

2020

## Health Literacy and Diabetes Among Refugee Women Residing in Arizona

Aline Nina Indatwa  
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# Walden University

College of Health Sciences

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Aline N Indatwa

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Walden University  
2020

Abstract

Health Literacy and Diabetes Among Refugee Women Residing in Arizona

By

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MPH, Grand Canyon University, 2015

BHSC, University of South Dakota, 2013

Dissertation Submitted in Partial Fulfillment

of the requirements for the Degree of

Doctor of Philosophy

Public Health

Walden University

February 2020

## Abstract

There is limited research available linking health literacy and diabetes knowledge to poor health outcomes among refugees. The aim of this study was to determine the levels of health literacy and diabetes knowledge and examine whether different factors (age, education, employment status, number of years lived with diabetes and length of stay since resettlement) are associated with health literacy and diabetes knowledge. A cross-sectional study was performed among 82 refugee women with a known diagnosis of diabetes and residing in Maricopa County, Arizona. A modified two part questionnaire (self-reported health literacy extracted from the European Health Literacy Questionnaire [HLS-EU-Q16] and diabetes knowledge was measured using the Spoken Knowledge in Low Literacy in Diabetes [SKILLD] tool) was used. Simple and multiple logistic regressions statistical methods were used to examine the associations between health literacy, diabetes knowledge and variables. 76.8% ( $N=63$ ) reported Low Health Literacy and 53.7% ( $N=44$ ) reported low diabetes knowledge. Low education was associated with low health literacy and years lived with diabetes was associated with diabetes knowledge. No significant associations were established between other variables and, health literacy or diabetes knowledge levels. Health care providers, public and private health sectors are therefore urged to develop evidence-based interventions that seek to address health literacy among refugee women at the individual and systematic levels. There is need for more research to better understand all the factors that are associated with health literacy, production of refugee-relevant educational material that will increase health literacy skills and reduce health disparities.

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## Dedication

Dear Mama Nyirarugo Miriam

It is extremely unfortunate that you grew up at a time and in a community that did not allow a girl child to go school. However, if your wisdom was to be combined with an education, I wonder what your life would be like today. You would not have had to sell things on the streets so your children can eat and go to school. This dissertation is dedicated to you. Thank you for giving me life, and for your support and continuous love. You are my rock and I love you Mama.

Special dedication goes to my late sister Maneza Mado Alice, whose life was involuntarily taken by rebels in the Gatumba Massacre, at age 25. Your life was a one-way ticket for our family to come to the United States. My heart hurts every time I think about how we are finally leaving a peaceful life without you around. You were and still are my role model. You will forever be cherished and loved.

I also dedicate this study to my superhero Dad Gahakanyi Jerome Maturutsa. Thank you for instilling the value of education in me at an early age. As an educator yourself, you made sure that school was always my priority. I am not mad at you anymore for making me repeat third grade even when I ranked 3<sup>rd</sup> among 46 students. You were preparing me for moments like these. I love you dad.

Finally, to the thousands of Banyamulenge women who never had a chance to go to school, to those who are still struggling to break societal norms and follow their dreams, and to all those who are breaking barriers, excelling in their education and changing the narrative of a Munyamulenge women; I dedicate this to you too.

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## Chapter 1: Introduction to the Study

### **Background of the Study**

Yun et al. (2012) defined a refugee as someone who is unable to return to their home country due to several reasons, such as persecution or fear of persecution because of their race, religion, nationality, membership to a certain social group, or political affiliation. It is important to highlight the distinction between a migrant and a refugee as authors in refugee studies have often used them interchangeably yet fundamental distinctions exist. Unlike a refugee described above, a migrant may choose to move to another country in search of better prospects and not entirely as a result of potential threat to their life (Edwards, 2015).

The factors that are associated with both situations may overlap. And these factors have been categorized into two groups; “push factors”—described as those that pose some negative influence to leave native country such as persecution, poverty, conflict; and “pull factors”—described as being the positive factors that influence an individual to choose settling in another country such as economic stability, employment opportunities, better socioeconomic prospects and better healthcare systems (Montesi et al., 2016). Such factors vary from individual to individual and from population to population. The profile of migrants is changing. In previous centuries, migration was mostly among farmers and general workmen. There has now been a shift to more educated individuals migrating to industrialized nations (Montesi et al., 2016; Misra & Ganda, 2007). However, this may not entirely be reflective of the current wave of refugees seeking refuge in countries other than their own as a result of various turmoil and conflicts.

As at the end of 2017, the United Nations High Commissioner for Refugees (UNHCR) estimated that approximately 65.6 million individuals were displaced worldwide (UNHCR, 2017), and studies have shown that this number is not expected to decrease, due to the rising conflicts, terrorism, and economic uncertainties (Montesi et al., 2016). In the United States, more than three million refugees have been resettled since the United States Refugee Act of 1980 was passed by congress (Krogstad & Radford, 2017). The state of Arizona is one of the states that resettles a significant number of refugees in the United States. The Arizona Department of Health Services reported that more than 62,000 refugees from 109 countries between the years 1980–2013 have been resettled in Arizona, with highest number of refugees resettling in Maricopa County (AZDHS, 2013). Of this total, 46% were women and the average age was 26 years (AZDHS, 2013). The United Nations reported that around half of the refugees worldwide are women (United Nations, 2016). By understanding issues that affect refugee women; I addressed knowledge gaps and developed sustainable and inclusive policies.

There is some evidence of a reduction in number of refugees resettling in the United States under the current U.S administration; however the need to study health threats associated with refugee women is still evident. There is a growing burden to the US healthcare system due to growing concerns of transmissible diseases and noncommunicable diseases (NCDs), which are becoming major health problems among refugee populations. Little is known about the extent to which these affect refugee women and the refugee population in general. Conditions such as diabetes are fast becoming major public health threats among the United States population and refugees

(Montesi et al., 2016). Globally, the World Health Organization (WHO; 2017) estimates that there has been an increase in number of people with diabetes from 108 million in 1980 to 422 million in 2014 and is estimated to increase to 7.7% of global disease burden, accounting for 439 million adults by 2030 (WHO, 2017). Estimates from the United States suggest that as many as 30.3 million people were affected in 2015 and the number is estimated to increase to at least 54.9 million between the years 2015 and 2030 (CDC, 2017; & Rowley et al., 2017). Not much is known, however, about the extent of the problem among refugee women and the refugee population in the United States in general, as not many studies have been conducted. However, some authors attempted to study the prevalence of NCDs such as diabetes in migrant populations within the United States, which is not entirely reflective of the estimates among refugee population as the terms migrant and refugee have been identified as not being interchangeable, by commentators such as (Montesi et al., 2016), . However, the majority of refugees are coming from developing countries and estimates from these countries suggest that the number of adults being diagnosed with diabetes will increase by 69% (Shaw, Sicree, & Zimmet, 2010). These estimates were my inspiration to study various diabetes-related impacts on refugee women.

Refugee women are prone to various negative health issues such as sexual harassment, communicable diseases, NCDs and poor mental health, compared to native populations. Poor socioeconomic background, sociocultural issues, refugee crisis, migration and resettlement processes, and other social determinants of health are some factors that contribute to poor health among refugee women (Wangdahl et al., 2014).



Despite successfully resettling into the United States, barriers to good healthcare exist among refugee women, especially for conditions such as diabetes. Poor integration, limited knowledge of the healthcare system, language and cultural barriers, and failure to understand the impact of diabetes on their health are some of the challenges hindering effective management of conditions such as diabetes among refugee women (Adu-Boahene et al., 2017). These may all be described under the umbrella of health literacy, which the Center for Health Literacy Promotion defined as the “degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions” (Center for Health Literacy Promotion, 2013). Ultimately, health literacy is about taking ownership of one’s health. Wangdahl et al., (2014) described health literacy as a major contributory factor to poor health among refugees. Understanding the levels of health literacy and diabetes knowledge among refugee women with diabetes remains an understudied issue.

Few studies have attempted to study health literacy levels among refugee women with diabetes. Gender plays a major role within refugee communities and different sociocultural norms may affect health literacy levels between and within the genders (Floyd & Sakellariou, 2017). Women play a major role in safeguarding health through dietary practices such as in studies conducted among Bhutanese refugee women in Ohio. In these studies, the authors found that certain dietary practices such as excess meat consumption, soft drinks, and sweetened fruit juices were found to be catalytic for chronic diseases such as diabetes (Bhatta et al., 2014). However, no evidence of health literacy was elucidated.

Education affects health literacy either positively or negatively, especially among refugee women. Refugee women were found to be less educated, more illiterate, and had poor English language proficiency compared to their male counterparts (Floyd and Sakellariou, 2017). Such evidence therefore warranted the need for me to study health literacy levels among refugee women in Arizona. I therefore aimed to identify health literacy disparities and suggest recommendations to address them.

### **Problem Statement**

Nothing is known about health literacy and diabetes knowledge levels for noncommunicable diseases (NCDs) such as diabetes, among refugee women residing in the state of Arizona. Despite some authors showing that diabetes and other chronic NCDs and associated risk factors (including, but not limited to, lifestyle, post-traumatic events, environmental factors, and genetic factors) pose significant challenges among refugees (Berkowitz et al., 2016; Montesi et al., 2016), much of what has been studied generally focuses on communicable diseases and mental health (Yun et al., 2012). This paucity in research presented an urgent need to understand the specific problem relating to lack of data on levels of health literacy and diabetes knowledge among refugee women with diabetes in the state of Arizona.

Conclusive data on diabetes prevalence estimates from which health literacy can be determined was also lacking. Benoit et al. (2016), attempted to analyze medical reports of 248,850 United States-bound refugees, and established that 5767 (2.3%) had diabetes. While the estimates provided by Benoit et al. (2016) may seem to be low, the rising numbers of refugees and the limited studies among these refugee populations

provided a thrust for me to understand the levels of health literacy and diabetes knowledge among refugee women residing in the state of Arizona. This is due to high number of cases at risk, duration of diseases, length of stay in the United States, associated healthcare costs, as well as availability of effective measures of prevention and treatment (Berkowitz et al., 2016; & Montesi et al., 2016). For conditions such as diabetes, understanding health literacy and diabetes knowledge levels would therefore be essential in (a) attempting to reduce any health literacy disparities, (b) addressing any socioeconomic barriers to improving health literacy, (c) identifying possible solutions to ensure equitable access to health information and thus ensuring an increased number of health literate refugee women, and (d) reducing burden on the United States healthcare system.

### **Purpose of the Study**

The main purpose of this study was to determine the levels of health literacy and diabetes knowledge among refugee women with a known diagnosis of diabetes who have resettled in the state of Arizona. Further purposes of the study were to explore the levels of health literacy and diabetes knowledge and understand whether different factors affecting health literacy and diabetes knowledge levels, were in existence. I employed social determinants such as age, education, employment, as well as other factors such as number of years lived with diabetes and length of stay or resettlement in Maricopa County, Arizona. I used epidemiological methodology to explain the complex relationships that exist between health literacy and diabetes knowledge levels and the aforementioned factors.

### **Research Question(s) and Hypotheses**

Research Question 1 (RQ1): What are the health literacy and diabetes knowledge levels among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona?

Research Question 2 (RQ2): How does health literacy and diabetes knowledge levels differ among refugee women with a known diagnosis of diabetes when stratified by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement.

Null Hypothesis ( $H_02$ ): Health literacy and diabetes knowledge did not differ by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement, among refugee women with a known diagnosis of diabetes

Alternative Hypothesis ( $H_a2$ ): Health literacy and diabetes knowledge differed by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement, among refugee women with a known diagnosis of diabetes

Research Question 3 (RQ3): What is the association between health literacy and diabetes knowledge levels and age, education, employment status, number of years lived with diabetes and length of stay since resettlement, among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona?

Null Hypothesis ( $H_03$ ): Age, education, employment status, number of years lived with diabetes and length of stay since resettlement had no effect on health literacy and diabetes knowledge levels among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona.

Alternative Hypothesis ( $H_{a3}$ ): Age, education, employment status, number of years lived with diabetes and length of stay since resettlement had an effect on health literacy and diabetes knowledge levels among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona.

### **Conceptual Framework**

A few frameworks relating to health literacy have been utilized in the development and evaluation of health literacy-related interventions, for example health literacy skills (HLS) theory (Squiers et al., 2012). This framework offers valuable information that may assist in understanding the differences in the levels of health literacy among refugee women in Maricopa County, Arizona. There is merit in its ability to provide (a) assumptions of an intrinsic relationship between health literacy and the aforementioned social determinants, (b) multilevel linkages between health literacy and the aforementioned determinants i.e. individual-level and contextual-level such as refugee women's family, surrounding environment, their sociocultural habits, work etc., (c) validated conclusions as a result of its extensive utilization in other studies of health literacy, and (d) health literacy information from different study demographics i.e. applicable towards a variety of study populations.

I used the framework for insights into the different levels of health literacy among refugee women and would elucidate knowledge gaps that require addressing. Where health literacy disparities were observed, I used the framework in an attempt to identify various individual and context-level barriers among refugee women with diabetes residing in Maricopa County, Arizona.

To answer the research questions, I linked the HLS framework to the widely-used and validated tool for studying health literacy among diabetes patients, the Spoken Knowledge in Low Literacy in Diabetes (SKILLD) Scale (Rothman et al., 2005; Jeppessen et al., 2012; & Peña-Purcell et al., 2014). I focused diabetes knowledge and employment of SKILLD tool to identify diabetes knowledge gaps and translated that knowledge into health literacy deficits.

### **Nature of the Study**

This study was quantitative in nature. I used a cross-sectional study design to focus on refugee women residing in Maricopa County, Arizona. I used purposive sampling to select the study population of refugee women with diabetes residing in Maricopa County, Arizona, from selected sites such as health centers, churches, and community centers. I used purposive sampling because I addressed a specific knowledge gap for a defined subset of the refugee population.

A primary inclusion criterion following identification of refugee women was known diagnosis of diabetes. Information on health literacy and diabetes knowledge levels was by designing a questionnaire that is grounded on elements of the SKILLD tool. This allowed the researcher to obtain quantitative data that could be used to estimate levels of diabetes-related health literacy among refugee women with diabetes. I considered interpretation of the questionnaire by cultural health navigators (CHNs) for specifically identified refugee population groups that had limited English language proficiency. I conducted the analysis of the data using SPSS, and both simple and multiple regression analytical techniques were applied to elucidate the relationships

between health literacy and diabetes knowledge and the identified social determinants of health.

### **Definitions**

[All definitions must be given in alphabetical order. Please change the order of your definitions.]

*Diabetes: is the condition in which the body does not properly process food for use as energy (CDC, 2017).*

*Health literacy: degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions (Center for Health Literacy Promotion, 2013).*

*HLS (Health Literacy Skills): a conceptual framework that hypothesizes the relations between health literacy and health-related outcomes and depicts how health literacy functions at the level of the individual (Squiers et al., 2012).*

*Refugee: someone who is unable to return to their home country due to several reasons, such as persecution or fear of persecution because of one's race, religion, nationality, member of a certain social group, or political affiliation*

*SKILLD: Spoken Knowledge in Low Literacy in Diabetes, a tool designed to assess knowledge of diabetes (Rothman et al., 2005).*

### **Significance of the Study**

#### **Significance to Theory**

Some authors have attempted to highlight the impact of health literacy on poor health outcomes among refugee population groups (Gele et al., 2016; Njeru et al., 2016;

Wangdahl et al., 2014); however, this information does not capture health literacy deficits among refugee women with diabetes. My goal was to fill this knowledge gap, to offer new thinking around health literacy deficits among refugee women with diabetes, and suggest sustainable interventions to improve health literacy and diabetes knowledge levels. As earlier described, some evidence exists highlighting the importance of studies among refugee women, and commentators like Floyd & Sakellariou. (2017) reiterated the importance to establish disparities in various health literacy-related issues among refugee women (Floyd & Sakellariou, 2017). Thus, the proposed research offered valuable insights into the theory around health literacy and the effects of social determinants of health thereof, among refugee women with diabetes in Maricopa County, Arizona. By conducting the research, I aimed to understand how the disparities added to the body of knowledge focusing on key issues that affect refugees, and how this information influenced policies that ensured development of sustainable interventions.

I utilized the information obtained from the study to better understand how healthcare services can be developed and tailored to meet the healthcare needs of refugee women with diabetes residing in Maricopa County, Arizona by (a) developing diabetes-related healthcare information that is targeted towards refugee women and is able to address gender-specific healthcare needs, (b) ensuring availability of education services that aim to address any disparities in accessing information on lifestyle modification such as health cooking since refugee women play a significant role in dietary practices within the refugee population and (c) ensuring availability of responsive healthcare services that can be easily navigated by refugee women residing in Maricopa County, Arizona.



Additional theoretical implications included effects of the identified social determinants on the health literacy and the potential policy implications around securing education for refugee women to improve general literacy, and provision of employment opportunities that empower refugee women to improve their overall socioeconomic status, which could be seen as a determinant for health literacy among refugee women with diabetes residing in Maricopa County, Arizona.

### **Significance to Practice**

Several researchers have affirmed that, due to inadequate health literacy and diabetes knowledge, refugee populations with known diagnoses of diabetes have generally negative perceptions and experiences with the United States healthcare delivery system and poorer management of diabetes (Bailey et al., 2014). Limited health literacy is associated with higher mortality rates, health disparities, increased costs, increased emergency visits and hospitalization, and worse overall health status (Hersh, Salzman, & Snyderman, 2015). Studying health literacy among refugee women with diabetes was relevant to public health practice, as it allowed me to understand how much attention should be devoted by public health professionals to improving health literacy among refugee women with diabetes. This would, in the long run, help public health professionals to develop programs that address sociocultural differences affecting refugee women with diabetes. Additionally, studying health literacy among this population was very significant to improving healthcare providers' knowledge about factors affecting refugee women with diabetes. Overall, this provided an opportunity for healthcare providers to develop and implement interventions that aimed to improve health literacy

and diabetes knowledge, thus potentially improving the health outcomes among refugee women with diabetes.

### **Significance to Social Change**

Improving health literacy and diabetes knowledge among refugee women with diabetes would have several positive social change effects. For instance, an increase in health literacy among refugee women with diabetes would help them become more involved in their healthcare plans, health services and activities. Increasing health literacy and having a better understanding of diabetes would help them better manage their diabetes. Riggs et al. (2016) stated that improving health literacy among refugee women is more than having access to information, understanding health information, and making health decisions, it is more about empowering refugee women, boosting their confidence, providing them support and the needed resources to manage their health. Thus, understanding health literacy and diabetes knowledge levels among refugee women with diabetes in Maricopa County Arizona would help health care providers enact positive social change by using multidisciplinary approaches and socially inclusive interventions. This would also lead to the development of policies that empower refugee women to act upon factors affecting their health, and make better health decisions. Moreover, the developed programs could help refugee women develop skillsets that enable them to understand diabetes-related healthcare information and access healthcare services, which in return would improve their health outcomes and potentially reduce the complications of diabetes (Wangdahl et al., 2014).

### **Summary and Transition**

In this study, I explored the health literacy and diabetes knowledge levels among refugee women with known diabetes diagnosis in the County of Maricopa County, Arizona and different factors that affected health literacy. The findings of this research may provide new knowledge that can be used to develop public health programs for both refugee women and health providers in Arizona and nationally. In this first chapter, I (a) described the background of the study, (b) provided a problem statement, and (c) discussed the purpose of the study and its theoretical framework. In the next chapter I will discuss the literature review related to health literacy and diabetes knowledge among refugee women.

