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Factors Affecting Adherence to Diabetes Management Recommendations Among Afro-Caribbean Farm Workers

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Abstract

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Dissertation Submitted in Partial Fulfillment

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Abstract

Type 2 diabetes mellitus (T2DM) is a global epidemic, impacting the economy and quality of life of affected individuals. The treatment and management of the disease often rely heavily on self-efficacy and provider guidance. Adherence to provider treatment regimens can help to prevent T2DM-related complications. However, non-adherence to T2DM regimens is a growing concern among minority populations, where T2DM is highly prevalent. Limited research is available for the Afro-Caribbean migrant farmworker (ACMF) with high rates of diabetes and an alarmingly high rate of non-adherence to treatment recommendations which is further complicated by low literacy, common cultural practices, and poor diets. The main objective of this phenomenological study was to examine the lived experience of this population, to determine causes of treatment non-adherence. The Health Belief Model was used as a theoretical framework to collect data from 15 participants then analyzed using hand coding. Results showed that: 'perceived susceptibility' to diabetes and acceptance of diagnosis was high; 'perceived severity' and 'diabetes health literacy' were low 'perceived benefits' included medication side-effects, and a cultural preference for folk medicines; and 'perceived barriers' were many, most notably decreased access due to distance from care. Adherence to medication was reduced by the need for time-off to travel to centers, or (if the job carried no health insurance) the cost of health care. Understanding these factors will help to promote social change by empowering health care professionals' to be cognizant of previously unknown factors that decrease medication adherence in the ACMF population.

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Dedication

I would like to dedicate this dissertation to my family past, present, and future, but most importantly to my mom Meritian Townsend who provided words of encouragement in times when I did not know I needed it and my dad Joel Townsend for keeping me fueled. To my Grandfather Norton Augustus Townsend the ACMF that made our lives possible today. For everything, you put in place, for your contribution to American Society, and for your steadfastness and diligence. From the hills of Jamaica to the pages of America. Lastly, I dedicate this dissertation to myself because this to date is my greatest achievement.

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Chapter 1: Introduction

Introduction

In 2017, Caribbean immigrants accounted for 10% of the United States (U.S.) immigrant population (Zong & Batalova, 2019). In 2013 the Caribbean community boasted a 6% increase in their population (Anderson, 2016). Caribbeans are among the top 10 foreign-born groups in the U.S. with higher rates of naturalization and higher English proficiency than any other immigrant group (Zong & Batalova, 2019). The Caribbean population, especially in the New England area, continues to be one of the fastest-growing immigrant populations. Over 40% of residents located in and around Hartford, Connecticut; claim to be mostly from the Caribbean (Craib & Overmyer-Velazquez, 2012).

The increase of this population, as with many other immigrant populations in the U.S., inevitably means an increase in the incidence of chronic diseases within the U.S. population. Chronic diseases like Type 2 diabetes mellitus (T2DM) disproportionately affect immigrants. Caribbeans, for example, have a higher prevalence of diabetes than any other African ethnic group (Bennett et. al., 2015). T2DM is linked to significant morbidity and mortality and is the seventh leading cause of preventable disease death in the U.S. (Centers for Disease Control and Prevention (CDC), 2015). Huang, Basu, O'Grady & Capretta (2009) projected that between 2009 and 2034 the number of people with diagnosed and undiagnosed T2DM will increase from 23.7 million to 44.1 million

with an expectation of costs of care of the Diabetes population to double in the next 25 years (Huang, Basu, O'Grady & Capretta, 2009).

Afro-Caribbeans continue to be a large proportion of immigrants entering the U.S., and a subset of this population is the Afro-Caribbean migrant farmworker (ACMF) community. Under the Immigration and Nationality Act of 1975, ACMFs have been traveling to work and living on commercial farms in the U.S. for decades (U.S. Immigration and Naturalization Services, 2015). While there continues to be an increase of immigrants in the U.S. population, the availability of care that tailored to them has not seen the same growth. Immigrants are more likely to face reduced access to care, immunizations, and this has severe social implications not just for the immigrant population but also for the nation as a whole (Jang, Yoon, Park & Chiriboga, 2016).

It is an expectation in society that the duty and aim of public health and health care is to cure, prevent, and alleviate disease (Sulmasy & Bledsoe, 2019). This expectation often is based on factors that affect the healthcare providers' role and society's reaction to that role. In American society, immigrants often experience reduced access to care; some, like Latino immigrant's experience negative responses from healthcare professionals when visiting health care facilities (Gelatt, 2016). Healthcare's early beginnings in American society saw healthcare providers visiting homes of the privileged for emergencies as well as continued care situations (Leonard, 2018). Historically, healthcare providers were part of the family, their educated opinion; more powerful than the medicine they were dispensing (Wear, 1992). In recent times, however,

the medicine and not the advice regarded as more powerful (Ross, 2007). The advice from health care professionals improved society in ways related to sanitation, disease prevention, and improved treatment strategies (Wear, 1992). Treatment recommendations and regimens in T2DM are related to exercise/diet recommendations (Xiang, Hernandez, & Larrison, 2015), strategies for improving quality of life, and taking prescribed medications (Costa et. al., 2015).

Following provider advice or treatment recommendations may save a patient's life and improve their quality of life (Burridge et. al., 2016). The extent to which a patient follows these recommendations relies on countless factors that begin with the first meeting and continue throughout every subsequent interaction.

The patient-provider relationship (PPR) is complicated for two reasons: its association with self-care behaviors (Mattingly, Tom, Stuart, & Onukwugha, 2017) and its relationship to chronic conditions, like pain (Sturgeon, Langford, Tauben & Sullivan, 2019). Understanding the complexity of this relationship can begin with understanding the factors that might affect it (Young-Hyman et al, 2016). Cultural competency affects the PPR relationship; there is a possible link to the respect of the presence of cultural competency in the PPR and positive clinical outcomes especially when coupled with two-way communication (Betancourt, Green, Carrillo, & Owusu Ananeh-Firempong, 2016). Betancourt, Green, Carrillo, & Owusu Ananeh-Firempong (2016) found that the presence of cultural competency with providers who treat Black patients improved the patients' Hemoglobin A1c (HBA1c) levels (below 7%). This study also showed that

communication was an essential factor in making clinicians aware that there is a difference in how Black patients respond to T2DM care. Other studies show that improved patient-provider communication can enhance overall patient outcomes where these relationships demonstrated patient-focused decision-making (Song et. al., 2015). Relationships built on mutual respect, collaboration, and provider understanding can go a long way to bridging socio-cultural gaps, regardless of racial composition (Cantle, 2018). Patient-focused decision-making is an essential way for providers to allow patients to incorporate their values and beliefs in the clinical encounter (Flickinger et. al., 2016). Studies of T2DM show that patients that display diminished attachment (decreased trust) demonstrated reduced adherence with provider suggested self-management regimens (Ciechanowski, Katon, Russo, & Walker, 2014). In this phenomenological study, I will look at factors that affect adherence to management recommendations in T2DM among ACMFs. Management recommendations included but were limited to prescription medications and lifestyle modifications.

Background

There are factors in other populations that affect the decisions of T2DM patients to adhere to their provider's management recommendations. There is a link between cultural competency (Betancourt, Green, Carrillo, & Owusu Ananeh-Firempong, 2016), perceived self-efficacy, and T2DM health literacy and patient-perceived barriers, predictive factors for (female sex, young, unmarried), type of delivery service, and medication cost (Brunton, Polonsdy, 2017). The determination of what these factors are

and how they affect decisions within this population can create methods for improving the delivery and acceptance of healthcare. In communities where chronic diseases exist at a higher prevalence than in the general population, adherence to management recommendations becomes increasingly important. The concern is more significant for these populations because barriers to adherence tend to be higher. T2DM, for example, is common among low-income ethnic minority communities (Sweileh, 2018), but adherence continues to be lower in these communities even with individualized and accessible care (Treif et. al., 2013).

A study conducted in 2013 in Baja California, Mexico found that the migrant farmworker population in that area had a high prevalence of diabetes, where prevalence was 12.8% in men and 36.7% in women (Goodman, Fraga, Bodine, Ibarra, & Garfein, 2013). In the same area in 2018, researchers found that the prevalence of T2DM was 21.8%, an overall increase for that area (Pacheoco et. al., 2019). The high prevalence and the continued growth in the incidence of T2DM signifies a need to understand factors that might affect or influence adherence to management recommendation in this disease within this population. Past studies have not been able to identify specific factors for this population. This study identified these factors so that public health has the tools to modify these factors. These factors have a large enough influence to decrease adherence in this population, so it is important to understand what they are for this population.

Culture and cultural competency are becoming important facets of improving healthcare. With American society well underway to providing health care to the masses

with Healthcare Affordability Act (HCA; signed into law March 23, 2010, and upheld by the Supreme Court June 2015), the question of what kind of healthcare is being provided and the diversity of the people receiving the healthcare will become as important as providing care. As much as overall access to care is becoming a rising concern for America's public health, specific care for marginalized populations should also be a concern. These marginalized populations belong to minority cultures. The importance of culturally competent health care providers will be integral to providing better care to these populations, especially with the steady increase in U.S. immigration (Jang, Yoon, Park & Chiriboga, 2016).

The Afro-Caribbean community contribute to American society by becoming permanent residents, citizens, seasonal nonresidents, and noncitizen farmworkers (Waters, 2016). The health care provided to them should be as important as the service they provide to American society. Immigrants in American society tend to have a hard time adjusting to life away from home as well as understanding Western diagnoses (McComb, Ramsden, Olatunbosun, & Williams-Roberts, 2018) and adhering to treatment regimens (Chong et. al., 2014). The addition of culturally diverse immigrants poses another issue for the treatment of chronic diseases. Immigrants, like first-generation Chinese Americans, tend to have decreased adherence to diabetes medication as compared to their white American counterparts (Chong et. al., 2014). The study by Chong et. al., (2014) is one of many that have illuminated a need to understand factors that impact adherence to management recommendation in chronic diseases like T2DM

among migrant populations in the U.S. (Plasencia, Hoerr, Carolan, & Weatherspoon, 2017).

Problem Statement

Patient adherence to management recommendations for T2DM is historically lacking (Olsen, 2017). The problem of adherence is likely rooted in factors that may go beyond the office visits and, because of this, steps should be taken to determine the exact nature of these factors (Crowley et. al., 2015). There is evidence to suggest that these factors may differ across culture (Neilson, Wall, & Tucker, 2015). Although the ACMF population became prominent in 1943 on cane farms, there is not much research, specific recommendations or much mention of the population in American society (National Farmworker Ministry [NFWM], 2015). With this in mind along with the lack of information on health behaviors in immigrant populations like this one, this study can be one of the first steps in providing reasons for adherence to medication regiments in T2DM.

Many patients, especially culturally diverse immigrant patients, may present new problems associated with adherence that stem from their preconceived notions from their own culture of herbal remedies or practices for curing chronic diseases (Er et. al., 2017). These problems are often associated with communication, satisfaction with treatment (White et. al., 2015), and culture sensitivity (Neilson, Wall, & Tucker, 2015). ACMFs would greatly benefit from a study that could determine the factors that affect adherence to T2DM management recommendations in their population.

Purpose of the Study

The purpose of this study was to understand the factors that affect adherence to T2DM management recommendations in the ACMF population. The issue of adherence to T2DM management recommendations concerns many minority populations, with Afro-Caribbeans being one of the populations disproportionately affected by this disease. A British study found that T2DM affects 40%–50% of Afro-Caribbean adults (Gatineau et. al., 2014). Recent studies found that there is a higher prevalence of diabetes and microvascular complications among Caribbean blacks (Bennet et. al., 2015). With a projected increase of close to 150% in diabetes cases in the Caribbean by 2030, it was important to understand the factors that mediate adherence among ACMFs, so that this information can benefit the population as a whole (Nixon, Leonardi-Bee, & Chattopadhyay, 2019). My goal for this study was to identify these factors so that their modification can improve patient adherence in this population to all chronic diseases. In this study, I focused on the factors that mediate adherence decisions in the ACMF population with T2DM.

Research Questions

The primary research question (RQ) for this study was what are the perceptions of diabetic ACMFs concerning the factors that influence their adherence to medical recommendations for Type II Diabetes management?

The secondary research questions for this study were:

1. What is the health literacy of ACMFs regarding diabetes and its treatment?

2. What are the perceptions of ACMFs regarding their diabetes care provider?

3. What are the perceptions of ACMFs regarding their susceptibility to diabetes?

4. What are the perceptions of ACMFs regarding the severity of their diabetes?

5. What are the perceptions of ACMFs regarding the benefits of the prescribed treatment for diabetes?

6. What are the perceptions of ACMFs regarding barriers to their adherence to prescribed treatment for diabetes?

7. What are the perceptions of ACMFs regarding cues to action in their adherence to prescribed treatment for diabetes?

8. What are the perceptions of ACMFs regarding their self-efficacy in adhering to prescribed treatment for diabetes?

The following HBM constructs were the basis for six of these secondary research questions (3-8): perceived susceptibility (RQ3), perceived severity (RQ4), perceived benefit (RQ5), perceived barriers (RQ6), cues to action (RQ7) and self-efficacy (RQ8). Two of the secondary research questions use the factors drawn from the literature relating to adherence: literacy (RQ1), and trust and cultural competency (RQ2).

For this study, adherence was an individual consistently taking the prescribed medication or adopting recommended lifestyle modifications recommended by their provider. These questions were structured in a way to explore the relationship between adherence and these factors in this population.

Theoretical Framework

The main theoretical framework for this study was the health belief model (HBM). The HBM was first used to find a way to understand the reasons behind patients deciding not to accept their diagnosis or follow their prescribed regimens (Stevens, 2014; Becker, 1974; Rosenstock, 1974). It was first composed of four parts; perceived susceptibility, perceived severity, perceived benefits, and perceived barriers, but has now grown to six parts with the addition of self-efficacy and cues to action (added by Rosenstock in 1988) (Rimer & Viswanath, 2015). Figures 1 and 2 on pages 30-31 are a representation of the HBM. They provide a multifaceted approach to symptom response (Kirscht, 1974), adherence to medical regimens (Janz & Becker, 1984) and finally perceived benefit. The constructs of the HBM were beneficial in determining the participants' beliefs related to adherence to management recommendations, whether they feel it is beneficial enough for them to adhere, the relationship between factors within or around the relationship, and how the PPR would affect adherence. I wanted to determine whether patients feel the decisions about their health and treatment are patient-focused, beneficial to them, and helpful in improving their quality of life. In using this theoretical framework I aimed to evaluate factors that influence patients' desire to comply with recommendations for managing their T2DM, whether these factors are cultural, PPR or patient-centered (culture, control, perceptions, and trust), and whether the management recommendations are medication prescriptions or lifestyle modifications.

Nature of the Study

This was a qualitative phenomenological study in which I used semi-structured interviews to determine ACMFs' perceptions of the factors that mediate adherence to T2DM management recommendations. I took note of the participant's body language as the interviews persisted. Participants were chosen based on their length of diagnosis (should be more than 1 year), their prescribed regimen (lifestyle changes and oral medication, or just 1 of each etc.), their cultural identity (Afro-Caribbean), and the amount of time from their date of entering the farmworker program (6 months or more). I used a phenomenological approach to collect detailed information on the lived experiences of the ACMF on the phenomenon of decreased adherence to T2DM management recommendations. The data I collected were from 25 ACMFs who met the previously described criteria.

Definitions

Adherence: consistently taking prescribed medication or adopting recommended lifestyle modifications recommended by their provider.

Cultural competency: healthcare practice in which the provision of healthcare is improved for racial/ethnic groups, thereby reducing the health disparities for that group (Truong, Paradies, 2014).

Assumptions

I assumed that adherence was affected by unexplored factors. Another assumption was that there was an accepted universal language used by the participants to

determine when and how closely they follow T2DM management recommendations. The last assumption was that things outside of the PPR might affect the factors that mediate adherence.

Scope

The scope of this study was ACMFs living in the Connecticut River Valley, diagnosed with T2DM. The setting for this study were farms in which these individuals live and work. The principal farms were the tobacco and produce farms in the Connecticut River Valley that have a significant population of ACMFs. From information gathered from the literature review, factors influencing adherence included trust development in the provider-patient relationship (PPR), demographics and their effect on PPRs, communication, health literacy, patient sense of control in their diabetes care, cost of healthcare, and access to healthcare.

Delimitations

The delimitations for this study were the research questions, the populations, and the chosen locations. Only ACMFs are a part of this study and only one that have been in the program for a specified number of times. While there were other farmers from different backgrounds on the participating farms, the focus was on the ACMF population because of the lack of studies aimed at them

Limitations

The population studied was very specific, and the data was not generalizable to other populations. Often the ACMF population is neglected in public health research,

and because of that may have different determinants of adherence than the populations most commonly studied in the literature review. The nomadic nature of the population can present problems in developing trust as well as eliciting their participation in a study that has implications in American society. As a member of the Afro-Caribbean population, I was able to reassure participants by speaking their language as well as explaining the benefits of their participation to American society and more importantly to their health.

Significance

Within the ACMF population, there are multiple unknown factors that affect adherence, especially in T2DM management recommendations. Researchers from previous studies suggested that adherence might have more to do with these unknown factors than anything else. While many studies have cited trust as an important modifiable factor (e.g., Winbush, McDougle, Labranche, Khan, & Tolliver, 2013), there is evidence that there are other factors, e.g., control (Gidron, 2019), cultural competency (Betancourt, Green, Carrillo, & Owusu Ananeh-Firempong, 2016), literacy (Funnell, Anderson, & Piatt, 2018), communication (Cantle, 2018)), and patient-perceived benefit (Olfson et. al., 2014).

The significance of this study lies in its ability to determine strategies aimed at improving identified factors that mediate adherence in management recommendations for T2DM in culturally diverse populations. Ultimately, the focus was to enhance the adherence of all chronic diseases. The results of the study can have possible applications

to future health care practices that are heavily dependent on patient adherence. The reason for this study was to gain usable knowledge on factors that affect adherence with T2DM management recommendations and then find ways to modify, improve, or control these factors, which will improve health outcomes.

Summary

The ACMF population is disproportionately affected by T2DM, and with the addition of non-adherence, the problem facing this population becomes more complicated. Adherence to provider recommendations is tantamount to successful management of T2DM. Adherence to these recommendations has shown to improve health outcomes in T2DM, especially regimens aimed at reducing HbA1c levels. The decisions to be adherent are not measured, and the factors that affect these decisions are unknown and are currently immeasurable as well. The ACMF population makes significant contributions to the society of the U.S. but research aimed at assuring they continue to make these contributions are lacking. Chapter 2 of this study will include a review of the literature related to the factors that have been shown to affect adherence in other populations and their possible application within the ACMF population. Identified factors of adherence improve health outcomes in other populations; there is a need to determine if these factors exist in this population and if they play a role in adherence to T2DM treatment recommendations(Nixon, Leonardi-Bee, & Chattopadhyay, 2019).

