

EXAMINING THE PERCEPTIONS OF DIABETES RISK FACTORS AMONG  
CONGOLESE IMMIGRANTS IN ILLINOIS

BY

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DISSERTATION

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## ABSTRACT

Diabetes is increasingly recognized as a serious, worldwide public health concern, due to its prevalence. Many scholars have focused on understanding the distribution of diabetes in terms of race, gender, and age. When considering the distribution of diabetes per ethnicity, researchers agree that African immigrants are not exempt of having diabetes. In addition, several studies argued that primary concerns of diabetes are diet, physical activity, and lifestyle. To further analyzing the study of diabetes distribution per ethnicity, some research focuses on the impact of factors such as diet, physical activity, and lifestyle on African immigrants. The aim of the current inquiry is to shine new light on these debates through an assessment of perception of risk factors associated with diabetes among Congolese immigrants by demographic-based. To accomplish such aim, a cross-sectional study was used to examine subjective responses on their perception of risk factors towards diabetes among Congolese living in the Champaign-Urbana area. A nonprobability sampling approach will be used to collect data on participants' perception and risk factors of diabetes. The guiding research questions are: (1) What are the demographic rates associated with the distribution of diabetes' perception of risk factors? And (2) What types of aspects increase the likelihood of risk factors in regards to diabetes? We hypothesize that more female Congolese will perceive diabetes risk factors than male Congolese. We also expect that education level will be the predictor of diabetes risk among Congolese immigrants. While this study sheds light on the perception of risk factors associated with diabetes among Congolese immigrants, it nuances the findings when it comes to the interplay between ethnicity and diabetes. The

implication of the current study will be crucial in addressing cultural competency discourse.

*To my wife Rebecca Lokoto Ilunga, and my sons Hosanna and Heaven's for their  
encouragement and caring love.*

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*“Great are the works of the Lord, studied by all who delight in them”*

*Psalm 111:2 ESV*

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## TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION .....	1
CHAPTER 2: LITERATURE REVIEW .....	10
CHAPTER 3: METHODOLOGY .....	36
CHAPTER 4: RESULTS .....	51
CHAPTER 5: DISCUSSION.....	76
REFERENCES .....	88
APPENDIX A: SCREENING QUESTIONS .....	97
APPENDIX B: IN-DEPTH INTERVIEWS USING PEN-3 MODEL.....	98
APPENDIX C: SURVEY QUESTIONS.....	101

# CHAPTER 1

## INTRODUCTION

### 1.1 DIABETES OVERVIEW

#### 1.1.1 Diabetes Definition

Diabetes may be defined as a group of diseases that affects how the body uses glucose (Mayo Clinic, 2014). However, this definition neither takes into account the cut-off value for diagnosing a person as diabetic nor refers to the type of diabetes. By 1998, WHO (1999) had agreed on a more technical definition of the disease. They defined diabetes as *a metabolic disorder of multiple etiology characterized by chronic hyperglycemia with disturbances of carbohydrate, fat, and protein metabolism resulting from defects in insulin secretion, insulin action, or both*. Advancement in elucidating the pathophysiology of this disease may result in further refinement to this definition.

Medicine currently distinguishes type-1 and type-2 diabetes. Historically, experts categorized these two types according to their age of onset, i.e., juvenile and adults diabetes (Fajans, 1981). Further research showed that an adult could develop juvenile-type diabetes as well, and the types were reclassified in terms of their reversibility, i.e., pre-diabetes and gestational diabetes (Fajans, 1981; Lawrence, 1951; Mayfield, 1998; Mayo Clinic, 2014). Another nomenclature distinguished the most common forms of the disease (i.e. diabetes mellitus, which includes type-1 and type-2 diabetes) and a rarer form (i.e. diabetes insipidus) (Mayo Clinic, 2013).

At present, diabetes represents one of the most serious public health burdens around the world. Approximately 366 million people lived with diabetes worldwide in 2011, with most individuals from low- and middle-income countries; this number is projected to rise to 552

million by 2030 (Whiting, Guariguata, Weil, & Shaw, 2011). On the African continent, Jackson, Adibe, Okonta, and Ukwe (2014) estimated that 15 million individuals suffered diabetes and projected this number as doubling over the next 20 years. Sedentary lifestyle, eating habits, and genetic factors have been pinpointed as determinants for this disease (Chan, Rimm, Colditz, Stampfer, & Willett, 1994). With the change in lifestyle from more active to more sedentary (Barwais, Cuddihy, & Tomson, 2013), the assumption is that the likelihood of developing diabetes will increase.

Upon coming to the US in July 2005 to pursue my dream of becoming a community health professional, one thing that especially attracted my attention was the extensive availability and the large-scale consumption of foods, two factors that both act as determinants for population weight gain in a society (de-Graft Aikins, Awuah, Pera, Mendez, & Ogedegbe, 2014). After a month of residency in the US, I noticed I was gaining a lot of weight, which increases the risk of developing chronic diseases such as diabetes. From my time as a medical student in my country of origin, the Democratic Republic of the Congo (DRC), I remembered that reducing calorie intake and burning calories by exercising (i.e. to eat less and to move more) are needed to minimize the risk of developing diabetes. This anecdotal evidence provides a concrete and experiential base not only for my interest in this topic, but also for the sorts of findings noted in the previous paragraph.

I have also since observed numbers of African immigrants, particularly Congolese, arriving in the US looking “slim” and after few months looking “chubby” due to weight gain; something that occurs also, in part, because Congolese people generally consider being plump a desirable body image (Okoro et al., 2014; Puoane, Tsolekile, & Steyn, 2010; Van Olmen et al., 2014). This remains true even when poverty, living in a rural environment, and age have been

identified as “protecting” factors against Congolese plumpness (Katchunga et al., 2012; Okoro et al., 2014). Culturally, being overweight signals happiness and wealth to many Congolese (Puoane et al., 2010). For this reason, Congolese immigrants may lack or underestimate the role of overweight as it relates to diabetes risk factors (DRF).

Diabetes in people of Congolese origin may be examined both domestically and abroad. The disease poses a major public health concern for people of African descent in general and is already prevalent in sub-Saharan Africa (Hall, Thomsen, Henriksen, & Lohse, 2011). For the Democratic Republic Congo, its prevalence was 3.5%, higher in urban areas than in rural areas and associated with age (Katchunga et al., 2012). Bayauli et al. (2014) similarly found that among Congolese the likelihood of developing diabetes increased with age and obesity/overweight status. Domestically, Tull and Roseman (1995) estimated the prevalence of diabetes among people of African descent in the US as 3.7%. The same study reported that the prevalence of diabetes in adults was 1.4 times higher in blacks than in whites. In 2009, there were 12.6% non-Hispanic Blacks, 11.8% Hispanics, 8.4% Asian Americans, and 7.1% non-Hispanic whites who were diagnosed with diabetes (Centers for Disease Control and Prevention, 2014b). In 2012, non-Hispanic Blacks had the second highest rate of diagnosed diabetes (13.2%), compared to American Indians (15.9%), Hispanics (12.8%), Asian Americans (9%), and non-Hispanic Whites, (7.6%) (International Diabetes Federation, 2014b).

A growing number of inquiries conducted both in Europe and the US on diabetes and African immigrants reported diabetes as prevalent among immigrants (Adhikari & Sanou, 2012; Creatore et al., 2010). With that upsurge, scholars have identified some contextual factors that may play a significant role in diabetes’ onset for this African immigrant cohort (Venters & Gany, 2011). These contextual factors include level of acculturation, healthcare access, and nutrition

and whether they act as protective or causal factors for diabetes among African immigrants (Oza-Frank & Narayan, 2010; Sofolahan-Oladeinde, Iwelunmor, Ilunga Tshiswaka, & Conserve, 2014).

By 2011 in Illinois specifically, the area of this dissertation, 9.7% of adults—all races included—had been diagnosed with diabetes (Illinois Department of Public Health, 2012), up 1.5% from 8.2% in 2010 (CDC, 2010). Blacks with diabetes accounted for 13.2% of diagnoses (International Diabetes Federation, 2014a). For Champaign county, according to CDC (2012), the proportion of diabetes in 2009 in that area—which has a relatively large number of French-speaking African immigrants (Ilunga Tshiswaka, Whembolua, Conserve, & Mwamba, 2014)—was estimated at 7.1% among Blacks. By 2012, the proportion of diabetes in Champaign County had increased to 7.8%, suggesting that diabetes remains pervasive and a growing problem in that area.

In light of this, a study is needed to elucidate factors that play a crucial role in diabetes among Congolese immigrants in the Champaign area.

More generally, there have been only a few studies to date that examined the rate and influence of cultural factors associated with diabetes among African immigrants to the US (Venters & Gany, 2011), despite the growing number of immigrants. In 2012, 4% of foreign-born residents in the US were from Africa, whereas in 1970 less than 1% were foreign-born residents (Gambino, Trevelyan, & Fitzwater, 2014). Marchiori, Maystadt, and Schumacher (2012) argued that factors such as poverty, environmental deterioration, and political insecurity in sub-Saharan Africa will likely increase the immigration from that area to the US. While this anticipated rise in numbers of sub-Saharan African immigrants suggests that more detailed studies on cultural factors associated with diabetes are needed, at the same time, we must also

remember that African culture is ethnically heterogeneous and cannot be treated or assumed to be identical everywhere (Brah, 1991).

For instance, researchers identify and use the “healthy immigrant effect”—a comparative measure of foreign-born versus native-born people with regard to their health—as way to argue that immigrants at their arrival are generally healthier than their native-born counterparts (Gushulak, 2007). This “healthy immigrant effect” concept has recently been challenged in that African immigrants are more prone to have cardiovascular diseases such as diabetes compared to their US-born counterparts (M. Y. O'Connor et al., 2014). More generally, an increased probability of developing diabetes among African immigrants correlates to the changes in diet, a more sedentary lifestyle, and a lack of access to healthcare facilities (Abubakari et al., 2013). A wider embracing of “Western” lifestyles as a result of epidemiological transition has also increased the likelihood of African immigrants developing diabetes, a disease thought primarily of as Western (Herman & Zimmet, 2012; Hu, 2011). As such, these qualifiers on the usefulness or accuracy of the health immigrant effect should motivate studies to look more closely at specific cultural features of populations studied rather than treating those heterogeneous cultures homogenously, as “African” or “immigrant” and so forth.

Scholars construct theoretical models or rely on the use of pre-established ones to better understand given behavior (Taylor, 2010). For the present study, theoretical model is necessary in that it helps to capture patterns involved in the interaction between individuals and their perceptions of DRF. It also would help to explicate and predict the onset of particular behaviors that originate from those perceptions. The current study utilizes two theoretical frameworks to explore the crucial role and relevance of culture, social norms, and environment with respect to the perceptions of DRF among a Congolese immigrant community.

The first theoretical model used in this investigation is the Health Belief Model (HBM). This theoretical framework highlights the role of sociocultural aspects around perceptions of health risk factors (Glanz, Rimer, & Viswanath, 2008). It underscores the importance of the early detection of disease through the lens of *perceived susceptibility* and personal benefits constructs (Glanz et al., 2008). To date, HBM has been successfully used in studies that emphasize how individuals can change health-related behaviors.

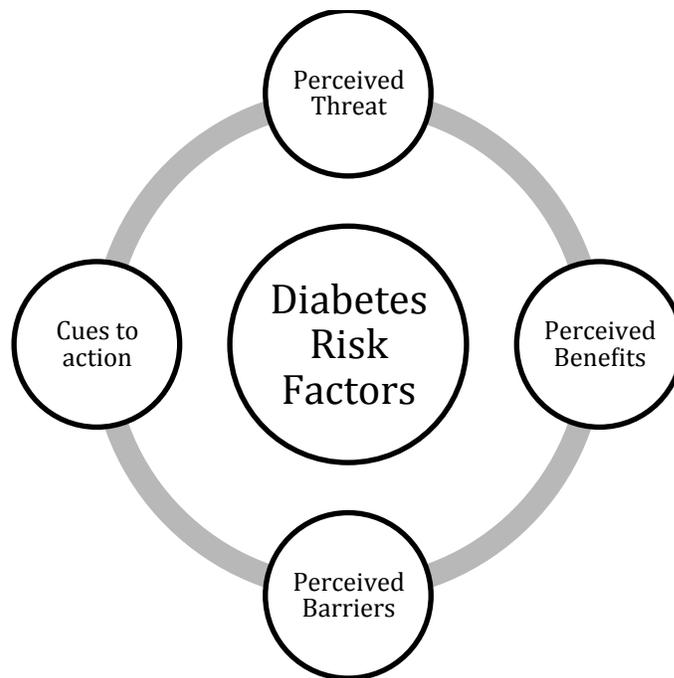
HBM constructs may prove of great importance for predicting why Congolese immigrants will take up specific actions for the prevention of diabetes, since the model's constructs include *perceived susceptibility*, *perceived severity*, *perceived benefits*, *perceived barriers*, *cues to action*, and *self-efficacy* (Glanz et al., 2008). By employing one of these constructs (*perceived susceptibility*) in perceptions for DRF, this study aims to elucidate to what degree Congolese immigrants believe they are susceptible to diabetes and, consequently, what their beliefs about the benefits of early diabetes detection center around. Such research around understanding how Congolese immigrants perceive DRF further informs the public health impact for the population at large.

In general, Glanz et al. (2008) have noted four basic steps of belief with regard to understanding the path of disease perceptions for people:

- Believing themselves susceptible to a disease
- Believing the seriousness of that disease for them
- Believing that taking certain available actions would benefit them and reduce both their susceptibility to and the seriousness of the disease, and
- Believing that the benefits of taking action outbalance the barriers to action.

This study highlight the HBM constructs summarized in Figure 1 below.

Figure 1. Model of perceptions of diabetes risk factors

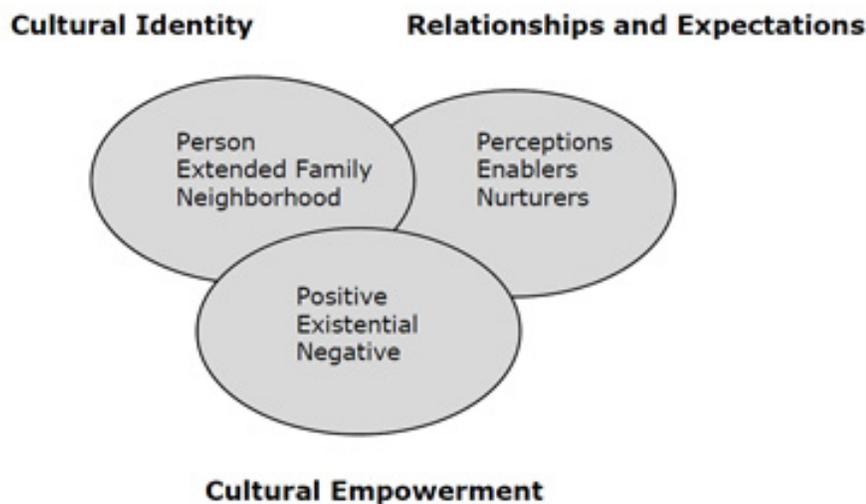


The second theoretical framework is the PEN-3 model, a cultural-oriented framework that uses the domains of *cultural identity* (*person, extended family, and neighborhood*), *relationships and expectations* (*perceptions, enablers, and nurturers*), and *cultural empowerment* (*positive, existential, and negative*) to categorize people's experiences (Airhihenbuwa, 1995). All three of these domains, along with their three subcategories, help to classify the cultural experiences of people that are relevant to health, in this case, DRF. In the PEN-3 model, the *cultural identity* domain specifically serves as the point of entry for developing programs and health interventions with populations, while *cultural empowerment* domain is in light of *positive, existential, and negative* aspects around behavior of interest (Airhihenbuwa, 1995). In this study, only one domain (i.e. *Relationships and Expectations*) of the PEN-3 model was used to understand the DRF perception among Congolese immigrants. The findings will be shared with

the Congolese community to ensure that the results align with the realities studied. This member checking helps establish the credibility of the findings (Lincoln & Guba, 1985).

The PEN-3 model has been used successfully in cultural competence studies to highlight not only risk factors but also protective factors (Iwelunmor, Newsome, & Airhihenbuwa, 2014; Melancon, Oomen-Early, & del Rincon, 2009; Scarinci, Bandura, Hidalgo, & Cherrington, 2012; Yick & Oomen-Early, 2009). As such, the model provides a way to assess perceptions of DRF among Congolese by highlighting these protective and risk factors. Using the PEN-3 model will also benefit the findings, so that they enable the development of culturally competent interventions and programs aimed at reducing diabetes among African immigrants in general. Unlike the HBM, the PEN-3 model highlights the positive aspects of a people's culture when it comes to the interaction of health-related matters.

Figure 2. The PEN-3 Model



**Figure 1. The Pen-3 Model**

*Note: Based on information from Airhihenbuwa & Webster, 2004*

The purpose of the current study is to understand the perceptions of DRF for Congolese immigrants using HBM and the PEN-3 model as guiding frameworks. This study is pioneering in

that it addresses the present lack of studies that identify the perceptions of DRF associated with African immigrants in general and Congolese immigrants in particular. In doing so, our findings may inform the construction of diabetes prevention programs aimed at reducing the incidence and prevalence of diabetes among Congolese immigrants.

The current research is guided by the following questions:

- (1) What is the relationship between demographic factors (e.g. education, age, and gender) and perceptions of diabetes among Congolese immigrants in East Central Illinois?
- (2) Is there a relationship between *perceived susceptibility* and diabetes risks?
- (3) What is the relationship between factors such as sedentary lifestyle and change in eating habits (i.e. unhealthy dietary behaviors) and diabetes perceptions among Congolese immigrants?
- (4) What role does the Congolese culture (e.g. parental influence) play in diabetes risk perception among participants?