## Chapter 2: Literature Review

In Chapter 1, I explained that there was a lack of information on health literacy and diabetes knowledge among refugee women diagnosed with diabetes and residing in the State of Arizona. I hypothesized that there existed varying degrees of health literacy among refugee women diagnosed with diabetes. By determining the levels of health literacy and diabetes knowledge among refugee women, considering various sociodemographic and contextual level factors, this study aimed to add to the existent body of literature focusing on refugee health research and identified social and policy implications for improving integration of refugee women into the United States healthcare system.

As identified in literature, the need for research into noncommunicable diseases (NCDs) such as diabetes among refugees was evident, considering the rising global estimates of NCDs in the developing countries from where most refugees come from (Montesi et al., 2016). The impact of this rising trend, coupled with the increased influx of refugees into the United States, remains understudied. The impact of refugee health and health literacy on the healthcare system is not well known. The impact on the healthcare system may be influenced by studies of this nature that will identify linkages between health literacy and various individual and contextual level factors such as education status, length of stay in the United States, and availability of healthcare services responsive to refugees' needs. Such studies can assist in supporting previous research (Riggs et al., 2016), by establishing means of empowering the often-neglected refugee women to take ownership of their health and therefore allowing me to suggest

sociocultural inclusive interventions that will assist refugee women in improving health literacy for conditions such as diabetes.

### **Literature Search Strategy**

To develop the literature review for this research study, I used the Walden University library to access several databases and other external sources. In order to run a comprehensive search, I searched different literature sources which included online databases, books, published and unpublished dissertations, and grey literature. I searched the following databases to identify the articles that fit the inclusion criteria set for this research study: Medline, CINAHL, ProQuest, PubMed, Science Direct, and the Center for Disease Control and Prevention, the Journal of the American Medical Complete, SAGE, and Google Scholar. The inclusion criteria included scholarly articles published within the last 5 years. These articles were peer-reviewed and written in English language, they were original studies, participants were restricted to adult refugee women only, and they addressed the disease of interest, diabetes. The exclusion criteria included but were not limited to studies published within the last 5 years, papers about treatment and laboratory-based science, and if they are non-peer-reviewed.

The key search terms were: *refugee women, diabetes, health literacy, diabetes knowledge, social determinants of health, refugee population health, immigration, health literacy skills theory, Spoken Knowledge in Low Literacy in Diabetes (SKILLD), access to health care, acculturation, years lived in the United States, age, gender, and employment*. The initial search generated 72 articles. I selected several articles because they fit within the aforementioned inclusion criteria and the rest were excluded due to not

fitting within the 5 years frame criteria and they did not apply to the study. Therefore, I included only the results from the chosen studies in this literature review.

### **Conceptual Framework**

Several theories are used in the field of public health to help understand individuals' behaviors and to develop public health interventions that address specific health needs. Studies have shown that when comparing interventions that are based on theoretical foundation versus those without a theoretical basis, those with an explicit theoretical foundation or with multiple theories combined were found to be more effective and thus produce larger effects (Glanz & Bishop, 2010). Most behavioral theories display the same ideas but their differences lie in the unique vocabulary they use to articulate certain factors that are considered to be important. Therefore, the use of theoretical frameworks is highly recommended in public health practice.

### **Health Literacy Skills (HLS) Framework**

For the purpose of this study the HLS framework was utilized. The HLS has been widely used in studying health literacy among populations with limited health knowledge. After studying several existing health literacy frameworks, Squiers et al. (2012) stated that there were few frameworks that encompassed full information of health literacy skills, which inspired the development of a new framework that explores all levels of health literacy. The HLS assumes a relationship between health literacy and health-related outcomes, while focusing on how health literacy functions at an individual level as well as how other external factors such as family, environment, culture, and community affect the individual (Squiers et al. 2012). This theory has been used

extensively in understanding health literacy levels of individuals and resulted in positive outcomes. This theory does not only focus on the health literacy of an individual but also the health literacy levels of health care providers and others. The diagram below is a depiction of the health literacy skills framework that was developed by Squiers et al. (2012).

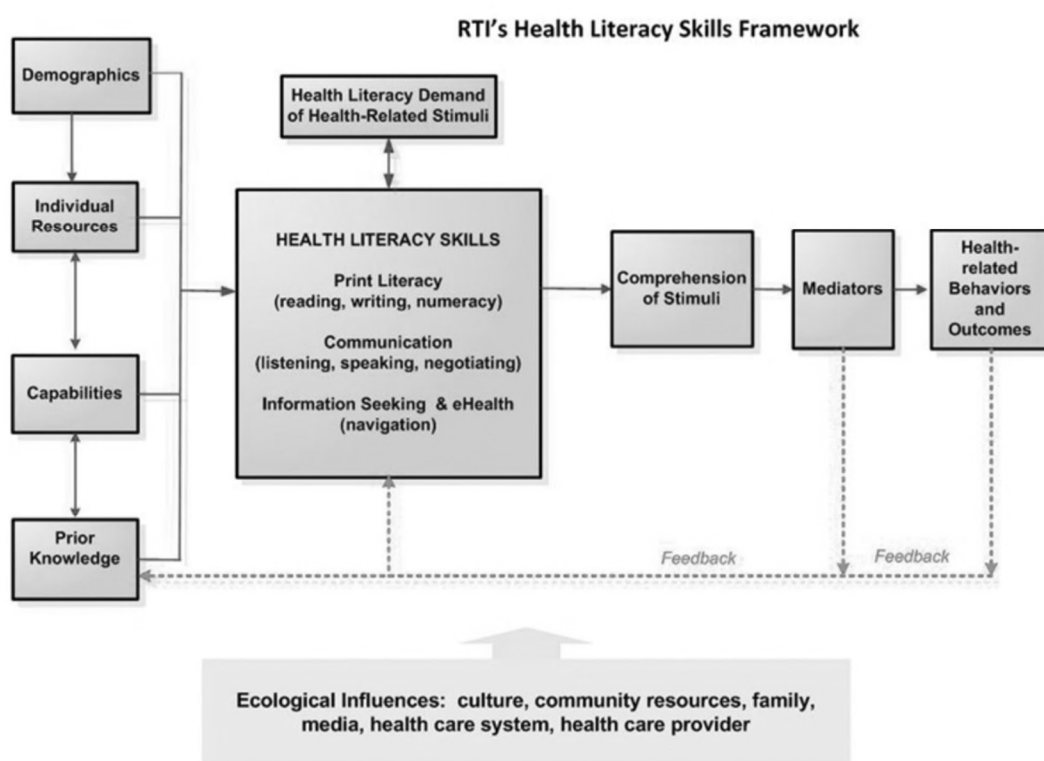


Figure 4. Health Literacy Skills Framework. (Ref: Squiers, L., Peinado, S., Berkman, N., Boudewyns, V., & McCormack, L. (2012).

Squiers et al. (2012) hypothesized that there were various factors that influenced health outcomes, factoring the health literacy component. The key factors included (a)

sociodemographic factors such as age and gender, (b) inherent knowledge of the disease and general healthcare, (c) available socioeconomic/cultural resources such as occupation, social networks, language and education, and (d) an individual's capabilities for example cognitive reasoning, visual and auditory (Squiers et al., 2012). These factors were found to have an influence on how an individual can process healthcare related information and comprehend it in such a manner that would influence positive health outcomes. To better understand the intrinsic relationship between diabetes and some of these factors among refugee women, I used the framework above as a guide to develop one for this study. Key variables for consideration were individual factors such as years lived with diabetes, age, education status, employment status, and length of stay post resettlement. The health system influences for consideration included availability of accessible diabetes-related health services that are tailored to accommodate refugees; availability of diabetes-related information that is tailored for refugees; and healthcare providers that provide relevant refugee specific services for diabetes. The interface at which these are interconnected centers on the individual's (a) ability to comprehend the available diabetes-related health information, (b) ability to read and interpret diabetes information and (c) motivation, awareness and ability to navigate Arizona Health Care Services for diabetes. I hypothesized that the availability of health services and information that is responsive to refugee's healthcare needs, may be preclusive of low levels of health literacy among diabetic refugee women who are able to comprehend the information, are motivated to integrate and can afford healthcare. The diagram below attempted to graphically elaborate this:



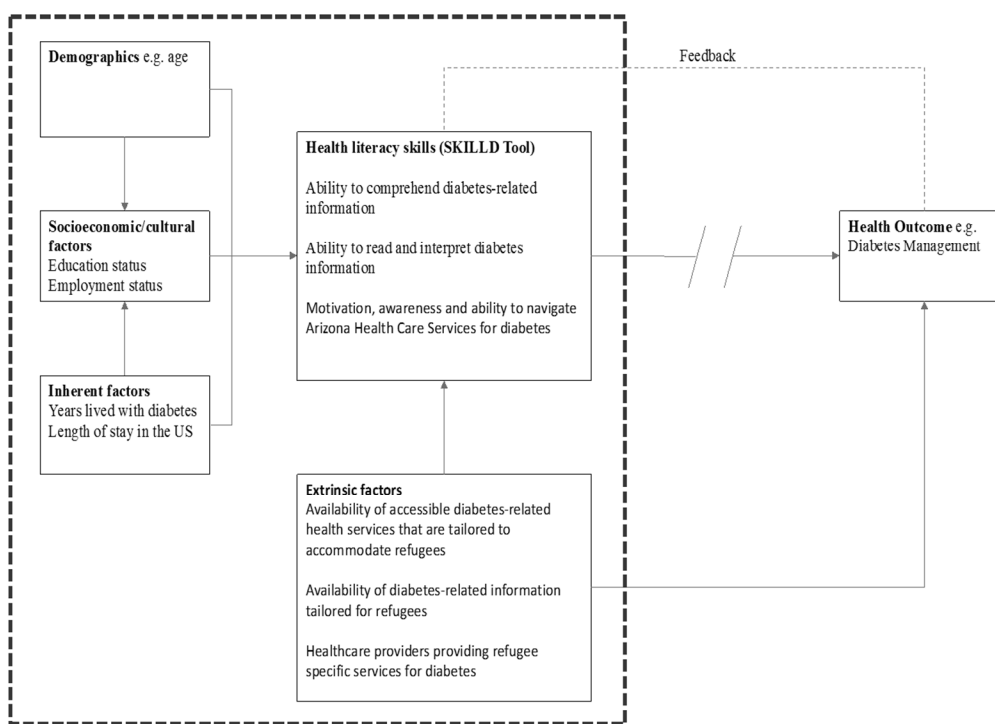


Figure 5. Health Literacy Skills Framework for Refugee Women Diagnosed with Diabetes Residing in Arizona.

The framework above was adapted from the Health literacy skills framework above by Squires et al., (2012).

### Literature Review

An individual's ability to obtain health information, understand and process the information, and possess the necessary skills that will allow them to make an informed decision about their healthcare, has effects on the individual as well as the society at large. The notion, coupled with the healthcare system's responsiveness to ensuring accurate healthcare information is available when required, is what has been described by some authors as health literacy (Mårtensson & Hensing, 2012; Cavanaugh, 2011).

Explaining these concepts within a refugee context is what I aimed to achieve in this current study. With the growing body of literature around refugee health, there is a need to explore the various interlinkages between individual and healthcare system processes that either promote high levels of health literacy or lead to low levels of health literacy among refugee women with diabetes.

There is a paucity of evidence obtained from studies exploring health literacy among diabetes patients (Cavanaugh, 2011). Exploring the effects of health literacy among diabetes patients therefore presented an opportunity to explore issues relating to 1) how much refugee women know about diabetes, 2) ability of diabetic refugee women to take care of their own health, and 3) issues relating to diabetic control i.e. knowledge of signs and symptoms as well as treatment (Cavanaugh, 2011). Mårtensson and Hensing (2012) presented a logical analysis of health literacy by highlighting that health literacy was not a static phenomenon. They argued that health literacy was dependent on various factors that made analysis of health literacy a complex exercise, as an individual's health literacy levels may be different from one measuring point to the next. A person's contextual environment (i.e. social, cultural, economic, etc.) varies from time to time, thus potentially leading to fluctuations in health literacy levels (Mårtensson & Hensing, 2012). In the context of exploring health literacy among refugee women with diabetes, it was prudent to explore how health literacy varies throughout the resettlement cycle i.e. longitudinal study from the point of arrival to the point of settlement. The feasibility of such a study is what the researcher needed to ascertain, given the potentially high loss-to-follow up rate.

### **Measuring health literacy - what are the available tools?**

Various tools to measure health literacy are in existence and possess their own merits. Tools such as Rapid Estimate of Adult Literacy in Medicine (REALM) have been used to explore patients' ability to read healthcare literature that is provided as part of their care (Davis et al., 1991). Within the refugee context, healthcare information, education and communication (IEC) material, treatment instructions and healthcare questionnaires may often be availed without consideration of the recipient's ability to read and comprehend the information contained therein. With such a tool, one is able to tailor the tool and estimate the levels of literacy among refugee women with diabetes.

Another tool that has been widely used is the Test of Functional Health Literacy in Adults (TOFHLA), which includes tests for numeracy and comprehension to determine whether patients have the ability to read and comprehend health-related information (Baker et al., 1999; Parker et al., 1995). This tool was found to be a valid and reliable measure of determining whether one lacked an ability to grasp health information and it was concluded that a significant number of patients had challenges with the reading component of functional health literacy (Baker et al., 1999; Parker et al., 1995). While this tool had its merits in objectively measuring functional health literacy, researchers have raised questions regarding its ability to objectively measure levels of health literacy among respondents with a fairly high literacy level (Cavanaugh et al., 2008). To this end, I considered to use a more robust and widely used tool known as the Spoken Knowledge in Low Literacy in Diabetes (SKILLD). Researchers have used this tool to objectively

measure diabetes knowledge among various groups and I therefore exploited its merits in an attempt to elucidate diabetes knowledge among refugee women enrolled in this study. The tool was described in greater detail in Chapter 3.

### **Refugees in United States**

Since the early 1980s, the United States of America continues to receive a significant number of refugees (Singh & Siahpush, 2001). The Office of Refugee Resettlement (ORR) reports that an excess of 3 million refugees resettled in the United States of America since 1975 (Office of Refugee Resettlement n.d.; & Wagner et al. 2015). With the upward projections of immigrants arriving in the United States that have been made by some authors based on the current trends, key questions that may remain unanswered relate to the projections of refugee populations (Passel & Cohn 2008; & Wieland et al., 2016).

### **Refugees in Arizona**

Focusing on the State of Arizona, the Arizona Refugee Resettlement Programme (RRP) reports that the total number of refugees resettled in Arizona from 1975 – 2018 is 82,982, with majority coming from Iraq, Vietnam, Republic Democratic of the Congo and Somalia (Arizona Department of Economic Security, 2018). Johnson-Agbakwu et al. (2016) went on to report some aggregated statistics for refugees of African descent and concluded that close to 14,000 refugees had resettled in the State of Arizona and for the past 26 years, close to 5,000 and 1,000 Somali and Burundian refugee women resettle in the State of Arizona, respectively. Based on statistics obtained from 2000 – 2009, Arizona was in the top 10 States receiving refugees with a total number of 21,896

refugees, mostly from Iraq, Somalia and Burma (Office of Refugee Resettlement, 2015; Eckstein, 2011).

Information on refugees from other countries resettling in the State of Arizona has also been presented by the Office of Refugee Resettlement (ORR), who reported that, in 2015 alone, a total of 3,133 refugees had resettled in Arizona, with majority originating from Iraq (652), Democratic Republic of Congo (624), Somalia (613), Burma (437), Burundi (154), Syria (127) and Sudan (111) (Office of Refugee Resettlement, 2015). With such projections in the numbers of refugees resettling in the United States, I was curious about how much is known about the rates of diabetes among these refugees resettling in the US and also levels of health literacy among those that are diagnosed with diabetes. Several factors come into play with regards to determining prevalence estimates of diseases such as diabetes among refugees resettling in the United States, such as provision of care in the country of origin, the conditions under which refugees are subjected to as they seek refuge in the US and personal factors (Eckstein, 2011).

### **Diabetes among refugees resettling in the United States**

Diabetes prevalence in low- and middle-income countries (LMICs) is on the rise, but still remains lower than in developed countries (IDF, 2017). Notwithstanding this rising trend, refugees and immigrants arriving in the United States of America have been reported as being generally healthier than the American population (Singh & Siahpush, 2001; Wieland et al. 2016; & Wieland et al. 2017). With increased length of resettlement, authors have predicted that refugees' health becomes synonymous with that of the American population especially with respect to cardiovascular disease risk factors and

diabetes mellitus (Creatore et al., 2010; Wieland et al., 2016; &Wieland et al., 2017). Yet, prevalence estimates on the rates of diabetes among refugees resettling in the United States remains generally lacking.

Some authors reported relative increases in diabetes and associated risk factors among refugees and immigrants resettling in North America (Berkowitz et al., 2016; & Bardenheier et al., 2018). Taking cognizance of the fundamental differences between refugees and immigrants, some findings from studies conducted among immigrants in Canada suggested higher risk of diabetes among women and respondents originating from South Asia and Africa (Creatore et al., 2010). In a study among Cambodian refugees and immigrants, Sharif et al. (2018) also supported the earlier findings by suggesting that a higher risk of developing diabetes was noted among refugees. Other factors such as low socioeconomic status and greater length of stay were found to be associated with higher risk of developing diabetes (Creatore et al., 2010). These findings help set the scene for this study by identifying key focus points such as considering refugee women, length of stay and socioeconomic status.

Selecting to review studies by refugee's origins required careful considerations as the refugee population was rather heterogeneous and there is a tendency to collectively attribute risk of the population, meaning estimation of health literacy of a subset of the refugees may not depict the true prevalence estimates given the variations in associated factors (Sharif et al. 2018). A similar notion was shared in a study assessing 10-year records for refugees arriving from Iran, Ukraine and Vietnam, whereby the authors concluded that when conducting such kind of studies, there was need to disaggregate the

findings by country of origin as respondents are not always homogenous depending on the factors unique to the refugees' country of origin (Nguyen & Rehkopf, 2016).

However, this current study would add value to the existent body of knowledge on status of health literacy among refugee women with diabetes and further studies could be conducted to determine individual and contextual level variances in health literacy.

Changes in various aspects of a refugee woman's health and well-being such as diet, lifestyle and physical activity are likely to be witnessed with the length of their stay in the United States. These changes are seen as a form of adaptation to the new environment to which they become accustomed to, which is known as acculturation. As refugee women try to adjust to their new environment, they become exposed to various extrinsic factors leading to various changes that may affect their health. From as early as the mid-90s, acculturation was found to play a role in shaping health of newly settled individuals as a result of increased susceptibility to noncommunicable diseases (NCDs) due to increased incidence and prevalence of NCDs risk factors amongst the refugee population (Palinkas & Pickwell, 1995). I was therefore interested in conducting further investigation into the impact of length of stay, as a proxy for acculturation in our study, among refugee women diagnosed with diabetes.

Fox et al. (2017) also supported the need for further studies to elucidate the relationship between acculturation and health. In this study, the authors attempted to describe the effect of sociocultural context on acculturation and health, by focusing on various sociocultural aspects such as ethnocultural composition, discrimination, differences between environment in the country of origin and the host country,

differences in cultures, assimilation, various policies affecting refugees etc. (Fox et al. 2017). I noted that the effect of acculturation on health of the refugees is modified to varying degrees as a result of the heterogeneity of the refugee population as well as the host population. Sociocultural context is not static but is a rather dynamic phenomenon for example a host environment could either be conducive or regressive for effective integration into the new environment. As a result of diverse ethnocultural composition, varying degrees of discrimination, availability of different health services with varying degrees of accessibility for refugee women, low/high assimilation rates affecting uptake of host environment diabetes health practices and policies that either facilitate or hinder access to effective preventive and treatment services for refugee women, all affect the manner in which refugee women will be motivated to adopt the host culture. These different factors needed to be unpacked by studying the impact of each factor on the degree to which refugee women integrated into the new host environment.