Chapter 2: Literature Review

Introduction

T2DM is an endocrine disorder with a multifactorial mode of development, treatment, and management. The disease is one of the leading causes of preventable blindness and contributes to approximately 250,000 deaths in the U.S. alone (World Health Organization (WHO), 2015; American Diabetes Association (ADA), 2015). The disease is treated medically with insulin, oral medications, and lifestyle management (ADA, 2015). Studies have shown that lifestyle management is one of the best predictors of improved prognosis, but one of the most difficult to control, since 85.2% of the people diagnosed with T2DM are overweight or obese (ADA, 2015).

Adherence to medical treatment recommendations is a significant factor in this population, but the reasons for poor adherence are not well understood, as the literature review shows. Current research on T2DM management continues to focus on improving medication regimens as well as increasing adherence to lifestyle modifications (Chatterjee, Khunti, & Davies, 2017). The WHO defines adherence as the extent that a patient's behavior allows them to follow recommendations from their provider as it relates to diet, medications, and lifestyle changes (WHO, 2016). There is a distinction between adherence, concordance, and compliance, where adherence is the patient's decision to agree to treatment recommendations (Chakrabarti, 2014), concordance is where patients make decisions with the input of provider, and compliance is acting in accordance with decisions (Duncan, Roberson, & Shapiro, 2015).

Decreased patient adherence with T2DM medical recommendations is a common problem; the Diabetes Audit and Research in Tayside Scotland (DARTS) study, for example, found that only 1 in 3 individuals suffering for T2DM were adequately adhering to oral hypoglycemic medications (Morales, Small, & Bogner, 2016). Adherence decisions are multifactorial. Factors that influence it are different across populations. The ACMF population is one of the minority populations that suffer from a disproportionately high prevalence of diabetes, a low rate of adherence to recommendations, and less than desirable health outcomes.

In this chapter, I explore factors that might contribute to this decreased adherence to better understand how to improve this phenomenon. This population is often faced with decreased access to healthcare, stemming from their seasonal presence in the U.S. health care system, which in itself could be another factor that may affect their adherence. The purpose of the study was to gather information to shed light on factors that might directly affect patient behaviors and their decision to follow treatment regimens. Chapter 3 will detail the methods this study to do this.

Literature search strategy

The literature review to explored factors that could affect adherence to management recommendations in minority groups (like ACMFs) suffering from T2DM. The research strategy for finding sources of literature for this study involved using the Walden health science library to search databases like MEDLINE with Full Text, PubMed, Dissertations & Theses at Walden University, and CINAHL Plus with Full

Text. Google Scholar's online database found articles that had links to full-text articles in the Walden Library. These databases conducted pointed searches in peer-reviewed journals like the American Journal of Public Health. Searches used keywords like medication*, adherence, healthcare, culture, Afro-Caribbean, diabetes, oral medication, Caribbean, minority, PPRs, patient control, farmworkers,* and *farm work*. The content of the articles and their reference sections found other relevant articles that did not populate in the search results based on the entered keywords. With the use of these keywords and review of the articles found because of them, other topics started to emerge, which led to additional searches, e.g., using the keywords *cultural competency, trust in the provider, patient vs. provider control, and patient benefit*. These keywords began to emerge as factors that might have a significant influence on adherence.

This study could lead to a model of adherence that helps healthcare providers to explore non-adherence in multiple diseases and populations. Narrowing the study's investigation helped me to determine the influence that these factors had on adherence in ACMF populations.

In this chapter, I explored factors that have a high probability of affecting adherence to recommendations for the management of T2DM in the ACMF population. Given the lack of studies aimed at improving or understanding adherence decisions in this population, the results provided illumination as well as clarification of any beliefs related to adherence to medication regimens in T2DM that may be present within the ACMF population. Issues regarding trust within the PPR, cultural competency, control in

PPRs, ways to overcome other barriers to compliance, and their perceived benefits were explored in this study. Table 1 details the terms reviewed for the literature related to adherence in T2DM medications.

Table 1

Factors associated with adherence to T2DM medication

Key terms searched	Books	Scholarly Journals	Secondary Sources	Reviewed	Used
Cultural competency	5	30	0	25	11
Patient control vs. provider control	0	7	5	13	2
Health care access	6	37	56	30	8
Patient perceived benefit & adherence	2	105	0	32	7
Farmworkers & diabetes	0	52	16	68	21
Minorities & Adherence	0	356	0	20	5
Cost of prescription medication & minorities		231	0	16	13
Adherence to diabetes medication	10	234	0	30	10
Patient-provider relationships & trust	7	955	0	106	12

Theoretical framework

The HBM is one of the first models that looked at patient behavior and health decisions. The model focuses on the importance of an individual's beliefs about health,

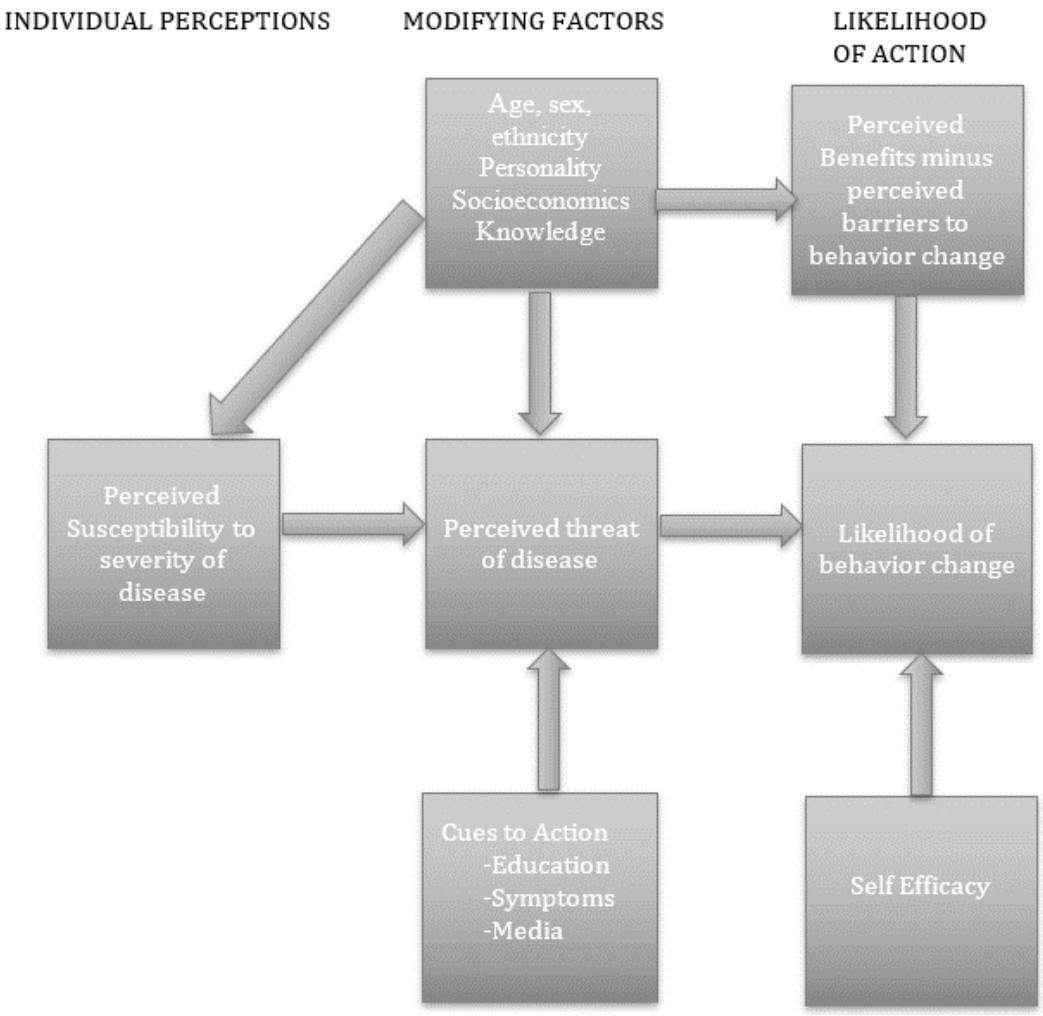
benefits, and control in the health care arena. The model posits that a person's willingness to comply with treatment is dependent on how much they believe their health is a risk and are willing to act in response to that threat (Becker, 1974; Rosenstock, 1974). Health beliefs are not only related to whether or not patients seek out health care, but it can also be related to decisions to continue to use health care. Zeng, Sun, Gary, Li, and Lui (2014) found that the health beliefs of Chinese immigrants (another population disproportionately affected by T2DM) had a strong effect on their T2DM management because they had a greater tendency to adhere to traditional Chinese medicine rather than Western medicine. This article provides strong support for the relevance of the HBM in this study. Caribbean immigrants are also known to choose a treatment based on cultural beliefs and childhood memories (Er et. al., 2017). This evidence that health beliefs influenced by life experiences and culture can strongly impact health care decisions was another good reason for the use of this model in this study.

The risk of developing complications from T2DM is very high (Reddy, Shang, and Natarajan, 2015), and it is crucial to determine what health beliefs are active in the affected population since these beliefs might be factors that affect adherence to treatment recommendations. These beliefs could be related to the component of perceived severity in the HBM. In the ACMF population, perhaps, this perception is different from other populations, and the perception of the severity of the complications of T2DM are less understood. The HBM has been used to explain risky health behaviors related to tuberculosis, cervical cancer, and cancer screenings (Glanz, Rimer, and Lewis, 2008). In

this study, to treatment recommendations in a disease with such severe complications could be considered risky behavior. Therefore, I looked at ACMF's perception of factors that are barriers to their ability to adhere to the treatment recommendations of their provider. Based on the review of literature depicts the possible interactions between the HBM and adherence in the ACMF population.

The primary RQ for this study was: What are the perceptions of diabetic Afro-Caribbean migrant farmworkers concerning the factors that influence their adherence to medical recommendations for Type II Diabetes management? The secondary research questions relate to the component application of the HBM. The original schema of the HBM is illustrated in Figure 1.

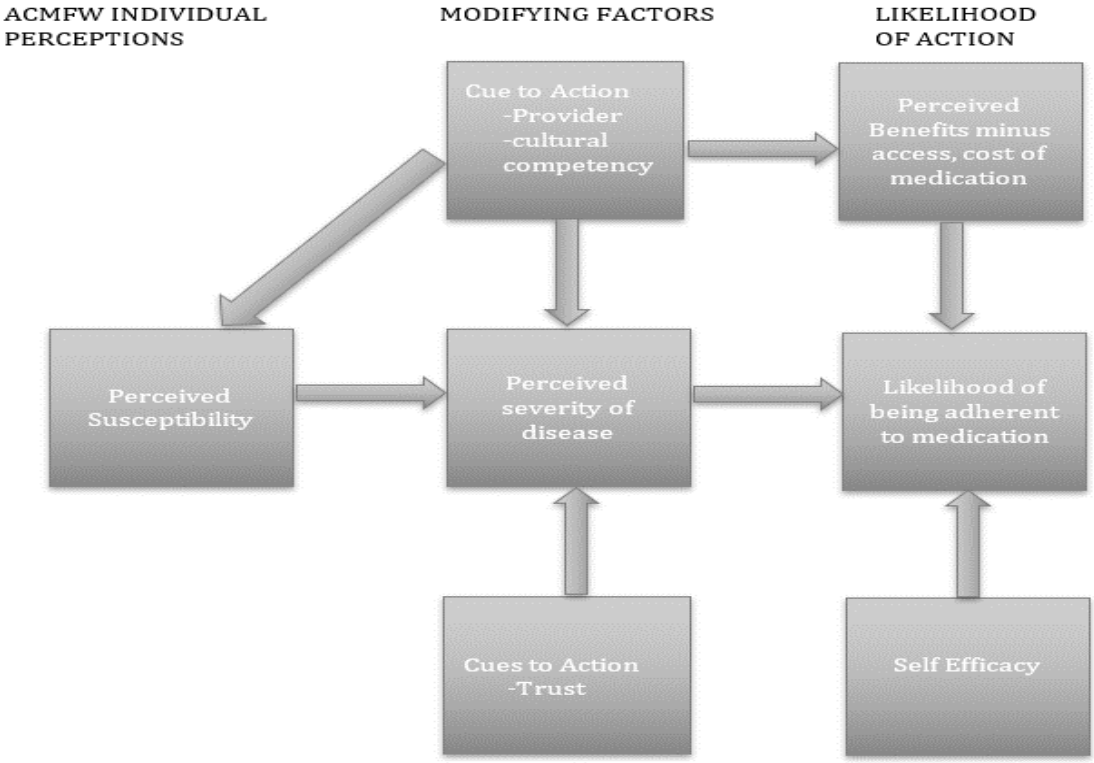
Figure 1. The health belief model as developed by Becker 1974



Following the publication and first use of the HBM, Glanz, Rimer, and Lewis (2008) revised the model to include perception of factors affecting adherence. A revised schema adapted from their work for the purpose of this study is in Figure 2. Figure 2 is a representation of how patient's trust of the provider and the provider's cultural competency is influenced by susceptibility to the disease and how these two may affect the patient's overall perception of the severity of the disease. Figure 2 also shows how the how these factors, along with perceived benefit, perceived barriers, and self-efficacy,

could affect an individual's adherence. Selecting the HBM for this theory stems from this theory's ability to measure perceptions. The research questions were tailored to reflect the constructs of the theory so that it can gather information related to the behaviors and perceptions of the phenomenon of adherence in this population.

Figure 2. The health belief model as a function of the perception of factors affecting adherence (Modified from Glanz, Rimer, & Lewis, 2008).



Literature Review

The factors that dictate adherence in the ACMF population have not been preciously studied. However, the literature shows multiple factors that appear to affect adherence in

other populations and may be present in this population. They are presented in chapter 2 as assigned to constructs of the Health Belief Model.

Table 2

Factors Affecting ACMF Medication Adherence, by Health Belief Model construct

HBM Construct	Factors affecting ACMF
Perceived susceptibility	Acceptance of the diagnosis Risk associated with diagnosis Type of T2DM
Perceived severity	Communication Patient literacy
Perceived benefit	Recognition of symptoms Intentional vs. non-intentional non-adherence
Perceived barriers	Access Cost
Cues to Action	Trust Cultural Competency
Self-efficacy	Ability to carry out behavior Self-efficacy's effect on medication use behavior

Perceived Susceptibility

The factors to be presented based on this HBM construct are Acceptance of diagnosis, risk associated with diagnosis, and type of T2DM. There is a possibility that decisions to adhere to management recommendations stem from the patient's perceived

susceptibility to a particular disease or the consequences of this disease. Perceived susceptibility, according to the HBM, may include the individual's acceptance of the diagnosis, as well as their estimates of re-susceptibility and susceptibility to the disease (Glanz, Rimer, and Lewis, 2008). If the diagnosed individual accepts the diagnosis, they might be more inclined to adhere to the management recommendations from their provider. In Diabetes patients surveyed for acceptance of their diagnosis showed that educational level was an important factor on whether or not or how well a person accepted the diagnosis of insulin-dependent diabetes mellitus (Due-Chistensen, Zoffman, Willaing, Hopkins, & Forbes, 2018). For any patient, hearing the diagnosis of diabetes may not be enough for them to accept not just to the diagnosis, but also the steps that may be needed going forward with this disease. In a study that looked at patients in a low income community center, who suffered from diabetes, researchers found that participants who were involved in acceptance and commitment therapy (ACT), as well as education about their disease, were found to be more likely to report better self-care in their diagnosis (Greg, Callaghan, Hayes, Glenn–Lawson, 2007). The assumptions made from this study, were that acceptance of a disease can be one of the first steps to ensuring that the patient can and will follow prescribed regimens needed to treat or prevent complications of their disease.

Another aspect of the patient's perceived susceptibility is their perception of the risk associated with their diagnosis. Diabetes type II is a silent killer (Todkar, 2016) with complications that often do not manifest until years after diagnosis, leaving many patients

undiagnosed (8.1 million undiagnosed, according to ADA (2014)) and mostly unaware of their risk. In a historical study, Hispanic migrant farmworkers were shown to "perceive diabetes to be an acute illness instead of a chronic disease" (Heuer & Lausch, 2006, p. 57). Participants, when interviewed, likened diabetes to appendicitis in that they experienced the phenomenon as a removed appendix, and the phenomenon went away; many expected the same for diabetes (Heuer & Lausch, 2006). Studies have shown that disease conditions that are considered eminently life-threatening with visible manifestations are often more likely to have better adherence (Sapkota, Brien, Greenfield, & Aslani, 2015). In Afro-Caribbean diabetics living in the UK diabetes treated with tablets were considered a milder form of the disease and individuals can see with this "type" felt it did not warrant serious concern (Er et. al., 2017).

Perceived Severity

This study looked at how communication and health literacy impacted the perceived severity component of the HBM for the affected individuals. The factors to be presented based on this HBM construct are communication and patient literacy. How well the provider communicates the disease's severity as well as the sequelae directly correlate to the individual's belief about severity. The other aspect of this is how well the patient understands the information presented.

Communication and Adherence. Health care communications come in many forms, from informing, influencing, and even motivating individuals or groups to take health care action (Collier & Baker, 2017). Poor communication between physicians and

patients might not correctly express the severity of the condition and can ultimately impede one or all of these forms. The decisions made by patients may be influenced by how well the provider communicates the disease's severity to them. Although Good communication has been shown to affect adherence (Young, Len-Rios, Brown, Moreno, & Cox, 2017), determining what "good" communication is for different populations not easily accomplished, especially for a population that is continually moving and changing.

Many migrant farmers have a general communication problem because of their foreign-born status and where health communication is concerned much is lost in translation because interpreters tend to omit seemingly irrelevant information (Holmes, 2019). In a population with possible low health, literacy communication becomes increasingly important because it may have implications related to continuing treatment outside of the office (Funnell, Anderson, & Piatt, 2018). In a study looking at medication refill adherence, researchers found that patients with poor communication ratings of their provider were found to be less likely to refill their oral hypoglycemic (Polansky & Henry, 2016).

Patient literacy and Adherence. According to the National Institutes of Health (2016), health literacy is how well individuals can obtain, process, and understands "basic health information" which can be used to make informed decisions about their health (p.1). Health literacy of a community has a distinct impact on the health of that community and health care provider's ability to help that community. The literacy regarding treatment is becoming just as important as the cure itself. Health literacy is not

just understanding what the disease is but to also understanding how to apply the given information (Batterham, Hawkins, Collins, Buchbinder, & Osborne, 2016). The health care provider must recognize the need to disseminate this information to their patient population in a way that they will understand it.

