

RESEARCH



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### Using Empowerment Theory to Improve Understanding of Type 2 Diabetes Mellitus in Haitian American Women

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#### ABSTRACT

**Introduction:** The CDC (2020) revealed that the age-adjusted prevalence of diabetes mellitus in the United States among the Black, non-Hispanic population is 16.8%. A study conducted by Bivins et al. (2021) revealed a 39% prevalence of type 2 diabetes mellitus (T2DM) among Haitian Americans (HAs) living in several states. In the literature, HAs are often grouped with Black Americans, yet Haitian American women (HAW) have unique struggles with treatment and management of T2DM. No prior study used the empowerment theory to improve the management of T2DM in HAW.

**Purpose:** To improve the understanding of T2DM in HAW using empowerment theory. This article is the second installment of a two-part series discussing findings from a 2017 hermeneutic phenomenological study conducted with 25 HAW living with T2DM in South Florida.

**Methods:** This phenomenological study used Van Manen's six research techniques to guide this qualitative inquiry involving 25 HAW.

**Results:** Several themes emerged from the data analysis. This paper discusses two themes that can be addressed through empowerment theory to improve health outcomes: (a) challenges to adhering to treatment regimen, with the subthemes of health beliefs, mistrust, and perceived powerlessness, and (b) recognizing the enemy—stress.

**Discussion:** This paper will demonstrate how nurses are well positioned to educate HAW with T2DM to manage their condition better and increase adherence to treatment by using the empowerment theory.

**Keywords:** Diabetes, Haitian American Women, culture, empowerment theory, adherence, Haitians, Haitian Americans

#### INTRODUCTION

Four hundred and twenty-two million individuals suffer from diabetes mellitus throughout the world (World Health Organization, 2023). In the United States, according to the Centers for Disease Control and Prevention (CDC), the age-adjusted prevalence of diabetes mellitus

in the Black, non-Hispanic population is 16.8%; however, a 2020 study found a prevalence of 39.9% in Haitian Americans (HAs) (Bivins et al., 2021; CDC, 2020). In the literature, HAs are often subsumed into the Black American demographic. The limited data on HAs suggest that Haitian American women (HAW) may experience language barriers, cultural

norms, health beliefs, and dietary habits, which create unique diabetes management challenges and result in complications (Bivins, 2018; Bivins et al., 2020; Vimalananda et al., 2011; Huffman et al., 2013). This, therefore, argues for more focused research into the specific challenges HAW face with type 2 diabetes mellitus (T2DM).

Haiti is a Caribbean country located on the western part of the island of Hispaniola, next to the Dominican Republic (Central Intelligence Agency, 2021). Today, because of longstanding economic, political, and ecological strife, Haiti is considered the poorest country in the Western Hemisphere (Samuels et al., 2012), and over the years, many Haitians have migrated to the United States. According to the 2013 American Community Survey, Haitians in Miami-Dade earned less than 33,000 per year, or 21% less than their counterparts in the community (Professional Research Consultants, 2013). Poverty accentuates and exacerbates the health challenges faced by the HA community. Awareness of specific aspects of Haitian culture is important to understand the particular challenges HAW face in addressing and managing T2DM. Although some Haitians acknowledge Voodoo as a legitimate religion, Haitian people's belief in Christianity is central to their perspective and is exhibited through a "fatalistic-like" dependence on God, prayer, and the Bible (DeSantis & Thomas, 1992; Giger & Hadad, 2021). The Haitian concept of health has a strong connection with prayer and mainly focuses on keeping a balance between hot and cold. Haitians perceive illness as punishment, "an assault on the body," and their fatalistic view of illness is reflected in the common expression "God is good" (*Bondye Bon*) and the central tenet that whatever happens is God's will (Colin & Paperwalla, 2013). In terms of nutrition, the Haitian diet is predominantly comprised of carbohydrates such as bread, rice, cornmeal, porridge, and plantains (Colin & Paperwalla, 2013). Finally, although Haiti

is classified as a Francophone country, only approximately 15% of Haitians speak French as either a primary or second language, while 100% speak Haiti's official language, Haitian Creole (Colin & Paperwalla, 2013). While there is little official data on the languages spoken by Haitians in the United States, many HAs likewise speak Haitian Creole as a predominant language.