As hypotheses related to each research question, we anticipate that:

- (1) There is no relationship between education, age, and gender factors and diabetes risk perceptions among Congolese immigrants.
- (2) The probability of a particular value of the *perceived susceptibility* is not associated with the value of diabetes risks among Congolese immigrants.
- (3) More sedentary lifestyle and changes in eating habits (i.e. unhealthy dietary behaviors) will likely be perceived as DRF among Congolese immigrant participants.
- (4) The Congolese culture would play a crucial role in diabetes risk perception among participants.

## CHAPTER 2

### LITERATURE REVIEW

This inquiry explores the perceptions of DRF among Congolese immigrants living in the US. We organize this literature review as follows: (1) diabetes definition; (2) sociocultural perspective of diabetes; (3) Health-Behavior Model (HBM) in diabetes studies; (4) PEN-3 model in diabetes inquiries; (5) diabetes in Illinois among African immigrants.

#### 2.1 Diabetes Definition

Any definition of a chronic disease will be subject to revision or improvement as advances in scientific knowledge about the disease occur. For the chronic disease of diabetes itself, scholars in 1998 agreed on a more technical definition of it as *a metabolic disorder of multiple etiology characterized by chronic hyperglycemia with disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action, or both* (WHO, 1999). This definition presupposes clarity about the terms within it. For instance, insulin is a pancreatic hormone that regulates blood sugar (WHO, 1999), while hyperglycemia refers to a raised blood sugar level in the body that can lead to serious damage to the body (WHO, 2015). These questions become crucial since—in order to innovate a biomedical test for the disease of diabetes beyond reports or identification of symptoms associated with the disease—this requires some degree of consensus about how factors or levels of insulin or hyperglycemia correlate to or indicate the presence of the disease itself.

Medical science further identifies several types of diabetes, mainly type-1, type-2 and gestational diabetes. *Type-1 diabetes* is an autoimmune disease caused by a lack of insulin production due to the destruction of beta cells in the pancreas. Here, the immune system of the body attacks and demolishes the insulin-producing beta cells (National Diabetes Information

Clearinghouse, 2014). Previously, type-1 diabetes was called juvenile diabetes or insulin-dependent diabetes mellitus because it most likely occurred among children and young adults. Nowadays, it was demonstrated that type-1 diabetes can occur to anyone regardless of age (National Diabetes Information Clearinghouse, 2014). *Latent Autoimmune Diabetes in Adults* (LADA), which occurs after age 30, represents another kind of slowly developing type-1 diabetes, wherein individuals with LADA would most likely produce a small quantity of insulin at the time of diabetes diagnosis. *Surgically induced diabetes* is another subtype of diabetes acquired after a surgery has been performed on the pancreas. *Chemically induced diabetes* refers to a condition where specific medications like steroids have caused a higher blood sugar level (Davidson & Moreland, 2013; National Diabetes Information Clearinghouse, 2014).

Type-2 diabetes, previously called insulin-non-dependent or adult-onset diabetes, is the most common form of diabetes due to its direct tie with lifestyle, age, and ethnicity (Centers for Disease Control and Prevention, 2014a). This condition happens when the beta cells in the pancreas fail gradually to produce sufficient quantities of insulin (Centers for Disease Control and Prevention, 2014a). Gestational diabetes is another form of diabetes that happens only on pregnant women during the second or third trimester of pregnancy (Centers for Disease Control and Prevention, 2014a). This form of diabetes can be a risk factor for type-2 diabetes among other people.

### 2.1.1 Etiology

Etiologically, diabetes may be acquired through lifestyle choices, genetics, or a combination of these factors (Centers for Disease Control and Prevention, 2014b; National Diabetes Information Clearinghouse, 2014; WHO, 2006).

In terms of lifestyle, studies found a positive correlation between an individual's weight or BMI, whether from lifestyle choices or due to heredity, and the onset of diabetes (Chan et al., 1994; National Diabetes Information Clearinghouse, 2014; Williamson, 1918), such that a reduction in BMI may potentially serve to decrease the risks of the disease's onset. Similarly, eating unhealthy foods and overeating have been implicated as a cause of increased gestational diabetes (Ryan, 2011), such that healthier or more moderate eating again may decrease the risk of the disease's onset.

In terms of genetics, studies have pinpointed Human Leukocyte Antigens (HLA) as a main risk protein linked to type-1 diabetes, whereby HLA genes will determine whether or not the immune system recognizes a cell as a part of the body or as a foreign part of the body. Still other genes have been associated with the mechanism and onset of diabetes among humans (National Diabetes Information Clearinghouse, 2014). Combinations of HLA protein variants may also have causal, protective, or no effect with respect to diabetes risk effects.

Whether etiologically influenced by lifestyle or genetics, we stress that diabetes is a *preventable* disease. A person may change his or her lifestyle choices, and genetic testing can assist to identify HLA and other genes linked to type-1 diabetes. As such, scholars express optimism around finding not only a cure for type-1 diabetes but also efficient preventative measures so that the disease never occurs in the first place (National Diabetes Information Clearinghouse, 2014).

### 2.1.2 Diagnosis

Early studies demonstrated a consensus among diabetes experts with respect to diagnosis. For example, in 1965 WHO proposed guidelines for a diagnosis of diabetes that were revised in late 1998 and reviewed once again in 2005 (WHO, 2006). In order to ensure that diabetes

diagnosis is pertinent, WHO and the National Diabetes Data Group (NDDG) recommended specific screening tests, including a written questionnaire, to determine whether or not a person is at risk for diabetes. Such diabetes-screening tests represent a first step towards determining the diabetes status of an individual. A positive diabetes screening test will then generally lead to a diagnostic test for diabetes (WHO, 2006).

According to The Global Diabetes Community (2014), different types of specific diagnostic tests for diabetes include C-peptide, fasting plasma glucose, GAD antibodies, HbA1c, oral glucose tolerance, postprandial plasma glucose, random plasma glucose, and type-2 diabetes tests. The C-peptide test measures the quantity of insulin produced by the pancreas, while the fasting plasma glucose test detects levels of impaired fasting glucose. The GAD antibodies test focuses more on the identification of type-1 diabetes or LADA, while the HbA1c or A1c test gives indication of diabetes control by the individual. The postprandial plasma glucose test measures blood glucose and shows the tolerance level of glucose in the body, while a random plasma glucose test is more useful for diagnosing type-1 diabetes and will analyze the concentration of glucose in the blood. Lastly, the oral glucose tolerance test focuses on insulin resistance, while type-2 diabetes test identifies the risk of developing type-2 diabetes (The Global Diabetes Community, 2014).

In general, screening tests are linked to the main varieties of diabetes (National Diabetes Information Clearinghouse, 2014). For example, WHO (1999) advised about differences in the diagnosis of asymptomatic or symptomatic diabetes. From these various tests and measures, then, a diagnosis of diabetes may follow. According to WHO (2006), for instance, a person is diabetic when either the fasting plasma glucose level is greater than equal to 7.0 mmol/l (126 mg/dl) or when a 2-hour plasma glucose level is greater than or equal to 11.1 mmol/l (200

mg/dl). Clinical diagnostic criteria for diabetes include increased thirst, unexplained weight loss, urine volume, and recurrent infections. Additional clinical signs such as drowsiness, coma, and high levels of glycosuria have been listed as diabetic symptoms in more severe cases (WHO, 1999).

### 2.1.3 Physical and Medical Implications of Diabetes

Thus, diabetes represents a chronic medical condition that exposes people to serious health issues, with several physical and medical implications that can substantially impact the lives of people with it.

For instance, the American Diabetes Association (2016) (ADA) lists numerous complications, including neuropathy (i.e., nerve damage) that can lead to foot problems and impairment of walking (American Diabetes Association, 2016). Impairment can also include tingling, pain, or weakness in the foot (American Diabetes Association, 2016), and, if not treated properly, increase the risk of amputation due to poor diabetes management (American Diabetes Association, 2016). Medically speaking, diabetes can cause skin complications (e.g. bacterial or fungal infections, itching), eye complications—which may lead to blindness—or kidney disease (American Diabetes Association, 2016). Skin conditions such as diabetic dermopathy (i.e. a harmless condition with light brown and scaly patches on the skin), necrobiosis lipoidica deabeticorum (similar to dermopathy, but painful), diabetic blister, and eruptive xanthomatosis (i.e. yellow, pea-like enlargements in the skin) arise as risks from diabetes (American Diabetes Association, 2016).

### 2.1.4 Disease Risk Factor Definition

According to WHO (2016), a disease risk factor is defined as any attribute, characteristic or exposure of an individual that increases the probability of developing a disease or injury. For

diabetes, risk factors such as family history, unhealthy eating habits, lack of physical activity, ethnicity, overweight, and increasing age have been correlated with diabetes onset (International Diabetes Federation, 2014b).

## 2.2 Sociocultural Perspective of Diabetes

### 2.2.1 Impact of Diabetes among Africans

As of 2011, 366 million people were living with diabetes worldwide, most of them from low- and middle-income countries; this number is expected to rise to 552 million people by 2030 (Whiting et al., 2011). In Africa specifically, diabetes accounts for 15 million cases, and this number is expected to double over the next twenty years (Jackson et al., 2014).

In Africa, diabetes is prevalent in Sub-Saharan areas, where the Democratic Republic of the Congo is one of the biggest countries (Hall et al., 2011). While sedentary lifestyle, eating habits, and genetic factors have been pinpointed as determinants for this disease (Chan et al., 1994), the increasing incidence of diabetes in Sub-Saharan Africa occurs also in a context of poverty, war, and political instability (Bayauli et al., 2014).

The challenge for reducing the incidence of diabetes in the Democratic Republic of the Congo in particular is therefore twofold: not only to improve the political economy, which will serve to revamp sectors such as healthcare, but also to educate people with regard to changing health-related behaviors. These factors can play a background role for examining the perceptions of diabetic risk factors among immigrants (Congolese) who have emigrated from this region.

### 2.2.2 Prevalence of Diabetes in the US and in the Democratic Republic of the Congo

According to The World Bank (2015), in 2014 the prevalence of diabetes among people aged 20 to 79 years in the Democratic Republic of the Congo was estimated at 7.6%, compared to 9.4% in the US. In 2015, the prevalence had decreased to 5.3% in the Democratic Republic of

the Congo, while increasing to 12.8% in the US (International Diabetes Federation, 2015, 2016). However, estimates suggest that Africa also has the highest level of undiagnosed diabetes cases (International Diabetes Federation, 2015, 2016). If so, a comparative lack of medical infrastructures, outdated equipment, and educational deficits will compound this problem (Abubakari et al., 2013; Dall et al., 2014). In general, a significant number of African diabetic patients live in urban areas (International Diabetes Federation, 2015, 2016). By contrast, while a greater prevalence of diabetic cases occur in rural locales in the US, when controlled for the factors of poverty, obesity, and tobacco use, there was a lower rural diabetic prevalence than in urban locales (A. O'Connor & Wellenius, 2012).

### 2.2.3 Impact of Diabetes among African Immigrants

Today, a majority of studies focusing on diabetes and African immigrants report diabetes as prevalent among immigrants (Oza-Frank, Stephenson, & Narayan, 2011). Venters and Gany (2011) explain this prevalence by emphasizing comparison studies and contextual factors associated with the etiology of diabetes among African immigrants. Here, contextual factors include the level of acculturation, access to healthcare, and quality of nutrition (Oza-Frank & Narayan, 2010; Sofolahan-Oladeinde et al., 2014). Particularly when Africans migrate to the US, they experience changes in eating habits, environment, and gender roles that both positively and negatively affect them (Lazur & Majors, 1995). This effect on lifestyle can influence diabetic risk.

Tull and Roseman (1995) estimated the prevalence of diabetes among people of black descent in the US at 3.7%. The same study reported that the prevalence of diabetes in adults was 1.4 times more frequent in blacks than in whites. In 2009, 12.6% non-Hispanic blacks, 11.8% Hispanics, 8.4% Asian Americans, and 7.1% non-Hispanic whites were diagnosed with diabetes (Centers

for Disease Control and Prevention, 2014b). In 2012, the proportion of non-Hispanic blacks diagnosed with diabetes increased to an estimated 13.2% (International Diabetes Federation, 2014a). Over the course of a period of fourteen years, chronic disease like diabetes remains one of the principal public health concerns for people of Black descent in general.

In 2013, an estimated 9% of foreign-born people in the US were from Africa compared to less than 1% in 1970 (Gambino et al., 2014; Zong & Batalova, 2015). This increased number of African immigrants in the US has led to an increased interest in studying the African immigrant cohort. Previously, however, researchers tended to aggregate the African immigrant cohort with the US-born African-descended people under the general category of “Black.”

Perhaps, with a relatively small community of African immigrants in 1970s in the US, researchers were more inclined to overlook sociocultural distinctions within the “Black” community. But this tendency to lump African-born and African-American individuals into the same group as “Black” must often obscure relevant socio-biological differences within both groups. Even within the “African” immigrant communities themselves, significant cultural differences exist (Brah, 1991); cultural differences in diet or eating style therefore may pose differential increases or decreases to diabetic risk.

Moreover, the discourse of ethnic identity within the African immigrant community operates as a specific factor that motivates sociocultural differences that exist between people of African descent (Dressler, 1993). This difference in ethnicity amongst African immigrants associates with a differentiation in health behavior due to cultural background. Given that the imperatives of cultural practice—among people of all ethnicities and whether with the status of immigrant or native-born—are just as often commands about what one *should* do or eat as much as what *not* do or eat, then any program of preventative measures, if it is to succeed, cannot rely

only on a factualness of medical knowledge but must also frame that knowledge in a culturally intelligible way for those the program aims to assist (Airhihenbuwa, 1995). This, then, requires researchers to disambiguate relevant sociocultural factors when they come into play, as is the case around the role of eating habits and diabetes (Airhihenbuwa, 1994).

#### 2.2.4 Explanatory Model of Diabetes among Africans

Understanding how Africans perceive diabetes through the lens of an explanatory model of disease therefore becomes crucial, since this allows the creation of culturally competent and tailored preventative measures, educational programs, and care (Airhihenbuwa, 1995). For instance, de-Graft Aikins et al. (2014) found that diabetes and its complications statistically associated not only with diet, family history, lifestyle factors (e.g. smoking, excessive alcohol consumption, and physical inactivity) psychological stress but also supernatural factors (e.g. witchcraft and sorcery) for participants in Ghana. The study's authors reported two theories—biomedical and lay—associated with the causes and complications of diabetes. The same study revealed that some diabetic subjects preferred not to disclose their status to people for spiritual reasons.

Similarly, in the Democratic of the Congo, Pepe (2010), conducted a study on a local hospital and found that the majority of participants believed that diabetes was caused by witchcraft. Consequently, people were relying on prayers to manage the condition. In this case, advocating for a form of prayer that involved 20 minutes of walking, as an increase of exercise, might well provide a more effective intervention into diabetes than simply insisting that people eat less or exercise more often. This—or something similarly motivated by an understanding of local cultural practice, rather than a rejection of it—would, again, represent a culturally

competent form of diabetes intervention potentially more effective than a conventional medical intervention.

Other studies have pinpointed sugar, poor diet, the supernatural, contaminated foods, physiological disruption, and family history as associated with the causal theories of diabetes in Ghanaians' perspectives (Aikins, 2004, 2005). This illustrates the tactical value of considering such factors—i.e., the cultural perspective of the affected population(s)—when implementing a program for preventative measures around a disease. In these studies, cultural, biomedical, and subjective models sustained the disease associations, and a major source of information for diabetes self-care practices was identified under the biomedical premise as a significant component of the local explanatory model of disease.

A comparative study between diabetic Africans and Europeans examining the knowledge, perceptions, and self-management of diabetes found that Europeans had high diabetes knowledge compared to Africans, with educational level being a determinant factor (Abubakari et al., 2013). Most Africans participants perceived diabetes as a benign condition that could be cured. Similarly, Jackson et al. (2014) found that 79.5% of Nigerian diabetics had more overall knowledge level around self-care, which also associated with level of education, and that participants had a negative attitude to the disease condition. However, Okoro et al. (2014) reported that an important number of Nigerians value a bigger body figure—same with the Congolese, our population of interest—which may be a hindrance to diabetes preventative measures aimed at reducing weight. Among South African girls, being overweight is also a sign of happiness and wealth (Puoane et al., 2010). This aligns with another study analyzing a diabetes care program in the Democratic Republic of the Congo that showed Congolese participants with diabetes had a tendency to be overweight (Van Olmen et al., 2014).

A quantitative study by Strategies for Improving Diabetes Care in Nigeria Research Group (2009) assessed the knowledge of diabetes among health care professionals (including medical practitioners, nurses, and health care workers), which yielded only 64.1% of respondents giving a correct answer of the blood glucose target cut-off value (90 – 108mg/L) for diabetes. The majority of participants (89.1%) knew that regular blood control reduces the risk of diabetic complications. This suggests that health care workers rely on a biomedical premise as a major component of their explanatory model for understanding and approaching diabetes.

Likewise, Ogbera, Adeyeye, Odeniyi, and Adeleye (2013) surveyed 263 health care professionals to assess their knowledge of diabetes. They found that 86% of health care professionals knew that diabetes was a chronic illness with no cure, while 71% stated the correct answer for the fasting plasma glucose level of 9 mmol/L. A proportion of 46% stated that urine can be employed for objectively diagnosing diabetes. The majority of participants also responded that weight loss should be maintained for a person diagnosed with diabetes.