The average grade level of migrant farmworkers is 7th grade, upon entering the U.S. opportunities may be available for continued education, but the need and desire to work to support their families is of far greater importance (NFM, 2016). With this in mind, a literate farm worker may not be health literate. Many chronic diseases like T2DM have levels of understanding related to when and how to take their medications and what changes need to be made to continue to manage their diabetes. Studies have shown that health literacy has a positive effect on adherence; the addition of these interventions have been shown to improve adherence, especially in racial-ethnic minorities (Miller, 2016). For the ACMF, health literacy may not be the most vital part of their visit to the provider; they may not have the time or resources to do research relevant research about their diagnosis so if they do not have access to the information, they may never have access to it. The Diabetes Study of Northern California found that patients with impaired health literacy were found to have decreased adherence to antidepressant medications (Bauer et. al., 2014). In contrast, Al Sayah, Majumdar, Egede, & Johnson (2015) found that health literacy influenced diabetes health knowledge but found no direct relation to self-care or adherence. The DISTANCE study consisted of an ethnically stratified random sample

while the latter study consisted of a low-income minority population; both studies bring to question whether or not health literacy has any effect on the ACMF population.

Perceived Benefit and Adherence

The factors to be presented based on this HBM construct are recognition of symptoms, and intentional vs non-intentional non-adherence. One would think that the main reason to be compliant with medications would be that it is beneficial to the individual and the benefits would outweigh the harm. Unfortunately, many patient populations either focus more on the disadvantages associated with a regimen or personal feelings/beliefs about a medication before they make their decision to be compliant. In a study of more than 24,000 adults that looked at unintentional to chronic disease medication, 34% of the study population reported that they intentionally decided to be non-adherent (Brett et. al., 2018). The study cited many factors that led to intentional or non-intentional non-adherence with a belief about medication necessity being one of them (Brett et. al., 2018). While treatment regimens may be proven reliable and helpful in a particular disease, the fact remains that the individual must also believe this.

An individual suffering from a particular disease may not be aware of how severe their disease is or is unaware of the symptoms. This unawareness from difficulty recognizing symptoms leads to individuals not being fully aware of the benefits of being compliant with their medication (Olfson et. al., 2014). Not being able to recognize symptoms or not regarding the provider's recommendations as beneficial can be reasons for non-adherence. Previous studies have shown that patients who regard their caregiver's

tone as dismissive tend to suffer from complications related to disease non-adherence (Brown et. al., 2016). Specific populations - African Americans, for example - have poor adherence to medication regimens for T2DM, prompting researchers at the University of Virginia to call for more significant efforts to improve T2DM self-management behaviors in these populations (Mosen, Glauber, Stoneburner, & Feldstein, 2017). Non-adherence in T2DM causes kidney failure; with 44% of new kidney failure diagnoses being directly linked to the disease in more than 40,000 Americans to (ADA, 2015). The issues regarding patient adherence within this diagnosis and the factors that affect it are a growing concern for health care and health care practitioners (Funnel, Anderson, & Piatt, 2018). This literature review was a valuable tool to investigate the relevant factors that may or may not dictate the development of an environment where the patient is confident that their adherence to the medication regimen is of mutual benefit.

Perceived barriers and adherence

The factors to be presented based on this HBM construct are based on access and cost.

Access to healthcare. For the migrant farmworker, access to healthcare is not as easy as being able to travel to a healthcare center. While traveling to the healthcare center might be the apparent concern once a farmworker gets to a healthcare center, other factors related to social status, cultural status, and economic factors become common impediments to the farmworker. Unfortunately, these factors prevent farmworkers from enrolling in any forms of health care programs like insurance, for example (National

Association of Community Health Centers, n.d). In 1962, the US government attempted to alleviate this problem for farmworkers by enacting the Migrant Health Act, which provided health care centers specific with the ability to provide primary and supplementary health care to migrant farmworkers and their families (Health Resources and Services Administration, 2016). The U.S. government also as has provisions within the Medicaid and SCHIP program that allow for better definitions of 'resident' status to determine state eligibility (NACHC, n.d). While these changes sought to protect and provide health care to this population, they made the pursuit of healthcare as complicated as the problems it is trying to solve (NACHC, n.d). Migrant farmworkers often do not reside in the state long enough to obtain insurance, have fluctuating income, so income requirements become difficult to determine, often fall prey to upper-income limits that vary from state to state, and finally also fall victim to difference in categorical eligibility which can also vary from state to state (NACHC, n.d). What this means is that many ACMFs are not eligible to participate in these programs because they are migrants under the Immigrant Responsibility Act of 1996 and the Personal Responsibility and Work Opportunity Reconciliation Act of 1996. These acts provide each state with its discretion on whether to provide non-emergency care to legal immigrants and also only recognize "qualified" immigrants leaving others without any access to health care (NACHC, n.d).

These acts, along with the introduction of the HCA, tried to alleviate the problems associated with migrant farmworkers obtaining health insurance and ultimately access to healthcare, but it, unfortunately, creates more problems than it solves. The HCA for

example, provides help for qualified noncitizens (migrant farmworkers are not qualified noncitizens), and also places, time limits on when farm employers are required to provide health insurance for farmworkers (must be 120 non-consecutive days, most migrant farmworkers are seasonal, so do not meet this stipulation) (Dembrosky, 2016).

Medication cost as a barrier to adherence. The cost of prescriptions has become a national concern since prescription drug costs rose from $40.3 billion in 1990 to $216.7 billion in 2006; this is an increase of more than five times in less than 20 years (Kaiser Family Foundation, 2015). Adding drug coverage to the existing Medicare plans will lead to a continued increase in Medicare/Medicaid spending over the next 70 years (Congressional Budget Office, 2019). For the American citizen/resident, there are programs in place like Medicare part D, and the Maximum Allowed Cost program (regulates drug company completion and increased prices) that may help to alleviate these increases, but unfortunately these programs do not extend to migrant farmworkers (Comptroller General, 1980). They do not provide them with any assistance in obtaining prescriptions, nor do they provide any methods in which to decrease costs. Brown et. al., (2016) linked adherence to patients being unable to afford their prescriptions in addition to their cost of daily living (Brown et. al., 2016). Prescriptions are often abandoned (prescription abandonment) for these reasons (Doshi, Li, Pettit, & Armstrong, 2018). The problem with cost affecting adherence is that patients choosing to not take medication because of cost do so for reasons that may not be apparent to the prescribing doctor.

T2DM is a reversible disease with medications that are available for alleviating symptoms as well as complications (MCCombie, 2017). When addressing the cost of diabetes; however, it is not just the medications; it is the costs of maintenance, monitoring, and lifestyle changes (higher costs for healthier foods). The total estimated economic cost of diabetes is 245 billion, with anti-diabetic agents accounting for 12% and medications for complications accounting for 18% of this cost (ADA, 2016). Non-Hispanic blacks account for more costs related to hospital visits, health expenditures, inpatient visits, and fewer office visits but more emergency room related visits (ADA, 2016). The ADA reports that 1 in 5 health care dollars are spent caring for Diabetes with health care costs for individuals who have Diabetes being 2.3 times higher than non-diabetic individuals.

The costs of medications are a constant concern for chronically ill patients, especially in uninsured or underinsured individuals. Individuals facing these concerns make adherence decisions based on the cost of their medication, out of pocket costs and prescription coverage (Herman, Alfulani, Coleman-Jensen, & Harrison, 2015). Poor health, low income, and decreased, or no medication insurance causes individuals to report decreased adherence (Brown et. al., 2016). Determining whether to adhere to medication for ACMF may come in the form of deciding whether to spend money on healthcare or to send money home for their families. It has long been a tradition for migrant farmers, and immigrants to send money home that not only keeps families going but is also a way to improve communities in their native countries (Barrett, Durden,

2018). Drug costs are another burden placed on this community that is not easily alleviated, especially when choices of whether to be adherent are between self and family.

Cues to Action

The factors to be presented based on this HBM construct are cultural competency and trust.

***Patient Trust as a cue to action*.** The WHO notes that a positive provider-patient relationship (PPR) might be one of the most important factors in improving adherence (Ranjan, Kumari, & Chakrawarty, 2015). This is supported by Gupta et. al., (2014) who conducted a prospective, observational study of the health care system and physician distrust; they found that of 1,232 hospitalized adults, 35% reported healthcare system distrust, while 16% reported interpersonal physician distrust. The authors noted that poor social support and coping skills contributed to both types of distrust (Gupta et. al., 2014). Trust is defined as a situation where both parties share confidence and reliance on the ability to become vulnerable as well as dependent on the other parties' actions (Merriam-Webster, 2019). In the health care setting, trustworthiness can be measured by the health care practitioners' ability to consistently act in the best interest of their patient, providing healthcare that benefits all involved (Dawson, 2015). With this statement, it can be assumed that performing these actions can earn the healthcare practitioner the patient's trust. The development of this trust through the years has been harder because of past blemishes on the health care system from exploitations like the Tuskegee experiments

(Alsan & Wanamaker, 2017) and unauthorized use of Henrietta Lacks' cells (Caulfield and Murdoch, 2017). Perhaps fueled by racially charged health care decisions in the past, studies like the one conducted by Lynch (2019) found that race might play a significant role in the physician-patient relationship and its effect on the outcome. The development and preservation of the PPR can rely heavily on a modifiable factor, like trust; however, the factors that mediate that trust are elusive. There is a possibility that these factors, can positively affect the relationship and patient outcomes related to adherence, especially in this disease (Birkhauer et. al., 2017). With trust as a possible factor of adherence being complicated by other factors, like racial and ethnic disparities in health, it is important to consider whether lack of trust negatively affects adherence decisions in the ACMF population. This population, unlike other migrants, is faced with multiple barriers to care – not only cost and language barriers like other immigrant groups, but also the fear of being mistreated because of their uncertain legal status. Within the population the barriers to care have been linked to cost and language but also to a factor that is not faced by the average American fear of not being treated well because of their immigration status (Farmworker Justice and the Nation Center for Farmworker Health, 2015). Studies show that racial and ethnic minorities tend to place less trust in their physicians as compared to their white counterparts, with that mistrust leading them to have a more negative view of their physician and their quality of care (Nie et. al., 2018).

Lynch (2019) looked at how the patient and provider interact within the relationship and how these interactions may have an effect on the patient's health and

ultimately, their outcomes. Lynch (2019) took a look at how culture, which may create differences between individuals within the PPR, can be looked at as a health determinant that can be influenced by the healthcare provider. With the results of the study claiming that there is adequate support that race, ethnicity, and language has an effect on the PPR and therefore the patient's outcome, emphasis should be placed on the PPR and whether it can be a factor that affects with management recommendations.

The days of blindly following an educated professional are over, as patients make decisions not based on provider knowledge, but on feelings like trust, comfort, and favorable interactions with their provider. Olsen (2017) reported that patients tended to report higher levels of medication adherence to diabetes recommendations to please the provider and or avoid shame. When patients suffering from T2DM become noncompliant, their mortality and morbidity increases as well as the stress on the health care system from increasing direct and indirect costs, ultimately leading to a decreased quality of life for the individual (Olsen, 2017). Previous studies have shown that patients who fail to comply with their provider's therapy had significant associations with complications related to the disease (Olsen, 2017). The reasons for this failure to adhere are not well understood, but the previously mentioned factors can be a step in the right direction. In a study looking at how participants felt about how they were perceived (whether they were being taken seriously or not) had a strong association with their confidence and trust in the general practitioner (Raude et. al., 2016). Specific populations of African Americans, for example, have poor adherence to medication regimens for

T2DM prompting researchers at the University of Virginia to call for greater efforts to improve T2DM self-management behaviors in these populations (Mosen, Glauber, Stoneburner, & Feldstein, 2017). This minority population, like the ACMF population, might show a general lack of mistrust of the healthcare system because of previous studies like the Tuskegee experiments. Diseases like diabetes, cervical cancer, and liver cirrhosis continue to plague this population not just because of barriers related to cost, English proficiency, health system familiarity but also factors that may be related to trust.

Culturally competent providers as cues to action. In social science research, there is attention placed on behavior evaluation and modification in a smaller group of people with the intent of using the results to benefit a larger group. One particular topic that has behavioral undertones is cultural competency of healthcare providers (Betancourt, Green, Carrillo, & Owusu Ananeh-Firempong, 2016). The arrival of so many culturally diverse populations in American society highlights the fact that the dispensing of effective health care to these populations must be intimately tied to cultural competency. The current gap in the research points to a need for culturally competent providers. Culture is an integral part of health care acceptance, especially in T2DM. In Haitian American (another Caribbean population) immigrants, culturally sensitive models were deemed important in developing treatment plans for TSDM (Bivins, 2017). A culturally competent provider can foresee barriers related to health based on a person's culture. They can use this to address these barriers before they threaten the patient's self-efficacy once out of the office.

The diabetic migrant farmworker population continues to be one of the most marginalized and oppressed (Newton, 2015), faced with daily struggles of living and working on a farm away from home and family while having to deal with a chronic disease heavily dependent on adherence. The stressors of this life cannot fail to have detrimental effects on the individual. Clingerman (2008) found that stress within this population is linked to higher fasting blood glucose levels, and Nyberg et. al., (2014) found that job strain independent of lifestyle choices within this population is linked to the development of type II diabetes. Afro-Caribbean farmworkers have been traveling and working in the U.S. since the 1930s (Baptiste, n.d), but have no concrete numbers that would come from regular health surveillance. While the prevalence of both types of diabetes in all farmworkers according to the National Center for Farmworker Health (NCFH) is likely to be the same as the Hispanic population in America, this number was based on Hispanics and not Afro-Caribbeans (NCFH, 2014). The NCFH conducted a separate study of 164 migrant farmers in 2012, which yielded a prevalence of 7.8% for both types of diabetes but admitted that the prevalence might have been underestimated because the numbers were based on health billing practices (NCFH, 2014).

The current research points to a need for cultural competency and improvement of patient efficacy as it relates to chronic disease management in all ethnic groups. In reviewing the literature, it is understood that cultural competency is important in medical practice and that its presence can improve patient ratings of care provided (Betancourt, Green, Carrillo, & Owusu Ananeh-Firempong, 2016) but has failed to conduct studies

that take into account how culture factors into affecting patient medication adherence. Lutz, Jong, & Rubel (2015) suggested that future study should look not just at barriers to receiving treatment in minority populations but also how to use patient feedback as it relates to those outcomes based on the treatment. Feedback about how culture is a possible factor affecting adherence can be one of the first steps in better understanding this minority population. The continued growth of diverse populations like this one is a cause for concern in the health care workforce, which should prompt awareness of the need for culturally competent practices (Sue, Sue, Neville, & Smith, 2019). While Betancourt, Green, Carrillo, & Owusu Ananeh-Firempong (2016) talked about how sensitivity to cultural differences is important to developing culturally competent approaches to health care, it is possible that many other factors might play a role in improving diabetes self-management (Gonzalez, Tanenbaum, 2016)

Self-Efficacy

The factors to be presented based on this HBM construct are ability to carry out behavior and self-efficacy's effect on medication use and behavior. Self-efficacy, according to the HBM, is the perception of an individual's own ability to perform a health-related behavior (Rimer & Viswanath, 2015). It is essentially the patient's own belief that they are capable of completing a recommended healthy behavior. This construct was added in 1988 and was a way in which to explain why individuals performed different health behaviors (Glanz, Bishop, & Donald, 2010). The addition of

this construct makes the HBM an even more useful tool for understanding health care behaviors in individual populations.

Al Sayah, Majumdar, Egede, & Johnson (2015) found that higher self-efficacy in patients suffering from T2DM was associated with improved medication adherence along with better glycemic control and self-care behaviors. The diabetic patient becomes more adherent, thereby improving their health outcome when there is high perceived self-efficacy. This study hopes to determine if self-efficacy is a driving force for adherence in this population. This construct of the HBM is becoming increasingly important in not just understanding behavior, but its adjustment can dramatically improve Diabetes self-care behavior (Brett et. al., 2018). It is important to determine if Afro-Caribbean Migrant Farmworkers have a high of low degree of self-efficacy. This construct is perhaps one the most important to this study because if the aforementioned factors are accounted for, it is important to determine whether this population will carry out healthy behaviors related to adherence. In a cross-sectional descriptive study that looked at factors that influence Diabetes self-care behaviors, researchers found that self-efficacy was influenced by other factors but found that when it was high, it had a positive effect on Diabetes self-care behaviors like adhering to treatment regimens (Reisi et. al., 2016).

Summary

Some major themes that emerged in searching the literature were that adherence has to do with more than just one factor within the PPR. Other factors are related to culture, control, treatment efficacy, as well as patient-perceived benefit. While these

themes may be prevalent in multiple patient populations, it is unknown which of them are significant predictors of adherence in the ACMF community. My review of the literature found that information regarding diabetes treatment regimens in this population is almost non-existent. This population plays a very important role in the survival of American society but still continues to face barriers to health care related to its cost, access, and their status as residents in American society (NCFH, 2015). The importance of adherence to recommendations for management in chronic diseases is apparent from the aforementioned studies. Healthcare providers have always stressed the importance of patient adherence, but from the reviewed literature, it seems that they have failed to take into account factors that may prevent or promote this adherence. The importance of the relationship shared between patient and provider is not disputed, but factors within it and how it plays a part in adherence to management recommendations might be somewhat undervalued. The overall sense after reviewing the literature is that the public is either unaware of the importance of adherence to management recommendations and or feels they are not in control of it. Sustainable change in how health care promotes adherence is possible if the public believes that they have a hand in the change and how it affects them.

Chapter 3: Methodology

Introduction

In the pursuit of improving health and quality of life, much of the battle is finding the disease, treatment or cure, but the rest lies with patient actions, like actions related to adherence to prescribed regimens. Factors within the patients' environment influence these actions. In this study I explored the factors from the perspective of ACMFs. The study assessed their beliefs about these factors and their bearing on their adherence decisions.

Medication adherence is an integral part of delivering effective health care and improving quality of life, especially for individuals suffering from chronic diseases. However, adherence is different across conditions and patient characteristics and is not well understood (Foot, Caze, Gujral, & Cottrell, 2016). In T2DM, adherence to medication is an essential part of preventing complications related to the disease (Polonsky & Henry, 2016), and in reviewing the literature I found some factors associated with T2DM adherence. In this study, the effect of these factors on adherence within the ACMF population will be explored deeply. This information could help in the development of strategies to promote medication adherence within this and other populations.

Research Design and Rationale

Primary research question:

What are the perceptions of diabetic Afro-Caribbean Migrant Farmworkers concerning

the factors that influence their adherence to medical recommendations for Type II Diabetes management?

Secondary research questions:

(1): What is the health literacy of ACMFs regarding diabetes and its treatment?

(2): What are the perceptions of ACMFs regarding their diabetes care provider?

(3): What are the perceptions of ACMFs regarding their susceptibility to diabetes?

(4): What are the perceptions of ACMFs regarding the severity of their diabetes?

(5): What are the perceptions of ACMFs regarding the benefits of the prescribed treatment for diabetes?

(6): What are the perceptions of ACMFs regarding barriers to their adherence to prescribed treatment for diabetes?

(7): What are the perceptions of ACMFs regarding cues to action in their adherence to prescribed treatment for diabetes?

(8): What are the perceptions of ACMFs regarding their self-efficacy in adhering to prescribed treatment for diabetes?