Before and upon resettlement in the United States, refugees must undergo medical examinations to determine their health status. As such, they are screened for conditions that have been found to be prevalent among refugees and are of public health importance (Mishori et al., 2017). While conditions such as diabetes are not a mandatory screening requirement (Benoit et al., 2017), capturing such information on chronic diseases such as diabetes, is particularly essential as this will help determine what impact this is likely to have on the healthcare system upon resettlement. As such, conducting comprehensive analysis of US bound refugees, within acceptable legal and ethical frameworks, has been attempted (Benoit et al., 2016). It was reported that out of the 248,850 records for



refugees aged at least 18 years, 2.3% (5,767) had diabetes with the highest prevalence rates being noted for Iraqi refugees (Golub et al., 2018) and also expressed concerns regarding the rising prevalence among the younger refugee population, which is likely to impact health care service provision when they resettle in the United States (Golub et al., 2018).

In another study conducted among United States-bound Iraqi refugees, high rates of chronic diseases such as diabetes were reported and the need for increased awareness among public health practitioners and policy makers was reiterated, citing the need to make inclusive healthcare policies and practices that aim to reduce the burden of diabetes among this population group (Yanni et al. 2013). Yet, not much is known about how refugees diagnosed with diabetes interact with the United States healthcare system and whether refugees are literate enough to comprehend the complex healthcare information in the host State. This was a particularly important phenomenon to explore and such findings from literature presented an impetus for this current study by pinpointing whether health literacy had a role to play in effective health care service provision among refugee women diagnosed with diabetes.

In other States, prevalence rates of diabetes among refugees have been reported as being higher than the general population (Rhodes et al., 2016; & Marshall et al., 2016). In the study among Cambodian refugees in California, it was noted that the prevalence rate of diabetes among Cambodian refugees was more than two times that of the general United States population (Marshall et al. 2016). Similar findings were also reported in other studies conducted among Cambodian and Vietnamese refugees, which also painted

a picture reflecting higher rates of diabetes in comparison to the general US population (Wagner et al., 2013). Yet, research on diabetes among refugee women resettling in the State of Arizona is lacking, which presented a research gap that this current study aimed to fill. Few, if any studies are available, that focus on refugee women. For example, a study conducted among Bhutanese women resettling in North East Ohio suggested prevalence rates of close to 7% among refugee Bhutanese women, warranting further studies that capture diabetes-related information from a larger cohort (Bhatta et al., 2015).

Other authors attempted to go beyond focusing on prevalence estimates and attempted to understand how refugees within a heterogeneous community live with diabetes (Kahn et al., 2013). Interestingly, of the 34 recruited participants, 41% (n=14) were refugees, and 76% (n=26) were women, but there was no indication of analysis for the combined sociodemographic characteristics. This study provided insights into patient perceptions regarding diagnosis, emotional responses to diagnosis, and symptoms and diet as a basis for diabetes management (Kahn et al., 2013).

These findings above highlighted some concerns regarding the high prevalence rates of diabetes among refugees, and the results obtained from the few documented studies cannot be generalized to the US refugee population. Moreover, no studies were found focusing on diabetes among refugee women resettling in the State of Arizona. This presented an opportunity for exploring the linkages between health literacy and factors such length of stay and education status among refugee women diagnosed with diabetes.

### **Health literacy among refugees diagnosed with diabetes**

Cavanaugh (2011) described health literacy as being a series of interactions between individual, health care system and the community. While several definitions of health literacy may be in existence (Keim-Malpass et al., 2015; & Kindig et al., 2004), there is a general consensus among commentators on the subject that, health literacy involves more than just individual's ability to read, understand and interpret complex health information but also involves contextual level considerations (Cavanaugh, 2011; & Osborn et al., 2011). In the USA, as much as 36% and 50% of all adults and those of low income standing, respectively, were found to be of low health literacy (Kindig et al., 2004; & Keim-Malpass et al., 2015). Yet, there remains a paucity of information on how many of these would make up the refugee population, and furthermore how many were women diagnosed with diabetes?

Notwithstanding the aforementioned characteristics of health literacy, it is a complex process which takes into account an individual's ability to read and write, as well as to understand numbers (Cavanaugh, 2011). Determining the extent to which one may be deemed literate is where the challenge was, as there are several factors that needed to be considered. More so in this era of increased cultural sensitivity, approaching the subject required the researcher to make racial and/or ethnic considerations, while attempting to objectively measure health literacy without any unprecedented bias. Exploring how these health literacy concepts can be applied within the scope of diabetes among refugee women, is what this study aimed to achieve.

Some authors attempted to identify the complex linkages between health literacy among diabetic patients in general, focusing on various aspects such as diabetes knowledge (Rothman et al., 2005; & Williams et al., 1998), adherence to treatment (Huang et al., 2018; & Osborn et al., 2011) and overall management control of the condition (Huang et al., 2018), among other factors. This suggests that there has been much interest to explore the linkages between the health literacy and diabetes management. However, few studies are available that focus on these key issues amongst refugee women. And as described earlier, focusing on the State of Arizona, this presented a niche for me to explore and elucidate information that may stimulate further research into the linkages between health literacy and diabetes among refugee women.

Conducting a literature search combining “health literacy”, “diabetes”, “refugees” and “women”, I retrieved no studies, which presented an information gap that this study then aimed to fill. Furthermore, I observed that no studies had been conducted in the State of Arizona, which has been found to receive a considerable number of refugees. Notwithstanding the paucity of studies encompassing the factors of interest, a study conducted in the State of Minnesota among Somali patients highlighted that diabetes knowledge was relatively low among Somali patients as measured by the SKILLD tool (Njeru et al. 2016). While this study did not directly measure the associations between low literacy levels and the reported factors for education, income and English proficiency, future research was suggested to capture the linkages between these factors and health literacy, as well as diabetes outcomes (Njeru et al., 2016). This current study therefore aimed to address the knowledge gap by incorporating variables such as

education status and employment status to try explaining any disparities in health literacy between different refugee women diagnosed with diabetes who have resettled in the State of Arizona.

Wangdahl et al. (2014) examined the differences in cognitive health literacy between the different refugee populations in Sweden and how the different determinants of health are associated with low levels of health literacy. In this cross-sectional study, the authors hypothesized that refugees tend to demonstrate low levels of health literacy, which tends to cause negative health effects on their health. A sample of 455 participants from carefully-selected sites was used in this study. Different statistical tests were conducted: Chi- squared Fischer's exact test, Spearman's Significance test, Binary logistic regression, and multivariate logistic regression. The results indicated that majority participants had low levels of health literacy. Some of the main factors that contributed to these findings were education and being born in Somali (Wangdahl et al., 2014). Furthermore, low levels of literacy were found to result from differences in sociodemographic factors as well as health factors. The authors urged that there is need for more research to identify more factors that are associated to health literacy among refugees. Findings from this study revealed the existence of low health literacy levels among refugees and need for further studies to find more factors that are linked to health literacy among this population (Wangdahl et al., 2014). Thus, it is evident to address this gap and to identify these factors and identify interventions that will improve health literacy levels among refugees population.

Gele et al. (2016) attempted to investigate the levels of health literacy among Somali refugee women residing in Norway reported of having higher rates of overweight and obesity, which are high risk of diabetes. The authors conducted a cross-sectional study with sample size of 302 Somali women who are 25 years and older (Gele et al., 2016). The authors conducted interviews using the short version of the European Health Literacy Questionnaire (HLS-EU-Q16). After collecting the data, health literacy was calculated as follows  $\text{Index} = (\text{Mean} - 1) * (50/3)$  where: “Index is the specific index calculated. Mean is the mean of all participating items for each individual 1 = the minimal possible value of the mean (leads to a minimum value of the index of 0) 3 = the range of the mean 50 = the chosen maximum value of the new metric. The metric scores for HL indices ranged between 0-50 with 0 being the lowest value and 50 the maximum” (Gele et al., 2016). The results indicated that 71% of participants reported lacking the ability to obtain health information, understand and act upon health information and to make appropriate health decisions (Gele et al., 2016). Also, the findings revealed that individuals who were unemployed had the (OR 3.66, CI 1.08–12.3) and those who were socially less integrated had the (OR 8.17, CI 1.21–54.8) and both unemployment and poor acculturation were independent predictors for low health literacy among Somali women (Gele et al., 2016).

With such findings, I was left wondering how much of an effect the resettlement process may have on refugee health, particularly for socially marginalized subgroups of this population i.e. refugee women who are unemployed and of an “inferior” social standing. The lack of understanding of refugee women’s background in their countries of

origin did not preclude the need to conduct further investigation into the factors that impact negatively on their health literacy. As Berkman et al. (2010) indicated, there exists various linkages between the individual and their society, which influence one's health literacy, and when an individual is found to have low levels of health literacy, this can impact the individual's health (Berkman et al., 2010). From this viewpoint, if I am able to understand refugee women's health literacy levels, particularly for conditions such as diabetes, I would be in a position to generate key messages that can influence policy aimed at addressing any variances at the individual level, societal level and healthcare system level. Therein lay a potential strength of the current study, which I used to address this information gap and add to the existent body of knowledge on the levels of health literacy among refugee women and the various factors that are linked to health literacy among this subgroup.

With the above in mind, health care reforms that affect the society are likely to affect the health literacy of the individual nested within the society, for example, the Patient Protection and Affordable Care Act (ACA) of 2010. The extent to which such reforms affected refugee women diagnosed with diabetes is unknown. Yet, such health care reforms must be inclusive. Where reforms are found not to be encompassing, health disparities occur and within the context of health literacy, the ACA of 1980 alludes to the need for (a) highly consultative process in developing communicate that promotes health literacy; (b) patient and healthcare provider education that is tailored to meet the healthcare needs for the consumers, thus improving their literacy and ultimately their health; (c) drug supplementary information that aids health care decision making and (d)

capacity building initiatives aimed at addressing health literacy needs gaps (Keim-Malpass et al., 2015; & Somers & Mahadevan, 2010).

Taking cognizance of these provisions above was essential for me to evaluate the extent to which, upon resettlement, refugee women diagnosed with diabetes were afforded an opportunity to make informed decisions about their health by navigating and comprehending the complex American health care system. Failure to navigate and a lack of knowledge of the healthcare system, led to health disparities, particularly among refugees (U.S. Department of Health and Human Services, 2010). Furthermore, while the purpose of this study was not to study the implications of the ACA on refugee women's health literacy, it was worthy for me to explore issues relating to an individual's socioeconomic status and education status, so as to determine whether future research needed to focus on addressing the knowledge gap around these sociodemographic factors in a bid to improve overall health literacy among refugee women diagnosed with diabetes.

As literature suggests a need for further studies that identify linkages between health literacy and various sociodemographic characteristics among refugee women, other authors reflected on the need for further exploring impact of health literacy on healthcare access (Floyd & Sakellariou, 2017). In a study focusing on health care access among refugee women with low health literacy in Vancouver, the authors identified that refugee women faced some health care access issues, and that resettlement services were not so accommodating with respect to service provision, language, ability to make informed decisions and choice of health care services (Floyd & Sakellariou, 2017).



Notably, the disparities that refugee women have been subjected to throughout their resettlement journey, seems to continue, thus raising the need for also elucidating the linkages between “*gender, low literacy and refugee status, to guide healthcare workers and policy makers in improving services for this population*” (Floyd & Sakellariou, 2017). This provided valuable information that influences positive shift towards inclusive healthcare service provision for refugee women diagnosed with diabetes.

Furthermore, studies involving refugee women may expose valuable information on gender-based social injustices and health disparities. In a study conducted among one of the fastest growing refugee populations in the United States, the Congolese, it was noted that healthcare services were often a challenge to navigate (McMorrow & Saksena, 2017). The authors suggested a need for addressing sociocultural issues and tailoring services such that they reduce health disparities among Congolese refugee women (McMorrow & Saksena, 2017). While this was a qualitative study, my study would add valuable insights from a quantitative perspective and contribute to the discussions around disparities in health literacy among refugee women with respect to key sociodemographic and/or sociocultural factors. This set the scene for further exploration of linkages between gender, literacy and refugee status within the context of diabetes, since research is generally lacking.

Research has shown a disparity in use of diabetes prevention interventions among refugee women, despite the high prevalence of type 2 diabetes in a Norwegian community (Gele et al. 2015). Gele et al. (2015) investigated Somali women’s knowledge of diabetes, how they access preventive health facilities, and factors that

inhibit them from receiving preventive services for diabetes. The findings from the study showed that most participants had some knowledge about diabetes. However, language barrier was identified as an issue among this population. Although participants reported that they understood the impact of sedentary lifestyle and unhealthy eating habits as risk factors for diabetes, they still reported living a sedentary life and undertaking unhealthy diet practices, and factors associated with these behaviors included limited access to physical activity facilities, and lack of access of health information (Gele et al., 2015). The authors concluded that developing public health interventions that are tailored to this population's cultural practices and language can definitely improve their lifestyle thus preventing diabetes (Gele et al., 2015). These findings demonstrated the need to explore various factors affecting refugees' wellbeing upon resettlement in the United States. Notwithstanding the already existent trauma and challenges that refugees have had to overcome in their journey seeking greener pastures and peace, several elements within the host country may further exacerbate poor integration into the healthcare system and into the community, thus exposing them to poor management of conditions such as diabetes.

Several key variables have been explored in refugee population research. Another variable which is becoming interestingly popular among researchers on the subject is length of stay in the host country (Gbala. 2016). In a study conducted by Gbala (2016), the association between the incidence of diabetes/chronic disease and sociodemographic characteristics; food practices and dietary habits; access to healthcare and insurance; and acculturation and the length of stay in the United States among Sub-Saharan Africa-born

populations in Minneapolis, was examined. The results indicated that increased length of stay in the United States was significantly associated with an increased incidence of diabetes/chronic disease, yet acculturation in the United States was not significantly associated with the incidence of diabetes/chronic disease (Gbala, 2016). The authors therefore concluded that length of stay in the host country did play a role in incidence of chronic disease/diabetes among refugees. Thus, there was need to develop public health programs that offered long-term sustainable interventions to allow for better integration into the society for refugees. As refugees resettle, there is a high degree of trepidation towards various aspects of the society, especially towards healthcare. Refugees with conditions such as diabetes, more so if they are women, are likely to be reluctant to seek healthcare for fear that services may not be tailored towards their needs, but this is likely to change with increased length of stay and as refugees become more conversant with their surroundings and services. How length of stay impacts on the refugee women's health literacy is under studied and this study therefore aimed to elucidate this relationship and offer valuable insights on certain aspects of the society that needed to be addressed in order to improve health literacy among refugee women, as they adapt to their surroundings.

Examining chronic noncommunicable diseases (NCDs) among refugees is increasingly becoming more important. As highlighted earlier, there is need to increase attention towards NCDs and not the traditional approach of primarily investigating infectious diseases. And even among the refugee population, focusing on the underserved subgroups such as women, presented valuable information that could otherwise address

healthcare system straining disparities. With the increased prevalence of chronic diseases such as diabetes in the refugees' countries of origin (Abegunde et al., 2007; & Yun et al., 2012), this current study is timely as it has potential to reveal health literacy disparities among refugee women diagnosed with diabetes, a chronic disease whose burden is on the rise in developing countries from where most refugees originate from.

The authors anticipated that reporting bias would be a challenge, whereby evidence of prior diagnosis may not be readily available and therefore rely on secondary data or self-report. Depending on the nature of the pre-settlement medical examination, some of this information may be available. Considering the large focus on infectious diseases and vaccination among refugee groups, this current study presents an interesting dimension to the body of literature in the sense that it aimed to derive its strength from the general paucity of information on diabetes among refugees and explore various sources of information i.e. literature, databases, self-report and medical records (Vergara et al., 2003). Such extensive sourcing of information aided in exhausting all sources of information, thus I obtained comprehensive and representative information.

As refugee women seek to integrate into the community, studies of this nature help to discover essential barriers to effective resettlement. And as healthcare for refugees may be provided through primary care, my research will provide valuable information for program development, majorly focusing on improving primary care service delivery. Improving primary care service delivery should be aimed at improving not only the services that are provided for refugee women, by ensuring that healthcare information that is available for conditions such as diabetes is understandable and is

sensitive to gender and culture. With such a study, I will potentially spark conversations around prioritizing refugee women diabetes education, tailored diabetes healthcare information, education and communication (IEC) material and strategies for improving overall education status.

### **Summary and Conclusions**

In chapter two, I summarized several peer-reviewed articles from credible sources related to health literacy among refugee women with diabetes. The literature review was guided by studies conducted among refugees that have resettled in different industrialized countries around the world. Taking into consideration that the literature on refugee population in the United States is very limited, it was advantageous to broaden the search to studies that have been carried out around the world. Through this literature review, I provided background information on refugees in the United States, diabetes among refugees in the United States, health literacy among refugees diagnosed with diabetes, and available tools that are used to measure health literacy and diabetes knowledge. Furthermore, I discussed the HLS framework.

### Chapter 3: Research Method

In this study, I attempted to address the knowledge gap related to health literacy among refugee women. Exploring the levels of health literacy and diabetes knowledge among refugee women diagnosed with diabetes and have resettled in the State of Arizona, allowed me to explore a different dimension to refugee studies. I therefore aimed to identify possible barriers to health literacy and inequitable access to diabetes-related information, while suggesting possible individual- and contextual-level practical, social and or policy implications.

The purpose of this study was to ascertain the levels of health literacy and diabetes knowledge among refugee women with a known diagnosis of diabetes who have resettled in the state of Arizona. I also attempted to explore the effects of age, education status, employment status, number of years lived with diabetes and length of stay since resettlement, on health literacy and diabetes knowledge among refugee women with diabetes.

In Chapter 3, I covered the methodology of the study, the research design, the rationale for the study choice, sample population, sampling methods, recruitment of study participants, the relationship that exists between the research questions and the research design, the measurement tools, data collection methods, data analysis procedures, and the external and internal validity threats.

## **Research Design and Rationale**

I used a cross-sectional research design to explore the levels of health literacy and diabetes knowledge among refugee women with diabetes in Maricopa County, Arizona and also whether age, education, employment status, number of years lived with diabetes and length of stay since resettlement had any effects on health literacy and diabetes knowledge levels. Additionally, I aimed at investigating if health literacy and diabetes knowledge levels differed by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement among the aforementioned population. Since there is no existing literature that explores this issue, I therefore explored the associations between the chosen variables and generated new information that would be used to develop interventions to increase health literacy and diabetes knowledge among this population. A cross-sectional design was appropriate for this study because of its nature of providing a snapshot view of the variables and outcomes of interest, in addition to being quicker and with limited costs. Furthermore, I used such kind of a study design because it did not require a follow-up (Creswell, 2013).