Yeoh and Furler (2011) conducted a study on Sudanese in Australia and found that participants had little or no knowledge about diabetes, which raised questions about the participants' education level. Perceptions of diabetes were strongly embedded in perceptions of health in general. Participants acknowledged that their likelihood of diabetes had increased with immigration due to changes in what foods and drinks they consumed and how active they were in their receiving country. Some participants acknowledged a decline in their physical activity that might lead them to an increased risk for diabetes.

Jasper et al. (2014) took a different recruitment approach, since an important number of studies done in Nigeria around diabetes had previously selected hospital-based patients. They recruited diabetes patients (n=184) from a general population and found that participants had

poor knowledge of diabetes with pervasive fallacies (i.e. originating from the culture), i.e., not knowing the contents of a diabetes diet, the effects of fatty food, or the effect of unsweetened fruit juice on blood glucose. This suggests that they were relying on a cultural model of diabetes knowledge. Another study conducted among Somali and Sudanese people found that the understanding of diabetes among participants focused only on symptoms and diet (Kahn et al., 2012). Hence, to know patient explanatory models around diabetes becomes salient, since it may guide healthcare providers to offer culturally relevant and appropriate patient education, prevention, and care around diabetes.

#### 2.2.4.1 Role of Cultural Beliefs and Practices in Diabetes Education, Prevention, and Care

Cultural beliefs play a role in determining an individual's disease perception and thus how willing they are to engage in preventative measures (Al Shafae et al., 2008; Jasper et al., 2014). This becomes more complicated in the face of the multi-ethnic character of the African community. A host of cultural beliefs and practices direct the way of understanding diseases and implementing preventative strategies (Orzech, Vivian, Torres, Armin, & Shaw, 2013).

One study that compared insulin resistance and beta-cell function based on the distribution of abdominal fat accumulation among different ethnic groups in Kenya found differential abdominal fat distribution associated with eating habits. These differences of eating habit are culturally determined—Kenyans regularly eat in large group meals—and thus become challenging to change when proposed guidelines are culturally presumptuous or too westernized (D. L. Christensen et al., 2014; Kohinor, Stronks, Nicolaou, & Haafkens, 2011). Around diabetes education, asking people to change mealtimes can interfere with a cultural stance regarding hospitality, since people want to eat collectively (Kohinor et al., 2011). Ignoring this kind of

factor likely would make a diabetes prevention program that insisted on changed mealtimes ineffective.

Overall, diabetes has emerged as one of the most important public health concerns for people of Black descent in general. Diabetes self-management care education (DSME)—i.e., programs that enable people with diabetes to learn how to manage their conditions and control their health (CDC, 2010)—is one response to this. In 2010, 60.2% of adult diabetics in Illinois reported receiving this education.

Nonetheless, it remains imperative to underscore the crucial role that culture plays when it comes to perceptions of diseases such as diabetes (Helman, 2014). In that light, an explanatory model of diabetes—a framework that elucidates notions about an episode of sickness and its treatment that are employed by those engaged in the clinical process (Kleinman, 1980)—must take account of how people use different approaches to diabetes depending upon their cultural understanding of the disease. For instance, some refer to witchcraft as one of the causes of diabetes (de-Graft Aikins et al., 2014). In order to control the prevalence and incidence of this disease, then, it is important to elaborate culturally competent programs that take account of this understanding. It may not be enough simply to insist that people must “drop” their superstitions. Moreover, studies show how some non-Western cultures have an holistic approach to understanding disease, i.e. that they can or should rely on spiritual, social, and biomedical concepts in order to understand the causation and treatment of their diseases (Tirodkar et al., 2011). Further studies argue that knowing the explanatory model of diseases held by people—in this case, Congolese immigrants—facilitates the affected populations receptivity to health promotion campaigns (Tirodkar et al., 2011).

### 2.3 Health- Behavior Model (HBM) in Diabetes Studies

The HBM constructs of *susceptibility*, *seriousness*, *barriers*, *benefits*, *self-efficacy*, and *cues to action* have been widely used in diabetic studies in order to understand the mechanisms of health beliefs and behavioral change. *Susceptibility* and *seriousness* are closely linked and constitute the *perceived threat*, as when individuals see themselves as susceptible to developing a disease by believing in the severity of that condition (Glanz et al., 2008). *Perceived severity* refers to the feelings about the seriousness of contracting an illness or not treating to the extent that that may cause medical, clinical, or social consequences (Glanz et al., 2008). In particular, *perceived severity* is used to specify consequences of risks and conditions (Glanz et al., 2008), while *perceived susceptibility* is associated with the belief about the chances of experiencing a risk of contracting a disease (Glanz et al., 2008). The *perceived susceptibility* construct has been employed to define populations at risk (Glanz et al., 2008).

An important number of studies that used the HBM framework have focused on people who have already developed the disease, specifically on diabetic regimen adherence (Becker & Janz, 1985; Glanz et al., 2008; Polly, 1992). Those studies found that the health beliefs of people living with diabetes are important predictors of physiological and behavioral outcomes (Becker & Janz, 1985; Polly, 1992). Ayele, Tesfa, Abebe, Tilahun, and Girma (2012) conducted a study among diabetic Ethiopians in local hospitals using the HBM and found that a large proportion of participants had moderate *perceived susceptibility* (78.4%) and *perceived severity* (50.5%). The same study revealed that patients with more education had high diabetes *perceived severity*. A similar study was conducted in Nigeria among diabetes patients using the HBM constructs by Adejoh (2014) and found that a positive relationship existed between *perceived severity* and diabetes management.

Overall, an important number of studies have used the HBM to focus more on diabetic *patients*. The current inquiry seeks to bridge the gap by using HBM as a theoretical framework for studying risk factors associated with contracting diabetes. Further, the current study uses only one HBM construct—*perceived susceptibility*—as it highlights the importance of *threat*, which is one of the most influential factors that can lead to changes of behavior.

#### 2.4 PEN-3 Model in Diabetes Inquiries

The PEN-3 model is a theoretical framework that highlights the importance of culture in health matters (Airhihenbuwa, 1995). The reason Airhihenbuwa developed the model in 1989 was to underscore the role of culture, which was apparently omitted in health studies or health interventions. As a consequence of that omission, an important number of inquiries, interventions, and preventative programs failed to meet their expectations, leaving people and public health issues unsolved. Thus, the PEN-3 model gives a voice to culture and stresses its impact when it comes to health promotion, health intervention, and disease prevention (Iwelunmor et al., 2014).

The PEN-3 conceptual framework has three interrelated and dynamic domains: (1) *Cultural Identity*, (2) *Relationships and Expectations*, and (3) *Cultural Empowerment*. Each domain consists of three dimensions forming the PEN acronym; Person, Extended Family, Neighborhood (*Cultural Identity*), Perceptions, Enablers, Nurturers (*Relationships and Expectations*), and Positive, Existential, Negative (*Cultural Empowerment*). According to Airhihenbuwa (1995), *Cultural identity* is the point of entry when elaborating an intervention program and may involve persons, extended family members, or neighborhoods. The domain of *Relationships and Expectations* is related to the perceptions of health problems, the available societal resources that encourage or discourage valuable health-seeking practices, and the

influence of family and relatives in nurturing decisions around valuable management of health issues (Iwelunmor et al., 2014). The domain of *Cultural Empowerment* is related to the identification of positive beliefs and practices when exploring health issues, the identification of existential values and practices that are harmless in terms of health consequences, and the identification of negative health practices that become barriers to desired health outcomes (Iwelunmor et al., 2014). Thus, the PEN-3 model has been used in diabetes inquiries to highlight the role of culture.

Purcell and Cutchen (2013) studied diabetes self-management education for African Americans and found that *feeling highly confident, fears about diabetes complications, and denial* were the perceptions in terms of *Relationships* and *Expectations*. They also found that religion and social support were positive *enablers*, while disliking needles, time consumption, and the cost of healthier foods were negative *enablers*. *Nurturers* consisted of family, friends, and health care providers. In terms of *Cultural Empowerment*, spirituality and family were *positive* dimensions, faith healing was an *existential* (harmless) dimension, and unhealthy traditional foods posed a *negative* dimension. Family represented the point of entry as defined by the *Cultural Identity* domain.

Based upon the result from their study involving people of Latino descent, Melancon et al. (2009) found the following barriers associated with knowledge, attitudes, and beliefs about diabetes: *a fatalistic view, language challenges, fear of deportation, mistrust of US medical personnel, and lack of financial resources and transportation*. Moreover, Cowdery, Parker, and Thompson (2012) applied the PEN-3 model in a diabetes prevention intervention among African Americans and revealed that a lack of diabetes knowledge, issues around *denial* and *stigma, a sense of inevitability, and the influence of family* prevailed as *perceptions*.

The PEN-3 model underscores the role of cultural aspects that are otherwise neglected and thereby threaten to falsify existing findings about how to intervene into, and provide preventative information, about this chronic disease. To our knowledge, no studies focus specifically on diabetes using the PEN-3 cultural model among Congolese immigrants.

## 2.5 Diabetes in Illinois among African Immigrants

Due to the lack of studies focusing on diabetes among African immigrants in Illinois, to characterize the prevalence of diabetes within this cohort, we must begin with either general data or the available findings about the category of Blacks generally, which likely includes African immigrants.

The Illinois Department of Public Health (2012) reported for *all* races in 2011 that 9.7% of adults in the state had been diagnosed with diabetes, up 1.5% from 8.2% in the previous year (CDC, 2010). By 2015, the rate of people with diabetes in Illinois had increased another 2.76% to 12.46% (Novo Nordisk, 2016). Novo Nordisk (2016) estimates that the prevalence of Illinoisans living with diabetes will reach 15.25% by 2025, the fourth highest in the Midwest.

Overall, non-Hispanic blacks diagnosed with diabetes specifically accounted for 13.2% of cases (International Diabetes Federation, 2014a). Locally, according to CDC (2012), the proportion of diabetes in 2009 in the Champaign area, which has a relatively large number of French-speaking African immigrants (Ilunga Tshiswaka et al., 2014), was estimated at 7.1%. In 2012, the proportion of diabetes in that county had slightly increased to 7.8%, indicating that diabetes is still a burden in that area. Further, 34% of Champaign residents reported that they were overweight, which is a DRF (Champaign-Urbana Public Health District, 2014). The mortality rate of diabetes among Blacks in Champaign was estimated at 56.7 per 100,000 people

in 2011—the highest mortality rate by race—whereas the national mortality rate of diabetes among Blacks is 46.6 per 100,000 people (CDC, 2015).

### 2.5.1 Factors Influencing Congolese Immigration

To date, there has been little agreement on the study of diabetes among immigrants. One often-used concept in health-related research about immigrants, however, is the so-called *healthy immigrant effect*: the notion that immigrants are in relatively better health on arrival compared to native-born individuals (Gushulak, 2007). A considerable amount of scholarship documents this observation (Ali, Mwendwa, Sims, Ricks, & Sumner, 2016; Kennedy, McDonald, & Biddle, 2006; McDonald & Kennedy, 2004; O'Connor, Dobra, Voss, Pihoker, & Doorenbos, 2016).

However, some research medically challenges this scholarship. For instance, African immigrants tend to be more prone to cardiovascular diseases like diabetes compared to their African-American counterparts (M. Y. O'Connor et al., 2014). Epidemiological transition—which relates closely to the interaction between medical breakthrough and demography—represents a factor challenges the “healthy immigrant effect” (Herman & Zimmet, 2012). O'Connor et al. (2016) have recently attempted to disambiguate intra-racial immigrant and non-immigrant populations with respect to diabetic risk factors, but acknowledge that more research is needed to confirm their findings and identify causes. Barcellos, Goldman, and Smith (2016) emphasize *undiagnosed* or unrecognized illness as a potential source of the effect as well; for example, amongst immigrants from Mexico “about half of recent immigrants with diabetes were unaware that they had the disease” (p. 1). That a lack of awareness about an existing medical condition plays a significant role in this analysis points away from a strictly medical understanding of immigrant health and suggests the need to include the kind of “cultural” and “perceptual” factors, which this study focuses on.

Other methodological challenges arise if we simply consider immigrants solely as they present at the border, so to speak. The criteria for documented immigration to the US vary widely by country, so that a selection threat may inform studies of documented immigration; more specifically, immigration screening procedures and the fact that healthier immigrants are already more likely to immigrate play a role (Oxman-Martinez & Abdool, 2000). For example, with Visa lottery immigration from Africa, the generally higher level of education required to qualify for immigration in the first place will tend to select African immigrants who are likely already more aware of diabetic risk factors (Abubakari et al., 2013; Commodore - Mensah et al., 2016). Similarly, existing efforts to combat diabetes in different locales around the world change the local picture of the potential immigrant. For example, while people can avoid long-term issues around diabetes by complying with a diabetes self-management education—e.g., the ABC goals (i.e. A1C, Blood Pressure, Cholesterol) (Casagrande, Fradkin, Saydah, Rust, & Cowie, 2013; Egge & Alexander, 2011), when this education is locally implemented in a culturally competent way (Airhihenbuwa, 1995), it in effect “creates” the apparently healthier immigrant, who then immigrates.

In order to study the perceptions of DRF among Congolese immigrants, then, it helps to understand factors that prompt immigration and may motivate potential immigrants. This helps to give policy-makers the necessary background information related to immigration (Helbling, 2014). Studies have shown a host of factors, including political, economic, and sociocultural, influence populations to immigrate (Prescott & Nichter, 2014; Veronis & McLeman, 2014). These prompting factors can positively or negatively influence the health and quality of life for immigrants in the receiving country (Beerli & Martin, 2004).

People who immigrate for political reasons—including forced immigration due to lack of freedom, wars, and social conflicts—often have their overall health changed due to what they went through before migrating (Beine, Docquier, & Özden, 2011; Pedersen, 2002). For example, people who have experienced armed conflicts in their native land (whether as soldiers or not) often suffer from mental or physical issues that can impact their overall health and the quality of health in the receiving country (Pedersen, 2002).

Economic factors also motivate people to immigrate, including poverty, lack of resources, inability to live a perceived desirable standard of life, and unemployment or underemployment. These features also can serve either as impeding or facilitating factors when it comes to health and quality of health, since immigrants will carry with them background experiences acting as barriers or facilitators of their overall health (Pedersen, 2002). For examples, studies have shown that immigrant people who have less than a high school diploma are less likely to understand the role of preventative measures like cancer or HIV screenings compared to those who do (Scarinci et al., 2010). Further, people from a high-profile poverty region often can have low motivation with respect to using medical resources (Remennick, 2006).

Sociocultural factors comprise another important element influencing the health and quality of health of immigrants in a host country. These include cultural practices and diseases—communicable and non-communicable alike—that may be linked to the overall health of immigrants in a receiving country. For example, female circumcision can have a negative impact related to gynecological and obstetrical and psychosocial life complications (Makhlouf Obermeyer, 2005). At the same time, sociocultural factors influencing immigration can also play

a positive role in overall health, e.g., traditional fresh eating habits that immigrants often maintain even after immigrating to new countries (McArthur, Anguiano, & Nocetti, 2001).

In 2013, The US Department of Homeland Security (2014) (DHS), estimated that 2,792 Congolese immigrated in the US, comprising 68 people through family-sponsored preferences, 35 people through employment-based preferences, 421 people via immediate relatives of US citizens, 1076 people through the diversity lottery, 1190 people as refugees and asylees, and 2 people in an unidentified other category. According to Prah (2013), the Democratic Republic of the Congo ranked sixth out ten countries in terms of countries numbers of refugees and immigrants to the US in 2012. Further, according to Baker and Rytina (2014), the state of Illinois in 2013 was one of the leading states of residence for lawful permanent residents with 4.1%. Champaign County in Illinois itself has a significant number of legal Congolese immigrants (Ilunga Tshiswaka et al., 2014; Thiersch, 2012).

That differences in political, economic, and sociocultural reasons for immigrating have differential influence on beliefs surrounding and quality of health for immigrants further informs any work that could serve ultimately to make recommendations for preventative measures around chronic disease like diabetes (Airhihenbuwa, 1995).