This study was conducted to determine the perceptions of ACMFs diagnosed with T2DM about factors affecting their adherence to medication. Using a qualitative approach was a great way to study the behaviors and perceptions of the ACMF population as it relates to the social phenomena of adherence to diabetes management recommendations. A qualitative study was possible for this population because it was used to define variables that were not previously defined population. There are likely

factors common to this population that affect their medication adherence in this disease. In this study I attempted to not only determine these factors, but also help to develop a strategy for using and or modifying these factors to improve adherence in this population, and perhaps within other minority populations.

The two approaches considered for this study were ethnography and phenomenology were considered for this study. Ethnography was a consideration because of its study of culture, and whether it has an effect on patient decisions. Phenomenology presented the chance to study the phenomenon of medication adherence, as experienced within this population. Ethnography was not chosen because according to Creswell (2017) it is specific to determining a cultural pattern of a particular group (usually a large one), which would exclude other groups. Phenomenology thus became the obvious choice. The benefits of using phenomenology according to Rahman (2017) for this study was its ability to provide an in-depth understanding of individual phenomena while allowing data to be collected based on those phenomena. Rahman (2017) cited that the disadvantages in qualitative studies are that data collection can take longer than other methods, and data analysis and interpretation can be challenging. In this study tradition, criterion sampling is typically used to select the participants that closely match the requirements for the study (Rudestam & Newton, 2015). The phenomenological approach allowed for a better understanding and reporting of the thoughts, feelings, and beliefs of ACMFs about medication adherence. The

phenomenological approach helped to determine the directly related factors that affected their adherence.

With the intent of determining what influences medication adherence in all populations, using the results from this study public health practitioners could develop questionnaires that could predict a patient's adherence ability. With modifiable factors, the aforementioned predictions could allow for correction. In reviewing the literature, I found that there might be factors that might contribute to medication adherence but did not specifically identify what the factors were or if they were modifiable. What these factors are, and how they influence this population, can be considered a lived phenomenon as described by Creswell (2017) and can be used to improve current policies especially those related to T2DM management recommendation adherence in ACMFs.

Role of the Researcher

As a new qualitative researcher, I am well aware of the importance of each participant's views of their experience. I am of Afro-Caribbean decent and I have lived in Connecticut for the last 26 years. To conduct this study, I made contact with the office of the Vice Consulate of Jamaica who employs the liaison for the ACMF population in the Connecticut River Valley (CRV). There is currently a Liaison from the Jamaican Consulate in charge of labor relations and worker welfare in multiple New England states. There were no personal or professional relationships with the intended participants. The Vice Consulate has direct contact with the ACMF but has no supervisory or instructor relationships within the population.

As in many qualitative studies I was the main instrument in this study, I conducted interviews of ACMFs and kept research journals throughout the process (Willig & Rogers, 2017). I had no experience in conducting qualitative research or working with human subjects, this study was my first. I did not participate in any activities shared by the population, and provided an outsider look based on observations and interviews. Biases that could have arose could have been related to my race, gender, and age. I used open-ended questions to avoid factors could have caused biased questions. There were no conflicts of interests regarding the work environment, and there were no incentives offered during this study. I made sure to stress the fact that there will be no repercussions based on answers and that the results of the study are not guaranteed to produce any immediate change that the participants may be expecting.

Methodology

The study took place on migrant farms located in and around the Connecticut River Valley (CRV) and will involve ACMFs diagnosed with T2DM and prescribed oral medication or lifestyle changes for maintenance. The farmworkers (individuals who live and work on the farm) were mainly male (90%) which could introduce bias, but the reality is ACMFs are predominantly males, of African descent with an average age of 33 (U.S. Department of Labor, 2015). The farms in this area were mostly tobacco farms, fruit farms, and plant nurseries. The CRV is home to more than 21,000 farmworkers and their families. Families live on the farm with their farm working relatives but do not necessarily work on the farm (Massachusetts League of Community Health Centers,

2015). Many farmworkers live on the farms year-round, but others like the ACMF are usually seasonal workers. Seasonal workers often sometimes translate to seasonal healthcare, especially in the case of migrant farmers. The study will focus mainly on the ACMF and their beliefs about factors that may impede their medication adherence.

There was a total of 15 participants in this study. Each participant was given a 60-minute interview with a total of 29 questions related to their background, time on the farm, diagnosis, and treatment regimen (see Appendix D).

The number chosen for this study is based on the assumption that saturation will be reached by this number as well as it is an adequate number to collect credible evidence in phenomenological research (Rudestam & Newton, 2015). I hoped that as the study continued to interview each of the 15 participants, there would be enough repeated beliefs and perceptions. This was the case and I was able to develop general themes. These developed themes are where the study expects to reach saturation, where continued data collection (interview answers) no longer leads to new data (Fusch & Ness, 2015). The selection criteria for participants followed the criteria described in the sampling strategy section. Twenty ACMFs were chosen to participate in the study farmworkers of any descent other than the Caribbean did not take part, as well as farmworkers of Caribbean descent who have been recently (less than 6 months) diagnosed with T2DM.

Sampling Strategy

Criterion sampling was used to select the participants of the study depending on their ability to meet. all the following criteria:

1. Participant of the migrant farmworker program for more than 1 year
2. Diagnosis of T2DM for more than six months
3. Currently taking prescribed oral medication
4. Has been prescribed lifestyle modifications
5. Has had contact with a health care provider in the U.S.
6. Identifies with the Afro-Caribbean cultures (Any one of the Caribbean islands)
7. Lives on agricultural farms located in the CRV
8. Must be a farmworker for more than 1 year

These criteria were the basis of participants used for this study, and as detailed in Appendix C. This sampling approach was a sound basis for determining the perspective of the ACMF population. The list of criteria was distributed to farmworkers on participating farms and posted in common areas on these farms and was a recruitment tool. The decision to use criterion sampling in this study stems from the fact that it was useful in identifying information-rich cases in the ACMF population who can provide information about the phenomenon of medication adherence.

Instrumentation

The data for this study were collected using 29 questions in a questionnaire (Appendix D) I developed during a 60-minute interview. The interview questions were reviewed by an Expert Panel using the Survey/Interview Validation Rubric for Expert Panel (Simon & White, 2011). This rubric, used with permission obtained from Dr. Marilyn K. Simon, was “designed to measure face validity, construct validity, and

content validity" (Simon & White, 2011, p. 2). With the utilization of this survey and allowing expert panel members to assess the interview questions, the face, construct, and content validity of the study were improved. The use of this survey for the expert panel was relevant because it ensured that the interview questions collected relevant data based on the experts in the field. Below I show the composition of the Expert Panel. It consisted of two individuals familiar with T2DM and ACMFs (committee member and Liaison), two individuals from the ACMF population (Farmworker 1 and Farmworker 2) and two individuals familiar with the guiding theory of this study (chairperson and committee member). The Expert Panel assessed the questions and rubric based on the survey. The chairperson of the study whose expertise is qualitative research suggested that the term 'diabetes be removed' from all questions and to use a standard term for the term 'doctor'. The chairperson also suggested adding a final closure question. The results of the survey are summarized below. The committee member who served as 2 sources of expertise (T2DM, qualitative research) suggested that the term healthcare professional be replaced with doctor. The liaison (ACMF expert) suggested that the questions be simplified to the 4th grade reading level. The two representative members of the population suggested that 'diabetes' be changed to 'sugar' and that the word improve be defined, the word was removed.

Many of the interview questions stem from elements of the theoretical framework outlined in chapter 2, as shown in Table 3.

Table 3

Alignment of Theoretical Framework, Research Question, and Interview Questions

Theoretical Framework	**Research Question**	**Interview Questions**
Health belief model	What are the perceptions of diabetic ACMF concerning the factors that influence their adherence to medical recommendations for T2DM management?	
Perceived susceptibility	What are the perceptions of diabetic Afro-Caribbean Migrant Farmworkers concerning the factors that influence their adherence to medical recommendations for T2DM management?	**Perceived susceptibility** 16. What part of your daily life do you think led to you having Sugar? 17. What do you believe you could have done to stop Sugar from happening to you?
Perceived severity	What are the perceptions of diabetic ACMF concerning the factors that influence their adherence to medical recommendations for T2DM management?	**Perceived severity** 18. How serious do you think your Sugar is? 19. How much do you think your other health problems might be caused by Sugar? 20. Some people say that following the doctor's advice will take care of your diabetes or Sugar. What does it mean to you for a person to have Sugar taken care of?
Perceived benefits	What are the perceptions of diabetic ACMF concerning the factors that influence their adherence to medical recommendations for T2DM management?	**Literacy** 4. What is your current treatment plan for your Sugar? 5. To what extent do you follow this plan? 6. What do you think your doctor wants you to gain from your Sugar treatment plan? **Perceived Benefits** 21. Is your Sugar taken care of? 22. How do you think your diabetes drugs help or harm you?
Perceived barriers	What are the perceptions of diabetic ACMF concerning the factors that influence their adherence to medical	**Cultural competency and perceived barriers** 11. How might the skin color of your doctor affect your relationship with them?

	recommendations for T2DM management?	12. Would you be more likely to take your medication/pills if the doctor is from the same background? Why or why not? 13. What are the Caribbean treatments for Sugar? 14. What remedies for Sugar do you know? 15. Would you share these remedies with your doctor? **Other perceived barriers** 23. Does the cost of your drugs affect if you take it? 24. Do you have any problems getting your medication?
Cues to action	What are the perceptions of diabetic ACMF concerning the factors that influence their adherence to medical recommendations for T2DM management?	**Patient trust as a cue to action** 7. On a scale of 1 to 10, how would you rate how much you trust your doctor? 8. Please explain why you scored your doctor this way. How do you believe your doctor can make this number better? 9. Do you believe your doctor trusts that you take the drugs they give you? Why or why not? 10. How do you believe trusting your doctor might help you follow their advice? 25. Please describe anything your doctor does or says that might make you want to take your medication/drugs. 26. Do you think the doctor understands your background? If they did would you listen to their instructions more?
Self-efficacy	What are the perceptions of diabetic ACMF concerning the factors that influence their adherence to medical recommendations for T2DM management?	27. What do you believe you can do to improve your Sugar? 28. Do you feel you have the tools/help you need to manage your Sugar on your own?

Interviews

The interviews were audio-recorded but not videotaped to protect the participant from any worries they may have about repercussions. Each participant's answer for each interview on the participant datasheet. After each interview, the interviewer will record non-verbal communication noticed before, during, and after the interview in the research journal.

Each participant had one interview; with a follow-up interview, so each participant had two data collection events. These interviews were semistructured, which allowed for follow-up questions at my discretion, which was either closed-ended or open-ended depending on the clarity of the information. The use of semistructured interviews for this study was expected to provide the participant and me with direction while allowing me to be able to delve into any response that warranted further exploration (Kallio, Pietila, Johnson, & Kangasniemi, 2016).

The interviews began with me greeting the participant, welcoming them to the study, letting them know their participation is voluntary, and asking if it is ok to record the interview (confirming the permission already requested and obtained in the notice to participant). I informed the participant that if at any time, they need a break or want to discontinue the interview they could. Once the participant was comfortable, offered water, the interview began. For each question, I announced to the participant that they were reading the question in its entirety and then repeated the question and gave the

participant time to answer the question. When the participant answered, I recorded as much as possible without interrupting the participant. Once the participant was finished responding, I asked follow-up questions on any unexplained responses. The participant was offered a break after ten questions are read and answered. After each interview, participants were thanked for their participation and informed that their information would be kept private and used only for information purposes. At this point, the participants received a $5 calling card as a thank you for their participation.

A detailed plan for the interview process was as follows:

STAGE 1:

1. Greet the participant, introduce self, and ask the participant to have a seat and ask if they are comfortable.
2. Offer the participant a small bottle of water.
3. Ask the participant if it is ok to record and subsequently begin recording if they agree

STAGE 2

1. Introduce the research and inform the participant of the aim of the research
2. Inform the participant that their participation is voluntary, and they can stop at any time
3. Inform the participant that their answers will be kept confidential
4. Inform the participant that they can choose not to answer any of the questions posed

5. Inform the participant that there are no right or wrong answers

STAGE 3

1. Give the participant some background information about the study and begin
2. Inform the participant that each question will be read in its entirety and then read again to give the participant time to answer
3. Ask participant questions 1 through 15 while recording

STAGE 4

1. At about question 15, was a small break in the interview
2. Ask participant questions 16 through 28 while recording
3. Inform the participant that this is the last question
4. Read the final question

STAGE 5

1. Ask if they have any questions
2. Thank the participant for their participation
3. Remind participant again that their information will be protected and only used for information purposes and destroyed after the completion of the dissertation.
4. Ask participant follow-up questions if applicable
5. Ask participant when they are available for member checking and make follow-up appointments
6. Offer $5 calling card.
7. Perform member checking at a later date based on transcribed information

Recruitment and Participation

In research that involves recruiting participants of African descent, it is important to remember the general distrust of the medical community by this race (Dale, Bogart, Wagner, Galvan, & Klein, 2016). With this in mind, I had to remember to alleviate any fears that might arise in these participants. Reasons for this distrust are; the decreased trust of people conducting the research, lack of knowledge or understanding of what the research is attempting to do, and fear of a repeat of past exploitations as was seen in the Tuskegee syphilis study (Alsan & Wanamaker, 2017). Many of the factors cited as being barriers to developing research trust by participants were seen mainly in clinical research. The fact that the study is not clinical research can put participants' mind at ease by ensuring them that they will not be harmed physically by any of the effects of the study. Another way that this study will alleviate concerns of participants who intend to participate is to build strong partnerships with a trusted member (the liaison) of the community.

The liaison has expressed interest in announcing the existence of the study to increase participation. I provided the liaison with information about the study, including its purpose and methods of collecting data. I took preliminary steps to improve the population's trust in me, by participating in the migrant farmworker clinic and visiting farms in the CRV. This clinic is a free healthcare service that is provided to farmworkers in the CRV to help improve access to care. The clinic uses medical students and area-practicing physician volunteers to offer diagnostic as well as screening services for

migrant farmworkers (University of Connecticut Health Center for Public Health and Health Policy, 2016). This clinic allowed me to be introduced as a part of the community interested in helping to improve the health and overall quality of life of the migrant farmworker. It also provided a platform to introduce me as a part of the Afro Caribbean community by providing interpreting assistance to fellow volunteers.

The marketing method that was used to contact and garner interest from participants were recruitment posters (see Appendix A). Recruitment posters were posted at all participating farms in the CRV asking for volunteers. The recruitment posters were displayed at the Afro-Caribbean Migrant Farmworker's living quarters as well placed in their mailboxes. Participants will then be contacted by mail after their completion of the screening questionnaire. The letter will request their consent to participate (Appendix B), along with a participant data sheet (see Appendix F). Once a participant completed the consent form, appointments were made for each participant to return for the interview. The interview questions are in Appendix D.

Data Collection

Interviews followed the steps as described above. After each 60-minute interview, the research journal was used to record reflections like any aspects of the interview that did not go as planned and needed improvements. The idea behind using reflexive comments in the journal is to promote transparency in the study and the validity of the data (Meyer, Willis, 2018).

For each interview detailed notes were taken of participants' responses, body language, and their level of comfort. The notes were analyzed to identify relationships noted in the study. There was a procedure to remove information that can be considered friendly banter and may not have any study benefit. The method checked the information gathered during the sessions that were found to be friendly banter against the interview questions as well as answers from other participants.

Data Analysis Plan

During the course of the study, a coding system was created to categorize and group the data. In qualitative interviews, codes are words or short phrases that can be used to represent an observation, belief, or perspective (Tracy, 2019). The themes from the literature review were used as potential guides to determine the coding system. The coding process was done in sequence starting with open coding (dividing the collected data into segments), then axial coding (making connections between the categories), and finally selective (identifying the main themes of the study) (Rudestam & Newton, 2015). The entries in the research journal will also be used to add supplemental information that may be lacking. Specifically, for the questions chosen, the Research Journal, as well as my hand coding crosschecked with coding using the NVivo software, should be very beneficial.

Trustworthiness

One of the concerns during this study was researcher bias as it relates to reflexivity. Reflexivity addresses the contextual relationships between the research and

the researcher (Dodgson, 2019). The concept of trustworthiness is directly related to the ethics of the researcher and the type of study. The researcher should choose a research method that allows for the ethical collection and reporting of data that supports the claims of the study. For the qualitative researcher, methods of establishing trustworthiness (like credibility, transferability, dependability, and conformability) are used and are from the methods used by the qualitative researcher.

Credibility

Two methods were used to ensure the credibility of the data: member checking, and site triangulation. In this study I aimed to promote transparency as well as openness to build trust within this population and credibility for this research. I will provide a summary of the study to the liaison, including questions that were used for screening and interview questions. Credibility in this study started from the beginning, with the choice of an appropriate method to carry out the study, method to select the participants, and ensuring that ethical procedures are followed before, during, and after the study as described in Creswell & Clark (2011).

Member Checking. The use of this form of validation in this study is another way to ensure validity, especially since much of the responses might be provided in a dialect of English (Caribbean patois). Member checking was a very useful staple in this study and helped to maintain accurate information. It was done at the end of each interview before the reflexive journal entries. Member checking was done after the interviews were transcribed. The information will then be presented to each participant, giving them the

chance to confirm their responses as well as contest any interpretations or wrongly recorded responses by the researcher. The participants were alerted at the end of each interview of the need to have a second shorter meeting to review their answers and confirm any interpreted meanings.

Site Triangulation. Triangulation is when data are obtained from multiple sources (or using two or more different methods) in order to crosscheck as well as corroborate them before determining themes (Rudestam & Newton, 2015). The method can be used for participants as well as for locations or participating organizations. For this study site triangulation was achieved by eliciting participation from multiple farms in the CRV. In site triangulation, the researcher elicits participation from individuals within different organizations to reduce the possibility of presenting only factors that are representative of one organization (Kornbluh, 2015). Site triangulation in this study will decrease the possibility of collecting data from only one farm, which might bias the results towards perspectives common to that farm and those participants (Kornbluh, 2015). The interviews will take place at multiple farms in the CRV allowing for site triangulation in this study.

Transferability

One important aspect of this study that was important in its transferability is the reflexive journal and the research journal. Both of these journals are centered on the researchers and their shortcomings and their achievements. The journals will help to provide background information not available in the collected data. They will provide

information about the farms, their locations, and background information about the participants. Transferability in a study allows for other researchers to be able to repeat the study conditions with other populations; having a detailed account of the study makes this easier for future researchers (Kornbluh, 2015).

Dependability

Much like transferability, dependability depends on how much detail the researcher can give to processes of the study, including plans, implementation, and execution (Kornbluh, 2015). In this study detailing the interview process from start to finish as well as how the data was collected, stored, and analyzed will help to ensure the study's dependability. A more detailed study will also help the reader to assess the extent to which the researcher followed the best research practices (Kornbluh, 2015).

Confirmability

Confirmability is related to how concerned the research is about objectivity; the concept is unable to be established without the presence of dependability, transferability, and credibility, (Lehner, Kraus, Wei, & Steinnocher, 2016). Confirmability was ensured in this study by strengthening the dependability (providing as much detail as possible), transferability (keeping detailed reflexive journals), and credibility (using site triangulation and member checking). The use of these strategies as a way to ensure conformability allowed data to be collected that is solely derived only from participants with a little research input as possible. The journals will also be helpful in this area

because they will help to give prevent any bias or misconceptions from the research spilling over into the study.