## PURPOSE

This article is the second installment of a two-part series discussing findings from a 2017 hermeneutic phenomenological study conducted with 25 HAW living with T2DM in South Florida. The first article, "Understanding Type 2 Diabetes Mellitus among Haitian American Women: A Cultural Perspective," discussed two themes: shifting cultural norms, with the subtheme of dietary restriction, and spiritualizing (Bivins et al., 2020). The current article will describe the remaining two themes: (a) challenges to adhering to treatment regimen, with the subthemes of health beliefs, mistrust, and perceived powerlessness, and (b) recognizing the enemy—stress. It will also consider how empowerment theory may be used to improve the health outcomes of this population by addressing the concerns voiced through the different themes and subthemes.

## METHODS

### Study Design

This research study employed Van Manen's (1990) phenomenological approach as a guiding theoretical framework to uncover the essence of the lived experience of HAW with T2DM. After receiving Institutional Review Board (IRB) approval, twenty-five ( $N = 25$ ) HAW with T2DM in three counties (Miami-Dade, Broward, and Palm Beach) in South Florida were recruited for the study. The study included individuals who self-identified as HA, female, aged 20-79 years old, living in South Florida, and diagnosed with T2DM for at least one year. Approval to conduct the study was received from

Barry University's IRB. Women interested in participating contacted the researcher by telephone, using the contact information provided in the flyer. The researcher explained the purpose of the study and obtained signed informed consent in English or Haitian Creole before starting the interview. Individual face-to-face, audio-recorded semi-structured interviews were conducted in a well-lit, private, and safe site.

### Analysis of Data

Twenty-five HAW participated in the study. Once the transcribed digital audio recordings were received from the transcriptionist, they were reviewed simultaneously with the transcripts. The qualitative software NVivo 11 and a table were used to organize the data. In the table, themes were highlighted to aid in visualizing the common links. Through the rich descriptions shared by the 25 HAW with T2DM, which provided historical and cultural context, the main themes and associated subthemes emerged and were grounded in the data. The researcher diligently reviewed the data several times until data saturation occurred. In keeping with member checking, all participants were given the opportunity to verify the accuracy of the transcripts.

## RESULTS

This phenomenological inquiry identified four main themes and four subthemes that illuminated the experiences of the 25 HAW with T2DM. In this section, the themes, (a) challenges to adhering to treatment regimen and its three subthemes of health belief, mistrust, and perceived powerlessness, and (b) recognizing the enemy—stress, will be discussed. The other identified themes—shifting cultural norms, with its subtheme of dietary restriction, and spiritualizing—were discussed in our previous article.

### Challenges to Adhering to Treatment Regimen

Challenges to adhering to treatment regimen, regardless of educational level,

socioeconomic level, or place of birth, emerged as a strong theme in this study. The associated subthemes—health beliefs, mistrust, and perceived powerlessness—provide more explanation about those challenges. According to Haynes et al. (1979), *adherence* refers to an individual's ability to follow lifestyle changes prescribed by health professionals regarding diet, exercise, and medications. In this phenomenological study, the HAW described their culture, their role as mothers and wives, and their duties to the community as barriers to adhering to their diabetes regimen. For example, Dominique, 50 years old, identified her cultural affinity to starchy foods, especially bread, as a reason for her struggle with adherence. Dominique noted: "I'm a Haitian-American girl. I'm someone who likes bread and rice. If I miss the rice for a week, I have to have my bread." Other participants described similar issues with food. Mona, 51 years old, stated: "I like candies. I like something sweet. I like *labouie* (porridge) sweet. I cheat sometimes." Likewise, Billy Jean, 58 years old, noted: "I think I was in denial of diabetes. If I go to an event, I want to prize myself by eating a nice Haitian cake. I do have a sweet tooth."