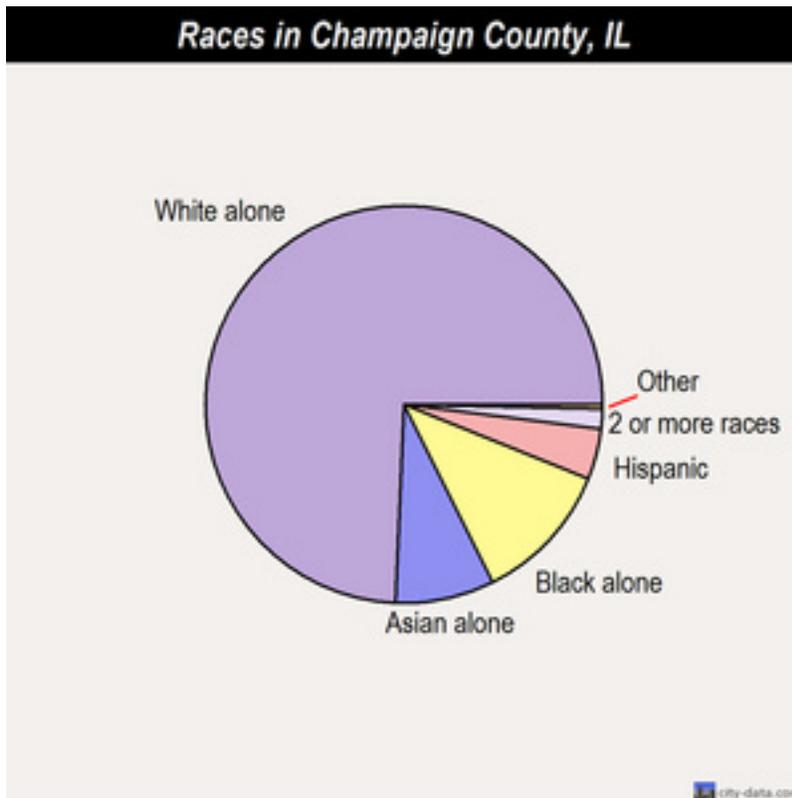
In all of this discussion, however, we must remain mindful of the history of racism (and eugenics) within the US and the often very volatile policy attempts to limit, demonize, or problematize immigrant populations. The healthy immigrant effect, for instance, seems more often utilized in a policy-setting or economic context than as an attempt to describe immigrant health, so that the sort of statistically grounded attack on the concept that Barcellos et al. (2016) develop may originate in, or simply participate in the long US history of, a policy hostility to immigration, if not to actual immigrants themselves. However, to attempt to enter into any such

detailed analysis of this point remains well beyond the scope of this dissertation and literature review. Nonetheless, the very fact of it once again underscores the need to not only consider diabetes in a medical sense but also within a broader, socio-cultural matrix of perceptions.

### 2.5.2 The “Black” Community within the Champaign Area

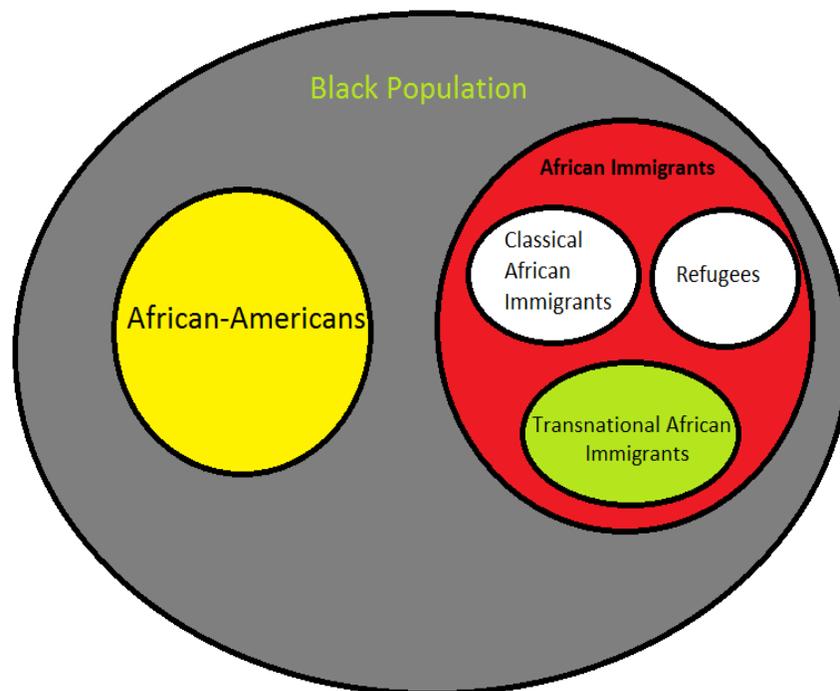
According to Champaign-Urbana Public Health District (2014), Blacks comprised 12.5% of the population living in Champaign County in 2013, the second largest population in the area after Caucasians. Moreover, over time Champaign County has become home to an important number of Congolese, who immigrated as diversity lottery holders or refugees due to insecurity and poverty (Ilunga Tshiswaka et al., 2014). Figure 3 presents the general ethnic demographics for Champaign County, Illinois.

Figure 3. Ethnic Demographics in Champaign County, Illinois.



Within the African immigrant contingent in Champaign County, there are three subgroups differentiated by residency status: classical immigrants, refugees and asylees, and transnational immigrants. A “classical immigrant” is a person who voluntarily comes to live permanently in a foreign country (Akyeampong, 2000; Schiller, Basch, & Blanc - Szanton, 1992), while a “refugee” or “asylee” is a person forced to leave their country of origin in order to escape war, persecution, or natural disaster (Akyeampong, 2000; Schiller et al., 1992). Furthermore, a “transnational immigrant” is a classical immigrant who forges and sustains substantive social relations between their community of origin and community of re-settlement (Schiller et al., 1992). Figure 4, then, diagrammatically disambiguates the category of “Black” people within Champaign County and the US generally.

Figure 4. The Lamberts-Ilunga Diagram of Black Migrants



### 2.5.3 Factors Influencing the Health of Immigrants in the Host Country

Cultural, political, and economic factors in receiving countries also influence the health of immigrants; that is, the way the receiving countries or communities react to the presence of immigrants can influence the overall health of immigrants (Beine et al., 2011; Veronis & McLeman, 2014). Further, whether or not the immigration policy of a host country has put in place mechanisms that facilitate or support immigration resettlement is another factor. While an important number of studies have identified culture as being salient for determining the integration of immigrants into host countries, it remains crucial to elucidate in what ways an immigrants' culture encounters a receiving culture (Helbling, 2014).

For scholarship regarding immigrants resettlement, the *acculturation premise* dominates as the most explanatory aspect for directing or dictating integration into the mainstream of a receiving culture (Caplan, 2007). Moreover, acculturation has been linked both positively or negatively to the overall health of immigrants in receiving countries (Caplan, 2007; Helbling, 2014). For instance, acculturation has been pinpointed as a causal agent in degrading the health of immigrants (Zsembik & Fennell, 2005). This study focused on the tobacco and alcohol consumption habits embraced by more acculturated immigrants (Zsembik & Fennell, 2005); i.e., that those who had been in the US longer drank and smoked more.

In general, acculturation positively associates with the duration of residence in a receiving countries, thereby also increasing the likelihood of engaging in more risky health-related behaviors that contribute to the deterioration of overall immigrant health (Caplan, 2007; Zsembik & Fennell, 2005). Amongst first and subsequent generations of immigrants, first generation people with less acculturation were less likely to develop certain diseases found in subsequent generations (Zsembik & Fennell, 2005). To the extent that acculturation implies an

understanding of the receiving country's culture, this can help immigrants to navigate into and through different societal systems. This process often remains more challenging for immigrants who more steadfastly hold to their homeland cultures and try to merge into the mainstream cultures through that lens (Beine et al., 2011; Caplan, 2007).

The community-driven quality of some immigrant communities of origin influences their overall health in different ways (Beerli & Martin, 2004). For instance, peer pressure has been shown to have an influence on health at times (Coggans & McKellar, 1994); i.e., people were more likely to change their health behaviors or to engage in specific behaviors due to influences that peers had on them (Coggans & McKellar, 1994). Further, the environmental structure also can influence immigrant health. Immigrants living within food deserts often can rely only on what is available, which will rarely if ever be as healthy and fresh as they used to have in their community of origin (Walker, Keane, & Burke, 2010). Immigrants also are more likely to suffer from social loneliness and isolation. Language barriers exacerbate this factor and can make social integration more difficult and challenging (McMichael & Manderson, 2004).

This then identifies a tension. On the one hand, the receiving country exerts pressures so that newly arrived immigrants will acculturate. To the extent that this process normalizes the immigrant experience in the country, it theoretically offers better access to available health services—assuming that those services are adequate and/or culturally competent—so long as culture, language, and homeland practice support those ends. On the other hand, the presence of a strong kindred community for newly arrived immigrants may also support immigrants by providing a fundamentally familiar living experience. Such communities can serve as a go-between or buffer with the culture at large, but the benefits of this circumstance sometimes

become outweighed if cultural practices hinder access to needed resources like health services in the broader community.

## CHAPTER 3

### METHODOLOGY

This chapter described the research methodology that guided this inquiry. The methodology chapter consisted of the research design description, the research participants included in the study, procedures of data collection, analysis of data, and trustworthiness and authenticity of the study.

The purpose of this study was to explore perceptions of DRF among Congolese immigrants to the US. The research questions associated with this inquiry were:

- (1) What is the relationship between demographic factors (e.g. education, age, and gender) and perceptions of diabetes among Congolese immigrants in East Central Illinois?
- (2) Is there a relationship between *perceived susceptibility* and diabetes risks?
- (3) What is the relationship between factors such as sedentary lifestyle and change in eating habits (i.e. unhealthy dietary behaviors) and diabetes perceptions among Congolese immigrants?
- (4) What role does the Congolese culture (e.g. parental influence) play in diabetes risk perception among participants?

As hypotheses related to each research question, we anticipated that:

- (1) There is no relationship between education, age, and gender factors and diabetes risk perceptions among Congolese immigrants.
- (2) The probability of a particular value of the *perceived susceptibility* is not associated with the value of diabetes risks among Congolese immigrants.
- (3) More sedentary lifestyle and changes in eating habits (i.e. unhealthy dietary behaviors) will likely be perceived as DRF among Congolese immigrant participants.

(4) The Congolese culture would play a crucial role in diabetes risk perception among participants.

In general, we anticipated that education, age, and gender will influence diabetes perceptions among our population of interest, and that sociocultural elements like eating habits and lifestyle practices will associate with perceptions around diabetes and thus its prevention. We anticipated also that increases of inactive lifestyle and changes in diet will be present among Congolese immigrants as contrasted with levels of activity and diet in the Congo.

### 3.1 Research Design

This study used a cross-sectional mixed-method approach as a research design to investigate the perceptions of DRF among Congolese immigrants. Researchers acknowledged that studies can benefit from a mixed-method approach because it allowed the integration of both qualitative and quantitative research strategies when exploring a topic (Doyle, Brady, & Byrne, 2009). A mixed method approach was appropriate for this study as it characterized not only a central phenomenon—the qualitative aspects of perceptions of DRF within a target population—but also the measure of a probabilistic association between the central phenomenon and the disease of diabetes itself.

As such, the quantitative aspect did not only enable analysis of the data via descriptive tables but also allowed computing the probability for perceiving DRF. Secondly, the qualitative aspect of this study enabled the collection, analysis, and interpretation of thematic elements that emerged around the perceptions of DRF within the target population via in-depth interviews, augmented by a photo-elicitation technique.

### 3.1.1 Informed Consent

The University of Illinois at Urbana-Champaign Institutional Review Board (IRB) approved this inquiry. Following the study's approval, contacts were made with Congolese participants explaining the relevance—i.e. risks, benefits, and ethical considerations— of the study and giving them the opportunity to freely participate or decline to participate in this investigation. Verbal and written consents were required from the subjects for participation. Participants understood that they could decide what to report during the interviews and surveys collection.

### 3.1.2 Data Collection Instruments

After obtaining approval from the Institutional Review Board of the University of Illinois at Urbana-Champaign for this study's research protocol, the study utilized surveys, photo elicitation, and in-depth interviews to collect data from participant Congolese immigrants. This data-triangulation technique—which uses different methods to collect data—has been proven effective in data collection for mixed method studies (Johnson & Turner, 2003).

Photo elicitation described a community-based participatory approach aimed at collecting data via photos or pictures (Harper, 1986). This technique allowed researchers to investigate the relationship between an individual and her or his environment. This study used photo-elicitation to look at participant relationships around the perception of DRF. Because photo-elicitation can serve as a means to spark discussions between investigators and participants during in-depth interviews (Clark-Ibáñez, 2004; Harper, 1986, 2002), this study used data collected by this means as a similar prompt as well. In particular, Clark-Ibáñez (2004) has suggested that pictures used for photo-elicitation might be provided by either the researchers or participants. For the

current study, investigators will provide pictures relevant to diabetes as an input to interview discussions.

Data collection for the quantitative portion of this study included questionnaire technique. Surveys were distributed either in French or English as needed by participants. Qualitative data collection included in-depth interviews and photo-elicitation, both of which have long been integral parts of qualitative research (Creswell, 2002, 2003). Photo-elicitation and in-depth interviews were conducted either in French or Lingala, as none wanted to do in English. Translations from English to French, or Lingala, or vice versa, were done by independent translators to decrease the risk of researcher bias in such translation (Douglas & Craig, 2007).

### 3.2 Research Participants

Participants who qualified for this study were males or females at least 35 years of age who have lived in the US for at least one year. Participants were either employed or unemployed as this might play a significant role in our findings. Azimi-Nezhad et al. (2008) found that unemployed individuals were more likely to develop diabetes as opposed to employed individuals. Participants were either married, single, or separated since marital status might imply different types of lives or activities could act as triggering or protecting factors for diabetes. The study identified participants along Congolese tribal lines—from the north, south, east, west, or center of the Democratic Republic of the Congo—since different tribes have distinct eating habits and cultural practices that could act as DRF (Termote, Van Damme, & Djailo, 2011). Participants were non-diabetic, insofar as this study focused on diabetes risk perceptions among people who have yet developed the disease. Participants were able to read, and write either French, Lingala, or English, not only in order to sign consent forms to abide by

ethical scientific research requirements, but also to complete the survey and understand in-depth questions.

Participants were recruited by word-of-mouth at two local church services attended by Congolese in Champaign. In the quantitative phase, sample size was 104 participants, equally divided by gender. From that total number, for the qualitative phase; 20 intentionally selected participants were involved, divided equally by sex. The principal investigator purposively selected subjects to be involved in this section using age, marital status, educational status, residential status, and employment status as criteria of selection. In other words, ten men and ten women participated in the qualitative phase, and fifty-two men and fifty-two women participated in the quantitative phase.

### 3.3 Data Collection

The qualitative portion of the study explored the central phenomenon of perceptions of DRF among Congolese immigrants. In terms of data collection, a female research assistant collected data among female participants, while a male researcher collected data among male participants, as men or women feel confident sharing their stories to their homogeneous peers (Johnson & Turner, 2003). This section proceeded by asking questions such as “When you think of the word *diabetes*, what first comes to mind?” and “*What does eating right mean to you?*”

To elicit and collect this data involved three steps, as follows:

#### 3.3.1 Step one: General screening and recruitment

Data were collected from participants in the Champaign area using purposive sampling to ensure the capture of diabetes perspectives among the population studied. Purposive sampling is a non-probabilistic approach that involves selecting participants based on the researcher’s knowledge of the community. This approach yields the most comprehensive understanding of

the topic being studied (Tongco, 2007). Since I, as the investigator, had knowledge of the Champaign County Congolese community—still a relatively young community (Ilunga Tshiswaka et al., 2014)—purposive sampling was suitable as it allowed the inclusion of Congolese participants of different ages, genders, and educational levels.

Prior to participating in the study, individuals were screened to determine their eligibility as participants. Screening consisted of questions to determine if a prospective participant met the inclusion criteria. Questions such as *“How old are you”* and *“How long have you been in the US”* and *“Are you currently diagnosed with diabetes”* were asked to determine eligibility prior to participating in the study.

### 3.3.2 Step Two: Socio-Demographic and Health Data Collection

For the quantitative phase, participants signed the consent forms following their study recruitment and then completed a survey of 51 socio-demographic (8 demographic and 43-item instrument) questions around perceptions of DRF. The study used a standardized diabetes risk perception survey, the Diabetes Perception Survey for Developing Diabetes (RPS-DD), developed by the Einstein-Sinai Diabetes Research Center (2014), to capture present trends in the perceptions of DRF by participants. Cronbach’s alphas are computed according to the subscales within the survey, i.e., personal control subscale has .68; worry subscale has .50; optimistic bias subscale has .71; personal disease risk subscale has .80; comparative environmental risk subscale has .81; and composite risk score subscale has .84.

### 3.3.3 Step Three: In-depth Interviews

During the qualitative phase, open-ended and detail-oriented in-depth interview questions (Legard, Keegan, & Ward, 2003) more deeply explored the participants’ perceptions around DRF. Interviews were recorded and transcribed, and transcripts were provided to participants to

member check them. At the beginning of each interview, we used *photo-elicitation* to enable inputs for discussions between the researchers and participants. Photo-elicitation is an interview procedure that involves the use of visual images—such as photos, videos, and paintings—to prompt comments from participants (Harper, 1986, 2002). This method has been successfully used for sociology, health, and anthropology inquiries (Harper, 2002). In-depth interviews immediately followed the photo-elicitation discussions and were conducted by two researchers, the principal investigator and another trained research assistant to conduct the study's investigation. That is, the male principal investigator interviewed male participants, while the female research assistant interviewed female participants to ensure that they are confident sharing views with their peers (Legard et al., 2003). Interviews were conducted in English (some participants used only few words in English), French, or Lingala (or a combination) to ensure that participants feel comfortable and confident in sharing their opinions around perceptions of DRF; French and Lingala are two of the most widely spoken languages in D.R. Congo (Bokamba, 2008; Ilunga Tshiswaka et al., 2014). Data collected during interviews (photo-elicitation and in-depth interview) were transcribed in their original language. For interviews in French and Lingala, independent researchers translated the foreign-language transcripts into English. The principal investigator and two researchers then coded the information generated using the English transcripts and also theme-map the data.

### 3.4 Data Analysis

Data were analyzed through two theoretical frameworks: the HBM and PEN-3 models (as described in the previous chapter) to ground this inquiry in theory-driven reasoning as they yield valid results (Grant & Osanloo, 2014). Moreover, as social research, the study's mixed-method design called upon both inductive and deductive logic to reach its desired goals and outcomes

(Hyde, 2000; Patton, 2005). Deduction described a process of beginning with premises or hypotheses presumed as true, and then determining what else becomes true based on that premise or hypothesis. By contrast, induction described a process that starts with specific observations and then builds towards descriptions of general patterns based on those observations (Patton, 2005). As for the quantitative section, we deductively analyzed the data in light of an existing theoretical framework: HBM, and determined what else becomes true based the hypothesis. The qualitative portion of this study began with particular cases (i.e. 20 Congolese immigrants) and inductively identified patterns that emerge from the analysis using open-ended questions around the perceptions of DRF among participants.