Ethical Procedures

This research study will attempt to provide insight into the factors that might affect medication adherence in the ACMF population. Data was collected using interviews as described in the aforementioned interview section and was analyzed to determine relevant as well as recurrent themes, which were eventually used for coding. The identified stakeholders for this study were the national center for farmworker health (NCFH), the Eastern Caribbean health outcomes research network (ECHORN), the American Diabetes Association (ADA) (Connecticut chapter). No collaboration was sought with these entities, but they were (ADA) made aware of the study and given access to the results by possible publication in American diabetes Association Journal, the patient education and communications Journal, and presentations at relevant conferences (American Public health Association conference and the Connecticut public health Association conference). Once the collected data from interviews have been coded, and the dissertation is completed and defended, the audio recordings, as well as the transcripts and any notes collected during the interview, will be destroyed as mentioned in appendix B.

Protection of participants

This researcher has completed the human research protections training online with the national institutes of health. In December 2012 (copy of the certificate can be found

in the appendix section). The researcher will also seek Institutional Board Review (IRB) through Walden University. The human research training, along with IRB approval, will ensure that the researcher is well versed in procedures that are needed to protect human subjects throughout the study. The study participants were Afro-Caribbean male farmworkers who will participate in individual voluntary interviews following their qualification to participate, and their signed consent forms (Appendix B) are collected. IRB approval was obtained; the approval number is notated in the dissertation.

For each interview the researcher will employ two methods of data collection audio recording and detailed, if at any time the participants requested not be recorded, the researcher will comply with this request and instead use only detailed notes. The researcher can and will promise confidentiality to the participant throughout the study. In the event that a participant becomes visibly emotional during the interview, the researcher will offer the participant the option of continuing at another time or discontinuing their participation in the study. If any participant drops out of the study step will be taken to recruit another participant using the same criteria (Appendix A).

This study is hoping to delve into attitudes and emotions that may cause distress to the participants. While proper approval was obtained, there is still a possibility that subjects might be harmed (National Bioethics Committee, 2015). The researcher will take steps to be very attentive to body language and comfort level of the participant. Another way that this study will hope to protect the participants is to watch for participant fatigue.

The researcher will offer refreshments at the beginning and will take note of the temperature of the room and the comfort of the surroundings.

Upon completion of this study, the researcher expects that the data collected will be used to better understand behaviors, perspectives, and beliefs of the participants. The participants' identity was protected by not including names in any document related to the study. If at any time a direct quote is used, the participant will only be referred to as "Participant." The ethical issues that were considered in the study are how long the interviews will last, what questions are asked during the interview, and allowing the participant to have the final say in how their data are used. The participant's privacy and confidentiality were protected and assured. As a way to ensure that the subject fully understands the risks and benefits of this study, they were provided with a copy of informed consent documents. The researcher will apply for Institutional Review Board (IRB) approval before beginning any data collection. The researcher does not foresee any conflicts of interest.

Summary

The phenomenological approach provides very personal, in-depth accounts of people's experience that can be compared and contrasted to the experience of others of the same background in a similar situation. This comparison can help to determine themes about the phenomenon in question in the study population. The phenomenon of adherence to medical recommendations is present among populations concerning many illnesses, but the reasons for it vary considerably. While the literature does not

specifically mention factors common to anyone population, the question of the existence of factors differing across populations and whether they are controllable continues to be a concern for the ACMF community.

This study will attempt to answer this question. Finding a factor or factors specific to one type of population can have far-reaching benefits in creating patient-centered care. In chapter 4 I will present the results of the interviews, and Chapter 5 will contain my interpretation of the data and conclusions of the study.

Chapter 4: Results

Introduction

The purpose of this qualitative phenomenological study was to understand factors that might affect adherence to type II DM management recommendations among ACMFs living and working in the CRV. Reduced adherence to T2DM management recommendations has been well documented and often linked to reduced glycemic control (Polonsky and Henry, 2016). The cost of non-adherence to these recommendations can take many forms, from social (complications of limb loss), monetary (increase hospital visits), and decrease quality of life (increased hospital visits and stays; Polonsky & Henry, 2016). For the ACMF, the daily struggles of life on the farm tend to take precedence over the need to be adherent to their T2DM recommendations. The typical farmworkers' day begins at 4 a.m. during the planting and growing season. Many workers only have time for coffee/tea and sometimes cold leftovers and other times no food in the mornings. Their days tend to end after 6 in all farm seasons. Farmworkers live in either grower housing (rent, sometimes collected from paychecks), government housing, or privately own homes where they rent (NFWM, 2018).

The CRV is home to more than 6,000 farmworkers in any given planting season (Connecticut Department of Labor, 2018). The lifestyle of these farmers often causes many chronic illnesses, including T2DM, which are often exacerbated by high-stress conditions and decreased freedom of movement due to stringent work conditions. The

ACMF believes that their daily work in the fields is “good exercise” (participant 11) but in truth, most of their time in the field is stationary, sitting and weeding/planting or standing and picking (Outreach Partners, 2015). Unfortunately, even with challenging work conditions farmworkers are not afforded the same protections as the American worker, nor the same benefits of workers compensation, health insurance, and disability insurance (Farmworker Justice, 2017).

T2DM treatment relies on medication adherence, and the study of non-adherence to T2DM medications in many populations is prevalent. The ACMF population, however, has no such studies and would benefit from this information (Patel et. al., 2016; Walker, Smalls, Hernandez-Tejeda, Campbell, Egede, 2014).

The HBM as a guideline, allowed me to examine the factors that affected adherence in other minority populations in comparison to this minority population. The primary (RQ1) of this study was “What are the perceptions of diabetic Afro-Caribbean Migrant Farmworkers concerning the factors that influence their adherence to treatment recommendations (which include medications, lifestyle changes, and dietary modifications) for Type II Diabetes management?” This study can be the first step in understanding the inner workings of this population and how their daily struggles affect their ability to care for their health. In this chapter I will summarize the data collection, descriptive statistics, trustworthiness, and data analysis techniques used in this study.

Participant Demographics

There were 15 participants all were men between the ages of 35-67, and all were farmworkers from the Caribbean island of Jamaica (see Table 5). The education level of the participants ranged from elementary to some high school.

Table 5

Participant demographics

Participant	Age	Owner/Self Insurance	Nation of Origin	Time on farm
1	35	None	Jamaica	4 years
2	65	Owner	Jamaica	15 years
3	42	Owner	Jamaica	7 years
4	43	Owner	Jamaica	17 years
5	67	Owner	Jamaica	20 years
6	42	Owner	Jamaica	15 years
7	54	Owner	Jamaica	13 years
8	60	Owner	Jamaica	19 years
9	56	Owner	Jamaica	16 years
10	47	Owner	Jamaica	10 years
11	59	Owner	Jamaica	12 years
12	62	Owner	Jamaica	18 years
13	51	Owner	Jamaica	8 years
14	64	Owner	Jamaica	14 years
15	57	Owner	Jamaica	11 years

Data Collection

There were no changes to the methods described in Chapter 3, but the participant challenges were late interviews and rescheduled and missed interviews. Reasons for this included longer than anticipated workdays, or conflicts in an already agreed-upon workday schedule. These extended the overall study time but did not affect the participants or the data. The proposed number of participants was 20, and 20 respondents were available to participate, but saturation was approaching at around 13 and completed at 15 participants.

Recruitment

The chosen target population consisted of ACMFs, participants of the farmworker program in the CRV who lived and worked on farms within the CRV. Recruiting posters (see Appendix A) were at all participating farms in common areas, outside of buildings, and on some buses.

Sample

I interviewed 15 participants for this study. Each participant visited the local library, and the interview took place in a library meeting room. Each participant had two interviews (the initial meeting for the interview and follow-up member-checking interview). Each interview took place at a local library meeting room. Some libraries were within walking distance of the farm, but others were a reasonable distance away

from where farmworkers had to drive or receive rides. In every instance, the participant was greeted in the lobby of the library and led to the meeting room.

Interviews

Each interview was at a public library meeting room with the provision of water and breaks throughout the interview as deemed necessary by me and interviewee. The interviews were scheduled for 60 minutes, including break time and recorded with permission from participants. Each participant was made aware that their interview would be transcribed and given to them to review for the correctness of speech and if they had any corrections or additions to make to their responses. The questions used in the interview were in the semi-structured format while adding follow-up questions as needed for clarification of responses. Each interview followed a set number of questions in a specific order. Each recorded interview was reviewed and transcribe using dictation software to enter the information into Microsoft Word. Transcriptions were stored anonymously by using dates of the interviews as identifiers.

Member Checking

For the member checking aspect of this study, each participant had a follow-up interview where they reviewed their transcribed interview notes for completeness and accuracy. There were no significant revisions or omissions; most participants questioned the use of broken English instead of proper English (some responses were written in Jamaican Patois instead of translating them to English). Keeping the response in Jamaican Patois preserved the participants meaning and prevents lost meanings. For

instances where the Jamaican Patois was not clear the exact wording English translation was included (Santo, Black, & Sandelowski, 2015).

Timeline

The timeline for the study relied heavily on the participants' work schedule and how much work they had each day. The first step in the study was to place the flyers (appendix A) at participating farms in the CRV. Each farm ranged from 1 to 6 hours away from my home base. Once a participant contacted the provided number, a phone screen was conducted using the screening questions (Appendix C). Participants that were able to pass the screening process were set up with interview dates and time, mainly at the end of the workday and on some Saturdays. Interviews were conducted at local library meeting rooms. I used a digital device to record data. There were no variations in the study and IRB approval was obtained for the study in September 2016, and initial interviews for the study began in March 2017 and concluded on October 2017. Follow up interviews began in December 2018 and concluded on March 2018. Participants obtained a phone card at the end of each interview.

Data Analysis

Interviews were member-checked and hand-coded. This method was the best fit for data interpretation based on the dialects used in many of the responses. Transcription of each interview led to the designation of the codes for each of the elements of the HBM, along with three other primary categories – literacy, trust, and culture (Table 4). The codes

allowed for the identification of the emerged themes. These are under the 'Results' section below.

Table 4.

Codes from collected data.

Category	Code/participant response	Theme
Perceived Susceptibility	My mom had it Dumplins, suck-suck Don't have time to eat full meal to take meds Never had it in my family Likes sweets Vegetables are not strong food Spend all day in field so hard work=(exercise) Drinks a few beers	1. If You Eat Bad, You Get Diabetes 2. I Would Have Gotten Diabetes Anyway
Perceived Severity	Unable to work & provide Don't want to faint like others Body turn rock	3. Diabetes Turn Your Body To Rock (Slows You Down)
Perceived Benefits of adhering	Lets me work Mostly when I feel funny, I take it	4. The Medications Are Bad, So I Use My Own Sometimes And Use The Ones From The Doctor When Mine Don't Work
Perceived Barriers to adherence	Owner brings us around payday Afraid to drive at night because of police Liaison brings us to places	5. Lack Of Transportation Often Delays Care 6. Cost Is Based On Availability Of Employer Sponsored Insurance
Cues to Action	Doctor said I would die Doctor talks to me for a long time Doctor tells them about their disease	7. More Time With Doctor Helps Build Trust And Motivation 8. My Results Speak For Themselves

	Doctor spends a lot of time with me.	
Self-efficacy	Try to eat right Can call Doctor if I need help Sometimes they let us grow our own vegetable garden Eats what is provided on farm Takes medication if feel faint	9.The Doctor Will Help Me
Literacy	Don't know what HBA1C is Sugar is not like Diabetes Two different types one is milder	10. Sugar Is Not As Serious As Diabetes

Evidence of Trustworthiness

In qualitative research, it is important to account for trustworthiness, in participant responses but sometimes, more importantly, the researcher conducting the study. One way to accomplish this for the qualitative researcher is the use of credibility, dependability, and transferability (Korstjens, 2018). In this study, to achieve credibility, I operated with complete transparency. The liaison received a summary of the study, a copy of the screening questions, and interview questions. The screening questions were a part of the recruitment poster. There are multiple sites in the CRV that house this population, and each site is a separate entity, using site triangulation a representative sample of the phenomenon faced by these ACMFs from as many sites was collected.

Member checking was a vital part of this study because the ACMFs used their native tongue, Patois, an English based creole language with West African influence (Cassidy FG: Multiple etymologies in Jamaican Creole. Am Speech 1966, 41:211–215). This dialect can be different in each region of Jamaica, necessitating confirmation of responses after interview transcription. To achieve member checking, participants had

follow-up interviews to verify and confirm their answers in the week following the initial interview. Each participant received a copy of the transcript to review to ensure all answers were recorded correctly and fairly represented their point of view in accordance with Anderson 2017's "*Criteria for Evaluating Qualitative Research"*.

Results

Perceived susceptibility

Theme 1: If You Eat Badly, You Get Diabetes

Questions 16 and 17 were designed to determine whether these ACMFs are aware of the likelihood of their developing the disease. Their responses to perceived susceptibility were often focused on family and diet while on the farm. For example, when asked what part of your daily life led to you having Sugar: one ACMF stated:

> "It's what you eat, and the family. My family father and sister have Diabetes, and they say it always follow the family. I remember the first time I went to medical in Kingston [Jamaica], and they say I have Diabetes. The morning I went to test the evening before I drink a lot of mango juice and that's when it came up on the Sugar. Mangos are sweet, so anything too sweet is not too good for you. They say fruit is good but must not eat too much ripe banana and plantain. I get that idea from my old people and doctor tell me not eat mango and ripe banana."

In the end, although he realized that certain foods are not suitable to eat with the disease, he felt that the body needs to have some of these things regularly but in moderation, "If

you even take a taste just a little piece. If your body keep away from certain things, you have to eat a little piece to keep up."

Many ACMFs believed that their T2DM was tied directly to their desire for sweets one ACMF stated: "Well sometimes you may eat a little starchy food and some of those or Sugar and sometimes our little sweet cookies and ice cream." This participant believed that he developed "Sugar" from his diet of sweets and starchy food. Another ACMF thought it was because when he was young, he had a lot of "suck suck" (a sweetened drink that is frozen).

Theme 2. I would have gotten Diabetes anyway

This theme emerged when trying to determine the ACMF's knowledge of their susceptibility to developing diabetes using interview questions 16-18. Other ACMFs believed that it is more than family because of what other doctors have told them about getting enough rest, one participant had this to say: "one time the doctor told me I didn't get enough rest and it is a family trend." This participant received his T2DM diagnosis while he was working in Maine and had a very grueling schedule, he said that: "I have to go to work in the night 12 a.m. Sunday night to six Monday evening. So, I wasn't getting a lot of rest because I was trying to send money back for college and for the house." The schedules of the ACMFs tend to follow this trend because of the need for crops to be planted during to planting season to be ready for the growing season.

The schedules are often very demanding, but often the food provided is familiar to the ACMF. One ACMF was distraught about a change that happened on a farm that took

away their kitchen and their ability to cook and replaced it with cafeterias with prepared meals and the cost removed from their paychecks, he stated that:

> They used to cook for us, they would use a lot of oil and batter and they don't care the amount that they put in your day still get it and it was more like I was eating at a fast-food restaurant every day.

These situations often lead to the belief that nothing could have been done to stop the development or progression of the disease. One ACMF believed that there was nothing he did to develop the disease nor nothing that he could have done to prevent the disease, he stated: "Well I don't think I did anything to have Sugar because I think it just happens and I don't think I can stop it." Another felt the same way, though he believed that: "well everybody has sugar, but it just affect the body, but you can't stop it if you're supposed to get it can stop it."

Perceived Severity

Theme 3. Diabetes Turn Your Body To Rock (Slows You Down)

This theme also emerged when trying to determine the ACMF's knowledge of their susceptibility to disease development. One participant when asked if he believed he could have done anything to stop the development of the disease stated that: "I don't know if I know I would stop it. Sugar is not a good sick. I wouldn't mind if I have a remedy. And if you eat too much things you shouldn't it turn a rock on you." The phrase "turn a rock" is repeated with the same sentiment by many participants when describing a belief that the disease would eventually turn their blood to rock, which will slow them

down and that's how they experience the disease as well as the complications. While many believed it was inevitable some believed that home remedies would have prevented the disease development and at times may work better than the prescribed medicine, a participant who was on oral medication thought that: "The only remedy for it is to try some home remedy to see if it works and if it not work then you have to stick to the medication from the doctor." Many of the home remedies included teas, spices, and bitter drinks.

The majority of ACMFs believed that eating "right" was the only way to have stopped it, not to have eaten so many sweets as a child or to not so many starchy foods as an adult. One ACMF believed that his blood becomes "rock" from not eating the right food and that only insulin would have prevented the development and the "rock" formation in his blood. The term "turn Rock" was a commonly used term when these respondents come to this conclusion based on the people around them that had Diabetes. One ACMF talked about his mother having the disease and how she lived with it, he stated that "my mother had diabetes so maybe that's the reason but hers wasn't that bad she lived to be 100." Another ACMF when asked how serious he thinks his disease is he mentioned that his Doctor "says it's not a serious sugar." He thought that the "sugar" going up and down meant that it was "not that bad." Some participants focused more on side effects in advanced cases which caused them to believe if there were no adverse effects on them, they did not have a severe disease. One participant believed that his disease was not very serious "because I don't faint like some people." Another participant

believed he was doing good because “I haven’t fainted.” He also went on to say he takes his medication based on how he feels, stating that “when I feel weird or when it [medication] doesn’t make me feel weird.

Perceived Benefits of Adhering to Diabetes Medication

Theme 4: The Medications Are Bad, And Don’t Always Work, Sometimes I Use My Own

This theme emerged when trying to determine the benefits of adhering to medication, questions 21-22. Many believed that symptoms that they were developing stemmed from the medications and not their disease one participant stated that since taking the medication: “my eyes are foggy now, and I have some dizziness when I pulled on my head.” Another participant believed that the severity would not be much of a problem if he had his “kids by his side,” he said he never had dizziness and that his kids always call and check on him, so that causes him to worry less.

Many ACMFs were unaware of symptoms of the disease and did not link any of the complications to the disease. One ACMF however stated regarding his T2DM and what it was doing to his body that “my stomach not moving enough sugars [and] my pancreas not working right.” This ACMF’s knowledge of the disease was particularly extensive and showed a level of understanding that was present in one other participant, who thought the sugars were being trapped in the pancreas and slowing down his body particularly his sex drive. When asked to explain further he stated that:

> It will slow you down as a man in performing with a woman you get slow down because of sugar it will work and your pancreas it eventually [sits] in there and it will really slow you down if it comes to the test.

The ACMFs all talked about being slower because of Diabetes, but not many understood why. Their greatest fear seemed to be that it would slow them down so much that they would not be able to continue working. Many of the ACMFs were accepting of the fact that Diabetes would eventually hinder their way of life but some felt that family and herbal medicine would prevent early mortality as is the case with this ACMF who stated, "Yes my mother had this, but she just drink a lot of bitters, and she lived to be very old."