### **Dependent Variables**

The dependent variables in this study were as follows:

1. Health Literacy: this was determined from the modified questionnaire which contains questions on self-report health literacy extracted from the European Health Literacy Questionnaire (HLS-EU-Q16)

- a) Self-reported health literacy (Questions 7 - 15), were coded *Very Easy, Easy, Difficult, Very difficult, Don't Know*, except for question 9 which was coded *Never, Sometimes, Often, Always, Don't Know*.
  - b) High Literacy – referred to composite code for all responses marked *Very Easy and Easy or Never, Sometimes*.
  - c) Low Literacy – referred to composite code for all responses marked *Difficult and Very difficult, Often, Always or Don't Know*.
2. Diabetes Knowledge: this was determined from questions from the Spoken Knowledge in Low Literacy in Diabetes (SKILLD) tool.
- a) SKILLD scores were graded based on an answer key developed by Rothman et al. (2005) (Appendix E) and the revised answer key adopted by Garcia et al. (2015) (Appendix F). Use of both answer keys was essential for avoiding ambiguity and to overcome medical jargon that is contained in the original answer key.
  - b) Individual scores for the 10 questions were coded as either being correct or incorrect, depending on the responses compared to the answer keys.
  - c) Low diabetes knowledge (LDK) was coded from those attaining <50% correct answers.
  - d) High diabetes knowledge (HDK) was coded from those achieving ≥50% correct answers

### **Independent variables**

The independent variables in this study were as follows:



1. Age: the number of years was defined as a grouped variable i.e. 18 – 24; 25 – 34; 35 – 44; 45 years or older. This was determined by asking the question, *how old are you?*
2. Education Status: was defined as the highest level of education attained. Based on the participants' response to the question, *what is the highest level of education attained?* Respondents would be classed as either having no schooling; primary education; high school education; tertiary or higher.
3. Employment Status: was defined as either unemployed; currently employed; self-employed; or retired. This was determined by participants' responses to the question, *what is your current employment status?*
4. Length of stay since resettlement to the US: was defined as a continuous variable that was determined by participants' response to the question, *how long ago did you resettle to the United States? Depending on the responses, responses would either be classified as less than 1 year; 1 – 5 years ago; 5 – 10 years ago; 10 or more years ago.*
5. Number of years lived with diabetes: was defined as a grouped variable that was determined by participants' response to the question, *when were you diagnosed with diabetes? Depending on the responses, responses would either be classified as less than 1 year; 1 – 5 years ago; 5 – 10 years ago; 10 or more years ago.*

## Research Questions

Research Question 1 (RQ1): What are the health literacy and diabetes knowledge levels among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona?

Research Question 2 (RQ2): How does health literacy and diabetes knowledge levels differ among refugee women with a known diagnosis of diabetes when stratified by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement.

Null Hypothesis ( $H_02$ ): Health literacy and diabetes knowledge did not differ by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement, among refugee women with a known diagnosis of diabetes

Alternative Hypothesis ( $H_a2$ ): Health literacy and diabetes knowledge differed by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement, among refugee women with a known diagnosis of diabetes

Research Question 3 (RQ3): What is the association between health literacy and diabetes knowledge levels and age, education, employment status, number of years lived with diabetes and length of stay since resettlement, among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona?

Null Hypothesis ( $H_03$ ): Age, education, employment status, number of years lived with diabetes and length of stay since resettlement had no effect on health literacy and diabetes knowledge levels among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona.

Alternative Hypothesis ( $H_{a3}$ ): Age, education, employment status, number of years lived with diabetes and length of stay since resettlement had an effect on health literacy and diabetes knowledge levels among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona.

## **Methodology**

### **Population**

The target population for the proposed research study was refugee women with diabetes that have resettled in Maricopa County, Arizona. According to the United Nations High Commission for Refugees (UNHCR), “a refugee is an individual who is forced to leave his or her home country as a result of war or fear of persecution for various reasons which may include, but not limited to, religious beliefs, membership to a particular social group, different ethnicity etc...” (UNHCR, n.d). The inclusion criteria were refugee women with a known diagnosis of diabetes, who had resettled in Maricopa County, Arizona and had a confirmed refugee status.

### **Sampling and Sampling Procedures**

While sample accessibility and availability challenges have been a drawback for the application of probability sampling among refugee studies, its merits have often warranted adoption as an appropriate sampling method for studies in general (Gele & Mbalilaki, 2013). For this study, I applied a more applicable and robust sampling method which is a non-probability, purposive sampling. Sampling was conducted by (a) identifying potential gatekeepers within refugee communities who were crucial in gaining access to potential study participants; (b) engaging refugee resettlement organizations

within Maricopa County, Arizona such as the International Rescue Committee (IRC), Refugee Focus, and Catholic Charities that have direct contact with refugee women; and (c) engaging local healthcare institutions that provide healthcare to refugee women, to gain access to those that are diagnosed with diabetes.

### **Procedures for Recruitment, Participation, and Data Collection (Primary Data)**

#### **Sample Size Considerations**

I found it challenging to determine an appropriate sample size for this study due to insufficient primary data being available on refugee women diagnosed with diabetes that have resettled in Maricopa County, Arizona. With the influx of refugees, a representative sample of refugee women was ideal in determining the levels of health literacy among those diagnosed with diabetes, which provided reasonable estimates to enable statistically significant conclusions to be made. I needed to avoid over- and under-sampling. I needed to avoid the risk of under-sampling, so as to avoid obtaining results that cannot be generalized across the population. I also needed to consider the risks of over-sampling, which would have created unnecessary ethical concerns by subjecting research participants to various interventions; furthermore, it would have resulted in resource waste.

Generally, sample size calculations require the researcher to determine the level of significance, power of the study, effect size, rate of occurrence in the population, and standard deviation (Kadam & Bhalerao, 2010). For this study, I applied a significance level ( $p$  value) of 0.05 (95% confidence level) was used, suggesting that it was accepted that the probability of low health literacy among refugee women with diabetes was 5%

due to chance. A power  $(1 - \beta)$  value of 80% was used for the study, which depicted the false negative rate that was accepted in order to closely accept or reject the null hypothesis (Kadam & Bhalerao, 2010). I accepted that there is a 20% (1 out of 5) chance of failing to detect the real difference between low and high health literacy and low or high diabetes knowledge, when in fact there was a difference. Determining the effect size for this study from previous studies was a bit difficult since no studies had been conducted to determine the effect of health literacy and diabetes knowledge among refugee women diagnosed with diabetes and residing in the State of Arizona. However, it is widely accepted that if the effect size is significant, then a smaller sample size would be required unlike when the effect size is smaller (Kadam & Bhalerao, 2010). I chose a conservative effect size of  $0.27 \approx 0.3$ .

Since no studies had been conducted in this area, specifically looking at health literacy and diabetes knowledge among refugee women diagnosed with diabetes, I found it challenging to determine the rate in the population and the standard deviation (variability of health literacy among refugee women diagnosed with diabetes in Arizona). Standard deviation would help determine sample size depending on the homogeneity or heterogeneity of the study population (Kadam & Bhalerao, 2010). The above can be summarized in the equation below:

$$\text{Sample Size} = 2 \times \frac{(\alpha + \beta)^2 \sigma^2}{\Delta^2}$$

Where  $\alpha$  is the value error depending on 1-sided (1.65) or 2-sided (1.96) test;  $\beta$  is value for 80% power (0.8416);  $\Delta$  is the estimated effect size; and  $\sigma$  is the estimated standard deviation (Kadam & Bhalerao, 2010; Noordzij et al., 2010; & Cohen, 1992).

For this study however, the sample size was estimated using the G\*Power 3.1.9.3 analytical statistical software. Given a significance level alpha of 0.05, 80% power, and an estimated effect size of  $0.27 \approx 0.3$ , a sample size of 102 was determined. The figure below shows the G\*Power 3.1.9.3 output:

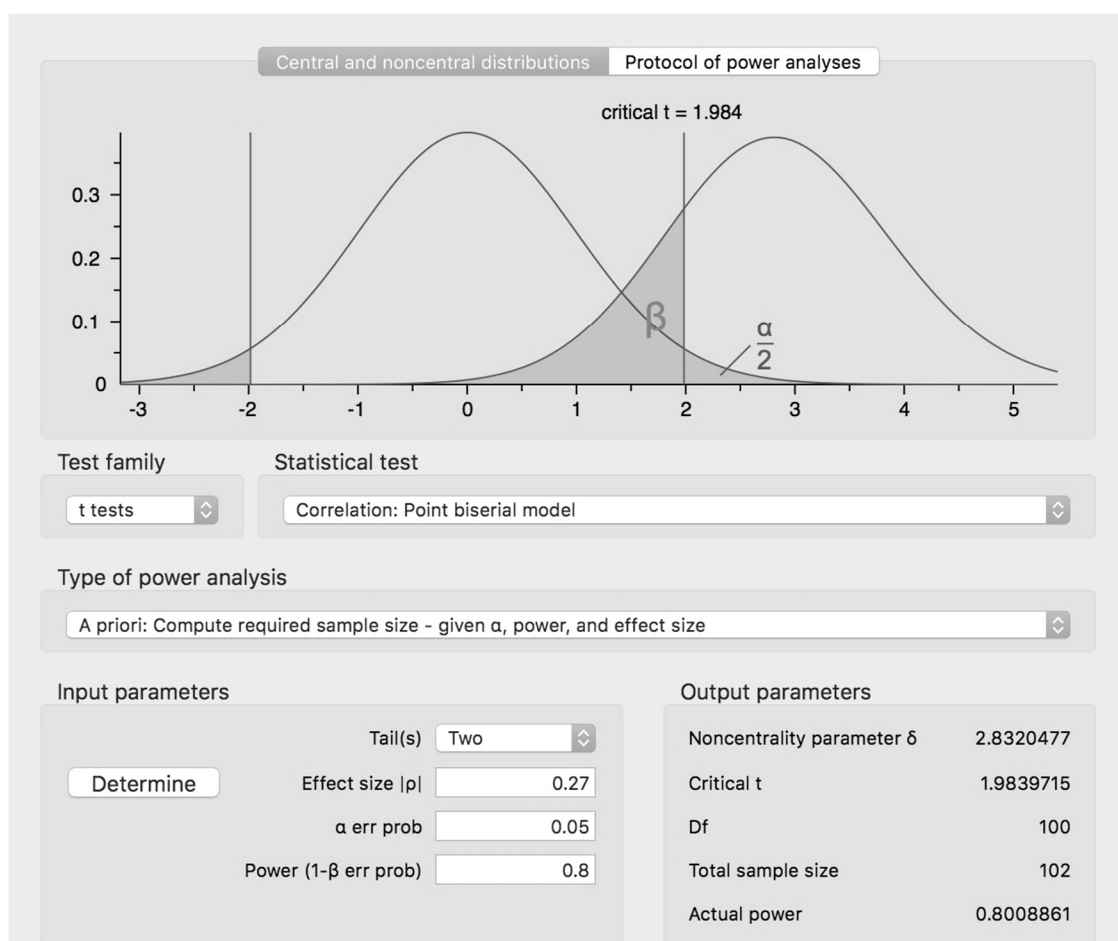


Figure 6. G\*Power 3.1.9.3 Analytical Software

Given a significance level alpha of 0.05, 80% power, and an estimated effect size of  $0.27 \approx 0.3$ , a sample size of 102 was determined.

### **Recruitment Strategies**

The recruitment of study participants primarily relied on primary data that was collected by face-to-face quantitative-based interviews, after identifying potential candidates from Maricopa Integrated Health System Refugee Women's Health Clinic and in the community. A large proportion of refugees resettling in the State of Arizona are women, which prompted the development of initiatives such as Maricopa Integrated Health System Refugee Women's Health Clinic that provide comprehensive support towards refugees accessing timely and responsive health care services (Maricopa Integrated Health System, 2018).

The challenges of obtaining accurate statistical data for recruiting suitable candidates for participation in the study that I faced were alleviated by exploiting a wide range of potential data sources. Access to the relevant data and participants required techniques such as identifying “gatekeepers” who were able to act as the go-between refugees and the researchers. Within the various organizations described above, refugees were assigned to case management officers, who were responsible for safeguarding the welfare of the refugees. Access to potential participants required approaching these gatekeepers with all the relevant information so that they understood the purposes of the research and was in a position to relay the information to the potential participants. In a paper by Singh and Wassenaar (2016), it was discussed that there exists a number of intricate and complex processes when exploring the role of gatekeepers in research.

Understanding some of these underlying issues was vital in ensuring research was conducted ethically and thus reliable estimates, for example health literacy data among refugee women diagnosed with diabetes and residing in Arizona, were obtained (Singh and Wassenaar, 2016). This demonstrated the key role that certain members of the community, who are sometimes overlooked, play in ensuring refugee welfare is upheld.

With regards to the process of recruitment, I used a phased approach which included vital steps such as design phase, where project documents such as project information sheet, questionnaires and consent forms were designed and developed. This step was a vital first step towards the birth of the project in the sense that the purpose of the study, the eligibility criteria, the benefits of participating, the procedures, the potential outcomes and other essential components were explicitly captured in the various project documents. I provided a clearly articulated and detailed research summary to the potential participants, which included all necessary information that could solicit their participation. I then shared these documents with potential study participants so as to provide adequate information. For the purposes of ensuring adequate information was received.

The next phase was to approach the gatekeepers with the relevant documents pertaining the project. Explicit statements on inclusion/exclusion criteria were essential as they assisted the gatekeepers in dissemination of the research proposal to potential participants. With a clear understanding of who can and cannot take part in the research, gatekeepers were then able to ensure only those that were most suitable for the research were provided with the opportunity to take part. I also had to consider approaches to



minimize unethical issues relating to exposure of otherwise ineligible participants to research, which may not be relevant to them.

The final recruitment phase involved interviews of participants. I interviewed the participants face-to-face based on their expression of interest to participate in the research. This interview afforded participants an opportunity to get a clearer understanding of their participation and to further think about the risks and benefits of the study, prior to giving full consent to participate.

Another potentially reliable method for sampling that I considered was the snowball sampling. Given the sensitive nature of the study and the fact that study participants may be difficult to recruit, the merits of snowball sampling were advantageous to the recruitment of sufficient study participants. Recruitment of subsequent participants relied on referrals from participants initially recruited through the aforementioned organizations. This non-probability sampling method had been used in prior studies that were conducting research among “hard-to-find” populations (Berg, 2004; Dragan & Isaic-Maniu, 2013), and was found to be somewhat reliable technique, despite its demerits of objective conclusions being drawn from the study.

### **Data collection**

The research was quantitative in nature. It relied on clearly articulated sampling protocols and outlining of data collection instruments that were fit for purpose i.e. data collection tools that could accommodate the diverse study population as well as the diverse study variables. I aimed to produce replicable results that could make statistical sense as well as being generalizable to the general population. The primary data

collection tool for this study was therefore a structured, face-to-face administered questionnaire that I developed. As described by Siniscalco & Auriat, (2005), a questionnaire is a survey instrument that consists of a series of questions that are administered to a selected group of people and used to gauge their responses on a particular topic. This questionnaire was a 25-question instrument that incorporated diabetes knowledge questions from the “Spoken Knowledge in Low Literacy in Diabetes (SKILLD)” tool as well as some questions from the modified version of the European Health Literacy Questionnaire (HLS-EU-Q16), and Swedish functional health literacy scale (English version). A sample copy of the questionnaire has been attached (Appendix D). The questionnaire was administered in English; Cultural Health Navigators were available to interpret for those who were not fluent in English. The questionnaire that I developed had been designed in such a manner that will allow even respondents with limited proficiency and comprehension to respond to the verbally administered tool. As described by Rothman et al (2005), the SKILLD tool comprises questions which are designed to: (a) cater for respondents with less than fifth-grade level capabilities; (b) capture a few components so that respondents are not overwhelmed; (c) accommodate different cultures and; (d) solicit open ended responses (Rothman et al., 2005).

### **Instrument development**

The proposed instrument for data collection in this study was a 25-questions tool that incorporated diabetes knowledge questions from the Spoken Knowledge in Low Literacy in Diabetes (SKILLD) as well as the modified version of the European health

literacy questionnaire (HLS-EU-Q16), and Swedish functional health literacy scale □ English version. These instruments have been used extensively to explore diabetes knowledge and health literacy in general (Njeru et al., 2016; Sorensen et al., 2015; Souza et al., 2016; Storms et al., 2017; Wangdahl et al., 2014; &Wångdahl & Mårtensson, 2015). As previously reported, employing concepts from these tools presented a comprehensive tool that was able to capture the true essence of health literacy among refugee women with diabetes, through a quantitative assessment of different external and internal factors affecting diabetes health literacy i.e. health information, engagement in health care management, and autonomy to make informed health decisions. Use of these tools in refugee studies set the tone for increasing the validity and reliability of the study, drawing positive implications from previous studies conducted among refugees.

### **Instrumentation and Operationalization of Constructs**

The 25-questions survey instrument that I developed incorporated components of Spoken Knowledge in Low Literacy in Diabetes (SKILLD) tool as well as the modified version of the European Health Literacy Questionnaire (HLS-EU-Q16), and Swedish functional health literacy scale □ English version. The designed questionnaire is attached as Appendix D. This is a structured, face-to-face administered questionnaire, which was designed to allow even low proficiency participants to be able to respond. In this instrument I incorporated validated tools that have previously been extensively used to elucidate diabetes knowledge and health literacy constructs, among refugee populations.

### **European Health Literacy Questionnaire (HLS-EU-Q16)**

The modified version of the European health literacy questionnaire (HLS-EU-Q16), was developed by incorporating elements from the European Health Literacy Survey (HLS-EU) (HLS-EU Consortium 2012). The HLS-EU-Q is a validated 47 item questionnaire which was used to obtain self-perceived information relating to the ease or difficulty of various health elements. A 4-point scale was used to collect responses to perceptions (HLS-EU Consortium 2012). Potential bias considerations were made when using this tool as it relied on self-report and also highlighted intricate linkages between a respondent's abilities and contextual level healthcare needs. Wångdahl et al. (2014) then went on to develop a modified version of the tool, which is made up of 16 questions that were aimed at obtaining respondents' perceptions across 4 health literacy measures i.e. (a) respondents' ability to access or obtain health information, (b) respondents' ability to understand health information (either written or spoken), (c) respondents' ability to process or appraise health information and (d) respondents' ability to apply and use health information (Wångdahl et al., 2014). Dichotomization of responses and calculation of sum scores of the responses then allowed the authors to conduct statistical analysis to determine inadequate vs. adequate health literacy. This was appropriate for this study as it has been extensively used to study health literacy among different refugee populations and it is a fairly simple and easy-to-execute tool.

With regards to reliability for the 4 health literacy indices (access, understanding, processing and application of health information), inferences for reliability were drawn from the tests for reliability conducted for the HLS-EU-16 instrument, whereby

assessments using Cronbach's alpha coefficients were conducted. The results showed relatively high Cronbach's alpha results across all 8 European countries (HLS-EU Consortium 2012). Interpretation however, ought to take into consideration both individual and contextual level variances. Another simple tool that draws similarities from the comprehensive HLS-EU-16 tool is the Swedish functional health literacy scale (S-FHL), which is a much shorter health literacy scale that consists of 5 questions assessing the respondent's ability to read and understand health information (Wångdahl & Mårtensson, 2015). The responses were then provided against a 5-point scale ranging from never to always. These were then categorized to determine whether a respondent possesses adequate vs. inadequate health literacy. Permission to adopt the tools for this study was sought and permission was granted.

### **Spoken Knowledge in Low Literacy in Diabetes (SKILLD) tool**

To understand the aforementioned intrinsic relationships, I considered a validated tool capable of objectively measuring literacy among this specific population. The Spoken Knowledge in Low Literacy in Diabetes (SKILLD) tool developed by Rothman et al. (2005), is widely used to assess diabetes knowledge among those diagnosed. The SKILLD tool is made up of 10 open-ended questions, which were designed to test African-American diabetic patients' knowledge towards diabetes self-management. In an initial test among a small sample, Cronbach's alpha was found to be 0.72, which demonstrated that the tool was only capable of assessing one dimension of diabetes knowledge (Rothman et al., 2005). Subsequent tests for reliability and validity yielded

low results for Cronbach's alpha (0.64); Content Validity Index of 1.00 i.e. requiring minor to no changes in phrasing the questions but not the actual content.