More narrowly, we used HBM to identify variables (themes) that serve as *perceived susceptibility* arising from the participant perceptions of DRF (Glanz et al., 2008). While the constructs of HBM are *susceptibility, seriousness, benefits, barriers, self-efficacy* and *cues to action* (Glanz et al., 2008), the current study focused only on one construct, i.e. *susceptibility*, which identifies vulnerability factors related to the perception of DRF. This selected construct was used for the quantitative analysis section of this study, such that it guided the analysis of the survey data.

The domains of the PEN-3 model with their respective dimensions consist of: *cultural empowerment (positive, existential, and negative), relationships and expectations (perceptions, enablers, and nurturers)*, and *cultural identity (person, extended family, and neighborhood)* (Airhihenbuwa, 1995). For this study, the domain of *relationships and expectations* was used to understand the role of culture in perceptions of DRF. Per Airhihenbuwa (1995), the PEN-3 model also identifies and captures the role played by culture in the perceptions of DRF.

For the quantitative section, descriptive analysis around DRF was first used; ordinal logistic regression was then performed to characterize the likelihood of perceiving DRF among Congolese immigrants. Statistical data software such as SPSS 23 was used for the quantitative analyses and NVivo 11 was used for the qualitative section analysis.

### 3.5 Research Bias

Mixed methodologists apprised of potential biases that are linked to both qualitative and quantitative aspects of this specific type of paradigm. Those biases can be categorized under the researcher-participants dialogue, study design, and findings' interpretation. For instance, the researcher's personal opinion and background, which will affect the focus and the angle of their investigation, will be interfered with the objectivity of the study. In this particular inquiry, the researcher bias caused by his judgment, opinion, and preconception was plausible given the fact that he was a member of the Congolese community. Research methodologists argued that researcher bias can skew study results, especially in qualitative studies, unless alleviating steps have been thoroughly implemented (Symonds & Gorard, 2008). For example, a strength of the study—the principal researcher's intimate knowledge of the population community under study—may also raise the threat of a selection bias. The use of purposive sampling, recognized as a valid research technique (Tongco, 2007), nonetheless risks selection bias as well. Tongco (2007) suggests that clear pre-established criteria when selecting participants and collecting data alleviate the effect of research bias raised by *purposive sampling*. This study implements such clear and pre-established criteria.

As noted previously with respect to the notion of the healthy immigrant effect, a threat of selection bias may already inform the population under consideration, i.e., that people who immigrate are already likely to be healthier or—principally for reasons of socioeconomic class—

will have had increased access to more current medical knowledge from around the world. Barcellos et al. (2016) further explore this by proposing diagnostic error—that immigrants from originating countries simply do not know that they have a disease condition—as another way to open up the concept of the healthy immigrant effect.

For this study, insofar as its participants consist of people who have immigrated, they have already been subjected to a process of qualification. Methodologically, this did not affect the course of the study—the study did not propose to explore perceptions around DRF for immigrants *and* non-immigrants, or simply “Congolese” in general—but it required the principal researcher to remain mindful that the population pool from which any selection can occur at all is already delimited in various ways. One of the most obvious of these was the predominantly religious, specifically Protestant, orientation of the Champaign county Congolese immigrant community. Here again, then, the research benefit of the principal researcher’s participation within the community under study may raise a threat of bias, but not around the interpretation of data. By assumption but also as a matter of validity within purposive sampling itself (Tongco, 2007), a researcher’s intimate knowledge of the community under study better aligned his or her ability to identify and frame data collected from that group. The threat of bias here, then, arises in the area of generalizability. This study met that threat in two ways. On one hand, it did not any wider reach for the findings beyond describing the perceptions of diabetic risk factors for Congolese immigrants, inflected by the factor—if any—of the different tribal origins for the participants. On the other, the quantitative portion of the study aimed at characterizing some *predictable* elements within disparate qualitative data, where this predictive capacity represented one of the hallmarks of generalizability (Creswell, 2003).

Another research bias associated particularly with the qualitative aspect of this inquiry involved a risk of subjectivity and thus raised a threat to its interpretive validity, insofar as the personal judgment of the researcher may permeate the study (Symonds & Gorard, 2008).

Triangulation and member-checking both have been suggested as techniques to minimize this kind of research bias (Lincoln & Guba, 1985). This study used triangulation both by incorporating the views of two other researchers and also peer debriefing technique.

Last, to use a mixed-methods approach may introduce methodological bias. This was not the question whether a mixed-method approach even works—there were several controversies over the entire validity of the approach, despite its increasing use as a method of research (Creswell, 2009)—but of potential researcher bias that entered into the approach once it was taken up.

While mixed-method research had “the logical and intuitive appeal [of] providing a bridge between the qualitative and quantitative paradigms” (Onwuegbuzie & Leech, 2006, p. 1), how to build this bridge remains an area of ongoing exploration and thus raises over-arching questions around validity of findings in general. Centrally, the issue involved the coordination of, or translation between, qualitative and quantitative data (Lieber, 2009). Quantitative methods often generated validity by extremely large sample sizes (Creswell, 2003), with thousands, if not tens of thousands of samples. By contrast, the resources required to collect and transcribe thousands, or tens of thousands, samples of qualitative data (interviews) remained prohibitive. And even once that raw qualitative data has been collected, the process of reducing that data to quantifiable form—an unavoidably human, and therefore subjective process—raised challenging questions around validity at this point (Driscoll, Appiah-Yeboah, Salib, & Rupert, 2007).

As Lieber (2009) noted, “Perhaps the most unresolved challenges to mixed method research relate to questions of data management, processing, and analysis” (p. 222). However, having proposed the problem in this way, Lieber (2009) also noted that complete qualitative and quantitative “method integration requires the establishment of a middle ground in which the data from both approaches are reliable and exist in forms that allow for combined analysis” (p. 222). In a general way, surveys (on the side of the participant) and coding programs like EthnoNotes (on the side of the researcher doing the coding) help to create this middle ground that coordinates the quantitative and qualitative paradigms, so long as an iterative process, sensitive to emerging themes and data, is in place (Onwuegbuzie & Leech, 2006). Lieber (2009) advocated also for the use of Cohen’s Kappa to demonstrate inter-rater reliability. Incorporating these elements into this study will thus help to decrease the risk of methodological bias.

### 3.6 Qualitative Analysis

A mixed-methods approach was particularly dependent on its qualitative aspect for validity (Creswell, 2009; Lieber, 2009). To put it roughly, insofar as quantitative analytical methods will “crunch” whatever data they received, achieving valid and reliable outcomes overall depends tremendously on feeding good qualitative data into those analyses. As such, we emphasized here the factors and issues that can strengthen the trustworthiness of the qualitative portion of this study.

We must take this care, because conventional (quantitative) paradigm researchers have characterized the naturalistic paradigm approach as lacking rigor, despite specific criteria for establishing trustworthiness in naturalistic inquiries (Lincoln & Guba, 1985). In light of this, naturalistic inquirers have proposed the specific criteria of credibility, transferability, dependability, and confirmability as establishing trustworthiness in qualitative research,

particularly given that the conventional paradigm criteria of internal validity, external validity, reliability, and objectivity cannot apply in naturalistic research (Lincoln & Guba, 1985).

As for the criteria of credibility, the current study used *triangulation* as the means for improving the likelihood of establishing credibility for the findings and the interpretations in this study (Lincoln & Guba, 1985). For this study, the principal investigator was helped by two other researchers to triangulate—i.e. establishing agreement within the themes encountered—the data. This study, then, collected data qualitatively through photo-elicitation and in-depth interviews and quantitatively through surveys, and then performed content analysis and statistical analysis upon this data. This mixed-method approach helped to strengthen the credibility of findings (Patton, 2005).

In addition to triangulation, the current study used *member checks* to further establish credibility of the results and interpretations. Lincoln and Guba (1985) have defined this approach as providing those members of stake holding groups from which data were originally collected the various analytic categories, interpretations, and conclusions of a study in order to check if the experience of that group has been accurately represented. For example, researchers may provide an interviewee the summary of their in-depth interview to obtain from that interviewee her or his reactions to that summary. Member checking represented one of the most pertinent techniques for establishing credibility (Lincoln & Guba, 1985; Patton, 2005). The transcript was shared with the interviewee to verify that it was interpreted in a way that she or he meant (Carlson, 2010). This gave the interviewee the chance to clarify or elaborate more on comments that she or he found incorrect or incomplete.

Similar to the external validity for quantitative research methods, transferability was crucial in qualitative methods for generating the generalizability of the study. The present study

used *thick descriptions* of the phenomenon to ensure transferability (Lincoln & Guba, 1985; Patton, 2005). According to Holloway (1997), *thick description* referred to the detailed account of field experiences in which investigator makes explicit the patterns of social and cultural interactions and contextualize them. The study also used auditing to ensure dependability, since one may not have credibility without dependability (Lincoln & Guba, 1985). Auditing allowed the research process to be traceable, logical, and documented. The audit trail was used for confirmability. The audit trail was conducted with a residue of records stemming from the inquiry. Records of data such as raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, materials relating to intentions and dispositions, and instrument development information were kept. For instance, an audit trail was performed in this study by keeping all the records. Further, another reason this study used the confirmability audit technique – in establishing confirmability – was to ensure that the findings did not derive from the inquirer’s imagination or were critically biased in some way but, rather, derived from data collected.

*Negative case analysis* – which is the counterpart of statistical tests for quantitative analysis aimed at establishing credibility – is a process of revising hypotheses with hindsight. Further, the process intended to reduce the number of exceptional cases to zero (Lincoln & Guba, 1985). The negative case analysis was conducted as follows: the hypotheses associated with this inquiry were checked against the interpretation of the information provided by participants through interviews to see if any deviating or disconfirming cases have occurred.

In terms of activities that increased the likelihood of credibility, *prolonged engagement* was one of them. Prolonged engagement is the process of spending an important amount of time with people being studied in order to learn their culture, to establish trust, and assess

misinformation potentially introduced by the inquirer or participants (Lincoln & Guba, 1985). For this study, the inquirer dealt with personal distortions before considering Congolese respondents' distortions when it comes to their perceptions of DRF. When dealing with personal distortions, the principal investigator did not give precedence to his own *a priori* values or constructions but did solely rely on data gleaned from the study (Lincoln & Guba, 1985).

Another salient activity that increased the probability of credibility was *persistent observation*, which is a process of observing deeply and ensuring that details and phenomena have been explored thoroughly (Lincoln & Guba, 1985). In doing so, the inquirer will be confident that he or she identifies irrelevancies and understands things in a non-superficial way. Also, the inquirer will avoid *premature closure*. For instance, the inquirer of this study observed deeply the Congolese immigrants—by spending time with them—living in the Champaign area to ensure that he or she was able to sort out irrelevancies associated with the perceptions of DRF.

*Peer debriefing* was another activity used in establishing credibility. Peer debriefing is the technique of exposing oneself to a disinterested peer who can ask pertinent and probing questions related to the study methods, biases, and conclusions (Lincoln & Guba, 1985). The purpose of doing so was to keep the inquirer “honest” and to make the conclusions more internally consistent and believable. This study used a fellow graduate student to serve as the debriefer to ensure that someone else independently pointed out the implications of what the inquirer was doing.

## CHAPTER 4

### RESULTS

The purpose of this inquiry was to investigate perceptions, attitudes, and values around DRF among Congolese immigrants in east Central Illinois. The results of the quantitative phase of the study are reported first and then followed by results from the qualitative phase.

#### Phase 1: Quantitative Section

The following research questions and hypotheses guided the Phase 1 results:

#### Research Questions:

- (1) What is the relationship between demographic factors (e.g. education, age, and gender) and perceptions of diabetes risks among Congolese immigrants in East Central Illinois?

Null hypothesis: There is no relationship between education, age, and gender factors and diabetes risk perceptions among Congolese immigrants.

Alternative hypothesis: There is a relationship between education, age, and gender factors and diabetes risk perceptions among Congolese immigrants.

- (2) Is there a relationship between *perceived susceptibility* and diabetes risks among Congolese immigrants?

Null hypothesis: The probability of a particular value of the *perceived susceptibility* is not associated with the value of diabetes risks among Congolese immigrants.

Alternative hypothesis: The probability of a particular value of the perceived susceptibility is associated with the value of diabetes risks among Congolese immigrants.

#### *Theoretical Framework*

The HBM, as the conceptual framework, guided the first section of this inquiry to ensure the capture of salient factors that play a significant role around perceptions of DRF for

Congolese immigrants. Glanz et al. (2008) reported that this theoretical framework has been successfully used to study various chronic diseases, including diabetes, since it predicts the role of health-related behaviors around those diseases. The HBM has different constructs (i.e. *perceived susceptibility*, *perceived severity*, *perceived barriers*, *perceived benefits*, cues to action, and *self-efficacy*) that underscore the process of forming, changing, and maintaining health behaviors. The present inquiry uses *perceived susceptibility* (i.e., belief about the risk of developing a condition or disease) to understand what potential factors are playing a significant role around the perceptions of diabetes risks among Congolese immigrants (Glanz et al., 2008).

### *Sample*

This study used purposive sampling for 104 Congolese immigrants (52 females and 52 males) aged at least 35 years old. The demographic variables of gender (categorical), age (continuous), educational level (ordinal), marital status (categorical was dichotomized), employment status (dichotomous), income level (categorical) were collected. The variable related to the participants' tribe was dropped, as most study subjects failed to answer that question. Table 1 summarizes the demographic distribution among Congolese participants.

Mean ages were 42.42 years and 44.29 years for Congolese immigrant women and men, respectively. For educational level, the "elementary only" rubric was excluded from analysis since no participants reported it. More females attended only high school (26.9%), as opposed to males (13.5%). Moreover, results yielded that the same percentage of females and males attended college, with both 36.5%. More females were employed (92.3%) and were making less than \$18,999 a year (58.3%), as opposed to employed males (90.4%) and were making less than \$18,999 annually (44.7%). Further, findings yielded that 10.6% of males made more than \$35,000 annually versus 6.3% of females, who made more than \$35,000.

**Table 1. Number and Percent of Congolese Immigrants by Demographic Factors**

	Female Congolese Immigrants		Male Congolese Immigrants	
	<i>N</i>	Mean ± SD	<i>N</i>	Mean ± SD
Age	52	42.42 ± 7.01	52	44.29 ± 7.30
	Number	Percent	Number	Percent
Educational Level				
High School or less	14	26.9	7	13.5
College	19	36.5	19	36.5
Bachelor	18	34.6	21	40.4
Grads School	1	1.9	5	9.6
Marital Status				
Married	43	82.7	49	94.2
Unmarried	9	17.3	3	5.8
Employment Status				
Employed	48	92.3	47	90.4
Unemployed	4	7.7	5	9.6
Income Level				
Less than \$18,999	28	58.3	21	44.7
\$19,000-\$22,999	9	18.8	4	8.5
\$23,000-\$26,999	5	10.4	4	8.5
\$27,000-\$30,999	3	6.3	9	19.1
\$31,000-\$34,999	n/a	n/a	4	8.5
More than \$35,000	3	6.3	5	10.6

### *Results*

Descriptive analyses were performed to understand the distribution of DRF among Congolese immigrants. Additionally, regression model was used to predict the likelihood of perceiving diabetes risks among our targeted population. For this quantitative section, data collection was conducted by means of survey; specifically, this included the distribution of a standardized survey instrument, the Diabetes Perception Survey-Developing Diabetes (RPS-DD) developed by the Einstein-Mount Sinai Diabetes Research Center, which is intended for

nondiabetic people (Einstein-Sinai Diabetes Research Center, 2014). The survey instrument is a 43-item questionnaire with four subscales (e.g. Personal Control, Optimistic Bias, Personal Disease Risk, and Comparative Environmental Risk) and some individualized items (e.g. Worry). This inquiry also analyzes the role of *perceived susceptibility* in the perceptions of DRF by selecting specific questions on the survey instrument that relate to the perception of susceptibility.

The RPS-DD is a 4-point Likert scale, with 1=strongly agree, 2=agree, 3=disagree, and 4=strongly disagree; 1=almost no risk, 2=slight risk, 3=moderate risk, and 4=high risk; or 1=increases the risk, 2=has no effect on risk, 3=decreases the risk, 4=don't know. Frequencies, measure of central tendency, and measure of dispersion such as means and standard deviations for the 43- items questionnaire were computed. The standardized survey instrument was translated into French and back translated into English by an independent translator to minimize the risk of principal researcher's bias (Douglas & Craig, 2007), as Congolese immigrants are Francophone (Ilunga Tshiswaka et al., 2014). Survey distribution was conducted during Congolese local church services and at participants' homes.

Ordinal logistic regression was performed (see results on Table 5) to predict the likelihood of perceiving DRF among Congolese immigrants. The ordinal logistic regression was relevant for the data given its Likert-scale format (Kleinbaum & Klein, 2010). The PLUM (Polytomous Universal Model) ordinal regression procedure was used in this study, where the dependent variable is "the risk of getting diabetes", which had a 4-point response (1=almost no risk, 2=slight risk, 3=moderate risk, and 4=high risk). Independent variables included: "feeling little control over risks to health", "if going to get diabetes, not much can do about it", and

“worry about getting diabetes”, which highlight the HBM’s *perceived susceptible* factor. Income and employment status are independent variables.