The assumption is that the general knowledge of the disease is that it is "not good," but ACMFs are unfortunately at a loss when understanding why their care is managed in the way that it is, or what management means for their disease. It was essential to determine what their drive was for taking their medication or practice the recommended lifestyle changes. Participants mostly equated benefits to how well they can complete their work. One participant stated that:

> It depends on the day sometimes I have the medication in the morning sometimes I have it at lunch it depends on what I [am] doing. Sometimes you take the medication it doesn't work so you have to eat a little something to balance your diet.

This participant went on to say that where he got the medication from was so far that by the time, he got home he didn't bother to eat dinner, he said: "so it takes a time for me to come back, so I didn't take it till the next day." This participant's like many of the others' decision to take the medications is often one of necessity, on participant stated, "when I take the medication, I know my Sugar is stable. I do my test like three times a week. My last sugar reading was 99 on Saturday." Many of the participants used their work schedule to determine how much they would adhere and when to adhere. One participant stated that:

> Sometimes it's hard because I have to get up really early in the morning and I might have to rush into work and grab food and get out into the field so sometimes it's kind of hard to remember to take it.

The benefits, for the ACMFs, centered on discomfort from the disease, inconvenience with following recommendations, and experiencing symptoms. A participant who had just started medication was concerned about it, causing his eyes to be "glassy" but continued to take the medication because of prompting from boss and doctor. He stated that:

> It's only when I put on the reading glass that I can see not everything if the word is fine (small) I cannot see so I don't know that's why I was calling the doctor but at the same time the boss was calling, and he said to just continue taking the medication.

When asked if he had ever had eye problems before the medication, he said no. Another equated the benefits of the drug to the fact that he did not have any symptoms, like others he knows with the diagnosis. When asked if his Sugar was well taken care of, he stated that: "[they] said when you Sugar get up you get dizzy to blackout and I don't have it. From I have Sugar that never happens." Another participant, when asked about how he benefits from the medication, stated that:

> Well I don't know about those pills are very big, and sometimes I take them, and they make me feel dizzy you know sometimes I have to skip so that I don't feel dizzy for that day especially if I have a lot of work to do that day.

When questioned further about if he let the doctor knows he refers to the fact that he just skips a few does and takes the medication when he needs it again.

Perceived Barriers to adhering to medication or lifestyle changes for T2DM

Theme 5: Lack Of Transportation Often Delays Care

This theme is related directly to the HBM construct of perceived barriers and emerged when trying to determine factors that affected ACMF's ability to get to the pharmacy/doctor's office for treatment and cost of getting the medication. The information gathered was in response to questions 11 through 15 and 23 through 24. For many of the ACMFs, the presence of the liaison from the Jamaican Consulate alleviated concerns about travel. Oft times, this individual acts as a social and medical chauffeur. Medications are brought sometimes from distances that take over 5 hours one way. The process from the ACMFs' perspective seems simple, but some understand that if the

liaison is unavailable for whatever reason, that would be a day that they may not get their medication. For other ACMFs, the option of driving to get the medication is possible if the owner lends them their car, but that can be dangerous for the ACMF. One ACMF recounted events that centered on being pulled over in a rural area and being detained and questioned because of the car registration not being in his name he stated that: "they stop me late at night cause the car not mine and took me away. My boss was sleeping, and it was hard being treated that way."

The ACMFs tend to not think of the ability to get their drugs being an issue because there is usually a second person involved whether it is the liaison or the owner of the farm. They often don't focus on the fact that they cannot get their medication whenever they want. A participant talks about how the boss will take them when he has time and sometimes sets up the appointments on the day, they get paid: "The boss would take us when they have time and sometimes, they make sure we go on the day we get paid." Another ACMF who understands the infrequency of someone being available said he did not have a problem getting the medication: "not if they bring it to us…for the times I might not be able to get it I just ask doctor for longer prescription." This participant thought that at times when he knew there would be less transportation, he would get more medication, but that also meant that he would have fewer encounters with health care professionals. One ACMF explained how different it is in Jamaica, where he can quickly get to the doctor:

> In Jamaica, you going to the doctor more often than you do here sometimes between 2 to 3 months. But sometimes when you are up here they want you to come as much as they want you to come in Jamaica to the doctor but because of the work schedule and the distance it sometimes impossible to get there and you don't want to pressure your boss to bring you to the doctor because you have sickness and you have to go to the doctor. Since the liaison officer is now the ones taking us it's not that much pressure on the ball, so we asked them to take us, and it's a little bit easier to get to the doctor.

Table 6 shows the relations between each of the ACMFs and how the visit the clinics in their area and the distance from their home farm.

Table 6

Travel to Local clinics or Health Centers

Participant	Transportation	Location	Distance one way
1	Liaison and ACMF	CHC Enfield	45 min
2	Liaison	CHS Inc.	20 min
3	Liaison	CHC Enfield	45 min
4	Liaison and ACMF	Generations FHC	45 min
5	Owner and ACMF	Generations FHC	60 min
6	Liaison	CHS Inc.	60 min
7	Liaison	None**	--
8	ACMF*	UCONN Clinic	30 min
9	Liaison and ACMF	UCONN Clinic	25 min
10	Liaison and ACMF	Boston Medical C.	2.5 hours
11	Owner and ACMF	CHC Franklin	1.5 hours

12	Liaison and ACMF	CHC Franklin	45 min
13	Liaison and ACMF	CHC Franklin	45 min
14	Liaison and ACMF	CHC Franklin	45 min
15	Liaison and ACMF	CHC Franklin	1.5 hours

*Use of owner car.
**This ACMF had not chosen a clinic for this season.

Theme 6: Cost Is Based On Availability Of Employer Sponsored Insurance

The cost of the medication is oft**,** dependent on the willingness of the owner to purchase health insurance. The decision of the owner to purchase insurance for the ACMFs is no longer protected or mandated (Gunsalus, 2013). Owners can now choose to opt-out of purchasing health insurance which rests the burden entirely on the ACMF. Once a migrant worker lands in the US, they have 60 days to learn about insurance and purchase the correct one for their needs. One prevalent issue that farmworkers face is the lack of state residency that prevents access to state-based programs like Medicare (Guilds, Richards, & Ruiz, 2016). Many farmworkers have the desire to purchase the drug especially if they "need" it; one farmworker stated: "If your body needs the drugs you have to buy it. You take the drugs you stay alive. That's it. So, I don't see it as being expensive." While another stated that:

> I used to before they take me over to Hartford it used to be like $300 for medication for three months' supply, but now that we go to Hartford (liaison travels to farms between 5-6-hour drive one way to transport ACMFs) I don't pay that much. At the pharmacy in Jamaica, the pills I get up here for my Diabetes is not there because it's so expensive up here so in Jamaica they can afford to carry

it (stock) in the pharmacy, but when I'm up here, I don't have a choice but to buy them. Even though it's a high price.

The prescribed medications used when the ACMF is in the U.S. working can sometimes vary and may not be the same dosage or trade name as the ones available in the Caribbean.

The cost of the medication for the ACMFs falls on the owner and the Liaison. One ACMF when asked if he had trouble affording his medication stated that "no not when the boss buys it", when asked what happens when the boss doesn't, he stated "well I wait until he does". Another ACMF when asked about if he has problems getting his medication due to cost stated that "Not really the owner helps us and the liaisons bring it to us sometimes, when asked why sometimes he stated "well they have to go to other farms first sometimes".

Cues to Action regarding the management of T2DM

Theme 7: More Time With Doctor Helps Build Trust And Motivation

Cues to Action refer to perceived readiness to make a recommended behavior change. In this sample, cues to Action were linked to trust and cultural competency in response to interview questions 7 through 10 and 25 to 26. The literature review coupled with the HBM showed the importance of these two factors in chronic disease management in similar populations. Trust, as well as cultural factors, are important in adherence for the ACMFs. They equate their trust level with the amount of time the doctor spends with

them, how nice the doctor is, and what transpires in the encounters. One participant rated his doctor based on the fact that she sat with him; he stated:

> I trust her a 10 because she sits down with me and talk with me. She explain and tell me. What she told me is that she said Mr. **** when you come back here, I want your Sugar to go down on a normal basis and your pressure, any time you leave here she want my body to come back to a normal.

For this participant, however, he was unsure what the "normal" his doctor referred to was. Another factor that helps with how much the participant trusts the doctor is how accessible the doctor is to them. A participant stated that:

> if I'm here right now and I call my doctor right now to talk to him he [will] call me right back to talk to me. This is my doctor in Jamaica, my doctor in America I saw him, and I am able to call and talk to him as well on the phone, and he tells me if everything is fine. This doctor here I was able to call him and talk to him about anything because he said any question I have I should call him.

The most important to all the participants was being able to talk to the doctor in any form whether, it was on the phone, or having extra time on their visit. One participant rated their doctor a 7 on the scale, stating that: "I think he wants me to be healthy so that I can work and provide for my family. Maybe if I was getting better faster, I could give them a higher number." For this participant, he felt that the medicine was not working as fast, when questioned further about the expectations his doctor may have provided, he said there were none and that he thought "it would be over by now". The concern trusting

the doctor depended on how much the doctor shared, how "nice" the doctor was to them, and how much time the doctor spends with them. One participant had this to say about his doctor: "I think I really trust her because she's very nice to me and she's from Haiti. And to me she really good to me she talks to me. I respect her, and I trust her." Another participant who scored his doctor an 8 attributed the score to the fact that his doctor went to school, and he should trust him he stated that "I would say an 8 because it's like they study for it and I don't, so you going off what they give you and what they tell you." When asked how the doctor could improve, he stated that: "Well if the doctor continues to show me everything and explains everything that's happening then I can score him higher because there's no other doctor that telling me about white blood cells and heart disease and everything."

Theme 8: My Results Speak For Themselves

When asked if they believed the doctor trusted them many thought the results would be indicative of what they did at home, and that the doctor would see that and know to trust them. One participant said: "one way they trust you is because when you go back to them, you are improved. So, if you don't improve most likely they won't trust you, and they wonder are you really taking the medication." Another participant who was unsure if his doctor trusted him assumed they probably did not because of the frequency of his prescription, he stated that: "Well I'm not sure about that because they are always asking me if I take the medication and sometimes only give me a month worth of medication so that I have to come back every month so they can check, so I'm not sure." Many

participants were either indifferent to this question or thought that the doctor didn't need to trust them because the results would speak for themselves. If the results of the follow-up exams were not enough for the doctor to trust them, one ACMF stated that "The doctor told me if I don't take the medication I'm going to die. I have to take it." Fear seems to be a common cue, whether it is initiated by the doctor or by what the participant has seen in others suffering from the disease one ACMF stated:

> Diabetes can [take] your eyesight, so you can lose your [eyes] if you get a cut you can lose your foot and it can give you heart disease and can give you also liver disease those things, she [the doctor] said can happen. So, because she says those things, I want to take the medication.

Most responses about cues were either fueled by fear or a need to provide for their families; however, the most common response about cues is whether they identified with the doctor and how much the doctor understands their background:

> I think the doctor understands because he encounters other Jamaicans on the farm yes because I told him that sometimes I'm there I can drink some juice, and he was telling me [what] I can eat, and he was just explaining to me not to eat the cookies.

The idea that the doctor understands what they are going through (being Jamaican and living while working on a farm) was determined by asking about what the doctor understands about their background. Some believed that the doctor understood their background, but the ACMFs who believed this had doctors of similar backgrounds (color,

Caribbean background). While many believed that since the doctor knew the background of the disease, it would be fine. One participant whose sentiment appeared in other interviews believed that it was harder to explain in English what they felt when the visited the doctor, he stated that:

> because sometimes they have to take the time to listen to what we are [saying] because the speed they don't really understand sometimes you have to break it down and let them know, so it takes more time to explain the same problems here than it does in Jamaica.

Self-efficacy of ACMFs adhering to medication or lifestyle changes for T2DM

Theme 9: The Doctor Will Help Me

This theme is related directly to the HBM construct of self-efficacy and emerged while assessing whether the ACMFs believed they could improve their Sugar and if they had the tools to do this. Many ACMFs are aware of the changes needed this diagnosis; one participant said: "You have to cut off...starchy food. No drinking alcohol, I don't drink alcohol and don't smoke." Many participants said that not smoking and doing drugs would help their T2DM. When questioned further, however, it seemed they were referring to improving overall health and not the disease specifically. Many felt that having the medication and the doctor's help would help them better manage their Diabetes even stating that: "I don't think I have the tools to do it myself because I have to go to the doctor and hear what it is and find out what it is." Many of the responses counted the doctor as a tool and medication from the doctor as another tool. The

participants did not consider themselves or their knowledge of the disease to be a tool and many did not think improvement was possible without the doctor and his instruction as is the case with this participant who said: “It’s not on my own, but it’s the doctor instruction, and the doctor tells me to keep away from ice cream and drinking soda. My doctor is my best tool.”

Literacy

Theme 10. Sugar Is Not As Serious As Diabetes

The interview questions 18-20 on severity perception bred many different mindsets and many were linked to the ACMF’s knowledge of T2DM in questions 4-6 (understanding T2DM). Many farmworkers used the term “sugar” to refer to the disease; they tended to understand what Diabetes was but overall preferred to use the colloquial term. One ACMF after stating he did not know “Sugar” or “Diabetes” later stated: “when you have sugar its diabetes,” he then later stated that his “immune system not functioning the right way.” When questioned further about what the right way is, he linked his immune system with his digestion problems stating: “like when you eat some food and the food doesn’t digest properly, I think that’s my thing too I don’t really does digest my food properly. I didn’t really go through it [Diabetes] to really know what it is.” Other participants exhibited beliefs that tended to think that Sugar was not as bad as Diabetes. Many ACMFs, when asked if they knew that Sugar and Diabetes were the same, was acutely aware while others felt that Sugar was not the correct name for the disease but did not know the “real” name. One ACMF stated that “Yea it’s the same thing I just tell you.

But this one [Diabetes] is more advanced", believing that Sugar was not as bad because it was not yet Diabetes.

Where one participant understood that the disease might mean that some things about lifestyle would inevitably change: "well when you have sugar things you used to do you're not able to do it anymore you can't work long hours like you used to", another father believed that it is not that serious: "Doctor say it's not a serious sugar, it's just following the vein. It will up, and next, it's down, it's not stable going and coming. It's not that bad." In questioning the participant further he was unsure of what his numbers should be or what they meant, when asked what he thought his doctor wanted him to gain from the plan: "he wants the sugar to come down on a level that everything is flowing all right", when asked what the level the doctor explained the Sugar should be it he did not know.

One participant who was on oral medication once a day also believed that his diagnosis was not that serious and used a term that is now used to describe pre-diabetes (Wojtowycz, 2019), he stated that: "While I don't think it's that serious, but I think it's just a touch of sugar." He went on to say, "I'm not in the hospital all the time and getting sick and falling down like some people have the sugar, so I don't think mine is bad and that it has to do anything else."

One widespread feeling from participants was that if the "Sugar" did not stop them from working, they did not feel it was severe enough. One participant stated that his T2DM was: "not very serious because I don't faint like some people, and I can still

work." Many of the participants thought that they could develop other diseases because of T2DM but wasn't sure of what they could be. One participant who at the time of the interview did not have any other chronic disease said: "I don't have any. I think it can cause others. I don't know the other health problems [that] develop because of it." One participant knew that his T2DM might be causing the other problems in reference to that he said: "I think the sugar will push the blood pressure up," he said that after being diagnosed with T2DM his "blood pressure was so high, so they sent me to the hospital."

Having control over their disease came in many forms Some ACMFs believed no more symptoms would exist as your sugar levels rise and fall, as one ACMF stated: "you won't feel any symptoms of when the sugar goes up or goes down." Another participant felt that: "it means I'm not in the hospital and falling down like people who are living with bad sugar." Overall many believed that sugar control meant a longer life with fewer symptoms: "it means you live longer, and that is very important to take care of it."

Summary

Members of the ACMF population living in the Connecticut River Valley suffering from type II diabetes were shown to be practicing a variety of health behaviors that have not been studied within the population. The exploration of the factors that affect their ability to be adherent to their diabetes management recommendations provided new information. The participants provided data that shed light on relevant background information on their lives and their struggles with healthcare. While the study focused on

Diabetes, much can be inferred about other chronic diseases and medical care access for the ACMFs. This study provided information on the themes that were projected to emerge in the literature review and the application HBM. There was an assumption that these themes may be present, but the underlying reasons for them were not as expected. The themes that support was provided for were perceived susceptibility to disease, the severity of the disease perceived benefits of adhering to the disease management recommendations, the barriers to adhering to medication lifestyle changes, cues to Action regarding the management of T2DM, and self-efficacy of ACMFs adhering to recommendations. The thirteen themes that emerged from the study were;

1. If You Eat Bad, You Get Diabetes
2. I Would Have Gotten Diabetes Anyway
3. Diabetes Turn Your Body To Rock (Slows You Down)
4. The Medications Are Bad, And Don't Always Work, Sometimes I Use My Own
5. Lack Of Transportation Often Delays Care
6. Cost Is Based On Availability Of Employer Sponsored Insurance
7. More time with doctor helps build trust and motivation
8. My Results Speak For Themselves
9. The Doctor Will Help Me
10. Sugar Is Not As Serious As Diabetes

The participants discussed their concern about cost and travel, but often it was alleviated by the presence of the liaison. The travel to the hospitals and pharmacies for example, for the farmworker it seems as easy as stepping outside their door and having the liaison take them and bring them back. The entire ordeal for the ACMF can take less than an hour while the trip takes up to 8 hours for the liaison. The cost can be alleviated by programs available from various health centers who opt to help, but distance and residency requirements impede most of these programs.

The farmworkers are motivated to be healthy to provide for their families rather than to improve their health. All participants believe the disease is incurable and place no restorative benefit on adherence except that it helps them to work. In the same vein, the participants used a line of remedies that were not shared with their healthcare provider whether it was because he did not or because they would instead not let the provider know they were taking them along with the prescribed medication. A new term “turn Rock” was a common sentiment present with many of the participants believe that the disease would eventually slow their blood and body down to the point of them not being able to like the wrong.

A discussion of the themes and their relation are in chapter 5, along with the findings, limitations, recommendations for future study, and implications for social change.

Chapter 5: Discussion, Recommendations, and Conclusions

Introduction

The following themes emerged from my semi-structured interviews: (a) If You Eat "Bad" You Get Diabetes (b) I Would Have Gotten Diabetes Anyway, (c) Diabetes Turns Your Body To ROCK, (d) 4. The Medications Are Bad, And Don't Always Work, Sometimes I Use My Own, (e) Lack Of Transportation Often Delays Care, (f) Cost Is Based On Availability Of Employer Sponsored Insurance (g) More Time With Doctor Helps Build Trust And Motivation, (h) My Results Speak For Themselves, (i) The Doctor Will Help Me, (j) Sugar Is Not As Serious As Diabetes.