The tool has been extensively used among different refugee populations such as Brazilian elderly diabetic patients (Souza et al., 2016); Mexican American respondent's self-assessment of type 2 diabetes management (Garcia et al., 2015); a study among Somali immigrants. exploring the impact of different variables such as age, sex, need for interpreter, income, education level, length of stay in the United States, years lived with diabetes, hemoglobin A1C, low-density lipoprotein, cholesterol, and blood pressure. This was aimed at assessing diabetes literacy and health outcomes (Njeru et al., 2016). The SKILLD tool has several merits, which warranted my consideration to incorporate it into this current study. These merits include (a) use of open-ended questions, which facilitated the individuals to express themselves freely in their own words thereby objectively assessing their knowledge; (b) allowed one to explore levels of diabetes knowledge among different population groups; (c) potential linkage to various statistical tools to conduct multivariate regression analysis; (d) semi-structured nature that allowed simple reporting and computation to draw statistical inferences. I sought permission to incorporate the tool into this study and permission was granted.

With respect to threats to validity (external validity, internal validity and construct validity), I took into account previous research utilizing the aforementioned tools that have been adopted for this study. Regarding operationalization, the study drew inferences from the theoretical framework developed by Squiers et al. (2012) that is employed in an attempt to establish the linkages between various individual and ecological influences on

health literacy, and ultimately affecting health outcomes (Squiers et al., 2012).

Connecting the variables to be measured in the study, to the intended outcomes was a crucial step I took in conceptualizing the research. By design, I aimed to elucidate the intricate relationship between various sociodemographic/economic variables, and other variables linked to acculturation, with health literacy and diabetes knowledge among refugee women diagnosed with diabetes and residing in the State of Arizona.

### **Independent variables included in the study**

By definition, I used demographics such as age, education status and employment status to define the impact of sociodemographic/economic/cultural influences on health literacy i.e. establishing whether health literacy differed depending on one's age, highest level of education attained and status of employment. Furthermore, I also explored inherent factors reflecting acculturation i.e. whether duration of diabetes diagnosis and/or duration of stay post-resettlement in the US had an effect on health literacy. Other factors which were likely to affect health literacy were extrinsic factors such as availability of health services which form the source from which I determined health literacy, however these would be considered for future studies.

### Rationale for inclusion of potential covariates and / or confounding variables

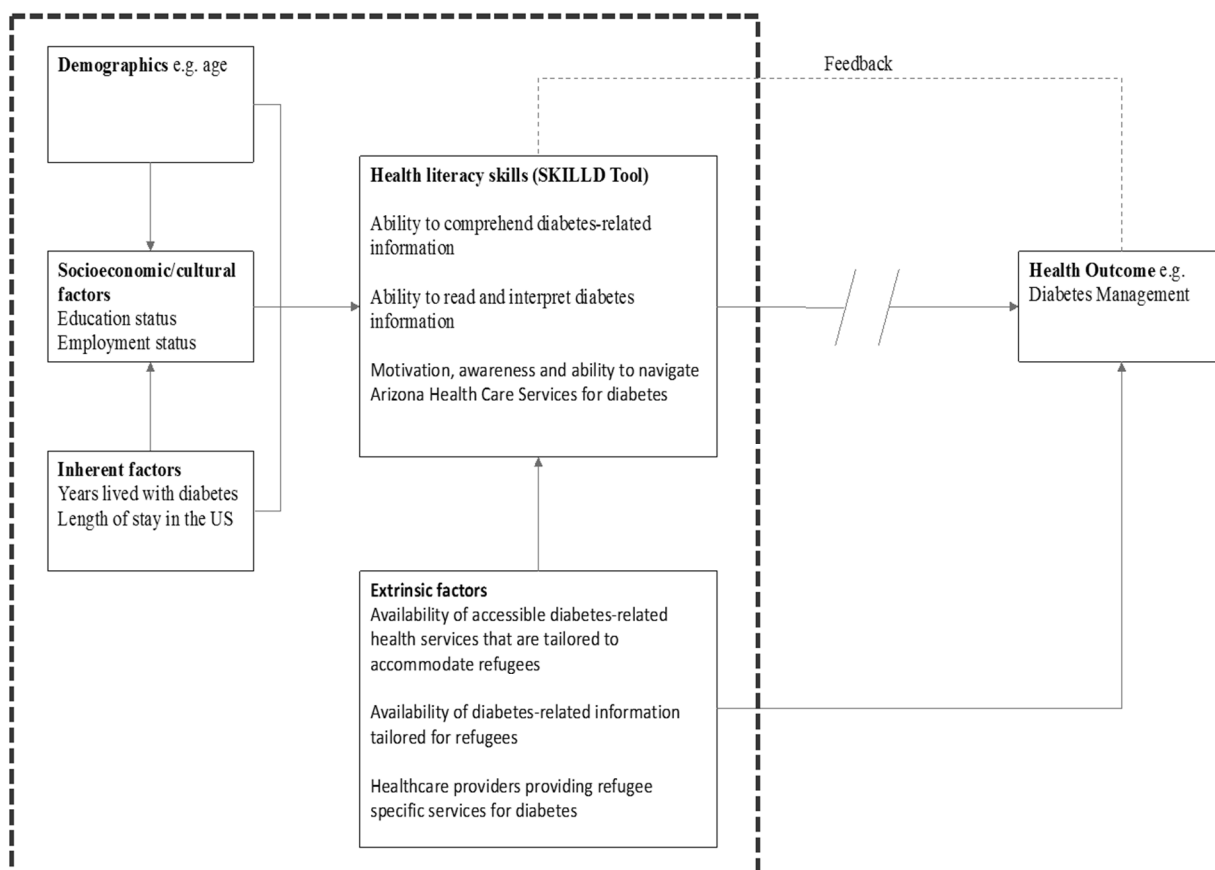


Figure 7. Health Literacy Skills Framework for Refugee Women Diagnosed with Diabetes Residing in Arizona.

Reference is made to the above framework, encompassing the covariates that were included in the study. I included age as a covariate in the study to provide essential information on demographics of the study population. Furthermore, I had established that studies involving refugees were often complex as a result of the widely accepted definition of refugees that does not take age and gender into account (Silva, 2003; &



Wedo.org, 2018). Inclusion of this variable elucidated key age-related issues that may be linked to the research questions.

Socioeconomic/cultural variables such as education status and employment status were essential variables that I required to understand the presence of underlying factors affecting health literacy among refugee women diagnosed with diabetes. As described by Marmot (2005) understanding social determinants is essential for understanding the underlying causes of ill health. I considered social determinants of health such as employment and education status, carefully within the context of refugee health, as these explanatory variables may depend on whether there exists any pre- or post-resettlement factors that are likely to affect health literacy of refugee women diagnosed with diabetes (Hollander, 2013).

Adjusting to new surroundings takes time, and this could be most evident among the research participants. Depending on the background, some refugee women were likely to take longer adjusting and navigating the new health systems. Variables such as length of stay were therefore key as this would help me understand whether the length of stay upon resettlement had a negative or positive impact on health literacy. Extrinsic factors relating to accessibility and availability of health services and information formed an integral component of the proposed framework. However, I did not include these in the analysis as the focus was to identify factors affecting refugee women from an individual perspective. Notwithstanding the value that these extrinsic factors can add to the research questions, future studies can explore the effect of these on health literacy among refugee women diagnosed with diabetes

### **Data Analysis Plan**

In this quantitative study, I used primary data sourced from respondents who met the inclusion criteria, through a structured 25-question questionnaire that I developed as per the aforementioned tools. I employed quantitative data analysis methodology i.e. (a) descriptive statistics to describe the characteristics of the study population; (b) test for hypothesis and (c) simple and multiple logistic regressions.

### **Research Questions**

Research Question 1 (RQ1): What are the health literacy and diabetes knowledge levels among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona?

Research Question 2 (RQ2): How does health literacy and diabetes knowledge levels differ among refugee women with a known diagnosis of diabetes when stratified by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement.

Null Hypothesis ( $H_0$ ): Health literacy and diabetes knowledge did not differ by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement, among refugee women with a known diagnosis of diabetes

Alternative Hypothesis ( $H_a$ ): Health literacy and diabetes knowledge differed by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement, among refugee women with a known diagnosis of diabetes

Research Question 3 (RQ3): What is the association between health literacy and diabetes knowledge levels and age, education, employment status, number of years lived with diabetes and length of stay since resettlement, among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona?

Null Hypothesis ( $H_03$ ): Age, education, employment status, number of years lived with diabetes and length of stay since resettlement had no effect on health literacy and diabetes knowledge levels among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona.

Alternative Hypothesis ( $H_a3$ ): Age, education, employment status, number of years lived with diabetes and length of stay since resettlement had an effect on health literacy and diabetes knowledge levels among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona.

### **Statistical tests that were used to test the hypotheses**

As indicated above, null hypothesis for research question 2 ( $H_02$ ) states that there is no difference in health literacy and diabetes knowledge respective to age, education status, employment status, number of years lived with diabetes and length of stay in the United States, among refugee women diagnosed with diabetes. The alternative ( $H_a2$ ) states that there is a difference in health literacy and diabetes knowledge with respect to the identified factors. The null hypothesis for research question 3 ( $H_03$ ) states that the aforementioned factors do not have an effect on health literacy and diabetes knowledge, whilst the alternative ( $H_a3$ ) states that these factors do have an effect on health literacy

and diabetes knowledge. This can be summarized by the following equations (Evans, 2013):

Null Hypothesis                       $H_0: \mu_1 = \mu_2 = \dots = \mu_k$

Alternative Hypothesis               $H_0: \mu_1 \neq \mu_2 = \dots = \mu_k$

In this study, I used an  $\alpha$  (type 1 error where the  $H_0$  is rejected when in fact it is true) of 0.05 i.e. adoption of a 95% confidence interval. I then used an F-statistic to test for the hypothesis, and this was obtained from the output of ANOVA, whereby if p-value is less than 0.05, the null hypothesis ( $H_{02}$  and  $H_{03}$ ) can be rejected and the alternative ( $H_{a2}$  and  $H_{a3}$ ) can be adopted. In other words, I accepted that there indeed was a difference in health literacy and diabetes knowledge with respect to age, education status, employment status, number of years lived with diabetes and length of stay in the United States, among refugee women diagnosed with diabetes. Furthermore, I also accepted that age, education status, employment status, number of years lived with diabetes and length of stay in the United States, did have an effect on health literacy and diabetes knowledge among refugee women diagnosed with diabetes.

### **Statistical tests and results interpretation**

I used descriptive statistics to describe the characteristics of the study population. This was given as measures of central tendency, frequency distributions and percentages. Further tests for collinearity were conducted by applying tests for correlation with outputs as correlation matrices for the variables that had been included in the study. I examined values depicting high Pearson correlation coefficients for possibility of measuring the same outcomes. I then conducted simple logistic regression to test for associations

between the individual variables and the outcome variable (health literacy and diabetes knowledge) to test the effect without confounding. This is depicted by the equation below (McDonald, 2014):

$$\ln[Y/(1-Y)] = a + bX$$

Following simple logistics regression, I then conducted stepwise multivariate/multiple logistic regression to test the effect of the variables on health literacy and diabetes knowledge. I used this method to test for the effect of the various independent variables in the presence of other variables i.e. confounding. This confounding was defined by Szklo & Nieto (2014) as the effect exerted by another variable or group of variables on the association between an explanatory variable and an outcome. The dependent/outcome variables Health Literacy and diabetes knowledge were a composite score obtained from the questions adopted from the SKILLD and HLS tools. I then dichotomized these composite scores into four categories i.e. High health literacy vs. Low health literacy and High diabetes knowledge vs. Low diabetes knowledge. Results were interpreted from the SPSS statistical output for binary logistic regression reflecting odds ratios, 95% confidence intervals and p-values. Output readings for odds ratios will be interpreted as likelihood of respondents having low health literacy or low diabetes knowledge for the respective independent variables as depicted by the equation for multiple regressions below (McDonald, 2014):

$$\ln[Y/(1-Y)] = a + b_1X_1 + b_2X_2 + b_3X_3 \dots$$

Table 1.

*Data Definitions for Variables Included in the Study*

Variable	Label	Variable measure	Type	Values
<b>Dependent</b>				
HL	Health literacy	Composite scores developed from the two-part questionnaire i.e. Health Literacy Variables and SKILLD Score	Categorical	Low Literacy High Literacy
DK	Diabetes Knowledge	Percentage Score determined from questions from the SKILLD tool - graded based on an answer key	Categorical	Low diabetes knowledge – less than 50% SKILLD Score High diabetes knowledge – equal to or more than 50% SKILLD Score
<b>Independent</b>				
Age	Respondent's age	How old are you?	Categorical	18 – 24 25 – 34 35 – 44 45 years or older
Educa	Respondent's education status	What is the highest level of education attained?	Categorical	No schooling primary education high school education tertiary or higher
Employ	Respondent's employment status	What is your current employment status?	Categorical	Unemployed currently employed self-employed retired

*Table 1. (Continued)*

Diagnos	Duration of diagnosis	When were you diagnosed with diabetes	Categorical	less than 1 year 1 – 5 years ago 5 – 10 years ago 10 or more years ago.
Stay	Duration of stay	How long ago did you resettle to the United States	Categorical	less than 1 year 1 – 5 years ago 5 – 10 years ago 10 or more years ago.

### **Ethical Procedures**

While Refugee populations are considered as a vulnerable population, it was necessary for me as a researcher to adhere to ethical procedures and standards when using this population in a research study. Research shows that the use of human subjects when conducting research studies are prone to significant risks and things can go awry; therefore, it is evident to plan accordingly and seek approval before proceeding with the research (Mandal, Acharya, & Parija, 2011). I identified several ethical issues associated with refugee research. Based on ethical standpoint, understanding refugee women's perspectives of whether the research will meet their needs is significant. Also, research has shown that low health literacy can threaten an individual's autonomy, thus leading to not being able to understand or process health information (Wangdah et al., 2014).

Research suggests that it is evident to ensure that participants understand their rights. Ethics approval was therefore sought from Walden University Institutional Review Board (IRB). Given the benefits that come with research studies such as improving practice, education, research, and policy, it was vital for me to assess proposed studies thoroughly to ensure that risks are minimized and the study corresponds with benefits (Klitzman, 2013). Therefore, I sought ethical guidance from IRB before proceeding with the proposed research study. After consent was given from the IRB committee, I then approached participants to obtain informed consent. I encouraged the participants to ask questions they might have, and to voice any concerns they might have or encounter during this process to ensure transparency throughout the study. All the participants who met the inclusion criteria then signed the consent forms to give the researcher permission to collect data.

Nijhawan, et al. (2013) affirmed that informed consent is a document that research participants sign and date in order to participate in a research study. The purpose of this document was to provide sufficient information to research participants in a language that they understood so they could make voluntary, proper and knowledgeable decision to either participate in the research study or not (Nijhawan et al., 2013). Some of the information included in informed consent forms included; the purpose of the study, the benefits, risks, and data confidentiality and security; therefore, it was essential to ensure that all potential participants signed and dated the informed consent. All data obtained for this study will be confidential. As the researcher, I was the only person to



collect data and have access to where data is stored and other study information relating to the study.

### **Summary**

In Chapter Three, I defined the methodology of this research study. The research study design and sampling procedures used to collect data were explained in detail. Different statistical analysis methods that were used to test the research questions and the hypotheses were explored. In this chapter, I also explained how the study survey questionnaire was developed and how each question would be measured. Furthermore, in this chapter, I described ethical procedures and informed consent forms that were used to avoid ethical dilemma. Moreover, I also discussed data management and security. In chapter four, I will present the results of data analyses obtained using SPSS Statistical software, and describe these in detail.

## Chapter 4: Results

The purpose of this study was to determine the levels of health literacy and diabetes knowledge among refugee women with diabetes living in the State of Arizona. I developed the following research questions and hypotheses to guide this research study:

Research Question 1 (RQ1): What are the health literacy and diabetes knowledge levels among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona?

Research Question 2 (RQ2): How does health literacy and diabetes knowledge levels differ among refugee women with a known diagnosis of diabetes when stratified by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement.

Null Hypothesis ( $H_02$ ): Health literacy and diabetes knowledge did not differ by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement, among refugee women with a known diagnosis of diabetes

Alternative Hypothesis ( $H_a2$ ): Health literacy and diabetes knowledge differed by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement, among refugee women with a known diagnosis of diabetes

Research Question 3 (RQ3): What is the association between health literacy and diabetes knowledge levels and age, education, employment status, number of years lived with diabetes and length of stay since resettlement, among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona?

Null Hypothesis ( $H_03$ ): Age, education, employment status, number of years lived with diabetes and length of stay since resettlement had no effect on health literacy and diabetes knowledge levels among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona.

Alternative Hypothesis ( $H_a3$ ): Age, education, employment status, number of years lived with diabetes and length of stay since resettlement had an effect on health literacy and diabetes knowledge levels among refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona.

In this chapter, I presented the results and attempted to answer these research questions. I presented different statistical analyses such as descriptive statistic that tests characteristics of the study population, f-statistic that tests the hypotheses, and simple and multiple regressions that test the association between the variables of interest.

### **Data Collection**

I targeted anyone who identified as a refugee woman with a known diagnosis of diabetes and residing in Maricopa County in Maricopa County, Arizona. The age group for the target population was 18 years and older. Data collection began in June 2019 and ended in October 2019. I used purposive sampling and employed two types of recruitment methods. First, I partnered with the Maricopa Integrated Health System Refugee Women's Health Clinic for recruitment purposes. Following ethics approval, I was granted access to their electronic medical records to identify refugee women aged 18 years and older diagnosed with diabetes. Diabetes diagnoses included Type I and II diabetes, gestational diabetes and pre-diabetes. I reviewed several medical charts and

identified diabetes patients using the ICD-9 and ICD-10 diabetes diagnosis codes. The cultural navigators started calling patients and asked if they would like to participate in the study using a script (See Appendix B). All participants who stated that they were interested in participating were invited to attend a clinic visit where an interview was conducted. Patients who speak different languages such as: Arabic; Burmese; Somali, Swahili, Kinyarwanda, Kirundi, Hahka-Chin, English, French, and other dialects were invited to take part in the study, since interpretation services were provided through the cultural navigators. Every Thursday, I scheduled several interviews while the cultural navigators interpreted.

The second recruitment method I used was through community outreach campaigns whereby I visited community churches, attended community meetings, contacted community gatekeepers and posted self-disclosure flyers (See Appendix C) at refugee resettlement organizations and at apartment complexes where refugees predominantly resided, and local African food stores. I then enrolled participants who self-disclosed as meeting the study's inclusion criteria. I individually interviewed participants who speak French, Swahili, Kinyarwanda, Kinyamulenge, Kirundi, and English, since I speak all the aforementioned languages fluently. For the other participants who did not speak the listed languages, I scheduled an appointment with the appropriate cultural navigators to conduct the interview. Before the beginning of any interview, I read the study information letter (See Appendix A) to the participant and obtained a verbal consent from the participant to complete the questionnaire. I emphasized the fact that the study is voluntary and participants can still opt out of the

study even at the last minute if they felt uncomfortable. All participants consented to participate in the study.