### Subtheme: Health Beliefs

Health beliefs are what individuals believe about their health based on the influence of their cultural backgrounds (Rosenstock, 2005). In this study, HAW had strong beliefs about what caused or prevented diseases, and they relied heavily on teas and alternative medicines to treat and manage their disease. For example, Eveline, 64 years old, a single mother of six adult children, explained her adherence routine confidently: "I don't read but I understand numbers. I check my blood sugar level. If I take the *asosi* tea (cerasee tea), I don't take the medicine. And then the next day, I take my pill." Similarly, Jojo, 59 years old, had not seen her provider for a year, relying on teas rather than medicines. She noted: "I eat normally

because I don't feel any symptoms; I don't feel anything at all. That's why I don't really check it. I make a lot of tea with leaves, *simin kontra*, and plants from Haiti, eucalyptus, and soursop."

### **Subtheme: Mistrust**

Mistrust emerged in the study as another subtheme to challenges to adhering to treatment regimen, as several participants expressed their mistrust in the healthcare system, the care they received, and their providers. According to Gilson (2006), *trust* is the belief that others will have your interest at heart; conversely, *mistrust* is being skeptical of the intentions of others and the inability to trust what they say. In the context of treatment and management, mistrust may lead to poor outcomes. For example, many participants highlighted their mistrust of medication. Germaine, 72 years old, who had been living with T2DM for 18 years, explained in a grave tone: "I would not like to have diabetes forever. I would like to find a medication that takes it away from me. But I don't know. These medicines, they give it to me like that, but they are not there to take away the diabetes." Billy Jean's medication mistrust was even more noteworthy, as she stated she feared insulin even though she is a nurse who understands its mechanism of action. Rosette, 33 years old, expressed a broader mistrust of the entire health system, believing that it intends to suppress knowledge about effective alternative therapies to treat diabetes because of a profit motive: "They're going to prescribe you this and that, but the medicine has some side effects that cause other problems."

### **Subtheme: Perceived Powerlessness**

According to Herdman and Kamitsuru (2014), the North American Nursing Diagnosis Association Diagnosis Manual for 2015-2017 describes *powerlessness* as the perception that one does not exercise a meaningful degree of positive control over a given situation. The following are quotes from the study participants

expressing their perceived powerlessness in the face of a lifelong struggle with T2DM. For Mona, feeling powerlessness about her T2DM also gave her a sense of powerlessness about her future: "I like to work. I am not lazy. I am a strong woman, but the sugar makes me feel like I am worthless. Diabetes affecting my sugar is a burden. It makes you feel lethargic... (exhaled deeply). Sugar can kill you.... It is a silent killer!" Dominique specifically discussed her challenges in adhering to treatment, explaining: "My food! The way I eat. Even if I said, OK, I'm going to try to get on my salad. And my chicken and everything. It's for one week, two weeks. But after that, I'm done. I'm tired of it. For more than 20, 25 years, I've been that weight. As soon as I lose 20 pounds or 30 pounds, I'm stuck. I get tired of it."

### **Recognizing the Enemy—Stress**

Stress emerged as a strong theme in this study, weaving together the different phases of disease diagnosis, progression, and resolution in the lived experience of participants. According to Cohen et al. (2016), *stress* is an individual's reaction to a life event that is considered harmful or threatening and may be a factor in disease causation. The HAW with T2DM who participated in this phenomenological study discussed the significant impact stress played in precipitating their initial diagnosis of diabetes; in their management of the disease and adherence to their present medical regimen; and in their future emotional, mental, and physical outlook.