With the introduction of this information, it is an expectation that the information gather from this population helps to foster productive experiences with health care providers. These providers can use this information to become better informed about the health care practices of this population. For this population, these factors surrounding literacy, access, and cost the main focus of this study.

This study was a qualitative study with the use of phenomenology. I used phenomenology, along with semistructured interviews, to allow me to look at individual phenomena as was described in Rahman (2017). The purpose of the study was to understand the lived experiences of ACMF's perception of the factors that affect their ability to be adherent to T2DM treatment recommendations.

A total of 15 ACMFs participated in the study. These individuals lived and worked along the CRV in Connecticut, Massachusetts, and New Hampshire. Using the

responses from the ACMFs I determined that there were many challenges faced by these individuals in their time working as migrant workers in the U.S. Every participant participated in some form of a health insurance program, whether it was employer-sponsored, individually sponsored, or program (Jamaican Government) sponsored.

Key Findings

Many participants talked about being slowed down by the disease or losing essential functions like energy, sexual function, and loss of limbs. Some individuals have died in the program due to complications from T2DM. Many participants felt that the disease "Sugar" was less severe than T2DM. Many ACMFs found solace in the fact that their provider spent more time with them. The more time spent with each participant, the greater their trust in the provider. Sticking to their treatment recommendations often conflicted with their work schedule; for example, some participants found it hard to adhere to their medication schedule because of early morning work and inability to always take their medication with meals. Adherence to diet recommendations was also dictated by the work environment, plus an inability to get "healthy food" despite living on a farm.

All participants used home remedies but did not share them with providers without being prompted. Home remedies were mostly based on bitter drinks and seemed to seek to increase fluid intake. Many ACMFs attributed much of their continued health to the combined use of both western and home remedies. Four different participants gave information on the home remedies that they used. Cinnamon was present in all four, each

saying that they boiled it and drank it as a regular treatment for the T2DM. These participants believed that much of the problems they had with the disease was because their blood had too much sugar, and therefore it slowed them down or "turned rock on them."

One participant had great faith in the presence of his family and their support in helping him deal with his disease. While no others mentioned family helping them with their disease, they did talk about the concern that their disease would stop them from providing for their families. Their families were often the motivating factor to work through pain and disease to provide. One participant was accepting of his fate, adding that he would be happy just being able to provide for his family. Participants either had faith in themselves, their providers in the US, home remedies from family members, or their providers in their home country.

Young and old participants had concerns about the side effects of the drugs, preventing them from working by making them dizzy or fainting. Many participants took the medication to avoid the inevitable, which many received information telling them they would die if they did not take their medication. Interestingly many participants admit they knew this could be a consequence, but this still was not a central motivating factor to adhere to their medication regimen, especially if it was not convenient to their schedules.

Interpretations of Findings

The findings in the study are interpreted based on the themes listed in chapter 4 as well as the HBM, the main theoretical framework used in this study. The limitations, implications, and conclusions of this study are also presented.

Sample Population

The farms in the CRV are important to crop supply and an essential way of life for migrant farmworkers. The sample obtained for this study was from ACMFs working on 11 different farms in four different states. The only afro Caribbean's that participated were Jamaicans because they were the most prominent group in this area. Many participants had a family predisposition to T2DM, but the most common risk factor was due to dietary regimen. Afro-Caribbeans are two to four times more likely to have or develop Diabetes than those of European ancestry (Ojo, 2013). Currently, there is not much attention placed on the Afro-Caribbean population, much less the ACMF population. The participants in the study all had a primary diagnosis of T2DM, one participant had concurrent hypertension, but none had heart disease or obesity. For African Americans, obesity particularly fat around the abdomen, is one the most common risk factors for developing T2DM (NIH, 2019). Some participants had trouble accessing medications due to cost and distance, but the presence of the Liaison alleviated the majority of these concerns. This individual is an intricate part of the ACMF's life and their ability to navigate the U.S. healthcare system.

Perceived Susceptibility

If You Eat "Bad," You Get Diabetes (Theme 1)

The realization that diet is an integral part of not developing T2DM was known to the participants. However, how the diet might contribute to T2DM development was not well understood. As mentioned, the participants did not have any obesity diagnosis or problems with weight gain. They did, however, have bad eating habits that ranged from skipping meals to only eating carbohydrates and "strong food." Many believe that their diet needs to contain "strong food" (usually high in starch and protein), vegetables are not enough to maintain strength for a hard day's work. Again, the ACMF's diet and, ultimately, their ability to remain adherent to their treatment regimen is dependent on their work schedules and what they think is necessary to continue working. Lee, Willig, Agne, Locher, and Cherrington, (2016) found that while non-Hispanic blacks were well aware of the need for dietary management in T2DM, they were unable to comply due to "various internal and external challenges." Many ACMFs cited their work schedules as being the reason they could not take their medication at the specified time because it required them to eat with the medication but did not always have time to prepare breakfast before leaving for work (work often begins at 4-5:30 am). Many ACMFs also believed that they received enough exercise from their work in the fields. It was a common thought that the "hard work" in the fields were more than enough daily exercise. Many ACMFs spent their workday bending over in the sun or kneeling while planting. Days start very early and end very late.

Many participants believed that the consumption of sweets would lead to Sugar they also believed that the consumption of sweets while being diagnosed with T2DM is not acceptable (two myths that have been addressed by the ADA: Singh et. al., 2017). These participants also used a common home remedy of drinking bitter juices or teas and thought that it would alleviate or treat the symptoms of T2DM (another myth addressed by the ADA (Singh et. al., 2017). One participant believed that eating sweet drinks and cakes as a child caused him to develop T2DM later in life. He is among the participants who also believed that bitter drinks were an excellent home remedy to either cure or prevented Sugar. There was a consensus that eating sugar or sugary things caused "Sugar." One participant expressed concern that many of his colleagues did not know that they were not supposed to eat banana and mangoes because they were too sweet for their disease to handle. Alperet, Butler, Koh, Yuan, & Van Dam (2017) found a correlation between consumption of whole tropical fruit and the risk of T2DM. The participant, however, was very clear that green bananas were good for his Sugar and that he made it a practice to eat as much as he could. When asked where he learned this information, he stated that his "old people just know, and they told him."

The diet of the ACMFs often consists of a large percentage of carbohydrates added to the equivalent percentage of protein. Studies have shown that the traditional Jamaican diet consists of higher than usually recommended for carbohydrates and sodium (Oladele et. al., 2019). The diets looked at in this study were very comparable to the ACMFs' diets. It consists mostly of rice and protein. A large percentage of the ACMFs

cook their food only a small percentage are on farms where prepared food is available at a canteen.

I Would Have Gotten Diabetes Anyway (Theme 2)

The ACMFs are very aware of the need for them to be well-rested to be able to perform their duties, but not many knew that lack of rest could adversely affect their health, especially their T2DM. Many ACMFs reported not having a full 8 hours of sleep, especially during the growing season. Workdays can start from 12 a.m. in the night and can end at 6 p.m. the same day. None of the ACMFs reported being able to take long enough breaks to possibly take a nap during the day, and all reported being too tired sometimes to cook either in the evening or the morning. While many ACMFs have access to kitchens, they do not have time to use them. The ACMF who was told by his doctor that his lack of sleep one season was one of the mitigating factors that caused him to develop T2DM was very conscious of this fact but still found it hard to be able to get enough sleep. Chattu, Chattu, Burman, Spence, & Pandi-Perumal (2019) found that a lack of rest was found to be related to T2DM. The direct correlation between rest and T2DM did not appear in the literature review and was not a part of this study, only its effect on adherence. The ACMFs often equated hard work with less rest, success, and the ability to take care of their families in their home country.

The idea that T2DM is an inevitable part of growing older or being a part of a family was very prevalent in the beliefs of these ACMFs. Some believed the disease would happen to them because of family history, while others thought their diets would

be the cause. The idea that stress and lack of sleep might be a factor was brought up by an ACMF mainly because his doctor told him that this was the reason for his T2DM. All of the ACMFs report having less than normal amounts of sleep during their time on the farm, especially during planting season. The ACMFs believed that T2DM development had to do with their families' eating habits instead of their genetic makeup.

Wang, Liu, Ren, Lv, and Li, (2015) found that family had a significant influence on a child's participation in physical activity. These ACMFs rely heavily on family trends and tend to replicate these trends in their own families. One ACMF was in the program with his son, and both of them had T2DM. They had the same eating habits (the dad often cooked for the son), sleeping habits, and of course type and amount of physical activity. Unfortunately, these two did not see a correlation between their diet and their diagnosis. They also did not accept the diagnosis of T2DM but instead opted to treat the diagnosis as "Sugar." They often chose to send money back home rather than pay for their medicine. They were not able to participate in any insurance programs and had to purchase their insurance as well as medication. The pair, unfortunately, could not manage their T2DM well enough to stay in the program. Termination of their contracts occurred before the end of the season.

Perceived Severity

Diabetes Turns Your Body To ROCK (Theme 3)

This word was continuously mentioned with the participants all explaining that it was a term they used to explain that they felt slower with the disease. The term is not

present in the literature. Many bodily functions are slowed down in T2DM. For example, wound healing becomes slower for patients with T2DM (Xie et. al., 2019); other functions continue to slow down or become impaired. The general thought is that the body slows down and leads eventually to death. The ACMFs are well aware of the dire consequence of their disease, but like developing the disease, many feel there is no changing the outcome. The ROCK that many speak of is a cultural definition of the increase in impairment of fasting blood glucose levels seen in T2DM (Bombelli, 2018).

The idea that they can and are slowed down by the disease is of great concern to the ACMFs because this impairs their ability to work and eventually their ability to provide for their families. The most important thing to the ACMFs is not their health, but their families their health becomes a secondary concern. While the slowing down of their body concerns them, it is only to the extent that it might affect their family.

Perceived Benefits of Medication Adherence

The Medications Are Bad, And Don't Always Work, Sometimes I Use My Own (Theme 4)

Cultural practices being used and sometimes preferred in treating many chronic diseases for Caribbean's is ubiquitous. Some of the treatments mentioned by the ACMFs are Sinkle bible (Aloe Vera), Bitters, (a bitter drink often filled with various spices), Cinnamon (steeped in water), and various fruit juices (mainly cucumber, no mango because of its tendency to be sweet). ACMFs mentioned that they were taking these medicines alongside the prescribed ones but often did not inform their health care

professional. One ACMF, when further questioned why he did not share this information responding by saying no one asked. The herbal remedies are shared with practitioners back on the island, and these practitioners sometimes ask them directly if they are taking a particular herbal medicine. In a study conducted to determine myths and beliefs about Diabetes, a reported 21% of the participants used non-western medicine in an attempt to treat their Diabetes (Salazar et. al., 2017).

An ACMF who had just gotten started on a new medication for his T2DM talked about how the drug made his vision fuzzy so sometimes he didn't take it. When asked if he shared this with his doctor, he mentioned that they said it would wear off if he continues to take the medication as prescribed. The ACMFs seemed to self-adjust when it comes to their medications electing to not share problems with cost or side effects. ACMFs often face a choice of taking care of their family or sending their children to school.

Perceived Barriers to adherence

Lack Of Transportation Often Delays Care (Theme 5)

The Jamaican government provides a liaison for the farmworkers to better facilitate their travel to the farm from Jamaica and their continued participation in the farmworker program (Jamaican Liaison Service, 2019). The service is mainly a way to put migrant workers in contact with farms that might be hiring for the season. The Liaison, however, seems more involved than was expected given the description of the position. For these ACMFs, the Liaison acts as a medical chauffeur. They travel from

farm to farm either bringing medication or bringing ACMFs to doctor's appointments and or hospitals. Many of the ACMFs live on farms where the owner would bring them to these appointments based on their availability, but more often than not ACMFs must wait for the Liaison or the weekly group that is organized by the owner of the farm. Farms are in rural areas where the nearest hospital can be up to a 2-6-hour drive. McLaughlin & Tew (2018) found that lack of transportation along with work hours that ended after clinic hours was a common barrier faced by migrant farm works. A clinic visit can take the entire day due to transportation, and often ACMFs opt-out of visiting the clinic for fear of disrupting the job by having not being able to work for the entire day. This concern is supported by Pysklywec, McLaughlin, Tew, Haines (2011) who found that farmworkers avoided taking time off of work for health concerns for fear of losing their jobs. The ACMFs are plagued by transportation issues affecting their adherence. Some ACMFs can use owner's vehicle but run the risk of being persecuted by local authorities when stopped with no way to prove their connection to the vehicles. Many ACMFs opt out of doctor visits because of the time it takes to travel as well as the time they have to wait for the liaison to get to their farm. This was one of the greatest factors affecting adherence making it sometimes impossible for ACMFs to get access to their medications. While the ACMFs tended to dismiss their lack of access to the clinic it was clear that they could not get to the clinic without significant intervention from the Liaison or the owner. None of the ACMFs were located near clinics that were in walking distance or on local bus routes. They tended to be very sure that someone would take them to their

appointments eventually. McLaughlin & Tew (2018) cited distance as a barrier to accessing healthcare based on farmworker work schedule, their fear of disappointing an employer, and loss of wages. Fox et al. (2018) also found that T2DM patients who had to travel 2 or more hours to access a clinic had higher HBA1c levels and reported lower satisfaction than others traveling less time to clinics.

Cost Is Based On Availability Of Employer Sponsored Insurance (Theme 6)

Cost as a factor of adherence for the ACMFs was solely dependent on outside forces (liaisons, owners). The ACMFs did not see the issue surrounding this factor because of their willingness to be patient until it was their turn. Many ACMFs waited until it was time for them to get their medication, they considered this the norm so therefore did not think it was a negative factor. In fact, many ACMFs are delayed in getting their medication due to cost because of issues surrounding their residency, insurance status, and transportation (Chavez, Kellerher, Matson, Wickizer, 2017). Many are not privy to the issues regarding their medication procurement but are somewhat aware of the cost to the owners which manifests in their unwillingness to miss work due to illness, which leads them to hide their illnesses (McLaughlin & Tew, 2018). In this study a father and son was removed from the program because of their unwillingness to admit their diagnosis which cause a lot of instances where they not only missed work but caused a strain on their ability to care (2 visits for dad due to fainting spells) for themselves while in the program.

The cost of T2DM on a global scale is estimated to be 675 billion dollars (Ogurtsova, 2018). While this factor is apparent from the responses of ACMFs and acceptable norms of medication procurement, the ACMF still does not see this as a problem. It seems that the ACMF has gotten used to getting their medication based on other's schedules and capabilities.

Cues to action

More Time With Doctor Helps Build Trust And Motivation (Theme 7)

Many of the participants (14 of the 15) rated the doctors very high (9 and above on a scale of 1-10) on the trust level with only 1 rating the doctor lower (7 and below) than the others because he felt that he would rate higher if he would get better faster. The ratings for the other 14 participants was based solely on time spent with the doctor. Other factors during the time spent depended on the information relayed during the time spent. The time spent with the patient was significant, but many participants could not relay the relevant information from their visits. Wong, Showel, Bleich, Gudzune & Chan (2017) found that Black patients were more likely to report that doctors did not spend enough time with them and also cited that spending more time with patients allowed for more information relay especially regarding lifestyle and medication counseling. Farmworkers are often unable to visit health care professionals as often as they should and when they do visit the health care professional often treats the visit as the first and the last. Many ACMFs receive larger amounts of medication than usual with the assumption that they might not be able to make their regular scheduled visits.

While many participants agreed that their doctors explained that they should have their sugar at a healthy level many when questioned admitted that they did not know what normal meant. One ACMF said that he understood that his sugar should not be going up and down, but he did know what the cause of the fluctuation or what the average level of his sugar should be. When questioned further about HBA1c, none of the ACMFs were aware of this lab or the normal number.

My Results Speak For Themselves (Theme 8)

Many of the farmworkers do not have a way to determine if their doctors trust them to be adherent to their medication. One ACMF was given only a month supply wondered why he wasn't given 3 months like others he knew, saying only that the doctor wanted to see him more. Instead, they believe that if they continue to feel good or do good or not have any episodes related to Diabetes that is an indication of their doctors trusting them. They do not seem to be concerned about the possibility that the doctors might not trust them once they leave the office. Many feel that they are delivering the required lab results but are not sure what the lab results mean. They tend to not ask questions about what the lab results mean because of the trust they have in the doctor.

Self Efficacy

The Doctor Will Help Me (Theme 9)

ACMFs in the study focused on what the doctor would do to help them to manage or treat their disease. The consensus was that since the doctor went to school, he knows better and can help them in all aspects of treating and managing the disease. This belief is

contrary to the body of literature. Current literature supports the idea the many patients trust people closer to them who have experienced the same illnesses, many use books and electronic materials to decide whether to adhere to the recommendations of the provider, and others tend to not trust the information based on past instances where there was a provider error (Low, Tong, & Low, 2016).

Literacy

Sugar Is Not As Serious As Diabetes (Theme 10)

Many ACMFs believed that Sugar was not as bad as Diabetes; it was as if they thought that the name Diabetes held a more severe meaning. Schorling and Saunders (2000) found that individuals who admitted to having sugar declined having diabetes early on in the study illuminating a culturally biased perception of the disease (Ledford, Seehusen, & Crawford, 2019). The participants of that study used two terms “Sugar” and “Sugar-Diabetes”. Some ACMFs were utterly unaware of the relation between the two, while others understood that it was just another name used in their culture. Many ACMFs, however, did not know the actual name of the disease, and one ACMF did not realize he was experiencing Diabetes. Unfortunately, many ACMFs treated their “Sugar” as if it was just a mild form with some ACMFs on large doses of Metformin but still believing they only had “Sugar” so there was not much to be concerned about.

Many ACMFs described friends that had Diabetes and how they would faint all the time and that they were not so bad because they only had Sugar. Many felt that they were experiencing the lesser form of the disease. Many ACMFs classified their T2DM as

a touch of sugar a common way to refer to prediabetes in the Caribbean (Mitchell, Allan, Koch, 2017). Many ACMFs weighed the severity of their disease based on how it impaired them if they were not showing outward signs (recognizable by them), they felt less concerned about the implications of being diagnosed with this disease.

For some of the ACMFs that were on oral medication and had episodes, they focused mainly on taking the medication to stop these episodes. This study did not ask specifically about complications due to Diabetes, but when asked about having other chronic disease and if they thought it was related to their Diabetes many ACMFs did not think this was the case. Many of the participants had separate issues like foot pain, prolonged wound healing, and increased susceptibility (many of the ACMFs reported always being sick especially when they have to come during the winter months to prepare for the growing season) during flu season. Studies have shown that individuals who are affected by T2DM tend to be more susceptible to complications related to the flu virus and should take precautions, including being vaccinated (Goeijenbier, 2017). Vaccinations were not the focus of the visits with health care professionals, but when asked about being vaccinated, ACMFs recalled being offered the flu shot in Jamaica but declining not seeing the need especially since they do not live in the US.