A total of 82 participants completed the questionnaire. After compiling all the data, I then transferred the data from the paper forms to an excel datasheet, which I then exported to SPSS for data analysis. The primary purpose of this study was to determine the levels of health literacy and diabetes knowledge among refugee women with a known diagnosis of diabetes who have resettled in Maricopa County, Arizona. Further purposes of the study were to explore the levels of health literacy and diabetes knowledge and understand whether different factors affecting them are in existence. This quantitative study included social determinants such as age, education status, employment status and other factors (participants' native country, primary language, and other spoken languages) as well as other factors such as number of years lived with diabetes and length of stay or resettlement in Maricopa County, Arizona. I used robust epidemiological methodology in an attempt to explain the complex relationships that may exist between health literacy levels and the aforementioned factors. SPSS version 21 was used to conduct data analysis.

### **Independent Variables**

The sample size for this study included 82 refugee women with a known diagnosis of diabetes who reside in Maricopa County, Arizona. The demographic variables that were measured included [Please note that all ranges must be written with an en dash with no spacing between the ends of the dash and the numbers. The names of countries cannot be abbreviated unless they are being used as adjectives.]

(a) age as a grouped variable (18 – 24; 25 – 34; 35 – 44; 45 years or older), (b) education status (no schooling, primary education; high school education; college education or higher), (c) employment status (unemployed; currently employed; self-employed; or retired), (d) Number of years lived with diabetes as a grouped variable (less than 1 year; 1 – 5 years ago; 5 – 10 years ago; 10 or more years ago), and (e) Length of stay since resettlement to the US as a grouped variable (less than 1 year; 1 – 5 years ago; 5 – 10 years ago; 10 or more years ago)

### **Dependent Variables**

Self-reported health literacy level was calculated using the European Health Literacy Questionnaire (HLS-EU-Q16). The Self-reported health literacy questions (7 - 15), were labelled *Very Easy*, *Easy*, *Difficult*, *Very difficult*, *Don't Know*, except for question 9 which was labelled *Never*, *Sometimes*, *Often*, *Always*, *Don't Know*. All the response categories were dichotomized. Health literacy level was then recoded and recategorized into two variables: High Literacy (HL), coded 1 which included all responses marked as *Very Easy and Easy or Never and Seldom*, and Low Literacy (LL), coded 0 which included all responses marked *Difficult, Very difficult and, "Sometimes", Often or Always*. Lastly all the responses marked as *Don't know* were treated as missing. Additionally, a sum score of all responses was calculated in SPSS and divided into the previously mentioned categories: High Literacy if the score points were 5-9 and Low Literacy if the score points were 0-4.

Furthermore, the Spoken Knowledge in Low Literacy patients with Diabetes (SKILLD) tool was used to determine participants' diabetes knowledge. Using the

answer key developed by Rothman et al. (2005; Appendix E) and the revised answer key adopted by Garcia et al. (2015; Appendix F). To avoid medical terminologies included in the original answer key, both answer keys were combined to provide a more comprehensive and robust analytical tool. The 10 questions from the SKILLD tool were coded as *correct or incorrect* based on the participants' responses. Then, diabetes knowledge was recategorized into two variables: Low Diabetes Knowledge (LDK) which was coded from those attaining less than 50% correct answers and High Diabetes Knowledge (HDK) which was coded from those achieving at least 50% or higher correct answers.

### **Missing data and data cleaning**

Notwithstanding the fact that missing data reduces the power of a study, categories coded as *don't know* were left blank and they were coded as missing. I excluded these missing values from the analysis to avoid introduction of bias and drawing unreliable conclusions of associations between dependent and independent variables. The process of coding the variables and excluding the missing data, allows for restriction to the cases that responded to all the relevant questions. This is known as complete data analysis, which would allow generation of reliable estimates.

### **Study Results**

Generally, this study examined the association between these five independent variables (a) age, (b) education status (c) employment status, (d) Number of years lived with diabetes, and (e) Length of stay since resettlement to the US, and two sets of dichotomized dependent variables, (a) High literacy vs. Low literacy and (b) High

diabetes knowledge (HDK) vs. Low diabetes knowledge (LDK). The following results are going to show the findings of the data analysis:

### Univariate Analysis

#### *Demographic Characteristics of Refugee Women Diagnosed with Diabetes (N=82)*

Table 2.

#### *Descriptive Analysis of Primary Language of Participants*

	Frequency	Percent	Valid Percent	Cumulative Percent
English	7	8.5	8.5	8.5
Swahili	9	11.0	11.0	19.5
French	8	9.8	9.8	29.3
Arabic	15	18.3	18.3	47.6
Kinyarwanda	9	11.0	11.0	58.5
Chin	3	3.7	3.7	62.2
Somali	5	6.1	6.1	68.3
Maay Maay	5	6.1	6.1	74.4
Burmese	4	4.9	4.9	79.3
Kinyamulenge	5	6.1	6.1	85.4
Kirundi	4	4.9	4.9	90.2
Lingala	1	1.2	1.2	91.5
Sango	1	1.2	1.2	92.7
Krio	1	1.2	1.2	93.9
Royinga	1	1.2	1.2	95.1
Hakha	2	2.4	2.4	97.6
Karen	1	1.2	1.2	98.8
Falam	1	1.2	1.2	100.0
Total	82	100.0	100.0	

Table 2 provides a description of study participant's primary language. Most participants spoke Arabic 15 (18.3%), and respondents who primarily spoke Swahili and Kinyarwanda were nine (11%). Those whose primary language is French were eight



(9.8%), English were seven (8.5%), and then, those whose primary language is Somali, Maay Maay, and Kinyamulenge followed each were five (6.1%).

Table 3.

*Descriptive Analysis of Refugee Women*

Characteristics	N (%)
	82 (100%)
Age	
25 – 34	11(13.4%)
35 – 44	31 (37.8%)
45+	40 (48.8%)
Educational status	
No schooling	30 (36.6%)
Primary School	24 (29.3%)
High School	20 (24.4%)
College Education or higher	8 (9.8%)
Employment Status	
Unemployed	50 (61.0%)
Currently employed	31 (37.8%)
Self-employed	1 (1.2%)
Number of years lived with diabetes	
Less than 1 year	
1 - 5 years	18 (22.0%)
5 – 10 years	30 (36.6%)
10 years +	14 (17.1%)
	20 (24.4%)
Length of stay since resettlement	
Less than 1 year	13 (15.9%)
1 - 5 years	28 (34.1%)
5 – 10 years	11 (13.4%)
10 years +	30 (36.6%)

Table 3 provides a descriptive analysis of the refugee women with diabetes that took part in the study. The total number of participants was ( $N=82$ ). All participants were women and they all had a known diagnosis of diabetes. Participants were classified into age groups, 13.4% ( $N=11$ ) participants were between the age of 25-34, 37.8% ( $N=31$ )

participants were between the age of 35–44, and lastly 48.8% ( $N=40$ ) participants self-identified as being between the age of 45 years or older, accounting for majority of the participants.

Majority of participants, 36.6% ( $N=30$ ), identified as not having any level of schooling, whilst 24 (29.3%) identified as having a primary education; 24.4% ( $N=20$ ) identified as having a high school education and 9.8% ( $N=8$ ) identified as having a college education or higher. A large number of participants, 61.0% ( $N=50$ ) self-reported that they were unemployed, whilst 37.8% ( $N=31$ ) self-reported that they were currently employed, and only 1.2% ( $N=1$ ) self-reported that they were self-employed. No respondents reported to be retired. Regarding number of years lived with diabetes, majority of participants 36.6% ( $N=30$ ) self-reported that they have lived with diabetes for 1–5 years; whilst 24.4% ( $N=20$ ) self-reported that they have lived with diabetes for 10 or more years; 22.0% ( $N=18$ ) for less than a year; and 17.1% ( $N=14$ ) for 5–10 years. The last demographic variable examined was the length of stay since resettlement, whereby 36.6% ( $N=30$ ) of all respondents self-reported that they have lived in the United States for 10 or more years; 13.4% ( $N=11$ ) for 5–10 years; 34.1% ( $N=28$ ) for 1–5 years; and 15.9% ( $N=13$ ) for less than a year.

Table 4.

*Distribution of Health Literacy Levels of Study Participants*

	Frequency	Percent	Valid Percent	Cumulative Percent
Low Literacy	63	76.8	76.8	76.8
High Literacy	19	23.2	23.2	100.0
Total	82	100.0	100.0	

Table 4 displays the frequencies and percentages of the Health Literacy levels. The results show that approximately 76.8% ( $N=63$ ) in the total study population have Low Literacy level, while 23.2% ( $N=19$ ) participants have High literacy level.

Table 5.

*Distribution of Diabetes Knowledge Levels of Study Participants*

	Frequency	Percent	Valid Percent	Cumulative Percent
Low Diabetes Knowledge	44	53.7	53.7	53.7
High Diabetes Knowledge	38	46.3	46.3	100.0
Total	82	100.0	100.0	

Table 5 shows the frequencies and percentages of the Diabetes Knowledge levels. The responses from the 10 questions SKILLD tool showed that 53.7% ( $N=44$ ) have low diabetes knowledge, whilst the remaining 46.3% ( $N=38$ ) have High Diabetes Knowledge.

**Results for Descriptive Analysis for research question 1**

A descriptive analysis was performed to investigate the levels of health literacy and diabetes knowledge among refugee women with a known diabetes diagnosis who

reside in Maricopa County, Arizona. The results in tables 4&5 show that majority refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona reported low health literacy 76.8% ( $N=63$ ) and low diabetes knowledge 53.7% ( $N=44$ ).

Table 6.

*Frequencies and Percentages of Refugee Women (Health Literacy)*

	High Literacy		Low Literacy	
	N	%	N	%
Age				
25 – 34	2	10.5%	9	14.3%
35 – 44	11	57.9%	20	31.7%
45+	6	31.6%	34	54.0%
Educational status				
No schooling	3	15.8%	27	42.9%
Primary School	2	10.5%	22	34.9%
High School	9	47.4%	11	17.5%
College Education or higher	5	26.3%	3	4.8%
Employment Status				
Unemployed	8	42.1%	42	66.7%
Currently employed	11	57.9%	20	31.7%
Self-employed	0	0.0%	1	1.6%
Number of years lived with diabetes				
Less than 1 year	2	10.5%	16	25.4%
1 - 5 years	7	36.8%	23	36.5%
5 – 10 years	4	21.1%	10	15.9%
10 years +	6	31.6%	14	22.2%
Length of stay since resettlement				
Less than 1 year	4	21.1%	9	14.3%
1 - 5 years	6	31.6%	22	34.9%
5 – 10 years	2	10.5%	9	14.3%
10 years +	7	36.8%	23	36.5%

Table 7.

*Frequencies and Percentages of Refugee Women (Diabetes Knowledge)*

	High Diabetes Knowledge		Low Diabetes Knowledge	
	N	%	N	%
Age				
25 – 34	3	7.9%	8	18.2%
35 – 44	13	34.2%	18	40.9%
45+	22	57.9%	18	40.9%
Educational status				
No schooling	11	28.9%	19	43.2%
Primary School	11	28.9%	13	29.5%
High School	11	28.9%	9	20.5%
College Education or higher	5	13.2%	3	6.8%
Employment Status				
Unemployed	24	63.2%	26	59.1%
Currently employed	14	36.8%	17	38.6%
Self-employed	0	0.0%	1	2.3%
Number of years lived with diabetes				
Less than 1 year	6	15.8%	12	27.3%
1 - 5 years	10	26.3%	20	45.5%
5 – 10 years	8	21.1%	6	13.6%
10 years +	14	36.8%	6	13.6%
Length of stay since resettlement				
Less than 1 year	6	15.8%	7	15.9%
1 - 5 years	12	31.6%	16	36.4%
5 – 10 years	5	13.2%	6	13.6%
10 years +	15	39.5%	15	34.1%

Table 6 and 7 illustrate the frequencies and percentages of the responses for health literacy levels and diabetes knowledge levels measured by respondent's age, respondent's education status, respondent's employment, respondent's duration of diagnosis, and respondent's length of stay since resettlement.

*Age:* majority of respondents 54% ( $N=34$ ) who were in the age group 45+, self-reported as having low health literacy. Whilst, most of those in the same age group 57.9% ( $N=22$ ) reported as having high diabetes knowledge.

*Education status:* majority of respondents who reported as having no form of education self-reported as having low health literacy 42.9 % ( $N=27$ ). Meanwhile, the same educational status group reported as having low diabetes knowledge 43.2% ( $N=19$ )

*Respondent's employment:* majority of respondents who self-reported as Unemployed 66.7 % ( $N=42$ ) reported as having low health literacy, while majority of those in the same employment category 59.1% ( $N=26$ ) self-reported as having low diabetes knowledge.

*Respondent's duration of diagnosis:* Among participants in the category of participants who self-reported that they have been diagnosed of diabetes between 1–5 years ago, 36.5 % ( $N=23$ ) self-reported as having low health literacy, while 45.5% ( $N=20$ ) self-reported as having low diabetes knowledge.

*Respondent's length of stay:* Majority of participants who self-reported that their length of stay since resettlement was 10 or more years 36.5 % ( $N=23$ ) self-reported as having low health literacy, while majority in the same category of length of stay 34.1% ( $N=15$ ) self-reported as having low diabetes knowledge.

### Bivariate Analysis-Logistic Regression

I conducted logistic regression to test the association between independent variables and dependent variables. The results for when each independent variable was considered are shown below:

Table 8.

#### *Bivariate Analysis-Logistic Regression (Health literacy)*

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	Upper
Respondent's Age			4.103	2	.129			
Respondent's Age(1)	.231	.898	.066	1	.798	1.259	.216	7.326
Respondent's Age(2)	1.137	.581	3.835	1	.050	3.117	.999	9.723
Respondent's Education Status			14.808	3	.002			
Respondent's Education Status(1)	-2.708	.951	8.115	1	.004	.067	.010	.430
Respondent's Education Status(2)	-2.909	1.039	7.843	1	.005	.055	.007	.418
Respondent's Education Status(3)	-.711	.858	.688	1	.407	.491	.091	2.636
Respondent's employment status			3.881	2	.144			
Respondent's employment status(1)	19.545	4.02E+04	.000	1	1.000	3.08E+08	.000	.
Respondent's employment status(2)	20.605	4.02E+04	.000	1	1.000	8.89E+08	.000	.
Duration of diagnosis			2.085	3	.555			
Duration of diagnosis(1)	-1.232	.895	1.896	1	.168	.292	.050	1.685
Duration of diagnosis(2)	-.342	.651	.276	1	.599	.710	.198	2.546
Duration of diagnosis(3)	-.069	.767	.008	1	.928	.933	.208	4.196

Table 8. (Continued)

Duration of stay			.616	3	.893			
Duration of stay(1)	.379	.740	.262	1	.609	1.460	.342	6.227
Duration of stay(2)	-.110	.631	.030	1	.862	.896	.260	3.088
Duration of stay(3)	-.314	.893	.124	1	.725	.730	.127	4.203

*Age:* I observed that the odds of high literacy among refugee women were increasing with age i.e. 1.26 and 3.12 for age groups 35–44 and 45+, respectively. However, these were not statistically significant, as reflected by the p-values that were greater than 0.05 and confidence intervals that cover 1. It is worth noting that, the age group 18 – 24 did not appear in the model since it had no participants reporting as being within that age range. Based on these findings, I accepted the null hypothesis that predicted that age was not a predictor of health literacy among refugee women with a known diagnosis of diabetes.

*Educational status:* I observed that health literacy appeared to increase with education status i.e. the odds of having high literacy increase with the more education refugee women diagnosed with diabetes, would have received. The ORs increase from 0.06 to 0.49, with those observed in the Primary School and High School categories being statistically significant. With these findings combined in this model, I rejected the null hypothesis and accepted the alternative hypothesis, which predicted that education status is a predictor of high among refugee women with a known diagnosis of diabetes.

*Employment status:* results obtained demonstrate distorted ORs. Therefore, I could not make any meaningful statistical conclusion on effect on health literacy from



this statistical analysis output. This could further warrant exclusion of this variable from the multivariate analysis.

*Number of years lived with diabetes:* I observed that the odds of reporting high literacy increase with the number of years lived with diabetes. The ORs increase from 0.29, 0.71 to 0.93 for refugee women reporting that they had been diagnosed with diabetes 1 - 5 years ago, 5 – 10 years ago, and at least 10 years ago, respectively. However, these results are not statistically significant as reflected by p-values that were greater than 0.05. Based on these findings, I accepted the null hypothesis, that predicted that number of years lived with diabetes was not a predictor of health literacy among refugee women with a known diagnosis of diabetes.

*Length of stay since resettlement:* the odds of reporting high health literacy appear to decrease, the longer the stay since resettlement. The OR decreases from 1.46 to 0.73, with statistically insignificant results. The results in the table above supports the Null hypothesis that predicted that length of stay since resettlement was not a predictor of health literacy among refugee women with a known diagnosis of diabetes.

Table 9.

*Bivariate Analysis-Logistic Regression (Diabetes Knowledge)*

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	Upper
Respondent's Age			2.950	2	.229			
Respondent's Age(1)	-1.181	.748	2.496	1	.114	.307	.071	1.329
Respondent's Age(2)	-.526	.483	1.185	1	.276	.591	.229	1.523

Table 9. (Continued)

Respondent's Education Status			2.524	3	.471			
Respondent's Education Status(1)	-1.057	.823	1.652	1	.199	.347	.069	1.742
Respondent's Education Status(2)	-.678	.837	.655	1	.418	.508	.098	2.620
Respondent's Education Status(3)	-.310	.858	.131	1	.718	.733	.137	3.938
Respondent's employment status			.062	2	.970			
Respondent's employment status(1)	21.123	4.02E+04	.000	1	1.000	1.49E+09	.000	.
Respondent's employment status(2)	21.009	4.02E+04	.000	1	1.000	1.33E+09	.000	.
Duration of diagnosis			7.980	3	.046			
Duration of diagnosis(1)	-1.540	.699	4.862	1	.027	.214	.054	.843
Duration of diagnosis(2)	-1.540	.623	6.114	1	.013	.214	.063	.727
Duration of diagnosis(3)	-.560	.728	.591	1	.442	.571	.137	2.380
Duration of stay			.301	3	.960			
Duration of stay(1)	-.154	.665	.054	1	.817	.857	.233	3.159
Duration of stay(2)	-.288	.528	.296	1	.586	.750	.266	2.113

Duration of stay(3)	-.182	.707	.066	1	.797	.833	.208	3.332
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*Age:* I observed that the odds of high diabetes knowledge among refugee women were increasing with age i.e. 0.31 and 0.51 for age groups 35-44 and 45+, respectively. Similar to the results obtained for health literacy, these results were not statistically significant, as reflected by the p-values that were greater than 0.05 and confidence intervals that cover 1. It is also worth noting that, like for health literacy dependent variable, the age group 18 – 24 did not appear in the model since it had no participants reporting as being within that age range. The results in this model support the null hypothesis that predicted that age was not a predictor of diabetes knowledge among refugee women with a known diagnosis of diabetes.

*Educational status:* I observed that diabetes knowledge appears to increase with education status i.e. the odds of having high diabetes knowledge increase with increased education among refugee women diagnosed with diabetes. The ORs increase from 0.35 to 0.73, however these were not statistically significant. The results in this model support the null hypothesis that predicted that education status was not a predictor of diabetes knowledge among refugee women with a known diagnosis of diabetes.

*Employment status:* results obtained demonstrate distorted ORs. Therefore, I could not make any meaningful statistical conclusion on the effect on diabetes knowledge could be made from this statistical analysis output. This could further warrant exclusion of this variable from the multivariate analysis.

