t know why. I thought maybe just he had an accident. He had diabetes and he had his fingers amputated because of diabetes. And you know just when I realized it was because of diabetes it started to scare me and so knowing that I’m already heavy set. [31-year-old Navajo woman with diabetic family members]

> Hilda Thomas: He ended up in the hospital where we almost lost him, that’s severe, yeah, that’s what I call severe, I mean, you know for him to fall over at work and they say he was in a coma for a little while there because he was so bad off and he didn’t know what was going on, he was in and out and stuff, so that’s a severe one. [53-year-old Meskwaki woman with diabetic family members]

As described earlier in this chapter, there is a moralizing discourse about diabetes care in the community. In cases of severe diabetes, moralizing discussions of patient care are more pointed. Community members expect that those who have suffered complications of diabetes will care for the disease more closely to avoid further complications – and these care expectations most often focus on consumption. One day while in the center kitchen preparing for senior lunch, a center staff member told me of an elder community member who was admitted to the hospital for her diabetes. This elder had already suffered diabetes complications, and the staff member informed me that this elder's daughter had found some empty cans of regular soda and candy wrappers in the trash. This staff member described this elder's consumption as reckless, particularly because she had already lost several toes.

Diabetes in Native Chicago is understood and organized by a local system of classification that has been shaped by what community members observe in cases of the disease among family and friends. These classifications shape behavior and discourses, not only of the individual living with diabetes, but of others in the community who interact with diabetics. This emic model of diabetes differs most significantly from the etic model found in biomedical literature in significant ways. First it is primarily focused on type 2 and borderline cases of diabetes. This model of diabetes is organized around the types of care intervention used to treat the condition. Individual experiences with treating the condition are shared in informal conversations. This emic classification system is both developed and upheld through these discussions. The kitchen conversation about the community elder who was admitted to the hospital is one such example of community discourse. This example demonstrates how this emic classification system is passed and maintained in conversations about individual experiences with diabetes.

Conclusion

In this chapter I have shown that diabetes is prevalent in Native Chicago. This prevalence of diabetes shapes local understandings and conceptions of the disease. Children are aware of the existence and sometimes of the care needs of this disease at a young age. There is little stigma surrounding the development of diabetes. There is, however, moralizing discussion of the care acts of others. And the community describes diabetes along a spectrum, defining the disease from mild to severe cases based upon the treatment needs and the effect diabetes takes on individual lives. These findings are of interest and can benefit multiple audiences.

First, for Chicago's Native community, the findings discussed in this chapter could contribute to the development of diabetes prevention and overall health promotion in the community. A final question I asked interviewees was what they would like to see happen in the future. The overwhelming majority of community members said they would like to see more education. In this chapter I demonstrated that due to the already high rate of diabetes in the community and the public health sector's labelling of American Indian peoples as at risk for developing the condition, fatalistic views about diabetes development are prevalent in the community. The development of education programs that focus on how to prevent diabetes that directly combats these fatalistic views would be of great benefit to the community, particularly if the programs are developed to reach all ages and make diabetes prevention an attainable goal. For instance, this could include cooking classes on how to make healthier versions of meals that families enjoy and are easy to make, or promoting additional physical activity by showing people how to work it into their already busy lives.

Second, for biomedical providers and for public health workers, the findings highlighted in this chapter can be used to improve clinical care and to develop programs for diabetes prevention. As demonstrated in the final section of this chapter, lay understandings of common diseases differ from biomedical models that are taught in classroom settings. The recognition that distinct patient understandings of disease exist and inform the way that patients think about and care for diseases at home is of great importance to improving care of medical conditions, particularly chronic conditions that are primarily cared for in home settings. With additional time in medical encounters, providers and patients could work more closely to ensure that each participant understands what the health problem is and what each participant can do to care for it. Second, there is a danger that comes with labelling any group of individuals as at risk for a particular disease, and that danger is a fatalistic view. While I have shown that a fatalistic view about diabetes in Native Chicago does not equate to inaction for all members of this community, it does for some. Labelling groups as at risk has unintended consequences that should be addressed in the development of public health programs and materials.

Lastly, the findings of this chapter offer contributions to anthropology. First, this study builds upon current scholarship on the diabetes epidemic in American Indian populations by documenting the prevalence of diabetes in an urban Native community. Second, I have shown that fatalistic views do not necessarily lead to passivity in this setting, wherein some community members strive to delay the onset of diabetes or to prevent it altogether through altering their habits. Further, this study contributes to studies of knowledge by combining with lifeworld theorizations to show that in this context of high rates of diabetes, children learn about disease through kin and care relationships. Based upon experiences with diabetes in childhood and later in life, a model of diabetes classification is developed and shared through discussions in the community that is distinct from the biomedical model.

In the next chapter I take a step back and look more closely at definitions of diabetes itself and local explanations for why there are high rates of this disease in Native communities both in cities and on reservations.

CHAPTER 7
LOCAL UNDERSTANDINGS AND EXPLANATIONS OF DIABETES

Introduction

Holly Wilton and I each recline on an armrest of the turquoise velvet couch in the Little Ones Room at the American Indian Center. The age and disrepair of this old Free Mason's building is felt through its inability to equally distribute and retain heat on this cold January day. Holly's awareness of the uneven heating pattern of the building is seen in her choice of wearing multiple layers – a grey and turquoise patterned shirt, topped with a draping black cardigan sweater. Holly is a 44-year-old Apache/Sioux woman who was raised in Chicago by her mother and step-father, a man she describes as her true father in the sense of the social role he played in her life. Holly has assisted both parents in caring for diabetes and she strives to take care of her health by watching what she eats and increasing daily physical activity. Diet is central to Holly's understanding of diabetes. She describes that Natives have higher rates of diabetes than other ethnic populations, explaining:

> One of the things that I think of in our diets that our bodies aren't used to as Native people is that the settlers brought, the government brought, gave us white products - the salt, the sugar, the flour, dairy, all those things were things our bodies weren't used to, and they each took a toll and, you know some of those things together or separate, however you want to say it came in the form of bringing diabetes… I think the bodies aren't able to process it. I think that Native people are used to very natural diets where they ate off the land, they ate grains, they drank teas from the earth. Everything was very simple and very pure.

Holly's explanation mirrors points made by Steven Barnes, quoted at the fore of chapter three. Native people did not encounter diseases like diabetes prior to contact with settler communities. In Holly's explanation, Native people share a similar physiology and the precolonial diet of indigenous Americans was one of purity before being interrupted and contaminated by contact with settler communities. Holly's use of the term "white" to describe the foods brought by settler communities and the government is seemingly intentional. The use of white foods in contrast to other foods has seemingly moved from spaces of biomedical education into community conversations, and this will be seen later in this chapter both in terms of food and intergenerational trauma. Many Chicago Natives refer to the foods that cause diabetes and to avoid if you have diabetes as "white foods," referencing not only to the color of the food – sugar, flour, and lard – but also to the race of the people who introduced these types of foods into the North American diet. By using "white food" here Holly may be alluding to race while retaining plausible deniability. Diabetes definitions and explanations constitute a local diabetes discourse that not only defines local understandings of the condition, but further contributes to discussions of Native history and group membership.

This chapter builds upon the materials presented in chapters three, five, and six. In chapter three, I introduced diabetes, describing the history of the disease from antiquity to the recent diabetes epidemic in American Indian populations. I showed that the contemporary American Indian diabetes epidemic is in great part related to colonial history and policies. In chapter five I described how a sense of a shared history contributes to local definitions of Native identity and group membership. And in the last chapter I described the ubiquity of diabetes in Chicago's Native population and demonstrated how the high prevalence of the disease, along with public health campaigns and local care practices, shape understandings of risk and classifications of diabetes severity. This chapter builds upon these discussions by exploring how conceptions of diabetes are situated within the experience and care for diabetes in Native Chicago and how these discourses of diabetes offer a look into local world views on evolution, colonial history, and Native identity. This chapter is organized into two halves. In the first half I show that local diabetes definitions are varied and situated within personal experiences with diabetes. In the second half, I document local explanations for diabetes with a focus on explanations for high rates of diabetes in American Indian populations. Local explanations, I demonstrate, not only offer local understandings of diabetes etiology, but strengthen notions of a shared Native identity in this urban space through discussions of shared history and shared bodies. The separation of diabetes definitions from explanations is an arbitrary one employed here to organize this chapter, and as it will become apparent in the pages that follow, there is great overlap in explanations and definitions for diabetes in local discourse.

Defining diabetes in Native Chicago

In chapter three I described that the current biomedical model defines diabetes as being characterized by hyperglycemia due to insulin resistance or deficiency. Though there is not a clear understanding as to why people develop the disease, genes and environment are described in this biomedical model as two of the most influential factors in diabetes etiology. The biomedical model of diabetes focuses on the disease on some of the smaller levels within the human body. While influenced by this biomedical model, local definitions of diabetes in Native Chicago focus on the experience of diabetes in individual and social life. Local definitions of diabetes vary and these variations correspond with different life experiences with the condition.

Biomedical models of diabetes influence local definitions of the disease. The terms blood sugar, pancreas, and insulin commonly arise in these local definitions:

> Lester Vinson: You know diabetes is just that your body's not producing enough insulin. [58-year-old Sioux/White man living with diabetes]

> Christy Ernest: Your body doesn't produce enough insulin, so basically that causes your blood sugar to be very high because your body doesn't produce enough insulin so you develop diabetes. [33-year-old Ojibwe woman with diabetic family members]

> Lois Bagby: Diabetes is a, I think it's where your pancreas doesn't make no insulin or, and and we take in sugar and we can't, it can't dissolve it or it can't get it out of your body, so we do it by going to the bathroom a lot too. It's, that's one other thing, we pee a lot, you know trying to get the sugar flow. We got to drink a lot of water to get it flushed out of our system. So it's, it's, it creates problems if we don't get the insulin to you. [58-year-old Ojibwe woman living with diabetes]

> Tiffany Galvan: Like if my daughter was to ask me, I would tell her that it's the sugars that are in your body they can't be broken down, they get too high and everything has to be even in your body in order for it to you know give you off the energy and stuff like that and I'd let her know it's just from eating too much sweet stuff and you know. [39-year-old Seneca woman with diabetic family members]

These local definitions share attributes with biomedical definitions of diabetes. Diabetes is described here as a problem within the body. Tiffany refers to the body being unable to break down food – here offering response to her 11-year-old daughter's hypothetical question on diabetes. Lois locates the failure in the pancreas, while she, Lester and Christy refer to it as a lack of insulin.

The incorporation of institutionalized medical understandings of health and disease into lay models of disease is common in populations worldwide. Linda Hunt's work on cancer in Southern Mexico demonstrates that understandings of cancer in this setting are influenced by both local experiences and expectations and by biomedical models (Hunt 1998). Puneet Chawla Sahota's work in a southwestern reservation community describes the continuing influence the thrifty genotype hypothesis has on contemporary understandings of diabetes (Sahota 2012).

While institutionalized medical models do influence understandings of human health and disease, the definition of disease in local communities is also greatly influenced by personal experience (Hunt 1998; Sahota 2012). In her work with a Canadian Ojibwe community, Linda Garro demonstrates that diabetes is understood through personal experience and encounters with the condition (Garro 2000). Through personal and social experiences with disease and disease care, local models of disease diverge from institutionalized models, in some cases significantly. For instance, Susan McCombie shows that common illnesses like "the flu" can be understood differently by biomedically trained epidemiologists and the lay public. She describes that the lay public understands "the flu" to refer to a gastrointestinal condition, whereas epidemiologists see "the flu" as referring to a respiratory illness (McCombie 1999). Local diabetes definitions in Native Chicago mirror some aspects of the biomedical definition of the disease while they are also being shaped by personal experiences with the disease and its care.

People experience diabetes in different ways. Some feel no symptoms when their blood glucose level is elevated, while others describe cases of polydipsia, polyuria, having wounds that will not heal, blurred vision, and feeling dizzy, fatigued, hyper, and/or weak. Lois Bagby's definition of diabetes quoted above refers to the experiences of polyuria and polydipsia. Sylvia Kistler who has been living with diabetes for six years defines the disease only by its symptoms:

> I'd say you have to use the bathroom all the time, you're thirsty and losing weight.

The symptoms of diabetes experienced in the day-to-day life of people living with it and caring for it factor prominently into their definitions of the condition.

In addition to the symptoms of hyperglycemia, people define diabetes with reference to the work that is required for its care. Physicians recommend people with diabetes manage the disease by testing blood glucose levels, following a diet plan that typically limits the amount of carbohydrates consumed at dedicated meal times, increasing daily physical activity, and/or taking oral medications or injections of insulin. In the next chapter I show that diabetes care affects not only individuals, but their family, their friends, and the larger community. Colin Harold, a 19-year-old Cherokee man, describes that developing diabetes in early adulthood has been particularly difficult because of the restrictions placed on his life:

> My explanation to that would be a very very bad disease to have. It don't allow you to eat the things you want to. You got to constantly check your blood sugar. Just really nonsense, especially if you're a kid. It's worse with sisters and stuff. It's not something that you would like to have at a young age.