Limitations of the Study

This phenomenology study was a great way to understand the thoughts behind the actions of the ACMF as well bring to light their struggles. The limitations of this study

stemmed from the schedules of the ACMFs the background of the ACMFs. The study intended to select ACMFs, but only one Caribbean country participated. The sample did not include female farmworkers. There was a limiting factor based on ACMFs' fear of reprimand for saying anything too negative about the program and how the work affected their lives.

This study only used interviews and no pilot study; this is another limitation. It could have been possible to observe participants and to record work situations, but this was not a part of the IRB permissions, and there was a concern that this type of information gathering would deter many ACMFs and farms from participating.

Another limitation could be from my background (Jamaican immigrant living in Connecticut). It is possible that upon finding out, my background participants were more inclined to provide information that would be more pleasing and or less likely to get them in trouble with the Jamaican government (loss of ability to participate due to health status).

Recommendations

The research results show that adherence is affected by access to transportation, work schedule, literacy, use of home remedies, and family ties. Further study is needed to determine common practices by this population relative to other common chronic diseases. Further study should use ethonographical studies that focuses on ascertaing the experiences of the ACMF living with T2DM and how their daily lives affect how they function with the disease. The information gathered from these participants is a first look

at this population not only relating to this disease but relating to their work on American farms. In this study I wanted to highlight the importance of the ACMFs and the contributions they make to American society and why their health is also American health. Further study should focus on how to make healthcare more accessible based on the amount of time spent in the US, how to reduce stigma/punishment related to reporting illness while working, and how to provide more health outreach programs.

The participants were a good representative sample of the ages of ACMFs who generally work on these farms. The study illuminated the need for increased health literacy as it relates to T2DM. While many participants had some information about their disease, many did not fully grasp what readings or numbers about their disease meant. While the participants admitted that they knew at least one person with the disease they did not seem to be aware of the high prevalence of T2DM not only in the farmworker population but also in the Caribbean population as a whole. Many of the ACMFs, although noting obvious problems with prescription drug procurement, medication adherence, procuring healthy foods, following healthy eating regimens, and practicing health sleeping habits, did not grasp the impact this had on their health and was more concerned with their ability to provide for their families.

It is very important to note the presence of the Liaison in this study. There were no questions focused on this individual because it was not clear at the start of this study how entwined this individual is in the ACMFs' lives. The Liaison acts as a medical chauffeur, an advisor, and sometimes a conduit to legal support. The presence of this

individual is an excellent resource for health care professionals who want to reach this population through education and health care outreach programs.

Implications

The ACMF population, is an unknown population. Before this study, the majority of studies or practices close to this population did not focus on this population. In the Hispanic migrant farmworker population, T2DM is of higher incidence (Hu, Amirehsani, Wallace, & Letvak, 2014), but these individuals sought family support (Reyes, Tripp-Reimer, Parker, Muller, & Laroche, (2017), and was able to cope better with lifestyle changes and adhere to treatment regimens (Baig, Benitez, Quinn, & Burnett, 2015). The prevalence of T2DM in the Afro-Caribbean is on the rise, surpassing projected increases by more than 3% (Bennet et. al., 2015). There have not been any previous studies to ascertain what the expected outcome of this population is, nor any studies illuminating the difficulties faced by this population as it relates to Diabetes adherence. This study not only looked at these difficulties based on other populations but also difficulties that are only present in this population.

The need for liaisons and how they function to help this population in daily life and how their presence can be further used to improve the quality of life of this population and aid health care professionals was a significant find in this study. Liaisons are a needed collaboration entity that can benefit the ACMFs, their employers, and health care professionals charged with caring for this population. With distance being one of the

most pressing factors that effects the ACMFs adherence, having the liaison to chauffeur the individuals is a much-needed commodity.

Social Change Implications

This study has provided information that is not available regarding ACMF populations. The ACMF population is one that is underrepresented in social science studies, with no information regarding their care available. Issues like distance to care, work schedule, home remedies, family, job security, and farm life should be a consideration when approaching this population.

The study is an attempt to find ways to improve the quality of life of the ACMF by helping them and their healthcare provider manage their health care. The farmworkers rely heavily on their liaison for social, physical, and medical support. Liaisons often cover a very large area of participating farms. This liaison that was the contact person for this study oversaw farms in Connecticut, New Hampshire, Rhode Island, Massachusetts, and Vermont. This individual is a great resource for individuals wanting to reach this population and directing any health initiatives within this population.

This study was a first look at the lives of ACMFs living and working on farms in the CRV and how that affects their adherence to T2DM management. The results of this study support the need for culturally competent caregivers, increased education as it relates to the disease and caring for the disease, and caregivers with specific knowledge about the life and schedule of these ACMFs. The data collected illuminated the fact that many ACMF do not understand their disease, nor do they understand the severity. With

services available to other vulnerable populations like nutrition education, health fairs, and improved general knowledge of the disease, initiative must be taken to make these services available to the ACMF population.

The most important tool that is lacking in the management of this disease for this population is adequate time management/lack of time and transportation. The literature on farmworkers focuses mainly on Hispanics with little to information about ACMFs. This study illuminated factors like time management, use of home remedies, the misconception on treatment, transportation, family influence on thoughts about disease, and the tendency to accept a final fate. It is vital for public health to acknowledge ACMFs as a vulnerable population in need of studies, programs, and initiatives aimed at chronic disease management. The population is in dire need of T2DM management help in order to reduce their complications and loss of life due to this disease. This research should be of interest to the Jamaican government, American farm owner, and regional legislators all of which benefit from ensuring ACMF health by increasing access to health care, improving culture competency, and improving quality of life for these seasonal and marginalized workers.

Conclusion

In completing this study, the lives of ACMFs and their daily struggles with T2DM adherence can be better understood. This study illuminated areas of improvement needed for this population that can be achieved with educating patients and providers. The ACMF are essentially invisible; their needs are unmet because they are unknown. The

ACMFs face hardships that are a direct encumbrance to their adherence and therefore, their quality of life. All participants reported at least one incident of being non-adherent due to distance from care, work schedule, family beliefs, cost of medication, and lack of understanding. The results from this study are supported by previous studies that looked at barriers to obtaining care. Distance for example, one of the major factors affecting adherence for the ACMFs has been cited by Rocque et al (2019) as a significant factor in reducing adherence while Hensley et al, (2018) cites vehicle access and transportation costs as influencers of non-adherence.

The major players in the prevention of complications and decreased quality of life are nurses, nutritionists, health literacy educators, liaisons, physicians, and other health care providers. Many organizations partner with providers to develop health and wellness programs aimed at keeping the employees healthy to minimize the cost of health care; this could be an excellent first step in helping to improve the quality of life for this population.

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Appendix A: Recruitment Poster

CARIBBEAN FARM WORKERS SUFFERING FROM DIABETES -WE NEED YOU!!!

THIS IS AN EXCITING NEW STUDY ABOUT YOUR TREATMENT DECISIONS.

Participants Must:

1. Have been a part of the migrant farm worker program for more than 1 year
2. Have been diagnosed with Diabetes type 2 for more than 6 months
3. Be currently taking prescribed oral medication
4. Have been prescribed lifestyle modifications
5. Have had contact with a health care provider in the U.S.
6. Identify with the Afro-Caribbean cultures (Any one of the Caribbean islands)
7. Live on agricultural farms located in the CRV

What does participation involve? How will it benefit me?

This research study is confidential and only the researcher and her dissertation advisors will have access to the information.

Information regarding the results of this study were provided to the participants directly through a summary of the results with a link to the completed dissertation. Additionally, you may contact the researcher at [redacted] for the results of the study.

Your participation could help to shed light on Diabetes Management Among Afro-Caribbean Farm Workers.

Earn a $5 calling card upon completion!!

To schedule an interview please contact Aretha M. Townsend at [redacted]

Appendix B: CONSENT FORM

You are invited to take part in a research study about factors that affect medication adherence in Diabetes Mellitus type 2 in Afro-Caribbean Migrant Farm Workers (Afro-Caribbean Migrant Farm Worker). The researcher is inviting farm workers who live on farms in the Connecticut River Valley (CRV) and have been diagnosed with Diabetes and are prescribed methods to treat the disease to be in the study. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by Aretha M. Townsend who is a Doctoral Student in the Public Health program at Walden University

Background Information:
The purpose of this study is to gather information about medication practices in Afro-Caribbean Migrant Farm Worker suffering from T2DM.

Procedures:
If you agree to be in this study, you will be asked to:

- Complete a 10-minute questionnaire that will determine your ability to participate in the study
- Participate in a 60-minute interview with 29 interview questions

Here are some sample questions:

1. On a scale of 1 to 10 how would you rate your trust of your healthcare provider? 1 being you don't trust them at all and 10 being you trust them with full confidence
2. What does it mean to you for your diabetes to be well-controlled?
3. Can you explain what you think is happening to your body because of Diabetes?

Voluntary Nature of the Study:
This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at Walden University or the CRV farms or The Jamaica Central Labor Organization will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:
Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as fatigue and possible distress related to sensitive questions. Being in this study would not pose risk to your safety or wellbeing. Participation in the study would help to provide a better understanding of beliefs and behaviors related to the decision to use medications or treatment guides available in T2DM.

Payment:
Participating in the study is purely voluntary and there will be no monetary compensation. Participants will be offered a beverage at the start of each interview.

Privacy:
Any information you provide will be kept confidential. The data collected through audio recording and transcribing will only be made available to the researcher and university officials. Once the study is completed the information will be destroyed (transcripts shredded, and recordings. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure by folders that are password protect on a computer that is password protected. The information collected will not be shared over the Internet (i.e. storage in cloud-like programs). Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:
You may ask any questions you have now. Or if you have questions later, you may contact the researcher via personal cell phone [redacted]. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is ([redacted].

The researcher will give you a copy of this form to keep.

Obtaining Your Consent

If you feel you understand the study well enough to make a decision about it, and you wish to take part in the study, please indicate your consent by signing below.

Printed Name of Participant _____

Date of consent _____

Participant's Signature _____

Researcher's Signature _____

Appendix C: Screening Instrument

Dear Research Participant,

My name is Aretha M. Townsend and I am a full-time doctoral student at Walden University conducting research on diabetes among Afro-Caribbean farm workers in the U.S. I am a member of the Caribbean migrant population having migrated to the US from Jamaica.

For my study, I am looking for Afro-Caribbean farm workers in the CRV who

- Have been a part of the migrant farm worker program for more than 1 year
- Have been diagnosed with Diabetes type 2 for more than 6 months
- Have been prescribed oral medication and lifestyle modifications
- Have had contact with a health care provider in the U.S.
- Identify with the Afro-Caribbean cultures (any one of the Caribbean islands)

If you are interested to participate in this study, you can continue in the screening process at this time to see if you qualify. It should only take about 15 minutes.

If you qualify and are willing to participate, I will be asking you to make an appointment with me to answer a series of questions (29) over a period of about an hour. Each interview will be recorded by hand by me as well as audiotaped by me. The information will only be used in this study and will not be shared for any other purpose. The audio from this study will be destroyed once I have completed my dissertation. Your participation will help to shed light on how Afro-Caribbeans respond to diabetes treatment recommendations.

If it is determined that you are not eligible to participate, the reasons will be explained, and you will be thanked for your time and effort. Should you have any other questions, I will answer them to the best of my ability.

If you have any questions at this time or before our interview, please contact me at: [redacted] or my dissertation advisor Dr. Schwab at [redacted] Appendix D: Interview Questions

Interview Questions

A. Literacy

1. Do you know what Diabetes type 2 is? If yes, please explain what it is?
2. Diabetes is often called 'Sugar'. Do you know what 'Sugar' is?
3. Please explain what you think is happening to your body because of Sugar.
4. What is your current treatment plan for your Sugar?
5. To what extent do you follow this plan?
6. What do you think your doctor wants you to gain from your Sugar treatment plan?

B. Trust in provider relationship and related cues to action

7. On a scale of 1 to 10 how would you rate how much you trust your doctor? 1 being you don't trust them at all and 10 being you trust them fully
8. Please explain why you scored your doctor this way. How do you believe your doctor can make this number better?
9. Do you believe your doctor trusts that you take the drugs they give you? Why or why not?
10. How do you believe trusting your doctor might help you follow their advice?

C. Cultural competency and related barriers

11. How might the skin color of your doctor affect your relationship with them?
12. Would you be more likely to take your medication/pills if the doctor is from the same background? Why or why not?
13. What are the Caribbean treatments for Sugar?
14. What remedies for Sugar do you know?
15. Would you share these remedies with your doctor?

D. HBM Specific Interview questions

Perceived Susceptibility

16. What part of your daily life do you think led to you having Sugar?
17. What do you believe you could have done to stop Sugar from happening to you?

Perceived Severity

18. How serious do you think your Sugar is?
19. How much do you think your other health problems might be caused by Sugar?
20. Some people say that following the doctor's advice will take care of your diabetes or Sugar. What does it mean to you for a person to have Sugar taken care of?

Perceived Benefits

21. Is your Sugar taken care of?
22. How do you think your diabetes drugs helps or harm you?

Perceived Barriers

23. Does the cost of your drugs affect if you take it?
24. Do you have any problems getting your medication?

Cues to Action

25. Please describe anything your doctor does or says that might make you to want to take your medication/drugs.
26. Do you think the doctor understands your background? If they did would you listen to their instructions more?

Self-Efficacy

27. What do you believe you can do to improve your Sugar?
28. Do you feel you have the tools/help you need to manage your Sugar on your own?
29. Is there anything else you would like to tell me about your illness?

Appendix D: Protecting Human Research Participants

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Aretha Townsend** successfully completed the NIH Web-based training course "Protecting Human Research Participants".

Date of completion: 12/16/2012

Certification Number: 1065322

Appendix E: Validation Rubric for Expert Panel (VREP)

Survey/Interview Validation Rubric for Expert Panel - VREP©
By Marilyn K. Simon with input from Jacquelyn White

Reviewers Name: _____

Expertise in Related area (please note courses taught, professional experience, publications, or degrees in related areas):

_____

Criteria	**Operational Definitions**	**Score** **1=Not Acceptable** (major modifications needed) **2=Below Expectations** (some modifications needed) **3=Meets Expectations** (no modifications needed but could be improved with minor changes) **4=Exceeds Expectations** (no modifications needed)				**Questions** NOT meeting standard (List page and question number) and need to be revised. *Please use the comments and suggestions section to recommend revisions.*
		1	2	3	4	
Clarity	The questions are direct and specific. Only one question is asked at a time. The participants can understand what is being asked. There are no *double-barreled* questions (two questions in one).					
Wordiness	Questions are concise. There are no unnecessary words					
Negative Wording	Questions are asked using the affirmative (e.g., Instead					

	of asking, "Which methods are not used?", the researcher asks, "Which methods *are* used?")					
Overlapping Responses	No response covers more than one choice. All possibilities are considered. There are no ambiguous questions.					
Balance	The questions are unbiased and do not lead the participants to a response. The questions are asked using a neutral tone.					
Use of Jargon	The terms used are understandable by the target population. There are no clichés or hyperbole in the wording of the questions.					
Appropriateness of Responses Listed	The choices listed allow participants to respond appropriately. The responses apply to all situations or offer a way for those to respond with unique situations.					
Use of Technical Language	The use of technical language is minimal and appropriate. All acronyms are defined.					
Application to Praxis	The questions asked relate to the daily practices or expertise of the potential participants.					
Relationship to Problem	The questions are sufficient to resolve the problem in the study					

	The questions are sufficient to answer the research questions. The questions are sufficient to obtain the purpose of the study.					
Measure of Construct: **A: (**Relationship to problem note questions in survey or interview)	The survey adequately measures this construct.***[Include Operational Definition and concepts associated with construct]*** ***List the questions from the survey or interview***					
Measure of Construct: **B: (**Relationship to problem note questions in survey or interview)	The survey adequately measures this construct. ***[Include Operational Definition and concepts associated with construct]*** ***List the questions from the survey or interview***					
Measure of Construct: **C: ( )**	The survey adequately measures this construct.* ***[Include Operational Definition and concepts associated with construct]***					
Measure of Construct: **D: ( )**	The survey adequately measures this construct.* ***[Include Operational Definition and concepts associated with construct]***					

* The operational definition should include the domains and constructs that are being investigated. You need to assign meaning to a variable by specifying the activities and operations necessary to measure, categorize, or manipulate the variable For example, to measure the construct *successful aging* the following domains could be included: degree of physical disability (low number); prevalence of physical performance (high number), and degree of cognitive impairment (low number). If you were to measure creativity, this construct is generally recognized to consist of flexibility, originality, elaboration, and other concepts. Prior studies can be helpful in establishing the domains of a construct.

Comments and Suggestions
Types of Validity

VREP is designed to measure face validity, construct validity, and content validity. To establish criterion validity would require further research.

Face validity is concerned with how a measure or procedure appears. Does it seem like a reasonable way to gain the information the researchers are attempting to obtain? Does it seem well designed? Does it seem as though it will work reliably? Face validity is independent of established theories for support (Fink, 1995).

Construct validity seeks agreement between a theoretical concept and a specific measuring device or procedure. This requires operational definitions of all constructs being measured.

Content Validity is based on the extent to which a measurement reflects the specific intended domain of content (Carmines & Zeller, 1991, p.20). Experts in the field can determine if an instrument satisfies this requirement. Content validity requires the researcher to define the domains they are attempting to study. Construct and content validity should be demonstrated from a variety of perspectives.

Criterion related validity, also referred to as instrumental validity, is used to demonstrate the accuracy of a measure or procedure by comparing it with another measure or procedure which has been demonstrated to be valid. If after an extensive search of the literature, such an instrument is *not* found, then the instrument that meets the other measures of validity are used to provide criterion related validity for future instruments.

Operationalization is the process of defining a concept or construct that could have a variety of meanings to make the term measurable and distinguishable from similar concepts. Operationalizing enables the concept or construct to be expressed in terms of empirical observations. Operationalizing includes describing what is, and what is not, part of that concept or construct.

References

Carmines, E. G. & Zeller, R.A. (1991). *Reliability and validity assessment*. Newbury Park: Sage Publications.

Fink, A., ed. (1995). *How to measure survey reliability and validity v. 7*. Thousand Oaks, CA: Sage.

APPENDIX F: Permission to use VREP

PERMISSION TO USE AN EXISTING VALIDATION RUBRIC FOR EXPERT PANEL (VREP)

July 6, 2016

To: Aretha Townsend

Thank you for your request for permission to use VREP in your research study. I am willing to allow you to reproduce the instrument as outlined in your letter at no charge with the following understanding:

- You will use this survey only for your research study and will not sell or use it with any compensated management/curriculum development activities.
- You will include the copyright statement on all copies of the instrument.
- You will send your research study and one copy of reports, articles, and the like that make use of this survey data promptly to our attention.

If these are acceptable terms and conditions, please indicate so by signing one copy of this letter and returning it to me.

Best wishes with your study.

Sincerely,

Marilyn K. Simon, Ph.D

Marilyn K. Simon, Ph.D

Signature

I understand these conditions and agree to abide by these terms and conditions.

Signed **Date** 7/9/16

Aretha Townsend

Expected date of completion: 6/2017