*Number of years lived with diabetes:* I observed that the odds of reporting high diabetes knowledge increase with the number of years lived with diabetes. The ORs increase from 0.2 to 0.57, with statistically significant results being observed for refugee women reporting that they had been diagnosed with diabetes 1 - 5 years ago and, 5 – 10 years ago. With the findings combined in this model, I rejected the null hypothesis and accept the alternative hypothesis, which predicted that number of years lived with diabetes is a predictor of diabetes knowledge among refugee women with a known diagnosis of diabetes.

*Length of stay since resettlement:* there is no observable pattern for diabetes knowledge as results reflect ORs of 0.86, 0.75 and 0.83 for respondents who reported that they had lived in Arizona for 1 - 5 years, 5 – 10 years, and 10 years +, respectively. No statistically significant results were obtained for length of stay since resettlement. The results in this model support the null hypothesis that predicted that length of stay since resettlement was not a predictor of diabetes knowledge among refugee women with a known diagnosis of diabetes.

### **Multivariate Analysis**

Table 10.

#### *Multiple Logistic Regressions (Health Literacy)*

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
								Lower	Upper
Step	Respondent's			14.759	3	.002*			
1 <sup>a</sup>	Education Status								
	Respondent's	- 1.059	8.783	1	.003*	.043	.005	.346	
	Education Status(1)	3.138							

Table 10. (Continued)

Respondent's Education Status(2)	-3.355	1.175	8.159	1	.004*	.035	.003	.349
Respondent's Education Status(3)	-.873	1.005	.754	1	.385	.418	.058	2.995
Duration of diagnosis			4.610	3	.203			
Duration of diagnosis(1)	-2.226	1.196	3.463	1	.063	.108	.010	1.126
Duration of diagnosis(2)	-.753	.871	.747	1	.387	.471	.085	2.597
Duration of diagnosis(3)	.565	1.135	.248	1	.618	1.760	.190	16.284
Duration of stay			1.537	3	.674			
Duration of stay(1)	.608	1.037	.343	1	.558	1.836	.241	14.012
Duration of stay(2)	.428	.843	.257	1	.612	1.533	.294	8.009
Duration of stay(3)	-1.161	1.374	.715	1	.398	.313	.021	4.623
Constant	1.219	1.020	1.431	1	.232	3.385		

a. Variable(s) entered on step 1: Respondent's Education Status, Duration of diagnosis, Duration of stay.

### Predictors of Health Literacy

I conducted a multivariate analysis to determine the effect of age, education status, employment status, number of years lived with diabetes, and length of stay since resettlement. Following stepwise logistics regression, the final model that I obtained to predict associations between health literacy and the independent variables excluded employment status and respondent's age, since these variables produced somewhat distorted odds ratios, and contained categories without respondents, respectively. The multiple logistic regression model showed no statistical significance for duration of diagnosis and length of stay since resettlement. However, a statistically significant result was demonstrated for education status, with an adjusted  $OR = .043$  ( $95\% CL = .005, .346$ ) for respondents reporting attaining at least primary school education,  $p = 0.003$ , and  $OR$

.035 (95% CL=0.003, .349) for respondents attaining at least high school education (Table 10). It is therefore worth noting that the model I used adequately supports the null hypothesis and conclude that age, number of years lived with diabetes, and length of stay since resettlement do not have an effect on health literacy, however also accept the alternative hypothesis, which predicted that education status has effect on health literacy among refugee women with a known diagnosis of diabetes.

Table 11.

*Multiple Logistic Regressions (Diabetes Knowledge)*

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B) Lower Upper	
Step	Respondent's Age			1.083	2	.582			
1 <sup>a</sup>	Respondent's Age(1)	-1.002	.966	1.075	1	.300	.367	.055	2.440
	Respondent's Age(2)	-.411	.693	.352	1	.553	.663	.171	2.578
	Respondent's Education Status			3.612	3	.307			
	Respondent's Education Status(1)	-1.534	.915	2.812	1	.094	.216	.036	1.295
	Respondent's Education Status(2)	-.949	.922	1.061	1	.303	.387	.064	2.357
	Respondent's Education Status(3)	-.639	.997	.411	1	.522	.528	.075	3.725
	Duration of diagnosis			6.774	3	.079			
	Duration of diagnosis(1)	-1.702	.930	3.351	1	.067	.182	.029	1.128
	Duration of diagnosis(2)	-1.773	.767	5.337	1	.021*	.170	.038	.764
	Duration of diagnosis(3)	-.527	.978	.290	1	.590	.591	.087	4.016
	Duration of stay			1.278	3	.734			
	Duration of stay(1)	.726	.943	.592	1	.442	2.066	.325	13.114
	Duration of stay(2)	.770	.724	1.132	1	.287	2.160	.523	8.925
	Duration of stay(3)	.129	.921	.020	1	.888	1.138	.187	6.920

Table 11. (Continued)

Constant	1.840	.958	3.688	1	.055	6.299
a. Variable(s) entered on step 1: Respondent's Age, Respondent's Education Status, Duration of diagnosis, Duration of stay.						

### Predictors for Diabetes Knowledge

I conducted a multivariate logistic analysis to examine the effect of respondent's age, education levels, employment status, number of years lived with diabetes and length of stay since resettlement. Similar to the stepwise model approach used for health literacy, employment status was not a good predictor for diabetes knowledge, thus I removed this variable from the model. Table 11 illustrates the results for the multiple logistic regressions model with four predictors. The results in the model showed that there was no statistical significance between three variables (Respondent's age, Education levels, and length of stay since resettlement), however, there was a statistically significant result for number of years lived with diabetes and diabetes knowledge  $OR=0.170$  (95%CL= 0.038, 0.764),  $P=.021$  (table 11). Just like the results obtained from table 10, it is therefore worth noting that the model I used adequately supports the null hypothesis and concludes that age, education status, employment status and length of stay since resettlement do not have an effect on diabetes knowledge, however also accept the alternative hypothesis, which predicted that number of years lived with diabetes has effect on diabetes knowledge among refugee women with a known diagnosis of diabetes.

### **Summary**

In chapter 4, I reported the results of the study. I presented the results in tables as well as provide a description of the results. In this study, I investigated the levels of health literacy and diabetes knowledge and their predictors in a total sample of 82 refugee women with a known diagnosis of diabetes who reside in Maricopa County AZ. I tested association between five main predictor variables (age, education status, employment status, duration of diabetes diagnosis, and length of stay since resettlement) and health literacy and diabetes knowledge in simple and multiple logistic regressions using stepwise model. Education status and duration of diagnosis were the only predictors that I observed to have statistically significant associations for health literacy and diabetes knowledge, respectively. The findings from the study support the hypotheses that education levels and duration of diagnosis are significant predictors of health literacy and diabetes knowledge. In chapter 5, I will further explore the findings of the study and provide recommendations for future research and limitations of this study as well as the implications for social change based on the results of the study.



## Chapter 5: Discussion, Conclusions, and Recommendations

This research study was driven by the need to investigate the levels of health literacy and diabetes knowledge among refugee women with a known diagnosis of diabetes and is residing in Maricopa County, Arizona. By reviewing literature, I observed that there were limited research studies conducted among refugees in the United States. Over the years, there has been an influx of refugees into the United States of America as a result of over 65.6 million of displaced individuals around the world (UNHCR, 2017). As this population resettles and assimilates into different cultural context from their place of origin, there was need to explore (a) whether different levels of health literacy and diabetes knowledge are in existence, and (b) how different sociodemographic predictors would affect levels of health literacy and diabetes knowledge among the refugee population. The limited research available has shown that low health literacy is linked to poor health outcomes and individuals with low literacy are prone to experience higher rates of illness, frequent hospitalizations, and other stressors that greatly affect their health (Riggs, et al., 2016).

Research shows that low health literacy is associated with stigma, which can affect people with low health literacy spoken interactions with their providers, thus leading to not benefiting from health services (Easton, et al., 2013). Easton, et al. (2013), concurring with the study by Riggs, et al. (2016), concluded that low literacy is associated with less appropriate access to healthcare services, poor or not being able to self-manage health conditions and poorer health outcomes. Building on the results of the

above studies, I conducted this study to examine the levels of health literacy and diabetes knowledge among refugee women with a known diagnosis of diabetes.

I used a 25-question survey instrument to collect quantitative data among 82 refugee women with a known diagnosis of diabetes residing in Maricopa County, Arizona. At the end of data collection, I exported all data from an excel data sheet to SPSS for data analysis. In this study, I used descriptive statistics to explain the population characteristics and the frequency distributions of all independent variables in relation to the dependent variables. Additionally, I conducted simple logistic regression to test the association between each independent variable (age, education status, employment status, number of years lived with diabetes, and length of status since resettlement), and health literacy and diabetes knowledge levels. Moreover, I used a multiple logistic regression (stepwise model) to examine the effect of each independent variable on the dependent variables.

### **Interpretation of Findings**

The first purpose of the study was to investigate the levels of health literacy and diabetes knowledge among refugee women with a known diagnosis of diabetes. The findings from the study showed that 76.8% of refugee women with a known diagnosis of diabetes, residing in Maricopa County, Arizona, reported low health literacy which means that they lack the capacity to obtain, understand and act upon health information and services, as well as making appropriate decisions for their health. The findings from this study were similar to the findings from a study conducted in Oslo, Norway among Somali refugee population (Gele, et al., 2016). In this study, 71% of Somali refugee

women were found to have low health literacy (Gele, et al., 2016). Some characteristics found in Gele, et al.'s (2016) study that can be applicable to the sample population for this study are that Somali women were not familiar with the Norwegian healthcare system, yet, they were expected to navigate the healthcare system and make healthy lifestyle choices. Participants in this study can relate to the exact same characteristics mentioned, in addition to many others such as cultural backgrounds, language barriers, poor education, and failure to fully integrate in the United States.

The results also showed that, 53.7% of participants reported low diabetes knowledge, meaning that they lack the capacity to understand their symptoms, diagnosis, and how to manage their diabetes on a daily basis. Based on the findings from this study, I agreed with the findings in a study conducted by Njeru, et al. (2016) on Somali refugees, where the authors that diabetes health literacy was relatively low among Somali patients with diabetes mellitus and they also struggle with diabetes management. Using some of the questions in the questionnaire (see appendix D), I sought to understand if the refugee population understand health information, are able to read health information, or if they know where to seek health care services when in need. Findings for the aforementioned questions indicate that the majority, or 76.8% of the refugee women struggle with health literacy issues, navigating the complex U.S. health care system, filling prescriptions, and following medical recommendations. The findings of this study are consistent with other studies in the literature, that identify that refugees struggle to navigate the fragmented United States health care system due to language barriers, health literacy, cultural issues, and poor education (Kotovicz, et. al., 2018, & Njeru, et al.,

2016). While examining how individuals in different age categories responded to questions, I found that most women in the age group 45+ self-reported as having low health literacy (54.0%). This might be a result of several factors such as, (a) older refugee women may not have had the opportunity for formal education compared to younger refugee women, (b) as individuals get older the harder it becomes to obtain, understand, and act up health information, and (c) majority in this age group were 60+ years old, thus, it might be difficult to retain health information. In the study by Almehawes and Toevs (2014), the authors concluded that older refugees were more vulnerable compared to younger refugee populations. Additionally, the findings of the study showed that women with low level of education self-reported as having low health literacy and low diabetes knowledge. In a study conducted by Gele, et al., (2016), the authors found that the level of health literacy increased as the level of education increased. Individuals with college level education and those with high school education reported higher health literacy compared to individuals with lower level of education, thus the authors' findings in Gele, et al. (2016) concur with the findings of this study.

After answering the first research question, I conducted a simple logistic regression to answer the second research question and aimed to establish how health literacy and diabetes knowledge levels differed among refugee women with a known diagnosis of diabetes when stratified by age, education status, employment status, number of years lived with diabetes and length of stay since resettlement. Results from the statistical output show that that there was no statistically significant association between age, employment status, and number of years lived with diabetes and length of stay since

resettlement and health literacy. In a study by Gele, et al. (2016) they also concluded that employment status was not a significant predictor of low health literacy, thus consistent with the results of this study on employment status. I assumed that employment opportunities for refugee women may be limited to employment opportunities whose effect on health literacy and diabetes knowledge may be inconsequential. Refugee women face challenges in terms of navigating the employment sector especially those that arrive when they are much older and not educated. They are limited to the types of jobs that may be available to them. In most cases they end up in manual labor occupations, working with other individuals in similar categories; thus, they are exposed to limited opportunities for integration into society. In the study by Gele, et al. (2016), the authors concluded that employment and integration were important variables and they played a crucial role in helping refugees network and create channels of information and knowledge that may help them develop health literacy skills and increase their health literacy level. Additionally, due to cultural backgrounds, they might end up being housewives, which also results in them being isolated from society, thus not being able to acculturate in the society. While the type of employment may be linked to level of education that one may have acquired, further disaggregation of the predictor may be required to determine whether different types of jobs may either predispose or be protective of low health literacy and low diabetes knowledge.

Results from the bivariate analysis showed a statistical significance between education status and health literacy; an increase in education level had a significant protective effect for low health literacy; i.e. low health literacy was found to be 0.06

times less among respondents who had received primary education compared to those without education and 0.05 times less among respondents with high school education compared to those without education. In this instance, I therefore accepted the alternative hypothesis that education status was a significant predictor of health literacy among refugee women with a known diagnosis of diabetes. Gele, et al. (2016) reached the same conclusion with the study results that health literacy levels increased as the level of education increased. Research shows that health literacy is a relevant factor related to diabetes, thus low diabetes knowledge can lead to diabetes complications and other negative health outcomes (Cavanaugh, 2011). This consistency with literature shows that when one acquires the relevant knowledge skillsets through formal education systems, there is a higher likelihood of being able to learn, comprehend and retain the information, and be able to apply it. In this case, the higher the education attained, the more likely respondents will be able to read, understand, comprehend and apply the information that is relevant to their medical condition.

When examining the association between independent variables and diabetes knowledge, the findings showed that there was no statistically significant association between age, education status, employment status, and length of stay and diabetes knowledge levels. The results of the study conducted by Njeru, et al. (2016), are consistent with this study's results as they also found that individuals' level of education and length of stay were not associated with high or low diabetes knowledge (Njeru, et al., 2016). However, I found a statistically significant association between the numbers of years lived with diabetes and diabetes knowledge, meaning that the longer the duration

since diagnosis, the more knowledge of diabetes one acquires. With the statistical significance of ( $p=0.05$ ) I accepted the alternative hypothesis that number of years lived with diabetes is a predictor of diabetes knowledge. I concluded that experiential learning may play a role in instilling basic skills and knowledge facets about the condition, regardless of the fact that education status did not yield statistically significant results. This means, the longer one lives with the condition, there is a likelihood that repetitive exposure to health visits, health care professionals, or even other patients, may keep refugee women abreast with information relating to diabetes (symptoms and management; Cavanaugh, 2012).

I used the binary multiple logistic regression to answer the third research question. In stepwise logistic regression model, the analysis showed that only education status had a statistically significant effect on health literacy. These results are consistent with the results in a study conducted by Gele, et al. (2016) and a study by Wångdahl, et al. (2014) that concluded that low education as well as being born in another country was associated with low health literacy. Whilst I did not look at the effects of country of origin on health literacy or diabetes knowledge, navigation of the American healthcare system may require one to have a certain minimum level of education. Differences in the education systems between United States and the countries of origin may present barriers to how one may be able to navigate i.e. read, write, understand, comprehend, appreciate, retain, and/or utilize the information relating to diabetes.

While investigating the independent variables that have effect on diabetes knowledge, the multiple logistic regression model showed that the numbers of years lived

with diabetes was the only variable in the model that had effect on diabetes knowledge. This result is consistent with that obtained in the simple logistic regression analysis. In other words, it means that even in the presence of confounding, number of years lived with diabetes, is definitely a predictor of diabetes knowledge among refugee women. In the studies by Souza, et al. (2016) and Rothman, et al. (2005), the authors observed a correlation between duration of disease and diabetes knowledge, thus agreeing with the findings in this study. However, both studies also showed association between SKILLD results and education level, which contradict the results of this study since there was no statistical significance between education and diabetes knowledge.

Various factors play a role in determining health literacy levels among refugee women. Adding the predictors to the saturated model was an attempt at observing the effects holistically, since various factors can affect health literacy and diabetes knowledge, with other factors having a multiplicative effect. This interaction effect may be subject to future exploration whereby different factors can be linked to determine their effects on health literacy and diabetes.

### **Limitations of the Study**

There were limitations that I observed in my study, which may have affected the results of the study. The first limitation of the study came as a result of me using a cross-sectional study design. This research design limits drawing causal relationships. The second limitation is the use of self-reported information, which can introduce a number of biases including recollection and reporting biases. The third limitation is the use of the



SKILLD tool. Although the validity of the SKILLD tool has been tested, there is a need for more aspects of validity for tools that are appropriate across different populations. Given the cultural, educational, and language backgrounds for the sample populations, I believe that lack of understanding certain questions might have affected the quality of data collection. Although cultural navigators were used to interpret questions to participants and ensure quality and complete data is collected, several questions were left unanswered or the participants stated that they did not know which lead to a large number of missing values in some items. Another limitation of the study is the use of a purposive sample. The purposive sample restricted the sample population by age, by refugee status, and by gender (female only). These restrictions increased the probability of bias in this study. I excluded all women under the age of 18, and also excluded other immigrants with different resettlement status such as asylum seekers. In this study, I estimated a sample size of 102 participants, used the power analysis with a given significance level of 0.05, 80% power, and effect size of  $0.27 \approx 0.3$ , yet only 82 respondents participated in the study. Hence, the findings of the study cannot be generalized to the excluded population or any other population that does not share the same characteristics with the sample population. Also, the smaller sample size might lower statistical power and increase beta-error, making some potentially significant association turning out to be insignificant at the end.

One strength of this study was the representation of the sample population. The participants were from 14 countries around the world, with individuals from countries with the most resettled refugees in Arizona and in the United States. Majority of

participants were from the Democratic Republic of Congo (DRC), Somalia, Iraq, Burma, and Syria. According to the Department of Health Services (Arizona Department of Economic Security, 2018) the most resettled refugees in Arizona are from Iraq, Somalia, and the Democratic Republic Congo and according to the National Immigration Forum (2019), the most resettled refugees in the United States came from the Democratic Republic of Congo and Burma for the fiscal year 2018. Thus, concerning the generalizability, the sample population was diverse and representative of most refugees in the United States. However, the findings of this study can primarily be applied to refugees in Arizona and they may also be used by individuals who work with refugees in the United States or globally who share the same characteristics with the studied sample population. In spite of the present limitations of this study, it is evident that this study is beneficial because it is the first of its kind to be conducted in the United States on a diverse refugee population and the findings have demonstrated an association between education status and health literacy and number of years lived with diabetes and diabetes knowledge. This shows that there is a need to develop interventions that seek to educate refugee women with diabetes and improve their health literacy skills and diabetes knowledge. This study also has potential to add value to the initial clinical assessments that are conducted among refugees upon arrival, so as to determine refugee women's health literacy status and be able to offer appropriate and relevant interventions.