Having diabetes in youth and early adulthood is difficult because the disease separates Colin from his age mates – he has to manage his blood glucose and be cautious of his food intake while out with friends who do not share these restrictions. Further, it is hard for him still living at home with younger sisters who he describes as "rubbing their candy in my face." These markers of disease separate young diabetics in the community from non-diabetic family and friends and can reduce care – a topic of discussion in the following chapter.

Care requirements factor into definitions of diabetes for patients and caregivers of all ages.

> Aria Mattes: It's having to do something you don't want to do. Having it, I guess, it's having something that can control the rest of your life if you can't control it. You don't want something that controls you. And that's just pretty much what it does if you don't get the strength to do what you're supposed to, which I'm finding out. [34-year-old Assiniboine woman living with diabetes]

> Phillip Golden: A crippling disease you know that you could avoid by watching diet and exercising, you know and checking in with your doctor you know. And watching your diet and keeping up on it, you know, monitoring. [52-year-old Micmac man living with diabetes]

> Lyle Evans: Oh, diabetes is an invasion. I mean it's just an invasion on your life. I mean a life that you, it's just an invasion on your life and an impact, the impact from that is, it's crazy. It's really crazy. For me it is anyways because to me diabetes is just it's an invasion on your whole life, it's just that's the way it is. [47-year-old Menominee man with diabetic family members]

Diabetes is referred to by those living with and helping care for the condition as "very very bad," "an invasion," "crippling," "crazy," "nonsense," and "something that can control the rest of your life if you can't control it." The experience of caring for and living with diabetes in daily life is central to defining the disease. The entire life of the person and his/her family and friends is altered by the requirements of diabetes management. The work involved for the day-to-day management is central to local definitions of disease.

Scholars studying the anthropology of knowledge, as discussed in chapter six, posit that people learn and know through engagement in the world (Downey 2007; Herzfeld 2004; Ingold 2000; Ingold 2003; Lave 1990; Mall 2007; Willerslev 2007). Ethnographer Annemarie Mol describes how physicians, lab technicians, and other health workers within one Dutch hospital hold widely different understandings of atherosclerosis. Mol shows that there are multiple ontologies of atherosclerosis based upon the perspective of actors in different departments in this hospital. In the clinic, atherosclerosis is a disease that causes pain while walking, in the hematologist's laboratory it is a blood disease, and in the pathology laboratory it is the thickening of the vein walls (Mol 2002). Similar to understandings of atherosclerosis in this Dutch hospital, definitions of diabetes in Native Chicago are situated within individual, social, and dialogical experiences with the disease – from those first observations made in childhood to the experiences later in life of developing and/or caring for the daily management of the disease. In Native Chicago, local community members not only witness diabetes care routines from a young age, but also become familiar with serious health complications associated with "severe" cases of the condition. Native Chicagoans incorporate these diabetes complications and the effect they have on the community into their definitions of diabetes:

> Natalie Dawson: Diabetes is a killer that's all I can say… just from my own experiences growing up, and I saw that all my life. I saw some horrific things and it scared me. [68-year-old Ottawa woman with diabetic family members]

> Bobbie Steward: It's your sugar levels and how you eat, if you don't eat right, then your sugar levels are going to go sky high and you could be blind, which my girlfriend… she went blind for two weeks and she did not know she was a diabetic, even though it runs in the family. She went to the hospital, she goes well I can't see. And they took her to the hospital, she got it down to where it should but she never knew she was diabetic. And one of my boyfriends I used to date, he now lives on the reservation in Wisconsin. He lost his, he's losing his eyesight, his legs are giving out from being a diabetic and his sister too. She lives here and she's a diabetic. She got one of her toes cut off, so as soon as I found out that, I thought well I'm taking my pills, I'm not going to be. You never know, your kidneys, one of the girls, my girlfriend's friend used to live next door, her neighbor, her kidneys failed because she was a diabetic, so anything can happen. [52-year-old Chippewa woman living with diabetes]

Local definitions of diabetes are, as Natalie Dawson describes, built upon what people have seen and experienced in their lives. These experiences shape understandings of the disease, and as Bobbie Steward describes, influence care practices.

In chapter six I described how fatalistic views of diabetes are widespread in Chicago's American Indian community. Some community members incorporate the presence of this view into their definitions of diabetes, referring to diabetes as a socially accepted disease. Virginia Hall, a 31-year-old Navajo woman explains:

> I would say diabetes is a lifelong condition that you really want to keep away from being diagnosed for yourself or a family member or even a friend, because diabetes affects your life in a drastic drastic way that people are not aware of. They are not aware of the ramifications of the individual and the person that are nearby the close, the loved ones, how it affects them physically, emotionally, you know, just in all aspects. It's, it seems and it seems like diabetes it seems to be in everyday thing, but it's just become so so common that people have just forgotten about it. And I think everyone needs to re-educated on the severity of the causes

> of diabetes and what diabetes can do to a person.

The ubiquity of the disease, as Virginia explains, creates a sense of normalcy about diabetes in the community. This sense of normalcy, both she and Barry Dahms contend, endangers Chicago's Native community and its future health and wellbeing. In an unrecorded interview, Barry explains that "diabetes is not a hereditary thing, but a socially accepted thing that makes you sick." Barry went on to explain that people are eating the wrong types of food and in great quantity. While Virginia and Barry describe diabetes as socially accepted, they promote increased education and prevention of the disease, particularly for younger generations.

Diabetes is defined in Chicago's Native community in several ways. These definitions are formed through life experiences – including attending biomedical appointments, reading print and electronic sources on diabetes, experiencing diabetes symptoms, caring for the disease, and witnessing family and community experiences with diabetes care and complications.

Local explanations for diabetes development

In Holly's explanation for why Native populations have high rates of diabetes at the fore of this chapter, and in Tiffany's definition of diabetes as the body's inability to break down food, the body's ability to metabolize food is central to diabetes definitions. In his definition of diabetes, Charles Mattes, the Sioux man described as supporting the eating the diet of one's ancestors in chapter six, offers a definition of diabetes from a slightly different vantage point of these other definitions. In his definition, Charles describes diabetes as a problem with specific types of food rather than with Native bodies:

> I define diabetes to be an allergic reaction to sugar, sugary foods, like starchy foods, high starchy foods. I don't believe that everyone should be consuming complex carbohydrates and a lot of sugar. It should be minimal. It should be a minimal part of Native Americans' diets as we live. We have a sensitivity to a lot of different foods and you know sugar being one. That's why I would, that's why I would guess that, that we're just not, I guess you could say programmed to eat that kind of a diet.

Charles' definition, rather than focusing on the individual body as the site of disease, focuses on the diet in contemporary America – a diet he describes as high in starch and sugar. As described in chapter six, Charles describes diabetes as a set of diseases falling along a spectrum of sensitivity to this new diet. Over the millennia before settler arrival, the indigenous peoples of the Americas evolved to eat a certain type of diet that was taken away through colonialism. Native bodies are not accustomed to eating this new diet, and as Charles elaborates, this new diet explains why Native populations have begun to develop diabetes in recent decades.

Biomedical researchers are still seeking for an explanation as to why people first develop diabetes. Presently, mainstream biomedical models focus on genetics and environmental factors for the cause of diabetes. In this section I look at the discourses on diabetes causation in Native Chicago. I show that while these explanations offer reasoning for why people develop diabetes, they further highlight and support notions of shared Native history and physiology that contribute to conceptions of Native identity and community in this city space. Two less commonly cited biomedical explanations for diabetes development are discussed in this section – stress and transgenerational epigenetics – where they correspond with local models for diabetes development.

Inheritance

In Bobbie Steward's discussion of diabetes complications quoted above, she describes a girlfriend of hers that lost her vision for a period of time due to a case of diabetes that this friend did not know about. Bobbie implies that the friend ought to have known that she had diabetes earlier, noting that the disease "runs in her family." Diabetes is considered an inherited disease in Native Chicago. Inheritance in this context is a complicated subject, as has been found in other locales. Inheritance can refer to genetic inheritance, family inheritance, blood inheritance, and social inheritance of behaviors and customs. In her research with American Indian communities in Arizona and southern California, Diane Weiner found that the description of diabetes as an inherited disease can be confounded in local interpretations. In this setting she found that doctors refer to diabetes as an inherited trait when speaking with patients. Weiner explains that the physicians in this setting refer to genetic inheritance, but their patients understand inheritance to be a social inheritance of lifestyle – such as the diet they eat (Weiner 1999; Weiner 2001). As explained in chapter three, local biomedical physicians describe diabetes as both a genetically inherited and socially inherited condition – referring particularly to an inheritance of eating customs and socioeconomic situations.

The diabetes epidemic among American Indian populations has been linked to a hypothetical thrifty genotype and while biomedical researchers have argued against the existence of a thrifty genotype to explain diabetes development in these populations, the idea of the thrifty genotype has lasting power in conversations about diabetes in reservation spaces. Sahota finds that community members on a southwestern reservation incorporate local understandings of the thrifty genotype hypothesis into their accounts for diabetes (Sahota 2012). The genotype in this context is understood as a type of survival gene that was once beneficial, but that in contemporary times interferes with the body's ability to process modern diets. The thrifty genotype hypothesis was not referenced by interviewees in Native Chicago, however, as I will discuss in the last section of this chapter. However, the idea of a specifically Native American body evolved to live and prosper in the environment of North America is a widely shared understanding that is present in local discussions of diabetes.

The idea of diabetes as genetically inherited or passed down in the physical makeup from one generation to the next was a common feature in diabetes explanations. I noted that Chris Cooper described the likelihood of all his siblings developing diabetes in the section on fatalistic views of diabetes in the previous chapter. This view is based upon Chris' conception of diabetes as a genetically passed trait:

> My younger sister doesn't have it yet. She's lucky. I don't know why, maybe she diets too much or something. But we, I never, you know I never ate a lot of sweets either. I don't, so I don't know why I got diabetes. They said it's like from eating sugar. But I don't eat sugar a lot. I think it's in, with me, it's my genes.

Chris' recognizes that many other people attribute diabetes to diet and exercise, but he finds this explanation inadequate for his case. Diabetes is referred to as a condition passed down the family line through genes.

As described by Diane Weiner, inheritance can refer to many things (Weiner 1999; Weiner 2001). In Native Chicago, diabetes was described as inherited genetically, through blood lines, through family lines, and through social means. Idella Chaisson, quoted at the fore of chapter six, questioned whether diabetes was in Native blood. This link between blood inheritance and diabetes is commonly cited by community members, as too is the idea that diabetes "runs in families:"

> Esther Thomason: my mom always told me that I have to watch out for that because it runs in both sides of my family [19-year-old Ojibwe woman with diabetic family]

> Tammy Lowe: it ran in our families [68-year-old Oneida woman living with diabetes]

Native Chicagoans link diabetes to inheritance. Some specifically refer to this as a genetic inheritance, while others speak in terms of blood and passage through a family line. In chapter five I described that Native identity is for some considered to be passed on through blood. In this setting Native identity is not directly spoken of as being inherited through genes. Diabetes, however, is described as being inherited through both blood and genetic lines in this community. Later in this chapter I show that a vulnerability to diabetes is considered a markedly Indian trait. So while genes are not directly spoken of in discussions of Native identity in Native Chicago, genes are indirectly related to local concepts of identity through their association with diabetes development. I noted in chapter three that some local biomedical providers describe diabetes as socially inherited through the passage of social traits like eating habits. Community members, in contrast, more often refer to colonial history when discussing the role of diet in diabetes development.

Colonialism, diet, and poverty

Life conditions are an equally important factor in diabetes causation in Native Chicago. Roy Nieves explains that while there are a lot of pieces that factor into why people develop diabetes, food is the primary piece:

> Diabetes comes from many different things. I mean the majority of it is from the food that we consume.

In chapter three I discuss the work of Lorelei de Cora, Yvonne Jackson, Betty Geishirt-Cantrell, and James Justice and describe how these scholars posit that the recent diabetes epidemic in Native populations can be attributed to the recent diet changes brought on by colonialism (de Cora 2001; Geishirt-Cantrell 2000; Jackson 1993; Justice 1993). In a collaborative work on diabetes in Ojibwe and Dakota communities, Linda Garro and Gretchen Chesley Lang describe that some individuals relate the disease to diet, specifically to the consumption of too much sugar, while others see a strong association between diabetes and the movement away from traditional Ojibwe and Dakota practices (Garro and Lang 1993).

In Native Chicago, this colonial history factors significantly into discussions of why people began to develop diabetes. Steven Barnes, quoted in chapter three explaining that American Indians did not encounter diseases like diabetes prior to contact with settler communities, continues his historical account of American Indian diabetes development:

> These people came and they cleared the land and killed everything that was on the land. Okay, now the Indians don’t have anything to eat. Here’s all these white people settlers colonies coming in. Okay, now what are they going to do? These Indians are starving, did they go and live off the colonists and they start eating all this stuff that they eat? And that’s the start right there, that’s, that’s my philosophy, but that’s, that’s what I think is because that they. You know back in their day, they were the healthiest people, you know what I mean, it’s like in, and now, and like I said, I’ve read in some books where they, even the elders tell them, you know the reason things are so bad is because you, you’ve gone away from your cultures and your original way your people were, the way you did things, the way you farmed, the way you prepared your foods, you’re, it’s all, the white man’s come with metal pots, you used to use all these old wooden bowls and stuff where you never, you never used the white man’s things, now you got all these white man’s comforts and all this stuff, you know.