Mireille, 62 years old, was adamant in believing her T2DM resulted from a great deal of stress: "I felt that I got diabetes because I had too much stress. It is stress that causes diabetes. Someone with a happy heart and good life doesn't develop diabetes." Similarly, Karine, 79 years old, had been living with T2DM for seven years. A survivor of the devastating 2010 earthquake that hit Haiti, Karine was diagnosed with T2DM that same week, and she believes it was a direct result of acute stress after witnessing the destruc-



tion of her city. She stated, "Really, it's stress and shock. Because I did not have diabetes before the earthquake." Among the participants, no one was more adamant about making the connection between stress and T2DM than 39-year-old Francia. She insisted that for a true treatment or cure for T2DM, blood glucose management was only part of a puzzle that must be solved; stress management and elimination must also be included. "I passed all day without food, but my sugar is up. Because of stress. You call me now and tell me, 'Francia, did you hear the news that X died?' Then my sugar is up! They don't have medicine for stress."

As this theme, recognizing the enemy—stress, demonstrates, study participants appeared to be in a constant struggle with stress. Although it seemed on the surface that dietary restrictions were the primary issue, stress made it more difficult for most of the HAW in the study to adhere to their treatment regimen. Some were keenly aware that stress contributed to their diagnosis and ongoing struggle with T2DM.

### **Empowerment Theory applied to Haitian American Women with Type 2 Diabetes Mellitus**

Challenges faced by HAW women may be addressed using empowerment theory. This theory is at the heart of a movement that helps individuals to gain a sense of control over their lives. For the present study, the researcher used empowerment concepts embraced by Rappaport (1981), Zimmerman (1986), and Spreitzer (1995). The integrated concepts from the empowerment theory connecting to the themes of this phenomenological study will be discussed in the following section. Critical consciousness or critical awareness is the process by which an individual acquires a greater understanding of the cultural and social (shifting cultural norms) conditions that shape their lives and the extent of their ability to change their condition (Rappaport & Seidman, 2000). The partic-

ipants strongly identified certain foods, such as rice, as part of their culture and found it difficult to adapt to the prescribed diabetic dietary regimen. By developing critical consciousness, HAW with T2DM may better understand how their shifting cultural norms may negatively affect their illness. They may learn to keep their traditions while making necessary changes, including incorporating a healthier diet to effectively manage T2DM and improve their health outcomes.

One way HAW may feel empowered to manage their T2DM is by gaining competence. Competence, described by Patricia Benner (1982) in her classic work on the stages of nurses' development, "From Novice to Expert," is "characterized by a feeling of mastery and the ability to cope in the clinical environment" (p. 405). Competence addresses the issue of recognizing the enemy—stress as it is a major component in the lives of the study's HAW with T2DM. Several factors contributed to the stress that the women experienced, such as low socioeconomic status (56%) and limited resources, which made it difficult for them to manage their T2DM. Furthermore, although 17 of the women have been living in the United States for more than 21 years, they still experienced stress navigating the U.S. healthcare system.

In addition to competence, self-efficacy is essential for HAW with T2DM. *Self-efficacy*, credited to Albert Bandura's (1986) social cognitive theory, is defined as "beliefs in one's capabilities to organize and execute the courses of action required to produce given attainments" (p. 3). Besides gaining competency, which is the ability to perform a task with mastery, self-efficacy addresses the challenges to adhering to treatment regimen. By using empowerment theory, HAW will develop an inner belief or a sense of self-efficacy, which will allow them to manage their diet, medication, and treatment regimen as they learn how to decrease stress in their lives.