### **Recommendations**

Refugee populations remain under-studied in the United States. The literature shows some studies have been done in some western countries such as Australia, Canada, Sweden, and Norway, however not much have been done in the United States in the past few years. Thus, given what previous studies have found and what I found, it is evident that there is need to explore the issue further to identify more predictors of health literacy and diabetes knowledge among this population. Despite the fact that I used the widely-used SKILLD survey questionnaire tool, that has been used among several refugee population studies and its validity having been tested, I believe that there is a need to explore more appropriate tools that can be used especially for a population with a limited educational background. Therefore, more quantitative and qualitative research is needed for understanding the level of health literacy and diabetes knowledge and different factors that determine them. A previous study by Wangdahl, et al. (2016) suggested conducting longitudinal studies that perhaps compare refugee population and indigenous population over prolonged periods of time to note how different factors influence health literacy among both populations. I concur with this suggestion because longitudinal studies provide the ability to identify or relate events to particular exposure, providing the opportunity to define found exposures, and also, to establish sequence of events and the impact they have on the studied population (Caruana, et al. 2015).

Additionally, due to a small sample size and purposive sample used in this study, future use of a larger and more representative sample size can help produce more representative results. I conducted this study within a limited timeframe; thus, it was

challenging to find more participants to take part in the study. Studies have shown that refugee groups are considered a hidden or hard to reach population, thus most researchers tend to use programmatic approaches when conducting research to reach these groups (Sulaiman-Hill and Thompson, 2011). In this study, I used non-probability sampling to identify participants. I therefore recommend that future researchers must combine several recruitment methods to reach more members of this population. In the study by Sulaiman-Hill and Thompson (2011), the authors suggested that one feasible way of identifying potential participants in the hidden or hard to reach populations is through a snowball sampling methodology. Therefore, future research might consider using this sampling method.

Furthermore, in this study I did not look at interventions that can be used to address or increase health literacy and diabetes knowledge levels, thus I recommend that future research must focus on identifying the best evidence-based interventions that can be used to increase health literacy and diabetes knowledge among refugee population with limited health literacy.

### **Implications**

The findings of this study fill a gap of the rarely researched topic on health literacy among refugee women with diabetes in the United States thus providing crucial information that can be used by different stakeholders in Arizona who work closely with refugee populations. The findings of this study can help different organizations develop health promotion activities that are tailored to this population. Social change is when one

is able to enact positive change (Walden University, 2017). The findings of this study can also be used to drive policy change in refugee healthcare, particularly for refugee women. Previous studies have shown that refugees lack health literacy skills (Gele, et al. 2016) and the findings of this study illustrated that majority of refugee women have low health literacy and low diabetes knowledge, thus there is need for addressing this issue and work with refugee communities to improve health literacy. In the study by Riggs, et al. (2016), the authors elucidated that increasing health literacy skills among refugee women will empower them to make better decisions for their health, thus improving their health outcomes. Additionally, diabetes management is a relevant skillset that one can learn to manage the disease, however with little to no knowledge of diabetes; it is difficult to know how to manage the disease. In a study conducted by Doyle, et al. (2017), the authors found a significant association between low health literacy and high health care utilization among certain ethnically and linguistically diverse patients with type 2 diabetes. Although the results from the aforementioned study by Doyle, et al. (2017) suggest that health care utilization and direct cost of care varied depending on individuals' language status, it is evident that improving health literacy among this refugee population with diverse languages, and providing appropriate diabetes education, can help reduce diabetes complications, which can reduce health care utilization, healthcare cost, and would improve the overall health outcomes of refugee women with diabetes (Doyle, et al. 2017).

## Conclusions

In this study, I examined the levels of health literacy and diabetes knowledge among refugee women with a known diagnosis of diabetes who reside in Maricopa County, Arizona. I included different predictors in the analysis such as age, education status, employment status, number of years lived with diabetes and length of stay in Arizona since resettlement. The results of this study demonstrated that there is an association between education level and health literacy and number of years lived with diabetes and diabetes knowledge. Taking the results obtained from this study, I suggest that future researchers should look into other health literacy and diabetes knowledge predictors that are homogeneous to all refugee population. The sample population I used for this study was diverse, thus the results can be generalized to the broader refugee population with the same characteristics. Health literacy is an issue of health equity, it is evident to note that, the issue of limited health literacy does not just affect refugee women with diabetes, it also affects other health aspects and their families, as it is seen that refugee women are at the center of healthcare decision making in their families (Bhatta, et al. 2014). Thus, the reported lack of health literacy and diabetes knowledge and management skills in refugee women demonstrates urgency and a call for action to tailor health care systems to accommodate refugee women's healthcare needs. Multiple stakeholders such as health care providers, health insurance companies, refugee community organizations, education sectors, private sectors, research institutions, and pharmaceutical companies, and policy makers should work together to address barriers that refugee women face, and develop interventions at individual and systematic levels,

that reduce health literacy. Additionally, there is need for more research that supports the need to increase health literacy skills and reduce health disparities among refugee women diagnosed with diabetes and among refugee populations in general.

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## Appendix A: Information Letter

Project Title: **Health Literacy and diabetes among refugee women residing in Arizona**

MIHS IRB#: 2019-029

Principal Investigator: Crista Johnson-Agbakwu, MD MSc

### **INFORMATION SHEET FOR PARTICIPATION IN A RESEARCH STUDY**

#### **Introduction**

You are invited to take part in a research study because you have been told you have diabetes and are a refugee.

#### **Why is this study being done?**

The purpose of this study is to learn what refugee women living in Arizona with diabetes understand about the disease. Learning what patients know and understand about diabetes will help us improve our health services to the refugee population.

Dr. Johnson is conducting this study with Aline Indatwa, a doctoral student at Walden University.

#### **What are the study procedures? What will I be asked to do?**



If you choose to be in this study, you will be asked to take part in a group interview with other refugee women. You will be asked questions about your thoughts and opinions about diabetes.

You will be asked questions by a trained interpreter to be sure you understand the questions asked and we understand your answers.

The interview will take place at Maricopa Medical Center or community center. The group interview will take about 30 minutes to 1 hour to complete. Once you complete the interview, you will not be contacted again.

**What other options are there?**

You can choose not to take part in the study. If you choose not to participate, it will not affect the care you receive in the Refugee Women's Health Clinic or any other clinic at MIHS.

**What are the risks and benefits of being in the study?**

There is a risk you may be recognized by someone in the group. Other participants may hear personal information shared during group interview.

There is a risk someone outside the study may see your name. Any information collected in the interview will not have any personal identifiers such as your name, data of birth or medical records.

The potential benefits of this study may include:

- Improved knowledge about your health

- Improved care for refugee women with diabetes education and health information

**Payment:**

There will not be payment for taking part in the study.

**How will my personal information be protected?**

Study records will be locked in a secure office. No personal data will be collected.

Research data will be kept on password protected file on a secure MIHS computer.

Researchers may publish study results. Your name will not be used in any publications or presentations.

The MIHS Institutional Review Board (IRB) may look at study records. This review will be to make sure researchers doing their job properly. The IRB is a group of people who review research studies to protect research participants.

**Contacts and Questions:**

If you have any questions concerning your rights as a research subject, you may contact the MIHS's Institutional Review Board at 602 344-5118.

**Appendix B: Cultural Health Navigators (CHN) Script**

My name is \_\_\_\_\_ and I am calling from the Refugee Women's Health Clinic. We are conducting research on behalf of Christa Johnson and Aline Indatwa on a

research titled **Health literacy among refugee women diagnosed with diabetes, residing in Arizona**, whose main purpose is to determine the levels of health literacy among refugee women with a known diagnosis of diabetes who have resettled in the state of Arizona. All personal information, including your name, address, and survey answers will be kept strictly confidential and will not be shared with any person or group that is not associated with this study. Your participation is voluntary and you may refuse to answer any questions you do not wish to answer. We will be asking people to take part in group interviews, where you will complete a questionnaire on your knowledge about diabetes. This group interview will last approximately one and a half hours to two hours.

Do you have any questions or concerns? Now that you have a basic understanding of the study, do you think you might be interested in participating?

#### **Screening Questions (If not aware about participant's eligibility)**

Before enrolling people in this study, we need to determine if you may be eligible to participate (Additional screening at a later time may be necessary beyond answering these questions).

- Are you a female between the ages of 18 – 65 years?
- Have you been diagnosed with diabetes before?
- Are you a resident of Maricopa County, Arizona?
- What is your primary language?

**Conclusion**

Thank you for taking the time to talk with me today. If you have any questions or concerns, please feel free to contact me. My name is [name] and I can be reached at [phone number] and/or [email address].

Health literacy among refugee women diagnosed with diabetes, residing in Arizona Self-disclosure guide for participants

Dr Crista Johnson

Aline Indatwa

Principal Investigator

Co-Investigator

MIHS

Walden

University

What is the study about?

The main purpose of this study is to determine the levels of health literacy among refugee women with a known diagnosis of diabetes who have resettled in the state of Arizona.

What is the study trying to achieve?

The study aims to:

- Improve knowledge about refugee women's health
- improve service delivery to refugee women such as health education
- Influence effective management of refugee women's health
- Gain a better understanding of the challenges faced by refugee women in navigating the health care system

Do I qualify to take part in the study?

In order to qualify, you must fulfill the following criteria:

- You must be female
- You must be a confirmed refugee woman
- You must be at least 18 years old
- You must have a known diagnosis of diabetes

- You must be a resident in Maricopa County, Arizona

What is involved in the study, if I decide to participate?

If you meet the criteria, you will sign a consent form. You will then be invited to take part in a focus group discussion, where you will complete a questionnaire that assesses your knowledge about diabetes. You are free to exit the study at any point. After completion of the study, the researcher will share the results with you.

Will my identity be revealed?

Your identity will not be revealed in any of the study material. Your responses will be kept anonymous and you will only be identified by a code.

Will I get paid to take part in the study?

There will not be any payment for taking part in the study. However you will be provided with translation services for select languages, water and a snack.

#### Appendix D: Modified Health Literacy/SKILLD Survey

Title of Project: Health literacy and diabetes among refugee women residing in Arizona

Researcher: Crista Johnson Agbakwu, MD/Aline Indatwa

Sociodemographic variables

Question 1: How old are you?

18 – 24     25 – 34     35 – 44     45 years or older

Question 2: In which country were you born? And what is your primary language?

Name of country: \_\_\_\_\_

Primary language: \_\_\_\_\_

Any other languages:

\_\_\_\_\_

Question 3: What is the highest level of education attained?

No schooling       Primary education     High school education       College  
education or higher

Question 4: What is your employment status?

Unemployed       Currently employed                       Self-employed        
Retired

Question 5: How long ago were you diagnosed with diabetes?

Less than 1 year     1 – 5 years ago       5 – 10 years ago                       10 or more  
years ago

Question 6: How long ago did you resettle in the United States?

Less than 1 year     1 – 5 years ago       5 – 10 years ago                       10 or more  
years ago

Health literacy variables

Question 7: How easy/difficult is it for you to read health information?

Very easy    Easy    Difficult    Very Difficult  

Don't know

Question 8: How easy/difficult is it for you to understand the message in health information?

Very easy    Easy    Difficult    Very Difficult

Don't know

Question 9: How often do you require assistance with reading and explaining health information?

Never    Seldom    Sometimes    Often    Always

Question 10: How easy/difficult is it for you to understand your doctor's or pharmacist's instruction on how to take a prescribed medicine?

Very easy    Easy    Difficult    Very Difficult

Don't know

Question 11: How easy/difficult is it for you to follow instructions from your doctor or pharmacist?

Very easy    Easy    Difficult    Very Difficult

Don't know

Question 12: How easy/difficult is it for you to judge which everyday behavior is related to your health (e.g. eating habits, exercise habits and drinking habits)?



- Very easy       Easy       Difficult       Very Difficult
- Don't know

Question 13: How easy/difficult is it for you to understand warnings about behavior (e.g. smoking, low physical activity and drinking too much)?

- Very easy       Easy       Difficult       Very Difficult
- Don't know

Question 14: How easy/difficult is it for you to find out where to get professional help when you are ill (e.g. doctor, pharmacist or psychologist)?

- Very easy       Easy       Difficult       Very Difficult
- Don't know

Question 15: How easy/difficult is it for you to use information the doctor gives you to make decisions about your illness?

- Very easy       Easy       Difficult       Very Difficult
- Don't know

### Diabetes Knowledge

Question 16: What are the signs and symptoms of high blood sugar? How do you feel when your blood sugar is high or when you were diagnosed?

Provide at least 2 answers:

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Question 17: What are the signs and symptoms of low blood sugar? How do you feel when your blood sugar is too low?

Provide at least 2 answers:

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Question 18: How do you treat low blood sugar? What should you do if your sugar is too low? How can you bring your blood sugar up if it's too low?

Answer:

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Question 19: How often should a person with diabetes check his or her feet? Once a day, once a week, or once a month?

Answer:

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Question 20: Why are foot exams important in someone with diabetes? Why is it important to look at your feet? What are you looking for?

Answer:

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Question 21: How often should you see an eye doctor and why is it important? How often? Why?

Answer:

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Question 22: What is a normal fasting blood glucose or blood sugar? When you get up first thing in the morning and check your blood sugar before you eat or take medicine, what should it be? What 2 numbers?

Answer:

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Question 23: What is a normal HbA1c (hemoglobin A1C) or “average blood sugar test”? When they draw blood from your arm and get an average blood sugar reading, what should it be?

Answer:

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Question 24: How many times per week should someone with diabetes exercise and for how long? How many times a week? How long or how much per day?

Answer:

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Question 25: What are some long-term complications of uncontrolled diabetes? Do you know anyone that has diabetes and had “bad things” happen to them? What are some of those “bad things”?

Provide at least 2 answers:

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End of Questionnaire

Appendix E: SKILLD Questionnaire Answer Coding

Item	Correct answers	Incorrect Examples	Score
1. "What are the signs and symptoms of high blood sugar?" If no answer: "How do you feel when your blood sugar is high or when you were diagnosed?"	Frequent urination, thirst, hunger, vision effects, headache	Have never had high blood sugar	Need at least two correct answers 136
2. "What are the signs and symptoms of low blood sugar?" If no answer: "How do you feel when your blood sugar is too low?"	Hunger, anxiety, heart effects, shaking, sweating, fatigue	Stomachache, vision problem, headache	Need at least two correct answers
3. "How do you treat low blood sugar?" If no answer: "What should you do if your sugar is too low? How can you bring your blood sugar up if it is too low?"	Drink soda, juice, or milk; eat candy or sugar; eat something; check sugar level	Take medicine, go to the doctor, walk, rest	Need just one correct answer
4. "How often should a person with diabetes check his or her feet?" If no answer: "Once a day, once a week, or once a month?"	Daily	Weekly, monthly	Need correct answer
5. "Why are foot exams important in someone with diabetes?" If no answer: "Why is it important to look at your feet? What are you looking for?"	Circulation, feeling, wound, infection, ulcer, amputation	Nonspecific: e.g., affects feet, trim toe-nails	Need just one correct answer
6a. "How often should you see an eye doctor?"	Annually	Twice yearly, monthly, only if problem	
6b. "Why is it important to see an eye doctor?"	Blindness, bleeding in eye, retinopathy, glaucoma	Nonspecific: e.g., affects eyes, acuity, cataracts	Need 6a correct and 6b at least one correct
7. "What is a normal fasting blood glucose or blood sugar?" If no answer: "When you get up the first thing in the morning and check your blood sugar before you eat or take medicine, what should it be?"	70-130 mg/dL, or 3.9-7.2 mmol/L	A number greater than 130	Need correct answer

8. "What is a normal HbA1c or "average blood sugar test"? If no answer: "When they draw blood from your arm and get an average blood sugar reading, what should it be?"	5%, 6%, or 7%	3%, 8%, or 9%	Need correct answer
9a. "How many times per week should someone with diabetes exercise?"	4 or more days a week	No exercise or 1, 2, or 3 days a week	
9b. "Each time, for how long should someone with diabetes exercise?" If no answer: "How long or how much per day?"	30 minutes or more	15 minutes or less, 15-30 minutes	Need correct answer to 9a and 9b
10. "What are some long-term complications of uncontrolled diabetes?" If no answer: "Do you know anyone that has diabetes and had bad things happen to them? What are some of those bad things?"	Amputation, stroke, coma, loss of feeling, heart, vision, circulation problems	Teeth, arms, lung, or mind problems	Need at least two correct answers

Appendix F: SKILLD Tool Knowledge Assessment Scale/Answer key

Rothman RL, Malone R, Bryant B, Wolfe C, Padgett P, DeWalt DA, ... Pignone M.

(2005). Spoken Knowledge in Low Literacy in Diabetes Scale: A diabetes knowledge scale for vulnerable patients. *Diabetes Educator*, 31:215–224. [PubMed: 15797850]

Revised Answer key obtained from:

Garcia, A. A., Zuniga, J., Reynolds, R., Cairampoma, L., & Sumlin, L. (2015).

Evaluation of the spoken knowledge in low literacy in Diabetes scale for use with Mexican Americans. *Journal of Transcultural Nursing*, 26(3), 279-286.

Question	Probe	Acceptable response
What are the signs and symptoms of high blood sugar?	How do you feel when your blood sugar is high or when you were diagnosed?	Needs at least (2): Extreme thirst, frequent urination, drinking or eating, blurred vision, and/or drowsiness/fatigue
What are the signs and symptoms of low blood sugar?	How do you feel when your blood sugar is too low?	Needs at least (2): Hunger, nervous/jitteriness, mood swings/irritability, confusion, sweaty, or fast heart rate  Revised answer key: hunger, nervousness, jitteriness, mood swings, irritability, confusion, sweatiness, fast heart rate dizziness, lightheadedness, weakness

How do you treat low blood sugar?	What should you do if your sugar is too low? How can you bring your blood sugar up if it's too low?	<p>Accept very general answer: Juice, milk, hard candy, 15 g of carbohydrates AND check blood sugar.</p> <p>Revised answer key: drink juice, eat candy, drink milk, eat sugar or sweets, drink sugared soft drink, or at least 15 grams of carbohydrates</p>
How often should a person with diabetes check his or her feet?	Once a day, once a week, or once a month?	Accept: Daily
Why are foot exams important in someone with diabetes?	Why is it important to look at your feet? What are you looking for?	<p>Accept very general answer: Prevention of morbidity due to neuropathic/immunologic consequences of diabetes (Refer to revised answer key)</p> <p>Revised answer key: Answer must be clear about action. The following are examples. Answers may vary but must be clear about consequences. Feet get damaged, check for sores, check for wounds, feeling/sensation changes or gets worse</p>
How often should you see an eye doctor and why is it important?	How often? Why?	<p>Accept: Seen at least yearly AND screen/manage retinopathy, glaucoma, blindness, etc</p> <p>Revised answer key: Answer must contain a two-part answer: Visits are yearly. Reasons can include check for eye damage, diabetes causes eye problems, blindness can occur, eyes can get damaged, glaucoma, or check for changes in eyes</p>



What is a normal fasting blood glucose or blood sugar?	When you get up first thing in the morning and check your blood sugar before you eat or take medicine, what should it be? What 2 numbers?	Accepted range: 70 (or 80) to 120
What is a normal HbA1c (hemoglobin A1C) or “average blood sugar test”?	When they draw blood from your arm and get an average blood sugar reading, what should it be?	Accept either: normal $\leq 6\%$ or target $\leq 7\%$
How many times per week should someone with diabetes exercise and for how long?	How many times a week? How long or how much per day?	Accept within: 3-5 times per week for a total of 30-45 min each (must include frequency and duration)
What are some long-term complications of uncontrolled diabetes?	Do you know anyone that has diabetes and had “bad things” happen to them? What are some of those “bad things”?	Needs at least (2): Blindness/impaired vision, kidney damage/dialysis, amputation, neuropathy/impotence/gastroparesis, or cardiovascular disease  Revised answer key: blindness, impaired vision, kidney damage, dialysis, amputation, wounds, infections, neuropathy, impotence, stomach problems, heart problems, foot problems, or high blood pressure