### *Descriptive Analyses*

We performed a descriptive analyses of the 43-item questionnaires asked in the survey instrument and generated a report of the frequencies, means, and standard deviations for the four subscales (i.e. Personal Control, Optimistic Bias, Personal Disease Risk, and Comparative Environmental Risk) to obtain the distribution of topic of interest. Table 2 below outlines these results by frequencies, means, and standard deviations.

**Table 2. Personal Control, Optimistic Bias, Personal Disease Risk, and Comparative Environmental Risk Frequencies, Means, and Standard Deviations by Female and Male Participants.**

Subscale	Items	Female					
		Frequency				Means	SD
		1	2	3	4		
Personal Control	Q1	7	21	18	6	2.44	0.873
	Q2	3	4	30	15	3.1	0.774
	Q3*	9	6	21	16	2.85	1.06
	Q4*	4	14	19	15	2.87	0.93
Optimistic Bias	Q6*	8	27	11	6	2.29	0.87
	Q7*	10	28	11	3	2.14	0.79
Personal Disease Risk	Q9	29	13	8	2	1.67	0.88
	Q10	26	18	5	3	1.71	0.87
	Q11	37	12	3	n/a	1.35	0.59
	Q12	19	18	5	10	2.12	1.11
	Q13	32	10	10	n/a	1.58	0.8
	Q14	32	9	7	4	1.67	0.99
	Q15	22	12	12	6	2.04	1.06
	Q16	31	11	9	1	1.62	0.84
	Q17	35	14	2	1	1.4	0.66
	Q18	30	13	7	2	1.63	0.86
	Q19	43	6	1	2	1.27	0.69
	Q20	33	14	4	1	1.48	0.73
	Q21	n/a	n/a	n/a	n/a	n/a	n/a
	Q22	37	11	4		n/a	0.63
Q23	42	9	n/a	1	1.23	0.55	
Comparative Environmental Risk	Q24	25	14	10	3	1.83	0.94
	Q25	28	13	6	5	1.77	1

**Table 2 (cont.)**

	Q26	17	21	10	4	2.02	0.92
	Q27	26	14	11	1	1.75	0.86
	Q28	31	5	9	7	1.85	1.14
	Q29	17	9	20	6	2.29	1.05
	Q30	24	7	16	5	2.04	1.08
	Q31	14	13	18	7	2.35	1.03
	Q32	20	7	14	11	2.31	1.2
	Male						
Subscale	Items	Frequency				Mean	SD
		1	2	3	4		
Personal Control	Q1	6	15	21	10	2.67	0.92
	Q2	2	5	29	16	3.13	0.74
	Q3*	3	13	19	17	2.96	0.91
	Q4*	5	10	19	18	2.96	0.97
Optimistic Bias	Q6*	9	21	17	5	2.35	0.88
	Q7*	7	28	14	3	2.25	0.76
Personal Disease Risk	Q9	32	12	3	5	1.63	0.97
	Q10	27	12	6	7	1.87	1.09
	Q11	30	14	2	6	1.69	1
	Q12	16	13	12	11	2.35	1.14
	Q13	26	9	13	4	1.9	1.03
	Q14	28	11	9	4	1.79	1
	Q15	17	12	17	6	2.23	1.04
	Q16	26	13	7	6	1.87	1.05
	Q17	25	16	4	7	1.87	1.05
	Q18	26	13	9	4	1.83	0.99
	Q19	40	7	3	2	1.37	0.77
	Q20	23	20	8	1	1.75	0.79
	Q21	30	13	6	3	1.65	0.91
	Q22	31	11	5	5	1.69	1
Q23	33	12	3	4	1.58	0.92	
Comparative Environmental Risk	Q24	21	14	11	6	2.04	1.05
	Q25	19	12	13	8	2.19	1.1
	Q26	10	16	20	6	2.42	0.94
	Q27	18	15	13	6	2.13	1.03
	Q28	23	7	12	10	2.17	1.2
	Q29	13	12	16	11	2.48	1.09
	Q30	19	7	14	12	2.37	1.21
	Q31	15	13	13	11	2.38	1.12
	Q32	18	11	11	12	2.33	1.18

\*Scoring was reversed to conform to conceptual direction of subscales

For this data, the mean risk of developing diabetes was 2.04 (for females) and 2.23 (for males) on the 1 (almost no risk) to 4 (high risk) subscale of Personal Disease Risk with 15 items. That is, women perceive less risk of developing diabetes than men. A summative subscale related to Diabetes Risk Knowledge yielded an average number of correct responses for female participants of 4.71 out of 11 and 4.58 out of 11 for male participants. Overall, Congolese participants had less knowledge about DRF, with females slightly more knowledgeable compared to males.

The results yielded that 15.4% of Congolese females reported that being Black or African-American increases the risk of developing diabetes, whereas only 7.7% of Congolese males reported that. The study also found that 50% of Congolese males reported that being 65 years of age or older increases the risk of diabetes, as opposed to 40.4% Congolese females. In addition, 90.4% of Congolese males reported that exercising regularly decreases the risk of diabetes, while 88.5% of Congolese females reported that. With respect to eating habits, 94.2% of Congolese males were aware of the notion that eating a healthier diet decreases the risk of developing diabetes, whereas 84.6% of Congolese females were aware. The findings also revealed that more Congolese males (96.2%) knew that controlling weight gain decreases the risk of developing diabetes compared to Congolese females (82.7%).

Tables 3 and 4 below outline the means and standard deviations of the four survey's subscales among female and male participants. All the subscale's standard deviations are less than 1.0, which indicates modest variability around the means.

**Table 3. Mean and Standard Deviation of Personal Control, Optimistic Bias, Personal Disease Risk, and Comparative Environmental Risk Subscales among Females**

Female		
Subscale	Mean	SD
Personal Control	2.81	0.42
Optimistic Bias	2.21	0.8
Personal Disease Risk	1.58	0.43
Comparative Environmental Risk	2.02	0.74

The highest mean score for subscales is the Personal Control, with 2.93 and 2.81 out of 4.00 for male and female, respectively. That is, these scores describe a slightly higher personal control over diabetes risks among participants, as the highest score indicates more personal control. The mean scores for the Optimistic Bias subscale were 2.21 (for females) and 2.3 (for males) out of 4.00, indicating a moderate tendency toward optimistic bias for both participants. The Optimistic Bias subscale is related to the concept of pessimism or realism about developing diabetes. The mean scores of Personal Disease Risk subscale, which measured the perceived risk across 15 diseases and conditions, were 1.58 for Congolese females and 1.8 for Congolese males. These mean scores of Personal Disease Risk indicate a relatively low perceived comparative personal disease risk, as the higher score indicates greater perceived risk. The Comparative Environmental Risk subscale—measuring perceived environmental risk—yielded scores of 2.02 (for females) and 2.28 (males) out of 4.00. This indicates that a relatively modest perceived personal risk from the environment. When comparing both genders, the results yielded that more males had a moderate perceived environmental risk than females.

**Table 4. Mean and Standard Deviation of Personal Control, Optimistic Bias, Personal Disease Risk, and Comparative Environmental Risk Subscales among Males**

Male		
Subscale	Mean	SD
Personal Control	2.93	0.53
Optimistic Bias	2.3	0.74
Personal Disease Risk	1.8	0.71
Comparative Environmental Risk	2.28	0.78

*Ordinal Logistic Regression*

Using the *perceived susceptibility* construct of HBM, an ordinal logistic regression was performed on the data. For this construct, variables such as “age” (continuous variable), “employment status” (dichotomous variable), “feeling little control over risks to health” (ordinal variable), “if getting diabetes, there is not much one can do about it” (ordinal variable), and “worry about getting diabetes” (ordinal variable) were used as independent variables. The regression model included the “risk of developing diabetes” (ordinal variable) as the dependent variable, with 4-point scale.

In particular, the current study used cumulative ordinal logistic regression. For *perceived susceptibility*, the assumptions of multicollinearity and proportional odds were met, given the full likelihood ratio of test comparing the residual of the fitted location model to a model with varying location parameters, with a  $\chi^2 (22)= 27.670, p\text{-value}= .187$ . In addition, the final model predicted statistically significantly the dependent variable (i.e. risk of developing diabetes) over and above the intercept-only model, with  $\chi^2 (11)=25.432, p\text{-value} < .05$ .

Table 5 outlines the ordinal logistic regression for the risk of developing diabetes among Congolese participants relying on the *perceived susceptibility* construct of HBM. The results yielded that unemployed Congolese are much more likely to think that they are in high risk for developing diabetes than employed Congolese, with OR=2.958 [95% CI, 0.724-12.076]; however, this was not statistically significant, Wald  $\chi^2(1) = 2.283$ ,  $p$ -value= 0.131. The omnibus test result indicated that only the variable “I feel that I have little control over risks to my health” has a statistically significant effect on the prediction of whether “risk of developing diabetes” is thought to be too high, Wald  $\chi^2 = 12.620$ ,  $p$ -value < .05. However, it does not explain which, or how, the levels (i.e. strongly agree, agree, and disagree) differ.

When disaggregating by response categories (strongly agree, agree, disagree, and strongly disagree), only the “disagree” group was statistically significant. That is, participants who disagree about “feeling little control over risks to health” are much less likely to perceive high risks of developing diabetes than the strongly disagree group, with an odds ratio of 0.223 [95% CI, 0.065-0.770],  $\chi^2(1) = 5.632$ ,  $p$ -value < 0.05 indicating that the effect was statistically significant. For the age variable, which was statistically significant, a decrease in age (expressed in years) was associated with a decrease in the odds of considering diabetes high risk, with an odds ratio of 0.930 [95% CI, 0.874-0.990], Wald  $\chi^2(1) = 5.181$ ,  $p$ -value < 0.05. Similarly, Congolese who agree that “if getting diabetes, there is not much one can do about it” are almost five times more likely to perceive high risk of developing diabetes than the strongly disagree group. This was statistically significant, with an odds ratio of 4.798 [95% CI, 1.068-21.563], Wald  $\chi^2(1) = 4.183$ ,  $p$ -value < 0.05. Further, Congolese who disagree on “worrying about getting diabetes” are much less likely to perceive high risks of developing diabetes than the strongly

agree group, with an odds ratio of 0.360 [95% CI, 0.125-1.037], Wald  $\chi^2(1)=3.583$ ,  $p$ -value< 0.058, which is marginally significant.

**Table 5. Ordinal Logistic Regression for Perceived Susceptibility**

Variables	OR	95% C.I. for OR		$p$ -value
		Lower	Upper	
Age	0.930	0.874	0.990	0.023***
Employment status				
Unemployed (ref=employed)	2.958	0.724	12.076	0.131
Feeling little control over risks to my health				
Strongly Agree (ref=Str. Disagree)	0.353	0.077	1.608	0.178
Agree (ref=Str. Disagree)	0.992	0.274	3.595	0.990
Disagree (ref=Str. Disagree)	0.223	0.065	0.77	0.018***
If getting diabetes, there is not much one can do about it				
Str. Agree (ref=Str. Disagree)	0.251	0.032	1.997	0.191
Agree (ref=Str. Disagree)	4.798	1.068	21.563	0.041***
Disagree (ref=Str. Disagree)	1.055	0.423	2.629	0.908
Worry about getting diabetes*				
Str. Disagree (ref=Str. Agree)	0.405	0.103	1.600	0.197
Disagree (ref=Str. Agree)	0.360	0.125	1.037	0.058**
Agree (ref=Str. Agree)	0.417	0.151	1.153	0.092

\*Scoring is reversed to conform to conceptual direction of subscales, \*\*marginally significant, \*\*\* $p$ -value< 0.05.

Overall, the quantitative section of this inquiry revealed that perceived personal control (subscale) was moderate for both Congolese female (2.81) and male (2.93) participants when it comes to risk of developing diabetes. Likewise, both groups of participants had a moderate optimistic bias towards the risk of developing diabetes, as optimistic bias is the mistaken belief

that one's chance of developing diabetes is lower than that of one's peers. Congolese female and male participants had a relatively low average of personal disease risk highlighting their health status. When comparing environmental risk subscale, the results yielded that the perception of the environment as risk was moderate for both groups (male and female). Only "age", "feeling little control over risks to health" (1 category of the questions), "if going to get diabetes, there is not much one can do" (1 category), and "worrying about getting diabetes" (1 category) for HBM *perceived susceptibility* construct were predictors related to the perceptions of DRF.

## Phase 2: Qualitative Section

The following research questions and hypotheses guided the analysis of phase 2 (i.e., qualitative section):

### Research Questions

- (1) What is the relationship between factors such as sedentary lifestyle and change in eating habits (e.g. unhealthy dietary behaviors) and diabetes perceptions among Congolese immigrants?

Hypothesis: More sedentary lifestyle and changes in eating habits (i.e. unhealthy dietary behaviors) will likely be perceived as diabetes risk factors among Congolese immigrant participants.

- (2) What role does the Congolese culture (e.g., parental influence) play in diabetes risk perception among participants?

Hypothesis: The Congolese culture would play a crucial role in diabetes risk perception among participants.

The purpose of this qualitative section was to identify cultural factors around the perceptions of diabetes risks among the population of interest. Such cultural aspects are salient in understanding the perspectives of people regarding chronic diseases such as diabetes (Abubakari et al., 2013). This qualitative approach extends the previous phase of this inquiry by using photo-elicitation and in-depth interviews. In a mixed method inquiry, the modus operandi of both quantitative and qualitative approaches must function in a complimentary and congruous manner. In particular, this study's quantitative section focused on collecting data via a specific standardized survey, which lacked any cultural component. Through the use of photo-elicitation and in-depth interviews, these permit the addition of cultural components around the perceptions

of diabetes risk among Congolese immigrants. Thus, while the quantitative section captured general factors (e.g. medical, eating patterns, and physical activities) around the perceptions of diabetes risks, the qualitative section expands on those general factors by culturally contextualizing them.

### *Sample*

The sample size associated with this qualitative section consisted of twenty Congolese (20) participants, purposively selected from the quantitative section's pool of 104 participants. Each of the twenty participants had completed the quantitative section prior to being asked if they were interested in participating in phase 2's photo elicitation and in-depth interview.

Participants were equally distributed by gender (i.e. 10 males and 10 females). The age range of phase-2 participants was 35-58 years for males and 35-56 years for females. The majority of study's subjects were married (i.e. 10 married men, 8 married women, and 2 divorced women). 7 men and 8 women were employed; 3 men and 2 women were unemployed. Further, 2 male participants were asylees and 8 other were legal residents, 2 female participants were asylees and 8 other were legal residents. Table 6 below outlines the demographic data of phase-2 participants.

**Table 6. Photo-Elicitation and In-depth Interviews Participants by Gender, Age, Education, Employment, Marital Status, and Immigration Status**

Research Participants	Gender	Age	Education	Employment	Marital Status	Immigration Status
1	Male	47	AS	U	M	A
2	Male	40	BC	U	M	A
3	Male	42	BC	E	M	LR
4	Male	45	BC	E	M	LR
5	Male	35	AS	E	M	LR
6	Male	41	HS	E	M	LR
7	Male	38	HS	E	M	LR
8	Male	50	AS	E	M	LR
9	Male	41	BC	E	M	LR
10	Male	58	AS	U	M	LR
11	Female	45	HS	U	D	A
12	Female	42	HS	U	M	A
13	Female	42	AS	E	M	LR
14	Female	41	BC	E	M	LR
15	Female	46	VC	E	M	LR
16	Female	45	BC	E	M	LR
17	Female	56	HS	E	M	LR
18	Female	48	HS	E	D	LR
19	Female	35	HS	E	M	LR
20	Female	47	BC	E	M	LR

HS: High School, AS: Associate degree, BC: Bachelor degree, VC: Vocational studies, U: Unemployed, E: Employed, M: Married, D: Divorced, A: Asylee, LR: Legal resident.

### *Theory*

When collecting interview data via photo-elicitation and in-depth interviews, the current inquiry formulated questions around relevant domain (*Relationships* and *Expectations*) of the PEN-3 model to gain further inputs related to the perceptions of diabetes risks among the population of interest. The phase-2 used semi-structured questions—which included eating and physical activity patterns—in order to investigate not only the individual’s perceptions, but also family member experiences and perspectives and the impact of community with regard to diabetes risks.

Questions in the *Relationships* and *Expectations* domain of the PEN-3 model were formulated around the perceptions or attitudes about DRF, societal or structural resources that stimulate or hinder effective health seeking practices, and relatives' or family's influence in nourishing decisions that surround effective management of diabetes risks (Iwelunmor et al., 2014). According to Airhihenbuwa (1995), *Perception*—the first dimension of this domain—refers to knowledge, belief, and values in decision-making that are focused either on persons or groups, underscoring the complementarity of emotion and rationality in behavioral outcomes. The second dimension associated with this domain is the *Enablers*, which focuses on resources and institutional support and wealth as measures of resources and power (Airhihenbuwa, 1995). The last dimension associated with this domain is *Nurturers*, which evokes support and highlights the role of traditions, rules, and expectations (Airhihenbuwa, 1995). While conducting the photo-elicitation and in-depth interviews, participants were asked questions around these three dimensions of the *Relationships* and *Expectations* domain in order to categorize their answers accordingly.

#### *Data Analysis*

Only one domain of the PEN-3 model guided the analysis on this section. That is, the analysis used the *Relationships* and *Expectations* to capture the insights around the perceptions of DRF among Congolese immigrants.