In chapter three I argue that diabetes has to be understood in the social and historical context, arguing that colonialism forced diet and other life condition changes that factor into the American Indian diabetes epidemic. The American Indian diet shifted through contact with settlers. As Steven describes, American Indians "were the healthiest people," and these diet and life condition changes have resulted in increased cases of diabetes along with cancer, depression, and obesity – over these few centuries, American Indians shifted from one of the "healthiest" populations to a population that suffers some of the worst health outcomes in a nation characterized by serious health disparities (de Cora 2001; Jackson 1993; O'Nell 1996).

Local explanations for diabetes include not only these diet changes, but also poverty in these life conditions. Tammy Lowe lived on the Oneida reservation until her late teens and attributes her development of diabetes at the age of 29 to her early life diet on the reservation:

> When I was growing up on the reservation we ate whatever we could, whatever there was for us to eat. I mean cause we were very poor so. You know nowadays, you know naturally quite a lot of people work so their food and diets are a little bit better. But at that time we, like I said, we ate what we what was put on the table in front of us.

Poverty and the political economy of food – the political and economic components organizing the distribution and accessibility of food – continue to factor into diabetes explanations in urban spaces. Debbie Hardin, a 47-year-old Ho Chunk woman with family members who have diabetes explains that diabetes affects socioeconomic classes differently in the city:

> I think poverty plays a big role in it too, because not everybody has the right foods to eat, so poverty plays a big role in a lot of things. You know I know a lot of people who eat organic, now I can't friggin' afford organic, no I can't afford no friggin' organic. You wonder why all these movie stars and everybody's so healthy and all this other stuff is because they had the means and the ways to hire this you know whatever the hell to get in shape and dietician and yeah. You have to have the means and the ways to you know, to eat right.

In Native Chicago, social and economic status is considered a factor for diabetes development and it works its way particularly into discussions of diet and exercise. The diabetes epidemic has been related to the change in diet from pre-colonial diets to diets high in fat and simple carbohydrates like sugar and white flour (de Cora 2001; Jackson 1993). In the city, diabetes is attributed to diet as well, and this diet is related to the city lifestyle. The political economy of food is considered by community members as a contributing factor to poor health (Fine 1994). People describe the need for meals that are quick to make, relatively inexpensive, and filling enough to keep them going through their workday, commute, school, and taking care of children. In Native Chicago the cost of food is the primary concern, and not only cost in terms of financial cost but also cost of time. Foods that are convenient and require little preparation are common. People frequently turn to fast food restaurants that are easily accessible in the city, or to premade or easy to make meals found in grocery stores that are inexpensive and have high carbohydrate, fat, sugar, and sodium content.

As noted in chapter three, some community health workers also associate diabetes in this community with social inheritance of eating habits. While the staff at the American Indian Center strives to serve foods that are considered healthier, community health care workers describe food at center events as concerning. While the American Indian Center had a dietician on staff, sodium, carbohydrates, and portion sizes were closely monitored for elder lunches. Today, staff continue to consider these factors, but will often provide second portions of food to those who ask for more, effectively doubling the intake for one meal. Staff members explain that they are concerned with when and where some community members will get their next meal. This food insecurity shapes the cooking, serving, and eating habits at community events. It is this response to these concerns that worry health care workers. As non-Native community health care provider Cheryl Burwell describes:

> They're great cooks, you know, and the food's good, and they just like, they pile it on. And that was one of my big discoveries. I mean to me it was a big discovery, was that really the feast or famine thing is still there. You know it's like eat all you can 'cause who knows where the next meal is going to be from, you know and you would hear that at different gatherings.

The uncertainty of food supply in the not-so-distant past shapes contemporary eating habits. More work on the daily diet and the history of American Indian diets in city spaces through history would be beneficial to studies of health and disease in urban Native communities.

Stress

Stress is described as an influencing both diabetes development and care in Native Chicago. Pauline Massey explains that the stress of trying to "make ends meet" living in Chicago played a role in her diabetes. Pauline raised her own two children and six foster children while working in the city. When she was laid off from her work two years ago, she not only lost her income, but also her home. Stress caused by financial burdens and work life were cited as factors in the development of diabetes in Native Chicago, and these stresses also played a role in diabetes management.

Psychological stress is described as a factor in diabetes causation in communities worldwide. In Gretchen Chesley Lang's work on Dakota understandings of diabetes causes, she finds that diabetes is related to diet, to loss of tradition, and to increased levels of psychological stress (Lang 2006a; Lang 2006b). Melanie Rock also finds Cree individuals describe a strong association of diabetes with both distress and duress (Rock 2003). This focus on the relationship of diabetes, emotions, and stress in patient perspectives is seen in other cultural contexts outside of American Indian populations. In a 1988 study, medical anthropologist Jo Scheder argues that growing cases of diabetes among migrant workers appear to be closely associated with high levels of stress (Scheder 1988). Jane Poss and Mary Jezewski describe how Mexican patients whom they interviewed considered *susto* or fear to be a causal factor, along with diet and obesity for diabetes (Poss and Jezewski 2002). Samantha Thompson and Sandra Gifford describe that members of the Aboriginal community they work with attribute diabetes to being out of balance (Thompson and Gifford 2000). Steve Ferzacca's study of health and healing in modern Java describes how community members associate modern ailments like diabetes to the newly developed urban condition of *stress* (stress) (Ferzacca 2001). Emily Mendenhall and colleagues find in their study of Mexican American patients living in Chicago, Illinois that the patients often saw stress as a significant factor in their diabetes development and for some, diabetes was considered the embodiment of stress (Mendenhall et al. 2010). Nancy Schoenberg and colleagues also find that diabetes patients from African American, American Indian, Mexican American, and rural white American communities in the United States believe that stress not only contributes to the development of diabetes, but it can also exacerbate the condition and hinder one's ability to care for the disease (Schoenberg et al. 2009).

The inclusion of stress as a possible causal factor for diabetes in medical models began in the seventeenth century. Thomas Willis, who contributed to the disease's classification by adding *mellitus* to the nomenclature *diabetes mellitus*, recognizing the sweetness of a diabetic patient's urine, included in his description of the disease the hypothesis that an overconsumption of ale as well as extended periods of sorrow contributed to the development of the disease (Willis and

Pordage 1684). Willis' inclusion of psychological distress as a factor in the development of diabetes has gained further support in the past few decades of biomedical research on the factors contributing to diabetes etiology. Per Björntorp argues that perceived stress results in activation of the hypothalamic-pituitary-adrenal axis, increased levels of cortisol production and reduced amounts of sex hormones; these reactions, Björntorp explains, contribute to the buildup of visceral fat, which along with the increased levels of cortisol, is associated with insulin resistance, thus creating a link between stress and diabetes (Björntorp 1988; Björntorp 1991; Björntorp 1997; Björntorp 2001). Pickup and Crook postulate a role of the innate immune system in diabetes development (Pickup and Crook 1998). In their hypothesis, the sustained activity of the innate immune system from stress results in an increased secretion of cytokines, cell-signaling protein molecules. These increased cytokines are then linked to the release of proteins and hormones from the liver, the adipose tissue, and the brain. Pickup and Crook explain that these released hormones and proteins are associated with insulin resistance; in their model then, if a person is predisposed to developing diabetes through family history or environmental factors, the innate immune system through reactions to stress may play a role in the development of diabetes.

Local and biomedical views of stress and how it might factor into diabetes differ in terms of perspective. In local explanations for diabetes that include stress, people define stress in terms of emotional stress and psychological stress. In the recent studies of stress on diabetes development, biomedical models focus on the physiological effects this emotional and psychosocial stress have on bodies – looking at hormone production as a factor in creating insulin resistant cells. While these perspectives differ, both local and biomedical researchers consider life stress a possible factor contributing to diabetes development.

Intergenerational trauma

Intergenerational trauma is increasingly gaining attention in American Indian health research. Community health worker Dacia Rice offers a definition of intergenerational trauma from her own experience growing up in Native Chicago and now working in the health care field:

> Our families are hurting. Our families, like whole entire units of families are in pain. And we don't really fully understand always what that pain is about. We just know that we're hurting. And, but it's not depression. Well I should say community isn't exactly viewed as depression, because I'm not feeling like I want to kill myself. So they're not being able to recognize this form of depression and so I'm living my life and I have my family and we're moving day to day and we're getting it done. We're getting it done on a bare minimum kind of scale. It's not a full functioning, it's not fully functional and operational, because we're just, we're running on zero constantly and you recharge only enough to make it through the next day…
>
> And a lot of it our families aren't talking about it. So we have families that have been hurt for whatever reason from, you know, two generations ago, they never talked about it. We know whatever secrets lie in, in grandma's closet, but we don't talk about it. Those are secrets that continue to remain secrets and you know about it, but we're not going to go there. And then now those same things are being, are occurring to us in some, maybe it's the same manner or similar manner or you know whatever. It's just a different scenery, different people involved, but there's the same things that are happening because nobody is teaching us how to talk it out. Instead it's like you have to bury it deep down inside ourselves and pretend that I'm good, I'm fine…
>
> We learn to put on a smiling face, and we learn to bury those things deep down, and we don't know how to you know so we learn to do those kinds of things and we can present as, no, I'm normal, and then it's like, okay we're waiting, we're waiting, she's going to look away, whew.

Intergenerational trauma is trauma that is passed from one generation to the next. As Dacia describes, this trauma is not only felt by community members in Native Chicago, but performed in wearing a smile to mask the hurt. Many events and policies in colonial history factor into local discussions of intergenerational trauma, including the boarding school system, forced removal to reservations, and individual events like the massacre at Wounded Knee. This history shapes Native health today. The high rate and experience of depression among the Flathead, Theresa O'Nell argues, can only be understood in the historical context that has led to the cases of depression among the Flathead (O'Nell 1996).

The concept of intergenerational trauma as a factor influencing Native health is moving from the biomedical community to local communities. In Native Chicago, depression and intergenerational trauma are widely believed to be closely related. Similar to intergenerational trauma, the negative effect that adverse childhood experiences or ACEs have on the future health of Native populations is a topic into which researchers in reservation communities are investigating. Studies have shown that the experience of sexual and emotional abuse, neglect, and/or household dysfunction can lead to significant lower health ratings in future life in terms of both physical and mental health (Felitti et al. 1998). Discussion of ACEs, unlike intergenerational trauma, did not emerge in my interviews or conversations with either community members or biomedical providers during this study.

Dacia Rice does not link the development of diabetes to intergenerational trauma, though some of her colleagues in the Native health care community do believe there is a link. One non-provider described a possible link between intergenerational trauma and the development of diabetes. Charles Mattes describes:

> Well I would say that it's a combination of things. It's not, it's such a problem where you can't just point to one, one thing and then say that's the problem. I think that there are several things … I also feel that there's a cultural, it's a matter of historical trauma. People have, people who have gone through, just about every one of us has family members and grandparents who have gone through the boarding school system and I believe just like with alcohol, there's a lot of

> depression that people had experienced as we've had our whole, our whole two or three generations of parents and grandparents have been you know pretty much wiped out and in a sense brainwashed so there was like not a lot of, so the parenting you know, they didn't understand how to be parents because they were taught that what they were was was wrong with the world, you know, they taught them worse things, they taught them to hate themselves and in turn they hated who they were and then their kids grew up hating themselves and just be a cycle, a whole cycle of, of very unstable households because you know it's this different
>
> understanding, they lost a lot of their teachings, so I believe that that's definitely a factor as well.

Charles is the only community member who described intergenerational trauma as a factor in the development of diabetes. Others spoke of the relationship between intergenerational trauma and depression and alcoholism in the community. In the next chapter I show how some community members describe how depression and intergenerational trauma affect diabetes management.

While community members did not often speak of diabetes as being caused by intergenerational trauma, nurses who have worked in the community for long periods of time, including the former wellness director of the American Indian Center Laura Cunningham, describe intergenerational trauma as a contributing factor to diabetes etiology in this community. Carla Roberts, a 24-year-old Native/white nurse, explains:

> I think it had a lot, it has a lot to do with, it's kind of a multitude of factors in terms of poverty, historically just coming from being, I think it has to do with historical trauma, poverty and kind of how we treat food now versus the way we used to… People should definitely, people are kind of starting to talk about it more in terms of relation to health care and it should be, definitely. Because you know it's, it could be just poverty as well, I mean if you look at other poverty, regions with extreme poverty they have obesity, diabetes, things like that as well. But that then also then their poverty they have historical trauma too. It's a lot to do with a lot of Native family, families have multitude of social issues, I feel like carry on, you know there's abuse, there's stress, there's broken homes, different things like that. You can't really raise healthy children if you don't live in a healthy mental environment and that cycle just kind of continues you know broken home leads to maybe that person having a broken home in the future with

> their family, so I feel like we definitely have a lot to do with it.

Intergenerational trauma is considered a factor in diabetes development by biomedically trained care providers who work primarily in Native health care more than it is by community members.