Lastly, self-determination is vital to help HAW with T2DM feel empowered. In the context of empowering individuals, Spreitzer (1995) proposed that *self-determination* reflects an individual's control or autonomy over behavior or motivation to attain a goal. For the participants of this study, self-determination connects with their focus on spiritualizing, which is evoking a higher power that facilitates the achievement of a specific goal, such as better health. Religion was very influential in the lives of the HAW, and prayer played a significant role in how they coped with T2DM. Along with competence and self-efficacy, self-determination is essential to empowering HAW with T2DM. Figure 1 (Bivins, 2018, adapted from Rappaport, 1981; Zimmerman, 1986; and Spreitzer, 1995) illustrates the concepts of individual empowerment. Figure 2 (Bivins, 2018) depicts concepts of individual empowerment connected to the themes. The concepts of individual empowerment, including critical consciousness, competence, self-efficacy, and self-determination, can be used to improve health outcomes of HAW with T2DM.

## DISCUSSION

### Challenges to Adhering to Treatment Regimens: Health Beliefs, Mistrust, and Perceived Powerlessness

Adhering is a difficult task for most patients (Chunhua et al., 2013; Virgoles et al., 2017). The theme, challenges to adhering to treatment regimens, included the subthemes of health beliefs, mistrust, and perceived powerlessness. These subthemes further explained why the participants had difficulty adhering to their prescribed diet, medications, and exercise regimens. Ens et al. (2014) used a survey to examine medication adherence in South Asian patients with coronary artery disease. They corroborated the importance of including culture in the care of patients, which was also significant in the current study.

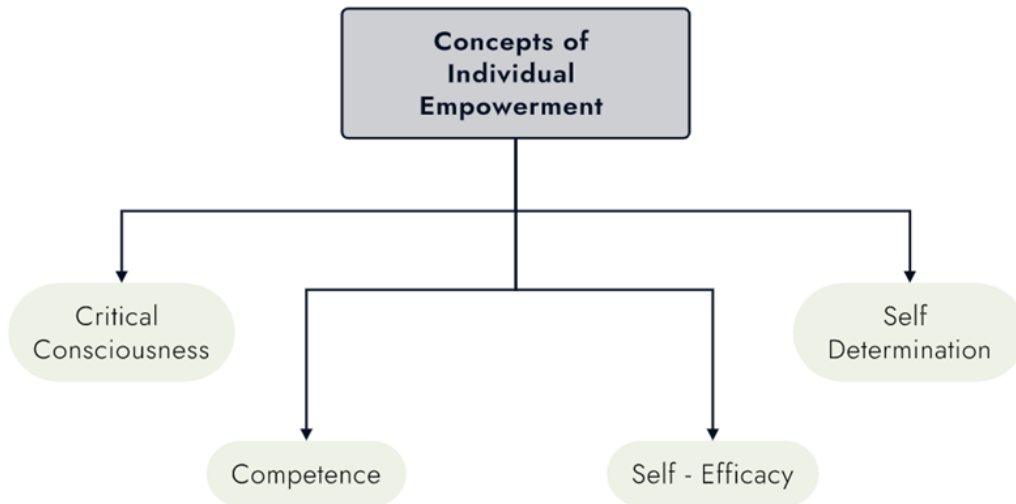
### Health Beliefs

In the study by Ens et al. (2014), the themes that influenced treatment adherence included language barriers, relationships (with physicians, pharmacists, and kinships), memory mechanisms, and the use of non-conventional medicines. The study results indicated that support systems were a dominant criterion in aiding these patients in taking their medication and that familial support was also important in keeping them focused on their routine. Ens et al. (2014) corroborated research findings from the present phenomenological study that a language barrier may be one of the reasons that HAW with T2DM struggle to adhere to their treatment regimen. The issue of a language barrier was reflected in the present study, as only 40% of the participants felt comfortable having the interview conducted in English.