NVivo 11 software was used for the qualitative analysis of data in this section. The primary and two other independent researchers triangulated the data by reading the transcripts, coding them and highlighting conceptual labels, creating categories, and identifying emergent themes that evolved from the data. The emergent themes were then situated within the conceptual framework of the PEN-3 model to ensure that the findings were theoretically based.

Analyzed data were presented back to participants for member checking (Lincoln & Guba, 1985). Only 10 participants (5 males and 5 females) were intentionally selected for member checking and they agreed that the interpretation of phenomenon and themes reflect their perspectives.

### *Results*

A total of six overarching themes emerged through the frameworks of the PEN-3 model. These emergent themes related to the *Relationships* and *Expectations* domain of the PEN-3 model include: “American fast foods cannot be consumed every day, Diabetes is related to sugar /Physical activity benefits” (Perceptions), “Unhealthy foods in supermarkets/Source of information” (Enablers), “Parental influence/I deserve a treat” (Nurturers). Thus, these themes evoke the participants’ perceptions about DRF based on the three dimensions (i.e. Perceptions, Enablers, and Nurturers) of the *Relationships* and *Expectations* domain.

#### Relationships and Expectations Domain

According to Airhihenbuwa and Webster (2004), “the *Relationships* and *Expectations* domain refers to the construction and interpretation of behavior typically based on the interaction between the perception people have about the behavior, along with the resources and institutional forces that encourage or discourage actions, including the influence of family, kin and friends in nurturing the behavior. The following themes were categorized under the three subdomains (*Perceptions*, *Enablers*, and *Nurturers*) of this domain:

*American fast foods cannot be consumed every day / Diabetes is related to Sugar (Perception)*

#### Photo visualization

During the photo-elicitation, participants were presented with pictures representing Congolese foods versus US fast foods in order to spark a conversation about DRF. The

“American fast foods cannot be consumed everyday” theme highlights the values and relationships that promote the perception of diabetes risks in relation to diet among Congolese. The following questions accompanying the pictures were asked of participants during photo-elicitation:

- What do you think about this picture?
- How does it relate to your eating habits?

Speaking about the difference that exists between American fast food and Congolese dietary habits, participants argued that American foods are rich in “fat”, and “sugar”, as opposed to Congolese diet. As a result of that, American fast foods cannot be consumed regularly.

*“I think this (pizza) is good food but not good to consume every day because I always fear with all the added ingredients, which cannot be good for my health... that's why I gave a detail I say no! No! I do not like pork, do not put pork on my pizza because I think pork will give me more fat.” (Male participant #4, 45 years).*

*“I think that everything they sell in the fast food restaurants, they do not think about the effect it can bring to consumers and as we prepare at home then I think that I can take it (happy meal) ... occasionally, so once a month, that's fine” (Female participant #15, 46 years).*

This dimension stresses the belief around the relationship between diabetes and specific foods. For the majority of participants, diabetes is essentially associated with the excessive consumption of sweetened foods. That is, study subjects seem to not recognize the interaction that exists between diabetes and lifestyle in general, nor its relationship with heredity. However, few participants who were able to pinpoint other factors than sweet foods had a friend or relative

who suffers from the disease, but overall there was a consensus among participants in terms of the relationship that exists between dietary habits and diabetes. For instance, participants commented that:

*“I think diabetes is primarily the excess of sugar in the body. The word diabetes evokes sugar and where there is a high consumption of sugary foods” (Male participant #7, 38 years).*

*“Yeah, because if we do not eat properly ... if we do not control diet and we have added sugar levels in the body and this is what causes diabetes” (Female participant #16, 45 years).*

The perception by participants around diabetic risk factors centers or limits diabetes principally or only to the (excessive) consumption of sweetened foods while overlooking other salient factors.

### *Physical Activity Benefits (Perception)*

#### Photo visualization

Here, pictures showing people walking on the street was presented to participants to spark the conversation about the relationship that exists between diabetes and physical activity. Although the participants often do not have the opportunity for greater physical activity, they expressed knowledge of the benefits of physical activity in relation to diabetes. For instance, participants mentioned that:

*“We eat a lot and we need to burn some calories. You consume, but also need to burn what you consume. Physical activity helps us to do it. Physical activity is a consumption of extra calories because when you take too much sugar; it is the extra calories that*

*create fat increase in the body that ultimately give too much weight to the heart. So physical activity is ... is a way to consume these extra calories! The body will be flexible and then what you shall eat there will be no extra that lugs around in your body so to speak” (Male participant #6, 41 years).*

*“A diabetic already has a very high sugar levels in the body and if s/he does physical activities ..., physical exercise allows to burn some calories in the body. While walking is the easiest physical activity one can do, it decreases sugar levels in the body” (Female participant # 11, 45 years).*

The “physical activity benefits” theme underscores that Congolese perceive physical exercise as important and beneficial in regards to diabetes prevention or management, but it does not highlight whether or not they practice it.

#### *Unhealthy Foods in Supermarkets (Enablers)*

The theme stresses that supermarkets—as a resource—do not always offer a variety of healthy food choices, particularly in relation to African foods. Further, the nutritional labels are not easy to read. For instance, participants argued:

*“But these grocery stores... I believe that we must always see, check what suits you, what does not suit you. Keep watching more on labels to see what is mentioned... This gives you an idea about the quality and quantity of calories that the product contains” (Male participant #8, 50 years).*

*“Not me personally, I find that stores do not help people to eat well, because at the entrance there are always sweet stuffs, even when you read food composition; the amount*

*of sugar found in food or drink, it is not written as a percentage, it is written in grams, this doesn't allow the person who consumes the food or the drink to know how many percentage of sugar. We can take for example salt you'll find they write 15% of sodium but for sugar, they write for example 45 gram of sugar. We don't even know what percentage" (Female participant #13, 42 years).*

This “unhealthy foods in supermarkets” theme highlighted the belief among Congolese that the supermarket plays a role in changing or maintaining healthy foods with respect to DRF. Thus, a perceived awareness of unhealthy supermarkets does not result in not shopping there, in part due to a general lack of alternatives or alternatives (like organic food co-ops) that are too distant, too costly, or that do not carry culturally recognizable health (Congolese) foods in the first place.

#### *Source of Information (Enablers)*

The theme “source of information” highlights to whom participants can go to learn about diabetes, since they recognized there is a lot of misinformation associated with diabetic risk factors. Ideally, Congolese are willing to rely on physicians to learn about diabetic matters. This underscores the trust that Congolese have in healthcare professionals when it comes to diabetes. For instance, participants argued:

*“I prefer to talk to specialists, a specialist doctor. Yes, but since he studied this matter and has the expertise. Rather than to go talk to someone, who can misguide me and can give me any ideas that uhh...non verifiable and it can be dangerous” (Male participant #10, 58 years).*

*“I go to the hospital when I have questions about diabetes, I go to the doctor. Doctors can give us information about the disease. They can tell us here are the symptoms of the disease” (Female participant #19, 35 years).*

Thus, this theme stresses that Congolese rely on medical specialists to learn about diabetes and any other factors that might play a significant role. Other sources of information were related to learning about diabetes from a diabetic friend or relative, but only 30% of participants argued that way, as opposed to 60% of participants who relied on medical staff.

#### *Parental Influence (Nurturers)*

Participants (65%) mentioned that they have been influenced by their parents about the primary knowledge they have on diabetes. This does not seem to contradict their willingness to go to physicians to learn about diabetic matters; in both cases, it seems to involve an assumption of authority and generally greater knowledge. At the same time, it denotes the first place where these participants learned about diabetic risk facts. It underscores the important role that parents play generally around the process of learning about diabetes. The majority of participants (65%) acknowledged that they first learned about diabetes through their parents, and in turn, have the same primary influence on their children. Participants commented:

*“Even our parents told us when we were growing up to avoid consuming lots of sugar. Well, when we were young, our parents were saying that we should eat well, even in Kinshasa, we were asked to eat “Bilolo” [a bitter vegetable] is good as it prevents diabetes” (Male participant #3, 42 years).*

*“I told you that I lived with a diabetic so I learned all this ... this is why things like rice ... I saw the doctor asked my mother (diabetic) ... if you eat rice it has to be a small amount*

*because rice has a lot of sugar. ... As always when we were children we were told by our parents if you take too much sugar you'll have diabetes" (Female participant #11, 45 years).*

This theme acknowledges that parents have a primary role in shaping their children's perspectives around diabetes. Most of the participants were told by their parents to reduce consumption of sweetened foods since they relate to or cause diabetes. They remember that lesson for their lives. This highlights the important role parents have and emphasizes the greater risk associated with parental misinformation, since it may tend to be received as more authoritative.

#### *I Deserve a Treat (Nurturers)*

Having a "treat after physical activity" refers to a discouraging influence of families and friends around community events. The theme related exclusively to male participants, who after a soccer match give themselves a treat by gathering together and drinking beer. Comments on this topic, however, were not made only by male participants; female participants also commented upon it.

*"After a soccer match, people are going to drink beer so they are replacing what they have burnt. So! Nothing changes. In short, this is our weak point" (Male participant #9, 41 years).*

*"But there is one thing to go play soccer and another thing to go drink beer right after the match" (Female participant #12, 42 years).*

This theme highlights the fact that male Congolese do engage in physical activity by playing soccer, but the treat that comes afterwards is a discouraging influence that they are aware of.

### *Phase Integrated Summary*

If the quantitative portion suggests an only moderate sense of risk around diabetes, the qualitative portion illuminates reasons why this may be and adds more to the understanding of the quantitative results. In many of the main findings above, we find an ambivalence: a recognition of the benefits of physical activity, but less up-take in practicing it; a recognition of unhealthiness around supermarkets, but enough barriers to alternatives (for various reasons) that they're not taken up; a recognized benefit of playing soccer, coupled with a knowledge that the treat after undermines soccer's benefits. In these sorts of ambivalent cases, there is a kind of "I know I should" or "I know I shouldn't" but "I'll take the risk anyway": whether because drinking beer after soccer with friends is socially pleasurable and beneficial or because no viable or feasible alternative to unhealthy supermarkets exists immediately in the world of the participants.

But there is contained within this "I know I should/shouldn't, but I'll take the risk" the empirical life-experience (of the participants) that so far, taking that risk has not resulted in diabetes. A man has played soccer and drank beer afterwards for years without contracting diabetes so, on an inductive reasoning, it would seem one could continue that indefinitely. Or the person could keep going to unhealthy supermarkets. Or s/he could continue not increasing physical activity. This lived experience of "I haven't contracted diabetes" (yet) points to the only moderate perception of perceived threat. However, some participants argued that beer consumption leads to diabetes.

*“Yes, I think there are sugar in other stuffs...I know things like...beer has sugar that causes diabetes” (Male participants #9, 41 years).*

*“Well, the weakness I wanted to share...after, a physical activity session people will go and drink beer. It looks like they replace what they have spent” (Female participant #11, 45 years).*

In considering the quantitative and qualitative data together in this way, we can see how an only moderate sense of perceived susceptibility around DRF “plays out” in its cultural context, as an ambivalence that (more or less) knows some of those risks, accompanied by decision-making strategies conditioned both by available circumstances and past experiences. Thus, unhealthy supermarkets are a risk, but so far decisions made in that milieu have not resulted in diabetes; or not practicing the acknowledged benefits of increased physical activity has not (yet) resulted in a diagnosis of diabetes. If the latter seems to exacerbate the risk, and the former to mitigate it, we may still note how both represent decision-making strategies and gambits in the face of the risks as presently understood. Contrary to an image that the participants simply don’t know the DRF—and there is certainly some misinformation and/or partial information, a problem shared often enough by the medical community itself—we see them negotiating risks based on their best information.

## CHAPTER 5

### DISCUSSION

#### 5.1 Policy Implications

Findings from the present study have significant public policy implications for diabetes among African immigrants in general, and particularly Congolese living in Illinois. For instance, the estimated cost associated with diabetes expenditure in Illinois in 2011 was 8.98 billion, including 6.6 billion in direct costs and 2.4 billion in indirect costs (e.g. premature death, disability, and work absenteeism) (Illinois Department of Public Health, 2014); effective preventative measures for this avoidable disease potentially puts that money back into the economy and to other ends.

Under the Patient Protection and Affordable Care Act (ACA) or Obamacare, preventative health services have no co-pay—cost nothing—for people with a new plan or one that has changed significantly since March 2013, when the law was passed (Health Care, 2016; Padula, 2012). The ACA therefore recommends that individuals with risk factors such as high blood pressure and obesity to be screened for diabetes at no cost whatsoever. The acceptable screening list includes obesity screening and counseling, diet counseling, and diabetes screening for adults with high blood pressure (Health Care, 2016; Padula, 2012). Although the ACA recommends diabetes screening at no cost, there were 27.8% people undiagnosed with diabetes in 2012 (CDC, 2014). This indicates that the ACA policy about diabetes screening may need to consider cultural competent intervention in order to better attract people, particularly Congolese immigrants, who are more inclined to have health insurance coverage (Ilunga Tshiswaka et al., 2014). Since the findings suggest that Congolese participants trust medical professionals as a source of information, this group would benefit from the ACA's provision, since it would encourage and

permit them to be screened for diabetes. However, this trust for medical professionals does not yet imply compliance with diabetes screening, as the process still must be culturally tailored and competent in order to captivate the targeted community. Thus, the key element here is to elaborate culturally competent screening strategies that can not only attract African immigrants such as Congolese, but also provide the information and motivational resources needed for physically active lives and healthier eating.

The ACA has instructed the Center for Disease Control and Prevention (CDC) to implement a National Diabetes Prevention Program (NDPP) aimed at reducing type-2 diabetes (the most prevalent form of diabetes) by bringing evidence-based lifestyle change to the community (Health Care, 2016; Padula, 2012). The ultimate goal of this program is to show people (e.g. Congolese immigrants), that diabetes onset can be prevented or delayed by changing or adopting specific behaviors such as healthier eating and increased physical activity. Inasmuch as lifestyle changes can improve the health of individuals at risk for developing diabetes by 58% over a three-year period (Padula, 2012), successful implementation of the NDPP could save the country 29.8 billion in medical costs and forestall 885,000 cases of diabetes over the course of 25 years (Padula, 2012). Findings from this study suggest that the success of a preventative program requires the consideration of perceptions (knowledge, attitudes, and values) around diabetes, among immigrant communities such as Congolese and the population in general. Further, the study results suggest that cultural component should be used to ensure that diabetes preventative intervention resonates with participants.

## 5.2 Research Implications

The current inquiry represents a step toward understanding factors that shape the perceptions of DRF among Congolese immigrants. We found that the majority of participants

(both males and females) had comparatively little knowledge related to diabetes risks.

Subsequent research, then, could shed light on what factors predict knowledge of DRF among Congolese and what strategies would foster an increased level of diabetes risk knowledge? With those strategies identified, one could then craft a culturally competent preventative program to decrease or even avert the risk of diabetes.

For some time now, the “healthy immigrant effect” has placed immigrants in better health category as compared to their native-born counterparts. Acculturation has been linked to, if not actually the causal factor for, the deterioration of health among immigrants in general (Uretsky & Mathiesen, 2007). This study more closely explores this implication by identifying the pre-existing perceptions around DRF that Congolese have. In other words, while one might question the healthy immigrant effect at its root—insisting that immigrants may only seem healthier due to undiagnosed conditions or conditions that they are not aware of (Barcellos et al., 2016)—we may take a less “extreme” position by considering this factor of awareness. That is, perceptions around DRF (and disease) in general do not “kick in” at the border but have their beginnings in the country of origin. As such, a culture that generates greater awareness around DRF may seem to be more healthy simply by virtue of recognizing risk factors for a disease.

In this study, while participants stated they learned from parents that diabetes is associated with sweetened-sugar foods, they did not note the association existing between lifestyle in general and diabetes. Also, it seems necessary to more precisely frame this parental assertion. In general, parents do function for Congolese participants as virtually absolute authorities, being placed on par by the participants with the authority of doctors. As such, the insistence that sweet foods cause diabetes functions as much to make a point about health as an assertion of parental authority over what children do or do not eat. In other words, confronted by

a child complaining about not having any sweets, the parental assertion that sweets cause diabetes serves doubly as a moment of medical education and control, and perhaps more often the latter than the former. Further support for this idea comes from the fact that any parental assertion about DRF—medically informed or not—would come imbued with this authority.

### 5.3 Future Research

The current investigation was a cross-sectional study that used a purposive sample and attempted to highlight the perceptions of DRF among Congolese. A subsequent longitudinal study is needed to shed light on the trajectory associated with these perceptions—whether they alter or remain the same over the course of time among Congolese. To compare any such changes over time would also illuminate the degree to which acculturation really does play a role in this and, if so, in what ways (i.e., what specific factors within acculturation play a role)? For parental authority, for example, children of African immigrants often learn in the US that they can counter their parents’ authority by threatening to call Child Protective Services (Rombo & Lutomia, 2016).

Under the qualitative phase, only the *Relationships and Expectations* domain of the PEN-3 model guided our analysis. Additional research is needed using the other two domains (*Cultural Identity* and *Cultural Empowerment*), to further articulate strategies for diabetes prevention. *Cultural Identity* will be needed to identify the point of entry for implementing a program (i.e., neighborhood, extended family members, at the level of the individual); *Cultural Empowerment* will identify positive, existential, and negative cultural factors that play a significant role in terms of DRF (e.g., the “valence” of parental authority, and whether it could strategically be used or should be avoided as a strategy for reaching those at risk for contract diabetes).