The role of transgenerational epigenetics is an area that is gaining attention in biomedical sciences and corresponds to these local discussions of intergenerational trauma. The field of transgenerational epigenetics studies of the passage of cell information between generations that are not encoded in DNA. Michael Skinner and colleagues posit that environmentally induced changes to epigenetic elements, including DNA methylation, histone modifications, chromatin structure, and hydroxymethlcytosine residues in the brain, can persist and be inherited by the next generation (Skinner et al. 2010). Though human studies are limited in contrast to animal studies, researchers find that one generation's experience of stress leading to neuroendocrine responses affect not only that generation but subsequent generations. Stephen Matthews and David Phillips describe that this passage has an effect on the hypothalamic-pituitary-adrenal axis, causing hypercortisolemia, which, as described above, can lead to insulin resistance, as well as depression and hypertension (Matthews and Phillips 2010). Transgenerational epigenetics is a young area of research that offers support to the argument that intergenerational trauma may play a role in diabetes development.

Local explanations for why people develop diabetes concern a wide range of factors that include family inheritance, diet, colonial history, stress, and intergenerational trauma. Local understandings of diabetes etiology, like biomedical explanations, describe diabetes development as complex and multifaceted. Diabetes is typically described as being caused by several of these factors together. As described in chapter three, the mainstream biomedical model for diabetes focuses on locating the cause for disease within the internal structures of individual bodies. I argue that the role that socio-political histories play in the development of conditions like diabetes should be earnestly considered in discussions of disease etiology.

Native identity and community in discourses of diabetes

These local discourses not only offer explanations for why people develop diabetes, but they further provide a window into local worldviews about Native identity, group membership, and colonial history. In local explanations and definitions of diabetes, there is an underlying discourse that speaks to local conceptions of Native identity, community, history, evolution, and race. As described in chapter six, race, while not a biological category is a socially significant category. In Native Chicago, the concept of race has converged with Native systems of categorization in local discourse about diabetes (Shoemaker 1997). Natives of all American Indian nations in these discussions are described as sharing a similar body, developed over millennia. These discussions speak of Native and former Native diets as "good," "natural," and "pure" in contrast with the diets of modern America that are seen as a significant factor in the diabetes epidemic among Native populations today.

> Rosanna Poni: I think of it like historically, like our food systems were ripped from our people, so federally mandated that, kill all of the bison. And they were almost completely disseminated. I think there's plant colonization, so people brought their different plants from whatever countries they were coming from and that either you know adversely affected plant life that was here or whatever it may be, introduction of like pig and cow and chicken. Those are not our natural foods. Fry bread as traditional as it may seem today, that was really just Native people being adaptive at a time when they were you know kept on reservations taken away from their foods systems and then only given federally mandated flour and oil and the government was feeding us foods that were not ours and our systems were kind of in a shock. Our systems are still in a shock reaction from that. [28-year-old Oneida woman with diabetic family members]

> Lois Bagby: We had a pure system. We weren't, we weren't, we were not accustomed to these, to all this sugar and all these products that were, that everyone else was. Natives had a system where they only had natural, so all this other stuff that was, that we had is unnatural to us, and so our bodies are not adjusted to it… Maybe down the line, maybe our systems will adjust to it, but right now we're still in the pure. We're still in the pure system. [58-year-old Ojibwe woman living with diabetes]

> Monica Harris: You know I mean I get down to like the basic like back in the day when the government put the Natives on the reservation and gave them these certain foods to eat and we had to figure out how to use these things to feed our families, which those weren't a part of our life. It was all, you know the wild rices, the good beef, you know the buffalo, and the deer, and the rabbits, you know, the good things, and the roots and everything that really was with our tradition and our culture for centuries before. So I think that played a lot to do with it. And they only had those certain eats and they couldn't hunt. Really. And not eating the beef, which is a lot more fatty, you know those things. And I think that has a lot to do with it today. It does. The past does have a lot to do with the future and that aspect. [44-year-old Sioux/Ponca woman living with diabetes]

Chicago's inter-tribal community is strengthened through these discourses of not only a shared social and political history of displacement and oppression, but also through a shared evolutionary history that is embodied today through the experiences of diabetes in Native communities. In chapter five I describe how a shared history of colonial oppression is referenced in local discussions of Native identity in the city. In these diabetes discourses, Native identity is defined in terms of a history predating colonialism – a shared evolutionary history that produced bodies that hunger for pure and natural foods and are susceptible to diabetes today.

The body is what Sherry Ortner would term an elaborating metaphor, a vehicle to organize a complex idea (Ortner 1973). Bodies have served as symbols for nation-states, sorting out the complexity of the social and political concept (Scheper-Hughes and Lock 1987). The body metaphor is also used to naturalize and elaborate state agendas. Emily Martin's work demonstrates how bodies serve as a metaphor for the nation-state, supporting local border policies and gender ideologies (Martin 1990; Martin 1994; Martin 1997). In these discussions of the susceptibility of Native bodies to diabetes today, the health of the social and the individual body correspond with group membership. The relationship of group membership with the health of the social and individual bodies is seen in contexts outside of Native Chicago. In her work on post-Chernobyl Ukraine, Adriana Petryna introduces her concept of biological citizenship. In this context, citizenship is tied to individual biology; here, a tie to Chernobyl allows one to make claims upon the Ukrainian government for compensation for exposure to radiation (Petryna 2002; Petryna 2009). In Native Chicago, a vulnerability to diabetes is a widely recognized characteristic of indigenous populations of North America. To be an indigenous American, one is also at risk for developing diabetes. This shared risk of developing diabetes, in turn, strengthens the ties of Chicago's inter-tribal community by binding together the citizens of many tribal nations as an ethnic enclave of indigenous Americans.

In Native Chicago, discussions of a shared biology serve to strengthen ties in a community that is made up of individuals whose ancestors came from distant locations across North America. These discussions evoke a sense of community, while further distinguishing Native communities from settler communities by contrasting the purity of ancestral Native diets and bodies to the impurity of the settler diets.

Conclusion

Human knowledge is tentative; it is ephemeral; it is located in particular historic moments. In this chapter I described how diabetes is understood in contemporary Native Chicago. The ubiquity of the disease in the community influences local understandings of what the disease is and why people develop it. In defining diabetes, experiences with the biomedical model through human interaction and through media play a role in addition to experiences with living with, caring for, and/or witnessing diabetes care in the community. Within these discussions, there is an underlying discourse of a shared evolutionary history that serves to strengthen the inter-tribal community bonds in the city. The findings of this chapter offer contributions to multiple audiences.

For both the local community and for the biomedical field, the findings relating to the political economy of food and food insecurity are relevant. As described in the previous chapter, attainable health education is a primary interest in the community, and because finding affordable and enjoyable healthy food is a widely shared concern in the community, programming that involves education on shopping for and preparing healthier affordable meals could benefit the community. Additionally, for the medical field, I have outlined the ways in which the local lay community understands diabetes and its causes. An awareness of these differences in understandings between biomedical models and lay model can be used to both develop improved public health campaigns and to facilitate clearer discussion during clinical encounters.

The findings of this chapter offer multiple contributions to the field of anthropology. First, this chapter builds upon theorizations of knowledge. Expanding upon the discussion of diabetes knowledge development that began in the previous chapter, I demonstrate that understandings about what this disease is are based upon individual and social experiences with the condition. Second, I continue to build upon scholarship on the diabetes epidemic in American Indian populations and on the anthropology of indigeneity while theorizing the relationship between human biology and human culture. In chapter three I argued that the diabetes epidemic in Native populations can be attributed to the social policies enacted through colonialism. In this chapter I have shown that human biology shapes human culture. In Native Chicago, being at risk for developing diabetes is a defining characteristic of indigenous American peoples. This study then builds upon studies of the American Indian diabetes epidemic by focusing on how diabetes is shaping contemporary discussions of indigenous identity.

CHAPTER 8
CARE IN THE CONTEXT OF CHRONICITY

Introduction

On an unseasonably cool day in late July 2013, Regina, Roy, and I were plating the elder meal as an assembly line at the American Indian Center of Chicago. On this Wednesday the smoky charred scent of burnt rice permeated the kitchen as we portioned out plates with a chicken taco, refried beans, rice carefully scooped from the top of the pan, and small condiment tubs of salsa and guacamole that one of the new volunteers had portioned out earlier. As Regina was urging us to move faster to get the plates ready for the servers coming in and out of the front kitchen entrance, we stopped and exchanged glances of concern upon hearing an unexpected voice booming just outside the kitchen walls. One of the volunteers poked her head outside the door and reported back that it was just Joshua making an announcement about the SoBe beverages that had been donated to the center. Joshua was telling his fellow lunch goers that they should not drink this product if they are diabetic, explaining that the nutrition label on the bottle was misleading. The 20 ounce bottle of the fruit-flavored beverage contained 2.5 servings in a single bottle – meaning that if one person were to drink the entire bottle, they would consume a total of 62 grams of carbohydrates, and not the 25 listed on the nutrition panel.

Joshua's announcement to the lunch attendees represents one component of the diabetes care work being performed in Chicago's American Indian population. Care in this context where diabetes is prevalent is done within and across multiple spheres, from inside individual households to community-wide considerations. As described in chapter three, because diabetes is a chronic condition that can result in serious, and sometimes life-threatening complications if left uncontrolled - for instance amputation, blindness, and kidney and heart disease – mainstream physicians typically expect patients with this diagnosis to perform a set of daily tasks to care for the disease. These tasks include testing blood glucose levels, counting and limiting the grams of carbohydrates in all consumed foods and beverages, exercising, examining feet for wounds, taking oral medications, and/or injecting shots of insulin.

This chapter explores care expectations and care practices in Native Chicago. In the first section, I look at expectations for care as described by biomedical providers in Chicago. I then explore local discourses from both patient and provider perspectives about factors that influence the performance of diabetes care work. In this section I describe how expectations of disease management differ between these perspectives. In the remainder of the chapter I focus on who, when, where, and how care work is performed – investigating the direct and indirect acts of care being performed by men, women, and children in individual households and on the community-wide level. In this chapter I argue that “care” for diabetes goes far beyond individuals’ self-care in this highly affected community.

Taking control of diabetes

People living with diabetes manage their blood glucose levels in order to prevent the development of secondary complications, which can be life-threatening. Common complications of diabetes include heart disease, kidney disease and failure, amputation of toes, feet, legs and hands, and impaired vision or blindness. The tasks for managing diabetes vary from patient to patient, but they include some combination of testing blood glucose levels, counting and limiting the carbohydrates in all food and beverages consumed, taking oral medications and/or subcutaneous injections of insulin, and increasing physical activity. The majority of this care work is completed outside of the biomedical setting by patients and family caregivers. As discussed in the methods chapter, the seeking of professional medical care is sporadic for some community members.

In interviews, biomedical providers describe how they focus on developing individualized treatment plans that take individual lifestyles and needs into account. American Indian Health Services nurse Janice Block explains:

> Every person, I think I would say from my experience every patient is individualized and each patient care plan should be different because everybody's different. It's individually based because what we do here is that we do a referral from either the doctor or myself and refer the patient over to the, to the dietician, and she creates a meal plan for them. So we have anywhere from like a, I want to say a 1500 calorie diet to an 1800 calorie diet if I'm not mistaken. But it's, they're different, based on what their needs are, what their level of education is, and how their habits have been.

Nurse Leah Weitzel explains that while treatment plans are individualized, many diabetes care routines factor in some combination of the same lifestyle components:

> Well healthy eating, however you want to do your carbohydrate, whether you want to literally count it or do the plate method, or whatever, but keeping that within the recommended guidelines. And a balanced diet, portion control – you can eat what you want but you have to watch when and how much you eat. And then regular, preferably daily, some sort of physical activity, but definitely several times a week and of moderate intensity. And then also stress management, I think it's important for both, because for it being a chronic disease and in order to practice the other healthy behaviors, a lot of times the stress has to be under control in the first place. And communication with family members and friends and whoever else may be involved so they understand what you need to do to practice those sort of healthy behaviors.

Leah does not mention medication, but instead focuses on the lifestyle changes individuals make to achieve diabetes control outside of the medical encounter. Biomedical providers recommend that people living with diabetes make significant lifestyle adjustments and perform acts of self-surveillance and discipline to achieve diabetes control. As Leah notes, providers do not anticipate that this care is entirely done by the patient alone, but that care may also be supported through the efforts of family and friends.

Patient understandings of disease can influence how providers develop these individualized care regimens. In talking with Eva Ramirez, an internist who works primarily with Mexican-American diabetes patients at Cook County Hospital in Chicago, I asked if experience with individual patients has altered her practices as a medical provider. She said that “it absolutely does,” and shared the story of prescribing insulin therapy for one man. Upon telling this middle-aged Mexican-American man that she was shifting his treatment from oral medications to daily insulin injections, Eva was taken aback by the man’s breaking down into tears. Eva explained that she often shifts her patients to insulin if their glycated hemoglobin (also referred to as hemoglobin A1c) test results are at a value of 8.0 or higher while taking oral medications like Metformin. In this encounter, she learned that from this man’s perspective, insulin was a death sentence. Everyone he knew who took insulin died soon after starting insulin therapy. Eva concluded her story by explaining that she learns from her patients, and because of incidents like this one, she has become more involved with the medical ethics board at the hospital, pushing for providers to give more information to patients rather than just prescribing treatment.