In this phenomenological study, HAW had strong health beliefs about what caused or prevented diseases. They relied heavily on teas and alternative medicines to treat and manage their disease. Several studies have supported that health beliefs greatly impact whether and how individuals adhere to their treatment regimen. Scholars have long commented on the health beliefs of Haitians in the literature. Historically, Haitians have used teas and remedies to treat different illnesses (Colin, 2005; DeSantis & Thomas, 1992). In a qualitative study, Brathwaite and Lemonde (2017) explored health beliefs and prevention practices for T2DM in Caribbean immigrants in Canada. The researchers found that most participants consumed a traditional diet, did not change their culinary practices based on their culture, and did not want to alter their ways even though most of them lived in Canada for an average of 29 years. This supports the present findings in this phenomenological study that it is difficult to change an individual's health beliefs and cultural practices.

**Figure 1**

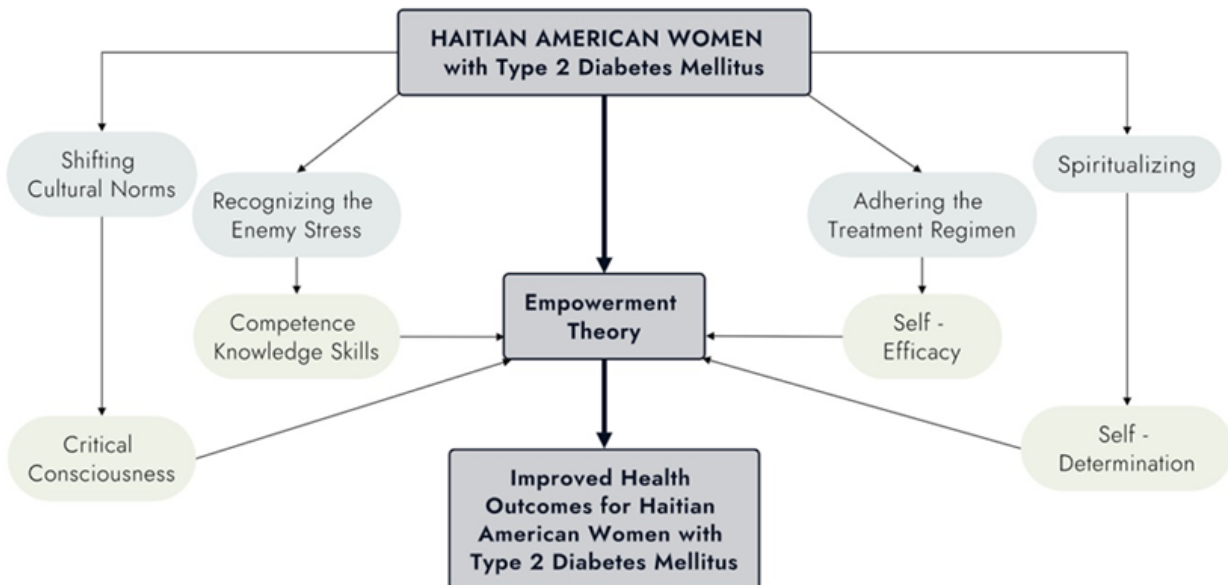
*Concepts of Individual Empowerment*



Note. From "The lived experience of Haitian American women with type 2 diabetes mellitus," by B. Bivins, 2018, (Publication No. 13807908) [Doctoral Dissertation, Barry University]. Copyright 2018 by B. Bivins.

**Figure 2**

*Concepts of Individual Empowerment Connected to the Study Themes*



Note. From "The lived experience of Haitian American women with type 2 diabetes mellitus," by B. Bivins, 2018, (Publication No. 13807908) [Doctoral Dissertation, Barry University]. Copyright 2018 by B. Bivins.

### **Mistrust**

Haitians do not trust prescribed medicine and healthcare professionals (Farmer, 2006). The HAW who participated in the current study expressed mistrust of the healthcare system, providers, and medication. Research studies have supported the theme of mistrust. Ayala et al. (2014) conducted a mixed-method study exploring the reflections of parents and caregivers of children with type 1 diabetes and their relationship with healthcare providers. The goal was to determine what was needed from healthcare providers to assist them in caring for a diabetic child. The sample included 63 parents and caregivers. The themes that evolved from the study were understanding the uniqueness of the family, who leads the care of the child, supporting them in times of stress, and fostering communication. Although this study did not specify trust, it explored the themes of improving communication and support by healthcare providers in the context of a trusting relationship. Trust has been found to help with adherence, health outcomes, and the relationship between a patient and provider (Robinson, 2016).