#### 5.4 Proposed Campaign Synopsis

According to the Champaign-Urbana Public Health District (2014), as of 2013, Champaign county was home to 204,897 people; 12.5% of them Black, and all of them are at potential increasing risk of diabetes. The present study, then, sets the stage for a successful DRF reduction program that takes into account the role of culture with respect to DRF among a sector of that community: Congolese immigrants. Such a program, however, not only promises a locally well-tailored, culturally competent program of intervention, but one potentially replicable in areas similar to Champaign county with respect to population size, demographics, and business types.

The purpose of this cost-effective campaign pilot proposal is to implement, conduct, and evaluate a diabetes prevention program among French-speaking Congolese immigrants in the Champaign area, a community both significantly at-risk for and in need of preventative diabetes interventions, and one of the Champaign county area's largest immigrant groups (Ilunga Tshiswaka et al., 2014). One major gesture of this culturally competent endeavor, then, involves translating any DRF reduction materials into languages spoken by Congolese immigrants (French, if not also Lingala).

The proposal campaign would consist of a health fair at which Congolese people living in Champaign would be invited to participate. The health fair would take place in a local church that already has numerous Congolese immigrant members. This intervention program is intended primarily for people without already existing diabetes in order to increase perceptions and knowledge around DRF—an area this study identified as lacking.

Champaign-Urbana local hospitals and Public Health Department would be invited to have some booths with brochures that explain things that Congolese people need to know

relating to DRF. However, the brochures would reflect culturally relevant materials presented in a culturally competent way. That is, there would be not only (relevant) nutritional information related to the types and availability of food that Congolese people eat in Champaign county, but also with the information framed in a way that addresses people of a Congolese background. Information could be of the type to advocate not drinking beer right after a leisure soccer match or dancing more often as a way to increase physical activity.

Participants would have the possibility of being screened for diabetes. There would be health professionals screening for diabetes and educating participants in relation to physical activity and healthy eating habits. In each booth, there would be interpreters to make sure that no one leaves the health fair without having questions answered.

Participants would also be encouraged to change or improve their health behaviors through healthier diet, avoiding smoking behaviors, and increasing physical activity (i.e. 150 minutes of moderate aerobic activity per week) (Laskowski, 2014). Again, however, such information must, and will be, presented in a culturally competent way.

An important part of this current proposal involves leveraging the authority of Congolese parents identified by this study and to empower them with correct information around the prevention of diabetes for their children. In the process of “teaching” their children, they will also be reinforcing a diabetes prevention discourse for themselves. This approach specifically addresses not only the lack of knowledge around this group’s association of diabetes and the consumption of sweetened-sugar foods identified by this study but also that the Congolese participants had primarily learned about diabetes risks from their parents, with this information being incomplete.

A conventional gesture at health fairs is to have health professionals present the information. This at least lends an air of authority to the warnings and cautions and facts being presented. In one sense, this approach would be beneficial for Congolese, as this study identified that Congolese trust the medical staff. However, we see from the results that this study's participants did not refer to "health care professionals" but to "doctors":

*I go to the hospital when I have questions about diabetes, I go to the doctor.*

*Doctors can give us information about the disease. They can tell us here are the symptoms of the disease (Female participant #19, 35 years).*

Moreover, this is framed specifically within a context of not being misled by false information:

*I prefer to talk to specialists, a specialist doctor. Yes, but since he studied this matter and has the expertise. Rather than to go talk to someone, who can misguide me and can give me any ideas that uhh...non verifiable and it can be dangerous (Male participant #10, 58 years).*

In this light, we must be cautious about too quickly assuming that Congolese would positively receive *any* health care professional as speaking authoritatively on these matters.

An overarching goal of the health education involves merely "putting the information out there" and persuading people to look into preventative measures for diabetes or simply to change their lifestyle and eating habits in a healthier way. If the people delivering this information are not perceived as speaking authoritatively, then a pamphlet of medically accurate information will likely not make it back to the person's home. As such, it may be that doctors—not other health care professionals or administrators—are the right people to deliver this message.

As a related note, while some dispute continues around the issue, researchers have noted that hurricanes with female names have proven more dangerous, because people take them less seriously. In other words, researchers implicate US culture's ambient sexism as a reason for people taking fewer precautions against female-named hurricanes (Jung, Shavitt, Viswanathan, & Hilbe, 2014a). While B. Christensen and Christensen (2014) have disputed this claim and the original authors have defended their work (Jung, Shavitt, Viswanathan, & Hilbe, 2014b), the issue underscores the necessity of considering whether female-bodied "health professionals" would be perceived as authoritatively as male-bodied ones. This already likely has a gendered bias; that is, the male quoted above who refers to doctors uses the pronoun "he"; while the female participants use the pronoun "they". If we may tentatively say at this point that the default or assumed pronoun for "doctor" would be "he", by contrast, for the "parent" who delivers information about diabetes—like eating sweets causes diabetes—the default pronoun is likely "she" because this will most often be the child's mother.

Again, because the overarching goal of this proposal involves persuading people to change their lifestyle and eating habits, that such persuasion happens in the most authoritative way means not only that "Just the facts" will not do, but also that we must consider the cultural norms around who is perceived as authoritative.

## 5.5 Limitations

A principal limitation of this study involves its purposive sampling, since it in principle limits the generalization of the findings to Congolese living in other areas of the US. As such, while this represents a limitation of the study, it nonetheless captures the actual local situation researchers will tend to encounter doing similar work with immigrants in the US.

Social desirability bias was another limitation associated with this inquiry, given the fact that the principal investigator knew personally the majority of participants involved in the study. Social desirability effect refers to systematic error in self-report measures resulting from the tendency of participants to avoid embarrassment and project a favorable image to others (Fisher, 1993).

The study's participants also included only Congolese aged at least 35 years. Not all Congolese immigrants living in Champaign had the chance to be selected and participated in this study, as the inquiry relied on purposive sampling technique. That is, the selection of participants was biased, since the primary investigator was the only person selecting participants intentionally. Again, however, this arises partly as a matter of the research topic. While diabetes and the reduction of DRF are public policy concerns for adults and children alike, to find points of entry for intervening into these issues arises more likely with the adult communities, who may also function as parents.

For the quantitative portion, the use of a standardize questionnaire raises questions less about the validity of questionnaires in general and more about the capacity of the survey used to capture all of the needed or relevant information for this study. On the one hand, for instance, the survey included questions about environmental factors related to diabetes that were not directly associated with this investigation; on the other hand, the survey did not ask questions (for instance, about sources of information in survey-takers knowledge about diabetes) that could have been relevant for this study. By relying upon an already-vetted survey instrument, we sacrificed the greater precision of information gathering that would have resulted if we'd crafted our own (untested and not-yet-validated) questionnaire in exchange for the already-vetted but not necessarily perfectly relevant information collected by the survey we used. While methodologies

for crafting valid questionnaires have existed for a while (Foddy, 1994; McDowell, 2006), even a well-made, newly crafted questionnaire requires testing and further modification in order to feel assured of its validity and reliability. Moreover, our purpose in this study was to take the state of knowledge reported on such a standardized questionnaire as an input or lens on the qualitative data later collected.

Overall, this study sheds light on the perceptions of DRF among Congolese, a relatively new community of African immigrants in Illinois. Nuancing some methodological shortcomings of treating the entire contingent of black people living in the US as homogenous, the approach in this investigation serves to illuminate not only factors around DRF among Congolese immigrants elsewhere in the US but also among any culturally distinguishable population within otherwise assumed-homogenous groups. The study provides a foundation for the premise—and a proposed, practical implementation of a preventative strategy for DRF reduction among a specific population—that public policy health interventions will be more effective when crafted in a culturally competent way with respect to the demographic group in question.

## 5.6 Conclusions

The current inquiry investigated questions related to perceptions of DRF among Congolese immigrants, disambiguated from an assumed homogeneity with the cohort of Black people in the US generally. While people of black descent have a higher prevalence of diabetes compared to other racially distinguished groups in the US, factors such as poverty, heredity, and lifestyle have been identified as DRF for the “Black” cohort in general. Locally, the incidence rate of diabetes continues to escalate among people of African descent in Illinois. This grounds a clear need to understand what other, possibly untested-for or unseen, factors might play a role in the incidence of diabetes among this cohort.

This study identifies one of those “hidden” factors as culture, which researchers most of the time overlook or do not include when attempting to generalize medical knowledge with regard to chronic diseases like diabetes and, more significantly, when seeking to craft policy interventions to eliminate, reduce, or mitigate those diseases.

In Champaign, Congolese immigrants comprise one of the fastest growing Francophone communities in the area. If the quantitative portion of this study suggests an only moderate perceived sense of risk around diabetes, the qualitative portion illuminates reasons why this may be and adds more to our understanding of the quantitative results; it informs data with a sense of culture. As such, the results yielded that Congolese, in general, have their prevailing way of understanding and interpreting DRF. For instance, they believe that diabetes is specifically related to the excessive consumption of sugary foods or drinks, congruent with medical findings that report sugar-sweetened beverages associated with a higher risk of diabetes. Congolese reported obtaining this belief from their parents when they were young, so that they, in turn, are conveying the same belief to their offspring, which stresses the significant role that parents (an authority shared in principle by doctors as well) play in shaping the views and perceptions around DRF. By contrast, the majority of participants did not see the direct connection between diabetes and lifestyle; those who did, generally learnt so through a diabetic friend or relative.

In terms of public policy implications and recommendations, this study provides evidence-based findings around perceptions of DRF among Congolese immigrants. As such, the findings from this inquiry illustrate the salience of a cultural component when planning and crafting intervention programs aimed at reducing the incidence of diabetes, particularly those supported under the ACA. At a minimum, the current study’s findings point the ACA policy

around offering diabetes screening tests at no cost to people with health insurance as a right and crucial direction to go.

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## APPENDIX A: SCREENING QUESTIONS

- How long have you lived in the US?

Less than 1 year

More than 1 year

- How old are? \_\_\_\_\_

- Are you currently diagnosed with diabetes?

\_\_\_\_\_

## APPENDIX B: IN-DEPTH INTERVIEWS USING PEN-3 MODEL

### Cultural identity (person, extended family, neighborhood)

#### Individual and Family History

- When you think of the word “diabetes,” what first comes to mind?
  - What influenced you to have these thoughts about diabetes?
- Do you or any of your family members have experience with diabetes?
  - What are their (i.e. family members) thoughts or experience with diabetes?
  - What factors do you think influence your or your family members to have these thoughts about diabetes?
- Who do you go to when you have questions about diabetes?

#### Eat Right

- (For Facilitator- According to CDC) **Learning how to eat right is an important part of controlling diabetes.** What does this mean to you?
  - Why is it important to eat right given diabetes?
- What do you think of grocery stores and supermarkets in the neighborhood where you live?
  - Can you describe the ways in which these grocery stores/other food shopping places help people to eat right given diabetes?

#### Physical Activity

- (For Facilitator: According to CDC) It is important for people with diabetes to be physically active. What does this mean to you?

- Why do you think it is important to be physically active given diabetes?
- What is your impression of physical environment such as parks or walking trails in the neighborhood you live?
  - Can you describe the ways in which these physical environments help people to become physically active?

**Relationships and expectations (perceptions, enablers, nurturers)**

- What are your thoughts on relationship between Congolese people’s eating habits and diabetes?
- When was the last time you received food, nutrition or eating information about Congolese diet and diabetes?
- (If information) Where did you receive this information?
- What did you think of the information you received?
- (If no information) What information on healthy eating would be helpful for you or Congolese people in the community about diabetes?
- What are some places where displaying messages about diabetes to reach other Congolese people would be helpful?

**Cultural empowerment (positive, existential, negative)**

- How does being a Congolese person impact what (foods) you eat?
- Who influences what you eat on a daily basis?
- Can you share examples of “Congolese food.”
- Describe how you prepare Congolese food.

- What do you see as the strengths of Congolese foods with diabetes prevention?
- What do you see as the weaknesses of Congolese foods with diabetes prevention?
- How does being a Congolese person impact being physically active?
- Who influences to be physically active on a daily basis?
- Can you share examples of activities you perform to be active?
- What do you see as the strength of Congolese culture with becoming physically active?
- What do you see as the weakness with Congolese culture with becoming physically active?
- Is there anything else you would like to share?

Thank you!

## APPENDIX C: SURVEY QUESTIONS

### DEMOGRAPHICS

1. What is your gender?

Female \_\_\_\_\_

Male \_\_\_\_\_

2. What is your age? \_\_\_\_\_

3. What is your region of origin (tribe)? \_\_\_\_\_

4. What is your educational level?

Elementary school \_\_\_\_\_

Middle school \_\_\_\_\_

High school \_\_\_\_\_

College \_\_\_\_\_

Bachelor \_\_\_\_\_

Grads school \_\_\_\_\_

5. What is your marital status?

Married \_\_\_\_\_

Single \_\_\_\_\_

Divorced/Separated \_\_\_\_\_

Widow (er) \_\_\_\_\_

6. How many children do you have? \_\_\_\_\_

7. What is your income status?

Less than \$18,000 \_\_\_\_\_

\$19,000 - \$22,000 \_\_\_\_\_

\$23,000 - \$26,000 \_\_\_\_\_

\$27,000 - \$30,000 \_\_\_\_\_

\$31,000 - \$34,000 \_\_\_\_\_

More than \$35,000 \_\_\_\_\_

## ATTITUDES ABOUT HEALTH

This survey will provide important information about how people feel about the risk of getting a chronic disease, like diabetes. There are no right or wrong answers. We are interested in *your* opinions and attitudes. Please answer each question as best as you can.

### General Attitudes

For each item, please circle the number below the response that BEST DESCRIBES YOUR OPINION.

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly disagree</b>
1. I feel that I have little control over risks to my health.	1	2	3	4
2. If I am going to get diabetes, there is not much I can do about it.	1	2	3	4
3. I think that my personal efforts will help control my risks of getting diabetes.	1	2	3	4
4. People who make a good effort to control the risks of getting diabetes are much less likely to get diabetes.	1	2	3	4
5. I worry about getting diabetes.	1	2	3	4
6. Compared to other people of my same age and sex (gender), I am <i>less</i> likely than they are to get diabetes.	1	2	3	4
7. Compared to other people of my same age and sex (gender), I am <i>less</i> likely than they are to get a serious disease.	1	2	3	4
8. Worrying about getting diabetes is very upsetting.	1	2	3	4

**Your Attitudes about Health Risks**

Below is a list of health problems and diseases. For each one, please circle the number below the words to tell us if you think **your own personal health** is at "almost no risk," "slight risk," "moderate risk" or "high risk" from these problems.

If you, or a family member, already have the disease (or had the disease in the past), please *also* check (✓) the appropriate line on the right.



	<b>Almost No Risk</b>	<b>Slight Risk</b>	<b>Moderate Risk</b>	<b>High Risk</b>	<b>Have(or had) this disease:</b>	
					<i>myself</i>	<i>family member</i>
9. Arthritis	1	2	3	4	_____	_____
10. Heart Disease	1	2	3	4	_____	_____
11. Cancer	1	2	3	4	_____	_____
12. High blood pressure	1	2	3	4	_____	_____
13. Hearing loss	1	2	3	4	_____	_____
14. Asthma	1	2	3	4	_____	_____
15. Diabetes	1	2	3	4	_____	_____
16. Osteoporosis (bone disease)	1	2	3	4	_____	_____
17. Stroke	1	2	3	4	_____	_____
18. Blindness	1	2	3	4	_____	_____
19. Foot amputation	1	2	3	4	_____	_____
20. Infections needing treatment by a doctor	1	2	3	4	_____	_____
21. Impotence (only in men)	1	2	3	4	_____	_____
22. Kidney failure	1	2	3	4	_____	_____
23. AIDS	1	2	3	4	_____	_____

### Environmental Health Risks

Below is a list of possible hazards or dangerous conditions in the environment around most of us.

For each one, please circle the number below the words to tell us if your **own personal health** is at "almost no risk," "slight risk," "moderate risk" or "high risk" from each of the following hazards or conditions.

	<b>Almost No Risk</b>	<b>Slight Risk</b>	<b>Moderate Risk</b>	<b>High Risk</b>
24. Medical X-rays (radiation)	1	2	3	4
25. Violent crime	1	2	3	4
26. Extreme weather (hot or cold)	1	2	3	4
27. Driving/riding in an automobile	1	2	3	4
28. "Street" drugs (illegal drugs)	1	2	3	4
29. Air pollution	1	2	3	4
30. Pesticides	1	2	3	4
31. Household chemicals	1	2	3	4
32. Cigarette smoke from people smoking around you	1	2	3	4

**Risks of Getting Diabetes for People in the General Public**

We would like you to **think about people in the general public** and NOT about your own personal risk of getting diabetes.

Circle the number below the words that best describe your opinion about whether each item listed below *increases (or raises) the risk* of someone getting diabetes, *has no effect on the risk*, or *decreases (or lowers) the risk* of someone getting diabetes.

	<b>Increases the risk</b>	<b>Has NO effect on risk</b>	<b>Decreases the risk</b>	<b>Don't Know</b>
33. Being Asian American	1	2	3	0
34. Being Caucasian (White)	1	2	3	0
35. Eating a healthy diet	1	2	3	0
36. Being Black or African-American	1	2	3	0
37. Being Hispanic	1	2	3	0
38. Having had diabetes during pregnancy	1	2	3	0
39. Having a blood relative with diabetes	1	2	3	0
40. Being 65 years of age or older	1	2	3	0
41. Exercising regularly	1	2	3	0
42. Being American Indian	1	2	3	0
43. Controlling weight gain	1	2	3	0

**Thanks!**