Medical anthropologists have noted the role experiences like Eva’s play in informing medical provider practice. Renee Anspach’s work on an intensive care nursery outlines how different providers have differing understandings and expectations for patient outcomes based upon their differing experiences with former patients, their interactions with current patients, their familiarity with literature in the field, and their respective medical training (Anspach 1993). Linda Hunt similarly describes how providers who diagnose and treat female reproductive cancer patients in Mexico are guided by local theories of the disease (Hunt 1998). Hunt explains that providers are influenced in their discussions with patients and in their understandings of cancer's causes by local concepts about gender, morality, justice, purity, and danger. Eva Ramirez' story shows that local understandings of disease may influence biomedical care to some degree. Patient experiences outside of the medical context play a role, albeit a small role, in shaping provider work.

"I knew I had it:" factors that influence care

As indicated in chapter six, not all people with diabetes diagnoses make lifestyle adjustments or follow care plans in the manner suggested by their biomedical providers. Local nurses express frustration with such cases. In an interview, volunteer nurse Violet Post discusses how she works with patients who have high blood glucose during the weekly health screenings at the center:

> Well I've gotten to know some of the people that work here. I usually ask them if they took their insulin this morning and if it's real high you know… we're supposed to follow up on it but some of these people have been diabetics for years so they know [in a characterized voice] "oh yeah I had I had ice cream list night or I had a big fudge sundae" or whatever they had or in the morning [in a characterized voice] "oh I had two donuts and I had coffee and this and that" so you know you try to tell them that you know maybe once in a while you can have to donut or half a donut but two donuts in the morning, I mean that's a bad start. Sugar goes up and then [in] a couple of hours it'll just drop.

Violet does not believe that all patients understand the relationship between food intake and blood glucose readings, as indicated in her characterization of patient statements about eating ice cream and donuts without realizing the effect it might have on their blood glucose levels later in the day. Violet tries to educate those she encounters by talking with them about diet and offering diabetes pamphlets and magazines to refer to at home. But she also gets frustrated with patients who she thinks just do not care, seeing her suggestions being disregarded by some individuals. Both the staff and volunteer nurses at the center kept a mental list of community members who they believed were not performing diabetes care tasks, and in meetings they would discuss these individuals and possible methods of promoting what they would describe as better diabetes care – including finding ways to lower costs of testing supplies and medications, or providing information about diet and nutrition in an approachable way.

Biomedical providers working with Chicago's Native community identify avoiding diagnosis and non-compliance as two challenges to diabetes care in the community. Dacia Rice, who has worked as a community health worker for over a decade, relates why community members do not always seek biomedical care. In our conversation on intergenerational trauma, described in chapter seven, I asked Dacia to speak about what types of effects intergenerational trauma can have on one's health:

> Non-compliance. Patients that walk in our door, in order to describe them properly is that they tend to be, they tend to be, the patients that walk in our doors are patients who are oozing with an open wound. They're not coming in for preventative medicine. They come in because they are feeling so ill that they are you know, they are not able to operate. And they've waited. They've known there's been a symptom for so long, but they ignore it. And so everybody knows, like when we think of especially like diabetes, I want to say community by and large knows the symptoms. It isn't that they don't, but so many times community members are like at the very, you know like in terms of finding out that they're, their sugars are out of whack, they've been out of whack for years. And they're just now walking in the door. You know and it's like their A1cs are at 10s, 11s, you know and it's like you know you're not even, they're not even finding out prediabetic or you know like something like that, they're finding out when it's already full blown, like you've already done damage to your body kind of mode. And they still don't do anything about it. They still, they might take the medicine,

> just like, just like anybody. You have some kind of illness, you take your antibiotics ‘til you’re feeling better and you’re like oh I don’t need it anymore.

Dacia’s mention of “full-blown” diabetes differs from the local classification of diabetes cases as full-blown. Here, Dacia uses “full-blown” to refer to the development of diabetes in biomedical terms – the individual is no longer prediabetic, but meets the diagnostic criteria of having diabetes. As a community health worker and an active community member, Dacia has seen the long term ramifications of intergenerational trauma and depression have taken on Chicago Natives.

I realized the gravity of the situation Dacia describes in an interview with Roy Nieves. Roy and I had worked together in various events at the center over the year before our interview. Roy’s mother has diabetes, and Roy has expressed a concern that he is likely to develop the disease someday. Though believing that he is at risk for developing diabetes, Roy explains that he is not ready to find out if he has diabetes at this point in his life:

> Meg: Do you ever get screened for it?
>
> Roy: No
>
> Meg: Have you thought about?
>
> Roy: I’ve thought about but then thinking about it’s like if you really want to know it’s like going to change your whole life. And right now I don’t want that to change. I mean I’m aware of it, and I’ve always thought about it too every once in a while like you know those sweets right there, I want it, you know, so I mean, right now my eating consumption has sort of turned

In the year since that interview, Roy has actively been trying to lose weight through exercise and diet. While he is making lifestyle changes that could prevent the development of diabetes, he is still not at a point in his life where he would like to know if he has already developed it.

Clinicians and non-clinicians alike use the language of denial to describe this pattern. However, in his case, Roy did not express any concern about current symptoms. Sylvia Kistler's experience more clearly exemplifies Dacia's description of an individual knowing that they are displaying trademark diabetes symptoms, but not immediately seeking diagnosis. In our interview, Sylvia explains that she knew for a while that she was displaying diabetes symptoms, but that she could not bring herself to see a doctor for some time:

> I've been feeling like this for about a couple months, I know something's wrong with me but I just I hated to face it. Like I denied it that I had it. But I really knew I had it but I just say no I don't have it.

Sylvia went on to explain that she only sought diagnosis after being prompted by Laura Cunningham at the American Indian Center's wellness program to follow up on the health screening performed at the center.

While biomedical providers, as discussed above, and some community members, as discussed in chapter six, describe some diabetics in the community as not caring for their diabetes, people living with diabetes have alternate understandings of their level of disease management. Both biomedical providers and community members speak of diabetes care in terms of control. Control of individual and social bodies is a central theme in medical anthropology. Michel Foucault's theorizations on biopower and self-care underlie some of these discussions (Foucault 1990). According to Foucault, states produce docile bodies that they control and manipulate through regulation, surveillance, and training practices. In the third volume of *The History of Sexuality,* Foucault explains that one cares for oneself by practicing self-governance through introspection (Foucault 1990). Theorists incorporate Foucault's concepts into analyses of contemporary medical practices. For instance, biomedicine, as described in chapter three, defines individual health and illness based upon norms created through statistical analyses (Clarke et al. 2003; Lock and Nguyen 2010). Scholars also describe the role language and discourse play in medical interactions to reinforce the authority of medical providers over their patients (Kuipers 1989; West 1998).

Medical anthropologists also describe how experiences of health and illness are discussed in terms of control by patients. Gay Becker describes how diagnosis with a chronic condition can cause someone to feel a loss of control for a period of time. The acute nature of diagnosis, Becker explains, is replaced as chronicity sets in and the patient reorients oneself, adjusting one's life to the condition with which he/she has been diagnosed, thereby regaining control (Becker 1997). People also develop individual identities through their discussions of health and disease. Lisa Capps and Elinor Ochs' work *Constructing Panic* narrates the life of a woman with agoraphobia. As they demonstrate, the research participant Meg constructs an irrational self, fearful of places through her narration of past events in which she describes herself as helpless and without control (Capps and Ochs 1995). Dorothy Broom and Andrea Whittaker discuss that in the case of diabetes discourses in Australia, patients speak about diabetes in moralizing terms of control. As they argue, people negotiate their patient identity through explaining their reduced levels of control by evoking the image of children, effectively lowering their agentive abilities when describing themselves as not following their diabetes care routine (Broom and Whittaker 2004). Individual experiences of health and disease are articulated using the language of control – control of individual bodies and choices.

Control is also a central topic in discussions of diabetes care in Native Chicago. In addition to this focus on control, individuals seek to identify themselves and their ability and choices to perform certain types of care acts in their own terms. There are a range of explanations for why individuals do not perform care tasks in the way in which biomedical providers suggest. The most common include the high financial costs of eating healthier diets and obtaining medical supplies, the difficulty in accessing fresh foods in contrast to the ease in picking up processed food items, and the time constraints of diabetes care in the city. As first discussed in chapter three, people describe being asymptomatic though having high blood glucose readings. Carmen Bertsch explains that she depends upon technology to care for diabetes:

> I've never been able to tell when it was high… I can't feel no symptoms… So the only thing that will work with that then is to take your count.

Many people agree with Carmen in that they do not feel a difference between what are defined as normal and as high blood glucose levels.[1,2] Diabetes care is closely tied to this at home care technology. The test strips for these blood glucose machines, however, are quite expensive. When diabetes patients do not feel ill and they cannot afford blood glucose machines and test strips, their diabetes management is tended to on their own terms. Sylvia Kistler describes that though she cannot afford the test strips to measure her blood glucose levels as frequently as her doctor recommends, she takes advantage of all opportunities provided to her to test her blood glucose levels for free, including the health screenings at the center and at local pharmacies:

> They check it over here [the center], or sometimes I go to that store where they got the machine, I check it there…When I'm walking by CVS, I'm oh I'll check my blood sugars. I'm going to go check my blood sugars.

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[1] Normal blood glucose ranges are determined individually by biomedical providers. Participants defined their normal ranges to vary between 65 and 120 mg/dL for before meals, and below 180 mg/dL after meals.

[2] The experience of low blood glucose levels are described as being felt in dramatic ways – sweating, feeling overheated, shaking, feeling dizzy, and being unable to concentrate. These experiences were described as rarely occurring but were very memorable to those who experienced them.

From the point of view of outsiders, Sylvia may be seen as not caring for her diabetes, when from her own point of view, she is doing the best she can in her current circumstances.

Financial burdens are high in chronic condition care and this burden affects care practices. There is a danger in placing blame on patients for not performing care activities without first understanding the larger context in which care is or is not being done. Todd Meyers describes how a Baltimore woman living with multiple chronic conditions split her pills, reducing her dosage in an effort to cut her costs (Meyers 2007). João Biehl and Vinh-Kim Nguyen describe how worldwide efforts against the AIDS epidemic met with challenges in implementing successful therapy courses. Local healthcare infrastructures are not capable of ensuring that the full antiretroviral course will be taken by patients; when patients do not adhere to the expectations of global healthcare organizations, these events can lead to the development of resistant strains of the disease from partially completed treatment courses, which in turn is often blamed on patient non-compliance without looking at larger issues (Biehl 2006; Biehl 2009; Nguyen 2005).

While some diabetics in Native Chicago describe themselves as striving to do the best they can in their circumstances, others describe a conscious choice to not follow biomedical recommendations for care. This choice is at times articulated in terms of performing a Native identity. Gerard Paul went for nearly a decade of his life without taking medication for diabetes after being diagnosed. In our interview, Gerard told the story of his history with the disease from his borderline diagnosis in the 1990s to his decision in the late fall of 2012 to begin taking prescription medications:

> When I found out I was borderline and they said I could control with weight and diet and all that stuff, I was like, okay, it wasn't a big deal to me. So when it came

> time for my next appointment, it didn't get any, it didn't decline any. It didn't really advance. I was still kind of like in the same area, so they started talking about medication and that's what kind of, I just don't like, I've never taken drugs, that's kind of my claim to fame, I've never taken any kind of drug, you know like prescribed sure for whatever, but nothing illegal. So when they started talking about medication, it kind of freaked me out. I had a negative vibe to it and I just, so from that point on, they're like if you, your next visit if you're the same or advance, they go you're going to be taking medication.
>
> And so from that point on, I didn't go to the doctor because I knew in my heart that I wasn't doing anything to, to fix the situation. Eventually I thought ah, it'll go away. I mean I really thought that, like if I didn't, you know if I didn't drink the tall glasses, cause I was drinking a lot of orange juice, I figured if I just stopped drinking orange juice it would go away. I mean that's how, you know silly my thinking was back then and I, I, I didn't go to the doctor for a very long time, even, you know I was early 20s, it got to be my mid 20s and you know, parents can't tell you what to do any more, so I just let it go. And I just for, for non-healthy reasons I just started losing weight, I don't know if that makes sense (laughs), but and then I stopped doing the pin pricking to see my blood count, I stopped doing that. I just stopped everything and just kind of lived life and eating unhealthy, not really exercising, I was gaining a lot of weight, so I knew that, and then of course, I understood the symptoms of diabetes, like frequent urination and fatigue and those two you know, and then, and then it was the urination that I knew that my blood was high. But yeah, you know I just didn't do anything about it. I will, I might be jumping, but I just started taking oral medication, I was borderline '91 never really professionally, nobody ever told me I was diabetic up until maybe six or seven years ago but then I finally started taking oral medication as of October of last year…Yes, and I probably trimmed a lot of years off my life, but I don't know. But I think that's, I think that's how I feel in my heart is that I lessened my lifetime (laughs). I laugh about it maybe it's just a nervous laugh, but yeah.