### **Perceived Powerlessness**

The participants in the current study had a sense of perceived powerlessness in their treatment and management of T2DM that stemmed from a social, economic, and cultural point of view. This was reflected in this phenomenological study by low income, lack of acculturation, the way they lived, what they ate, and how they interacted in their social circles. Sheridan et al. (2012) explored the health beliefs of ethnic minority populations regarding their health providers. This qualitative study included 21 men and 21 women, and 32 participants were from minority populations suffering from diabetes, pulmonary conditions, congestive heart failure, and arthritis. The findings of the study revealed that individuals from minority populations expressed that their interaction with healthcare provid-

ers left them with a sense of powerlessness. In addition, Forsgårde et al. (2016) explored the meaning of patients' and families' experiences of dissatisfaction in an emergency room in a hermeneutic phenomenological study. The sample included six participants in total: four males and two females. The findings of that study revealed four major themes: powerlessness, struggling for control, lacking knowledge and information, and receiving and providing support. The researchers suggested that nurses increase the frequency of rounds, provide information to patients and families, and include them in the care plan. Those findings are consistent with the current phenomenological inquiry in which the participants experienced feelings of powerlessness due to a lack of support from their healthcare providers.

### **Recognizing the Enemy—Stress**

Stress also emerged as a major theme in this study of the lived experience of HAW with T2DM. According to Baum (1990), stress is an emotional reaction coupled with biochemical, physical, and mood changes aimed at dealing with the offending situation to change or accommodate the effects. The impact of stress and its consequences were vivid in the lives of the HAW with T2DM. Not only did the participants identify stress as a precursor to diabetes, but they also expressed that stress made it difficult for them to cope with the disease. Schwartz et al. (2014) conducted a quantitative cross-sectional descriptive study to assess the help-seeking behaviors of Haitians as it relates to stressors and emotional support. The sample size included 150 Haitian subjects from New England, ranging in age from 22 to 88 years old ( $M = 40.72$  years,  $SD = 12.62$ ), with women comprising 60.1% of the sample. The results revealed that subjects were more apt to seek help from a family member and that clinicians should partner with Haitian families and the Haitian community to support these individuals. The regular identification of stress as a major factor in man-



aging T2DM revealed in the current study suggests the importance of targeting this issue for HAW.

### Significance and Implications for Future Research and Policy Development

Freire (1970/2014) and Rawls (1971) advocated for social justice for marginalized individuals. In accordance with their philosophy, nurses are well-positioned to promote social justice for HAW. As such, nurses must get involved with policy to lobby government agencies to increase medical funding for immigrant and marginalized communities, such as HAs. Access to nutritional support and education that is culturally tailored may also influence better health outcomes. Furthermore, HAW with T2DM and others who are similarly situated in the immigrant experience must be empowered to get involved in their care. The findings from this study may serve as an impetus for health policy changes to provide responsive and optimal care to individuals from diverse patient populations. Future studies should explore the impact of empowerment on glycemic control in HAW with T2DM. To our knowledge, there are few studies on the prevalence of diabetes in HAs. As such, researchers should explore the prevalence of diabetes and risk factors that are associated with this population.

### CONCLUSION

The narrative interpretations of the 25 HAW in this study provided a rich description of their experiences with T2DM and revealed the lived essence of the phenomenon. Empowerment theory, specifically individual empowerment, was used to conceptualize the themes and explore the behaviors necessary for the participants to exert control over their management of T2DM. Using empowerment theory to assist HAW in managing their T2DM may improve overall health outcomes.

### DECLARATION OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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