Gerard added to his description later in our conversation:

> I know, I just didn't. Every time my diabetes comes into question, people are like, people who know my family are like didn't grandfather pass away because of complications from diabetes, I'm like yes. They're like, and then they would say don't you know people who get their arms or feet amputated, and I'm like yes, I know people like that. They're like why don't you learn from that. And I was like I don't know. I'm very aware of it, I know the complications, I know that you could go blind, heart attack, stroke, I know all that can happen, but why doesn't it happen, why doesn't it help me. I don't know, maybe it is a mental thing. I'm not really sure, but people think I joke about you know when you, when I learned about Native culture because when I started to really be respectful of spirituality and ceremonies, I was probably in my mid-20s, and so I'm really,

> I'm not a traditional Navajo, I'm not a traditional Native by any means, but I do things that have traditional aspects, you know song is part of that, being a singer. Navajos, they do sunrise ceremonies, but I wasn't brought up that way. But I respect it, I would like to do that, but it takes such a big commitment, not to say that I don't respect the culture or the practice, it's just that I need to be in the, it needs to be embedded or somewhere with inside my head you need to do that. But where was I going with this, over the years it's kind of been gifted to me. I do think the Creator has, and this is where people just like roll their eyes at me or just think I'm being silly, but I do believe Creator does have a path in mind for me so that I'm not saying I should not do anything about my diabetes. Obviously I am because I started taking the medication, but if it so happens I get heart failure because of diabetes, then I think that was the path that was given to me. So, I am at a point in my life where I'm like yeah, western medicine is going to help, it's going to help. I've come to that conclusion. And it was recent, within the last five years. So why didn't I take medication five years ago when I had that revelation or epiphany, I don't know, I just felt for some reason last October.

It was in the early 1990s that Gerard was first diagnosed as a borderline diabetic and he chose at that time to not follow up with future visits. In his narrative, Gerard focuses on his choice to not care for diabetes, first attributing his choice of not taking medications as "silliness" and youth, and later relating this to his Native identity and relationship with the Creator.

The choice to not use western medicine or take pills is related to a distinctly Native behavior in this community. Lyle Evans, a 47-year-old Ho Chunk man, described how his mother would check her blood glucose, but was "hard headed" – a trait he linked with being Native in several contexts in our interview – in terms of her diabetes care needs:

> Lyle: She's having some diabetic issues in regard to amputation issues, but she's she's hard headed and she doesn't want that kind of thing to happen and she'd rather just live with it and whatever, you know, because of the Native American thing, but she lives in Wisconsin right now, so she's kind of undecided about that, so she has some cancer issues too.
>
> Meg: Can I ask what you meant by the Native American thing?
>
> Lyle: Just the belief system that she, yeah, she doesn't want, she's not going to let anybody cut anything off her body that shouldn't be cut off.

Explanations for care practices that do not meet biomedical recommendations incorporate Native identity into the narrative. Both Gerard and Lyle describe rejecting and avoiding western medical treatment as a Native characteristic. The relationship between diabetes, care choices, and traditional Native life has been described elsewhere. Linda Garro and Gretchen Chesley Lang's research in Dakota and Ojibwe communities describes that members of these communities relate the development of diabetes to movement away from traditional Native practices. Some individuals in these communities, they explain, have returned to traditional lifeways in an attempt to avoid diabetes (Garro and Lang 1993). While outsiders may define the actions of people like Gerard as not taking care of their diabetes, people living with diabetes have alternate understandings of their level of disease management that is built upon their capabilities for caring for the disease in their current circumstances, and their definitions of care in relation to their identity as a patient and as a Native individual.

Depression and stress are two additional factors that play a role in diabetes care practices in the community. While the experience of living with diabetes often included life burdens brought on by the disease, for instance, financial hardship, depression, increased stress, and physical limitations, many of those living with diabetes were also caring for additional illnesses, including: high blood pressure, high cholesterol, arthritis, cancer, HIV, bipolar disorder, depression, irritable bowel syndrome, and mobility limitations. Health care providers say that diabetes is a manageable disease, but it is one that takes time, patience, and practice. As noted in chapter seven, community health worker Dacia Rice believes that depression inhibits care practices. She elaborates on the role depression may play in preventing care work:

> I was working with her [a diabetic patient], trying to make sure at the time she was on insulin, and you know I'm always asking her, how are your feet doing and how is everything going, and going through everything, the long list. Oh, you

> know I noticed there was something on the bottom of my other foot. What's on the, what's going on? She's like I don't know, it's kind of a an open sore. Not what you want to hear right. And then it's like well, I know you were telling me last week you had a podiatrist appointment, when is that appointment? (sigh) I don't know. That's in my other purse. And because this is a home visit and we're sitting there staring at each other, could we, could we find out when that is? Oh I don't know. I'm physically right here. Right here at your disposal. You can tell me where the purse is, I can go get it for you. You could help yourself to it. All that I want it for is so I have an idea of when that appointment is so I can make sure that I'm calling you, reminding you that you have this appointment, you need to go in and if you're not going in, we need to be calling immediately, getting you into the doctor because you already lost one toe. I don't know, I'm not a medical professional to understand the whatever's this wound looks like. But I do know enough to know that if it's an open wound, you need to be in there. 'cause your blood sugar is too high. Oh, can I just call you back for that information. It's like depression to the ninth degree, right. It's like anything that's preventing you from keeping yourself healthy from like that downward

Diabetes, from Dacia's view point can be worse off if one is dealing with depression caused by intergenerational trauma. As discussed in chapter seven, though people do not often link intergenerational trauma to diabetes development, they do associate the effects of the trauma to depression and to issues of non-compliance in Dacia's terms. Several diabetes patients confirmed Dacia's explanation, elaborating on how depression hinders care work from time to time, while other interviewees also described diabetes as a contributing factor to their depression and other mental health concerns.

Family motivating care

While these issues challenging care in the community are significant concerns, care work is being performed in direct and indirect ways. Family members of all generations influence care practices performed by patients. While Gerard Paul explains that he witnessed family and friends succumb to diabetes complications, he for a time was unmoved by this knowledge to perform certain care acts, like taking medications. Others had different reactions. Kenneth Bracey, a 20-year-old Cherokee/German man, was motivated by witnessing his uncle's complications with the disease.

> My uncle, that's the one that I had seen went blind. He's the one that influenced me to keep on like checking my stuff a lot, more than I should and keep an eye on track so that I don't end up like he did.

While Kenneth is motivated to avoid the complications of his uncle, others turn to younger generations for motivating care. Doris Bennett, a 47-year-old Potawatomi/Puerto Rican woman, looks at her grandchildren and looks forward to being there for her family throughout the future:

> What motivates me is my grandkids, you know to be there for them, to take care of them, 'cause like I said, they're, one's autistic and it's you know nobody really wants to take care of an autistic kid unless you have to, and so I'm trying really hard to make sure that I can be here longer to help with that one, I know I've been bad in the past and laid up in the hospital, but this time I'm trying to just straighten it all out.

Doris and others explain that they perform diabetes care not for themselves but with their family in mind. Laura Heinemann describes a similar case among people on the wait list for an organ transplant. These individuals, Heinemann describes, explain that they do not want the organ for themselves, but to be around to support others in their lives (Heinemann 2014). This same reason is cited in Native Chicago, where people strive to care for diabetes to fulfill personal and familial obligations and responsibilities.

Gender and care

Both men and women in Chicago's Native community are involved in the day-to-day care of diabetes. In interviews with participants living with diabetes, we discussed their daily care routine and I found a statistically significant difference (p=0.005) between male and female participants as to whether they receive help from others with their diabetes care.[3] Women more often than men are caring for their diabetes on their own. 92 percent of diabetic women (23 of 25 women interviewed) stated that they did not have another person helping them care for diabetes, while 53.3 percent of male diabetics (8 of 15 men interviewed) stated that they did not receive help for their diabetes care. For both the male and female diabetics I spoke with then, the majority of each group saw themselves as the only person involved in their daily care for the disease.

Oftentimes caregivers are family members who provide care in daily life. The work caregivers perform includes performing medical procedures, taking care of day-to-day household tasks, and working with health and insurance services to ensure patient care (Levine 2000). Historically, women in the United States have been more associated with caring types of work, holding, for instance, roles in nursing (Abel 2000; Acker 1989). Today the role of caregiver is taken up by both men and by women. However, studies have shown that women more often than men take on the role of caregiver, particularly in cases where there is a sole caregiver (Abel 2000; Allen and Webster 2001; Aronson 1992; Buhler-Wilkerson; Marks 1996). In Jane Aronson's study of women taking on care of elderly, she found that while many of the women felt a need for more support, these women further felt great responsibility to take on the care work on their own, fearing that no one else would take on that role (Aronson 1992). Susan Allen

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[3] This finding is based on a two-proportion z-test.

and Pamela Webster note in their study that this trend is changing, where men in younger couples are more likely to play a role in caregiving than they are in older generations (Allen and Webster 2001).

Studies of Native gender roles in recent history show that women today tend to do most of the household labor, including cleaning, preparing food, and caring for children, but that men in Native cultures tend to be more involved in this household labor than are men in other ethnic groups (Hossain 2001). There is little data on American Indian women's lives in the precolonial era. According to scholars, Rayna Green, Teresa LaFromboise and colleagues, and Bea Medicine, much of what has been recorded about women prior to the mid-twentieth century was focused on famous female figures, shaded by stereotypical writing, grossly misinterpreted by the writer, and has often lumped all Native cultures into one group (Green 1980; LaFromboise et al. 1990; Medicine 1988). There is evidence that women were powerful and that many Native societies were gender egalitarian (Howell 1995; LaFromboise et al. 1990; Leacock 2003; Smith 1999). By the time most scholars began to take an interest in women's lives, the role of women in Native cultures was already influenced by contact with other cultures, from the Spanish, French and British cultures to the cultures of other peoples indigenous to the Americas (Howell 1995; LaFromboise et al. 1990). In Chicago's Native community, women have played a pivotal role in the development of the urban Native community. Women today continue to play a vital role in Chicago's Native community, with women taking on leading roles in many of the city's Native organizations (Straus and Valentino 2003).

In interviews with family members of diabetics, more women than men described themselves as being involved in the diabetes care of their family members. 70.6 percent of women (12 of 17 women interviewed), and 61.5 percent of men (8 of 13 men interviewed) said they were involved in the care of family members with diabetes. While the proportion for women was slightly higher, it was not statistically significant (p=0.602).[4] These family members described their care work to include: shopping, cooking, doing research, changing their own eating habits, sympathizing, attending medical appointments, administering insulin injections, and running errands with patients. 23.5 percent of women (4 of 17 women interviewed) and 46.2 percent of men (6 of 13 men interviewed) stated that they were not involved in the day-to-day care of diabetes for family members. For the 4 women and 3 of the 6 men who said they were not involved, they explained their non-involvement to be due to living too far away from the family member to participate in care. The 3 remaining men who were not involved in the care of diabetes simply stated that they were just not involved.

In this community, female diabetics often prioritize care for their families over care for themselves. Based on our conversations, it seems for many of these women, the care for diabetes may not be as pressing of a concern as some family matters. In one of our many discussions, Tammy Lowe describes how she was once able to control her diabetes through diet alone, but because of her family's fixed income, she and her husband, who had other health concerns, could not always afford to eat separate meals:

> Of course to eat a certain kind of food and to fix it a certain kind of way and everything else like this and that. We didn't have that kind of money. We were both on fixed incomes. We were both on disability, so I mean we couldn't just go out and get what just what I had to eat and then say get him what he wanted to eat. It was just too expensive.

In a later interview, Tammy expanded further on how she managed her care in the household as her husband's health deteriorated.

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[4] This finding is also based on a two-proportion z-test.

> Because of taking my husband here, bringing him home, taking him there the next day, you know, so I never had time to have a balanced meal. I'd make sure when we got home, my husband was hungry, I'd fix him something and then I'd just go ahead and ate anything that was fixable, or just throw together a sandwich in the fridge. Well that's what I would fix, you know for myself. [It] was really rough at that time, and so I didn't take, I wasn't taking my medicine for one thing because I knew that, well I was supposed to eat meals then take my medicine.

In Tammy's description, she was responsible for caring for the family and preparing foods for the family to consume. Her health took a secondary place as she forewent her own health needs to care for her husband's – prioritizing his dietary concerns and care needs over her own.

Almeda Cortez sees this as a continuing problem today among her tribe on the Choctaw reservation. Almeda believes that while many diabetic men will go without caring for their diabetes, women will intend to monitor and care for the disease, but will be prevented from eating properly by their household responsibilities to their families:

> But I think the reason why they cause them so much problem to stick to their diet is there see they have some children, they have children and a husband and they have to cook for them. If she cooks a diabetic way, they not going to eat. They going to be complaining. And then by the time that you get through cooking for them, you're too tired to cook for yourself.

Women in the community describe that they and other women they know forgo their own care needs in order to care for other family needs.

Men in the community also prioritize the health of a spouse over their own. Miguel Hoke, a 60-year-old Menominee man, describes how he put off his own health needs in order to care for his wife:

> I was too involved with my wife being home, taking her home for hospice, so I just left all my, I left all my medical stuff off to the side until I got everything situated and I went back in 2010 and started getting taken care of myself.

Miguel suffered a heart attack while his wife was first in the hospital and learned at that time that he had diabetes. As he explains, he focused his attention at the time on his ailing wife and did not return to the doctor for his heart condition or his diabetes until several years later after his wife passed.

Child care and work obligations can also interfere with individual care routines. Carmen Bertsch describes how she focuses more on caring for her grandchildren than on managing her diabetes. Having several young children to get off to school each morning and a demanding job as the social services director at a Chicago community center, Carmen had little time for adhering to regimented orders in caring for a disease she does not feel:

> I don't eat regular like I should I try to, but it's so hard when you gotta go to work and this and that and you just don't have time… I usually forget to take my medicine… So usually when they come, the American Indian Health comes on Wednesdays… it [her blood glucose level] is usually pretty high. It's in the two hundreds you know.

According to Carmen, her doctors had been "getting on her case" for not monitoring her diabetes as they had instructed her. However, as evident in Carmen's statements, balancing time between work, family, and personal care is difficult, and when she does not feel physically ill from diabetes, she does not prioritize its care over other pressing family and work concerns.

For the women I spoke with about their personal care of diabetes, it is clear that their own health may take a backseat to other household concerns. These women prioritize their responsibilities as mothers, wives, and workers over that of caring for diabetes. It is important to note here that the majority of the diabetics I spoke with – men and women alike – do not always feel physically ill when their blood glucose is higher than what doctors describe as normal – so the urgency of caring for diabetes may not be immediately felt, while family care and work responsibilities may be a more pressing concern. For both male and female diabetics, the majority of each group describe themselves as the sole caregiver for their diabetes management. However, women are more likely to be without additional assistance than men. Women also more frequently describe their prioritization of household work and family needs over diabetes care, while both men and women prioritize their employment obligations over care.

Children providing care

Because diabetes is so prevalent in Chicago's Native population, children are aware of the disease at a young age. As described in chapter six, with high rates of diabetes, children remember first learning of the disease through observing and witnessing the care routines of adult family members. In many instances, children participate in care work. Kevin Dorn is a 32-year-old Ojibwe man who grew up in a family surrounded by diabetes. For Kevin, giving his mother injections of insulin was part of his childhood, and something that he continues to do today:

> Basically just like whenever she needs to get shot up, you know, that's what I do. She puts, she fills it, whatever amount she needs in it, then she pinches herself and I got to shoot it. I've been doing it since I been a kid. That's just something I grew up naturally.

As Kevin explained in our conversation, he lives with his mother and returns home throughout the day to administer his mother's insulin. Children have been seen to incorporate themselves into the care work of family in the context of epidemics. Jean Hunleth's discussion of tuberculosis treatment in Zambia focuses on the role that children play in ensuring parent tuberculosis patients adhere to their medical treatment regimens. In the context of the tuberculosis and HIV epidemic in Zambia, as Hunleth describes, these children perform these care practices to protect the future of their childhood by helping their parent survive (Hunleth 2013).

Care that younger generations provide in Chicago involves the administering of medications in addition to cooking and providing reminders for care. Aria, a 34-year-old Assiniboine woman, describes how her children monitor her eating:

> The kids are pretty good about it. They're the worst when they catch me eating something I shouldn't be… Mom the doctor said you're not supposed to have that. Mom you're going to have to give yourself insulin. Mom!

Aria's children, like Kevin, learned to participate in diabetes care in early in life. Tiffany Galvan, a now 39-year-old Seneca woman, describes how in her teens she researched information on diabetes so that she could help take care of her grandfather when she lived with him on the reservation during summers:

> I talked to the nurse. We have a community building on our reservation and it has a clinic inside, so I went in there and I asked her, you know what is diabetes, what is that stuff, you know. And she's like oh, and gave me all kinds of books and pamphlets and everything. So I did my own research, and I'm like, oh okay. I knew what he could have and what he couldn't have, so. And then I had to start cooking for him too, because that's when I knew he wasn't supposed to have some of the things that he was having, you know.

Tiffany translated this diabetes care learned on the reservation to her Chicago home a decade later when her father was diagnosed with diabetes. Now in her late 30s, Tiffany is utilizing this knowledge again to prevent her 11-year-old daughter who was diagnosed as being on the borderline of diabetes from developing the condition.

Children growing up in Chicago's Native community become aware of diabetes at a young age and some take on the role of caregiver for their family members. The knowledge of diabetes and its care needs increases with age and many children who first observe and participate in diabetes care in childhood continue to do so as adults, both within families and within the larger community.

Living with diabetics

In the context of this epidemic there are many households where there is more than one diabetic living in the home. In these instances, diabetes patients receive additional assistance from their fellow diabetics in both direct and indirect ways. In Helena Edmonds' home, both she and her husband were diabetic. Before her husband passed, they would take turns testing the other person's blood glucose levels – a task both of them disliked:

> You do mine [blood glucose test] today and I'll do yours tomorrow. So we worked out a little game plan to how to deal with it because they tell you well you got to do this and you got to do that. Well, yeah, but there's a way to deal with it.

Though Helena and her husband were testing their blood glucose levels fewer times than what was recommended by their physicians, they were doing some testing at home through the assistance of one another. Diabetics living with other diabetes patients describe other forms of direct care they assist one another with, including shopping for diabetes-friendly foods, cooking low carbohydrate and low fat meals to share, and walking together for exercise. Not all care assistance, however, is performed through direct actions. Diabetics living with other diabetics describe receiving a great deal of help in the household by just seeing a sibling or a spouse in their own diabetes care routine. Seeing, a glucometer or medications in a central area of the home serves as a reminder for individuals to take medication and test blood glucose levels.

While patients help one another, they also receive both direct and indirect forms of assistance from non-diabetics living both with them and separate from them. In an interview, Steven Barnes describes his wife as a “watch dog” who reminds him what he can and cannot have to eat. In an interview with his wife Susan, she explained how her husband’s having the disease has not only changed his lifestyle, but it has altered their life together:

> We don’t eat out. All our meals, most of the meals are prepared at home. If we do eat out it’s off a light menu.

Throughout our conversation Susan emphasized that the changes brought on by her husband’s diabetes affected the two of them by using the pronoun “we”– in describing trips to doctor’s appointments and changes to the household diet. Susan’s use of this plural first person pronoun highlights her view that her husband’s diagnosis with diabetes was not one that just affected his personal life, but one that has altered their life together, so much so that she too orders off of a light menu when they go out to eat.

Julie Livingston describes in her work on a cancer oncology ward in Botswana that cancer is not something that happens to a person, but something that occurs between people (Livingston 2012). Livingston’s suggestion is provocative for thinking about all types of human care because it calls attention to the nature of illness and how individuals often experience illness in multiple spheres, sharing the care experience with medical providers, family, friends, and support networks. Though the majority of both male and female diabetes patients in Chicago’s Native community do not describe the assistance they receive from others as care, work that thoughtfully takes diabetes needs and care into account is being performed in both direct and indirect ways. This care work, in a sense, is hidden (Olesen 1989).

In 2007 Arthur Kleinman described providing care as being fundamental to being human (Kleinman 2007). The meaning of care is shaped and defined by the context in which care is being performed. As scholars argue, care has to be understood in terms of local contexts – historic, economic, social, cultural, and political (Han 2011; Han 2012; Klaits 2009; Yates-Doerr 2014). Care can take on many forms from direct actions of administering medications to indirect forms of support, such as eating similar meals to reduce difference. In her work on the logic of care and the logic of choice, Annemarie Mol describes how care is an open-ended process in which a care team is involved in the constant negotiation between technologies, knowledge, and local bodies. Central to Mol's argument is that care is based in relationships – in her example of diabetes in a Dutch hospital, diabetes care is created in the relationship and engagements of patients, medical providers, and medical technologies (Mol 2008). Building upon Mol's definition of care as relational, others extend this discussion beyond patient-provider contexts.

In 1989 Virginia Olesen urged medical sociologists to begin to look beyond professional care to forms of "hidden" care – and to investigate the role of gender, class, and race in both professional and hidden care. In the credit economy of Chile, care work is extended beyond family lines when neighbors offer support to those in need of financial assistance (Han 2011). In Duana Fullwiley's study of sickle cell in Senegal, she found what she defines as therapeutic economies – contexts in which sickle cell patients expand kin-networks in the space of sickle cell patient groups where a sense of normalcy is developed amongst those sharing the disease (Fullwiley 2011). Frederick Klaits' work in Botswana explores how one small church works to promote loving and caring actions in the aim of increasing life potential in the context of the

HIV/AIDS epidemic (Klaits 2010). In her study of diabetes care practices among Turkish women in Germany, Cornelia Guell describes how a diagnosis with diabetes affects family and social life. She shows that the women mitigate the effect of diabetes on their social life by creating ways to take care of their diabetes while participating in social norms, for instance, clearing their plate after eating and returning to the table to socialize without the risk of refilling their plate (Guell 2012). Caring for chronic conditions, then, is often woven into social worlds.

I here extend studies of care by looking at care in the face of chronicity in a population facing epidemic proportions of disease. I argue that in a community facing epidemic rates of disease, care – care as thoughtful actions with diabetes treatment in mind – is enmeshed in the everyday lives of not just those living with the disease, but also the lives of others in their lives. Members of Chicago's Native community incorporate not only diabetes care, but awareness of other chronic condition needs into their lives, not only for those living with the disease, but also for the family of diabetics, the friends, and even the larger community. Care in this context involves a wide range of activities: conducting research, attending appointments, shopping, cooking, administering medications, doing exercise, eating diabetes diets when not diabetic, reminding patients about foods, watching for signs of hyperglycemia in others, providing education and advice, and considering diet needs for larger community events. I show that through care work, ties binding members of Chicago's Native community are strengthened.

While it is easier to provide care for diabetes patients if one is living with them, living a distance from family members does not preclude one from being involved in diabetes care. Susan described how she calls her son living on a reservation in New York State to give him information that she has learned about diabetes management. Holly Wilton describes how she helped her parents by picking up grocery items for them. After years of seeing her parents reject the sugar-free items she would purchase, she began to disguise the sugar-free items so that they would get the cookies they desired, but ones that were safer in her view for them to consume:

> I would look for you know anything diabetic friendly, sugar free, and I'd peel labels off, you know like I said, or I'd hide them or something so that they didn't know it was that way. 'cause I knew if they saw the label, they wouldn't eat it. So I would do that.

Family members participate in direct forms of diabetes care both while living with family members with the disease and while living a distance from them.

Some of the care that is provided is indirect as well. For many of the non-diabetic caregivers I spoke with, living with diabetics led to the development of great sympathy for the struggles their family and friends faced in living with the condition. Maintaining a diet low in fat and low in carbohydrates is what most diabetics I spoke with struggle with; each diabetic I spoke with had a favorite food or meal from their pre-diabetes life that they missed the most – ranging from fry bread to Chicago dogs with a side of long salted french fries. Non-diabetic caregivers describe how they sympathized with this difficulty, and how they participate in the diabetic lifestyle by eating the same foods as their diabetic family members in order to reduce any level of difference that the diabetic family member may feel due to his/her diabetes. Virginia Hall describes how during family functions there would be a wide spread of food that her father's diabetes restricted him from eating. Virginia explained:

> You could see it in his eyes but he couldn't have it… When I would see my dad eat, I would see a small portion of salad… And you would see him looking at other people's plates, and I knew what he was going through, so I didn't have steaks, or corn on the cob with butter on it, I didn't have soda. I used to eat kind of similar to what he had, so he wouldn't feel so bad.

Listening to Virginia tell this account with a trembling voice, I was struck by the degree to which she felt her father's struggles with diabetes and its care. As Virginia explained throughout our interview, she strove to make her father feel less different, in hopes of encouraging him to eat a healthier diet to care for diabetes.

Friends also provide support, knowing what diabetes can do to a person when left uncontrolled. Vincent Small, a 55-year-old Seneca man, describes how he chose to eat the same meals as his diabetic friend so that she would be less tempted to have the higher fat and higher carbohydrate meals.

> Whenever I was around Lois I wouldn't eat things that I knew she couldn't eat, so I wouldn't eat them. She'd say I'm going to have a salad and this and I say, oh I'll have that too. You know that wasn't eating that greasy cheeseburger or fried chicken, I was just eating whatever she ate too. And she'd always tell me, no you eat something good. I said no that's alright with me.

Diabetes patients describe how this type of support is helpful for them, to have another person following a similar routine to them, so that they do not feel a difference between their own actions and those of others. In Chicago's Native community, non-diabetics are involved in diabetes care in both direct and indirect ways – from Kevin administering insulin injections for his mother to Virginia and Vincent eating similar meals as their diabetic family and friends to support eating what is often viewed as less desirable options of food.

Community considerations of diabetes care

Diabetes care is done not only within the interpersonal relationships of family and friends, but is also considered on a communal level. For the winter holidays of 2013 Rebecca

Mastin made more than 60 loaves of banana bread to share as a gift to elders at the American Indian Center. As she gave them to volunteers to help her distribute to the elders at the senior lunch, she explained that half of the loaves were made with sugar and the other half were made with the low carbohydrate sweetener Splenda, intended for those with diabetes. Members of Chicago's Native population are acutely aware of the prevalence of diabetes in the community and their actions are influenced and shaped by this knowledge. In Joshua's announcement to the senior lunch crowd, his warning was not intended for one friend or family member, but for the wider community to hear and consider. Members of Chicago's Native population incorporate a concern for diabetes care for the community into their routines.

While individuals are shaping their actions with diabetes care in mind, community events are another space where diabetes care is considered. In an interview, Lois Bagby contrasted going out to eat at an event or restaurant outside the Native community with the events held within the Native community:

> When you go places, I mean I went to a luncheon. It was like a diabetic nightmare. You know, every, the whole table's set up with nothing but sweets. You know, it's a luncheon, it's an honor, it's a birthday party for someone. Being a diabetic, it's like whoa, I'm not supposed to eat ANY of this. But I think people haven't adjusted to our diabetes yet and it should be more food out there. Restaurants should carry more food. I think if people would even get a restaurant where they have sugar free food, I think it would do a great business.

Moments later Lois contrasted the food at these events with those held within the Native community:

> They make vegetables and yeah, we can eat if we want to. You know there's a big selection of food, so you can adjust it to your [diet].

Staff and volunteers prepare a great number of meals and feasts within the kitchen of the American Indian Center each year, from the weekly senior luncheons to holiday events, town hall meetings, and community ceremonies. I observed during my time in this kitchen a significant transition from a time when it once employed both a dietician and a chef to today where staff members from unrelated departments have taken up the reins to ensure that seniors have a weekly meal at which to socialize. Both before and after this transition, I noted that most of the meals are made with what the center can afford through its purchases from the Greater Chicago Food Depository and with what they can get for free from the depository. As noted in chapter seven, community health workers like Cheryl Burwell are concerned with the portion sizes of meals during community events, particularly large celebrations and holidays. As Lois notes, however, the availability of vegetables and other diabetic friendly food options at these events exhibits an awareness of diabetes care needs in the community.

Today the staff and regular volunteers for the meals take not only diabetes into account when preparing meals, but also high cholesterol, high blood pressure, dental concerns, and arthritis – rinsing off canned fruits and vegetables to reduce the amounts of sugar and sodium served to lunch attendees or peeling the skin off of fresh oranges served for dessert to cut back on food preparation labor for lunch goers with arthritis swollen fingers. Helen Baumann, a 22-year-old Arikara/Omaha/Odawa woman, and at the time of this interview, staff cook at the center, explained her considerations for purchasing and preparing food for the senior meals at the center:

> I don’t really like buying desserts. I usually forget about it and we pull out cans from back. No desserts, well I try to get them sugar free, if I, if I can get it from the food depository sugar free then I’ll like load up on them… I try giving them fresh fruit if, like if I know I have the time to stand there and cut it up, then I did it or someone to help. I like getting fresh fruit though, but also I’m trying, I try

> cooking with no salt. Yeah, none of the stuff I make I add salt to it. Most of the seasonings I have in the kitchen are salt free.

In Chicago's Native community, there is a heightened awareness at the community level of the health of the population. Community organizers consider these factors when organizing and preparing for gatherings, while individuals likewise think of the health of the larger community.

Conclusion

Care work is shaped by relationships and by context. Diabetes care is thought about and performed on multiple levels in Chicago's American Indian community. While diabetes patients may not immediately identify the work of their family members, friends, and community members as care, the work that is being done thoughtfully incorporates the needs and wellbeing of diabetics into mind. Because there are high rates of the disease, children learn about it at a young age through first observing adult diabetes care and by later researching and becoming actively involved in diabetes care routines. Diabetes in the community is so common that there are many households with multiple diabetics within the home, creating a setting where they directly and indirectly participate in each other's care – from visual reminders to performing blood glucose tests. Diabetes care is further considered at the community level – where event organizers take diabetes along with other community health needs into consideration as they plan and prepare meals. The findings described in this chapter offer contributions to several audiences.

First, the local community can utilize some of these findings to evaluate the contemporary care for diabetes in the city. As I have shown, there are common struggles many community members face in caring for the disease. And there are common aids supporting diabetes care in the community. Participants described the success of diabetes support groups in the past. I would argue that diabetes support groups would be greatly beneficial today. The topics covered in this chapter could provide a basis for conversation for several diabetes support group sessions, in which participants could discuss ways to overcome some of the obstacles and methods for increasing care support.

This chapter contributes to biomedical and public health audiences in its description of care on the ground level for Native patients living with diabetes. I have shown that care is not always possible to achieve at the level expected by biomedical models for care, because of complications of life and finances. I have also demonstrated that care is done outside the clinical encounter not only by the patient, but also by family, friends, and the larger community. Education about how to best treat and manage diabetes, then, should be more broadly available to community members who participate in care. More education, beginning at a young age on diabetes care and prevention would be of great benefit to this community.

For anthropology I have shown that Chicago's Native community is strengthened through care. In the face of an epidemic in the context of chronicity, care for disease is woven into the everyday lives of community members. In this context, there is a heightened awareness beginning in childhood about diabetes and its detrimental effects on family members. Today members of Chicago's Native population are thinking about and acting upon community wide health concerns – developing more varied diets for events, organizing and hosting the first 5K run event for the 61st annual American Indian Center Powwow held in September of 2014, planting, tending, and monitoring Native gardens with traditional plants around the Chicago area. The care for this disease that so greatly affects Chicago's Native population is done within individual households, but also is on the communal mind. This builds upon the findings in previous chapters on the relationship between human biology and human culture. In chapter three I traced the causes of diabetes to colonial history, showing how social and political histories affect human health. In both this chapter and the previous chapter I have shown that human health influences culture. In the previous chapter I demonstrated that there is a relationship between local concepts of indigenous identity and diabetes. I build upon this finding in this chapter to show that Chicago's inter-tribal community is strengthened through the shared care work taken on by its members.

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CONCLUSION

While diabetes has been found in human populations for several millennia, cases of type 2 diabetes were rare in American Indian populations prior to World War Two. Today American Indians have some of the highest rates of diabetes worldwide. The majority of the research on this epidemic focuses on reservation populations. While rates of diabetes climbed in reservation areas, they also grew in cities, where nearly 80 percent of Native people live today. In this dissertation, I have explored experiences with, understandings of, and care for diabetes in Chicago's Native community. Through this exploration, I have illustrated that the relationship between human culture and human biology is a reciprocal one, in which colonial history has played a significant role in producing this diabetes epidemic in Native populations and the high risk of developing diabetes is being incorporated into contemporary discussions of indigenous American identity in the urban space. This dissertation offers findings to three main audiences, including Chicago's Native community, biomedical and public health communities, and the field of anthropology.

Local community

I have presented material from this research to Chicago's Native community three times since 2013. The community responded to this research with engaged discourse about how to reduce rates of diabetes in the city, and what they can do to improve diabetes care for those who have it. Community members are interested in the development of diabetes support and awareness through education. They would like to see education about diabetes that is attainable and that offers feasible suggestions for preventing diabetes and improving its care. The development of wellness education programs that focus on how to not only prevent diabetes but more generally improve health outcomes would be of the greatest benefit. The community could work on the development of education programs through grants to meet these needs.

In addition to educational programs that promote healthy lifestyles, there is an interest in the development of diabetes support groups. In chapter eight I described the common struggles faced and the support experienced by community members living with diabetes. Diabetes support groups have been successful in the past in encouraging diabetes care practices, and if started up again, they would be of benefit to many members of the Chicago's Native community.

Finally, this dissertation further documents a period in the history of the American Indian Center of Chicago. This organization is the oldest center of its kind in the nation, having opened its doors in the fall of 1953. During the early years of this study, the American Indian Center seemed to be filled with a constant hustle and bustle. The center employed nearly two-dozen people, the first two floors of the building were lit up throughout the day, and visitors to the center were immediately greeted with the woodsy scent of pine floor cleaner. Today there are few staff members, more than half of which are employed as part-time employees. The building lights are turned off unless the room is in use. And the formerly characteristic scent of the pine floor cleaner is missing, because there is no one to clean the floors.

The American Indian Center of Chicago is facing a real financial crisis that threatens the continuity of its existence that could have far reaching effects on the community. The center continues running on a bare-bones staff and through the generous donations of time, money, and supplies by community members and staff. As I described in chapter five, the center is an important place of gathering for the Native population of the greater Chicagoland area. The center's wellness program, as described in chapter, has also played a significant role in providing care for the community. This program is now limited in the services it can offer due to this funding crisis. While some community members seek health care services on their own means through American Indian Health Services of Chicago and through one of the many other healthcare options in the city, the center's program was able to meet the health needs of those who did not have time or avoided these other health care facilities. As described in chapter eight, the wellness staff has played a role in diabetes care and diagnoses in the past – some Chicago Natives were first alerted to the likelihood of having diabetes through a health screening at the center, and for some, the health screenings at the center were among the only ways in which they have their blood glucose levels tested. This financial crisis that the center faces could potentially have serious ramifications for the health and wellbeing of Chicago's Native community.

Medical audiences

The major findings in this study could also benefit medical audiences, both in individual clinical encounters and through the development of public health campaigns aimed at reducing health disparities for Native populations. First, as illustrated in chapters six and seven, there are varied understandings of diabetes held by Chicago's Native community members. These understandings have been formed through individual and communal experiences caring for and observing the care for diabetes. As I have shown, these lay understandings at times are quite different from the definitions of diabetes in biomedical publications. I argue that an awareness of distinct lay understandings of diseases like diabetes that are cared for primarily in the home setting would be beneficial to the exchange of information and ideas in clinical encounters, wherein with both more time and awareness, providers and patients could work more closely to ensure that each participant understands what the health problem is and what each participant can do to care for it.

In terms of public health campaigns, this study offers multiple findings that can contribute to the development of more effect public health campaigns. First, there is a danger that comes with labelling any group of individuals as at heightened risk for developing a particular disease, as is seen in the commonly shared fatalistic views of diabetes in Native Chicago. Though some people actively attempt to prevent the disease, others take a passive stance and accept that they will one day develop diabetes. Labelling groups as at risk has unintended consequences – while it may be intended to promote preventative action, in some cases it creates the opposite response.

Second, in terms of public health campaigns and education, this study provides substantial information about how and who to approach through education in Native Chicago. Prevention and provision of care is not always possible to achieve at the level expected by some contemporary public health models (see for instance the “take charge of diabetes” management system outlined in Lorig 2012). As noted above, education needs to be attainable for learners of all ages and to provide concrete examples through demonstration that diabetes prevention and management are feasible tasks within the reach of local communities.

Anthropology

This dissertation contributes to anthropological studies of identity, knowledge, indigeneity, and contemporary American Indian life. First, this dissertation builds upon scholarship on American Indian life through documenting contemporary discourses about Native identity and community in an urban setting. I have demonstrated that Chicago's Native population, representing more than 100 tribal nations from across the United States and Canada, both have and have not assimilated into American city life as policy makers in Washington, DC had hoped they would. While living and working the city space, Chicago Natives participate in the development of inter-tribal alliances and activities, while also maintaining contact with home reservation communities.

Second, this dissertation contributes to theorizations on human knowledge development and passage. I have shown that diabetes is part of the lifeworld for many Chicago Native community members. It is often encountered in early in childhood. In this setting, the process of learning about diabetes is embedded in relationships of caring for kin. Based upon individual and communal experiences with diabetes in childhood and later in life, an emic model of diabetes classification is developed and shared through discussions in the community. This model shapes contemporary care practices and expectations.

The findings of this dissertation additionally contribute to the vast and growing scholarship on the American Indian diabetes epidemic. Previous studies have focused on the role of colonialism in generating this epidemic, on Native perceptions of diabetes etiology, and on challenges to diabetes care in reservation settings (de Cora 2001; Garro 2000; Garro and Lang

1993; Hickey and Carter 1993; Jackson 1993; Rock 2003; Roy 2006; Smith-Morris 2005; Weiner 1999; Weiner 2001). This study builds upon these previous studies in its focus on an urban Native population and on the effect that diabetes has had on contemporary discussions of indigenous identity.

Within Chicago, Native identity is a complex and contested topic. Discourses of Native identity in the city center around discussions of blood, appearance, shared history, language, and performance. The experience of colonial oppression suffered by generations of American Indian peoples is a history of survival and resilience. Surviving the boarding school system, the forced removal to reservations, and the discrimination in city spaces is a shared history that urban Natives index today in speaking about identity and membership in this inter-tribal community. It is also a history that contributes to the development and experience of intergenerational trauma and related health concerns today. As described in chapter six, the shared history referenced in discussions of Native identity reach beyond shared histories of colonial oppression, to an evolutionary history that produced bodies that hunger for pure and natural foods and that are susceptible to developing diabetes today. Much research could be done on Native foodways in this multi-tribal community, and how food-related practices index shared identities and vulnerabilities. I have gestured toward some of the questions here, and hope to explore them in greater detail in subsequent work.

In documenting and analyzing diabetes in Chicago’s Native community, this dissertation theorizes the relationship between human health and culture. I have demonstrated that history and society shape human health. The diabetes epidemic in Native North America is the embodiment of a long and continuing history of colonial oppression and forced migration. The epidemic status of diabetes in Native communities also shapes modern culture and society. I have described how Native identity is articulated through, and the inter-tribal community of Chicago is strengthened in discourses of shared physiologies that represent a common evolutionary history. While cultural and social histories shape contemporary human health, human health simultaneously shapes modern culture.

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