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Barriers to Type 2 Diabetes Management Among Older Adult Haitian Immigrants

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Abstract

Purpose—The purpose of this study was to describe the experiences of older adult Haitian immigrants in managing type 2 diabetes mellitus (T2DM).

Methods—A descriptive qualitative approach using semistructured interviews was conducted with 20 older adult Haitian immigrants with T2DM. Interviews were transcribed verbatim and categorized using NVivo. An iterative descriptive data analysis method was used to examine the data, compare codes, challenge interpretations, and develop themes inductively.

Results—Older adult Haitian immigrants reported that T2DM affected every aspect of their lives. Financial hardship and social isolation were described as the major barriers to T2DM management, which forced them to choose between basic needs and health care, and at times, they had to forgo medications or avoid seeking medical care. They recognized that creating and maintaining good community support was the key to self-management of T2DM.

Conclusions—Financial hardship and social isolation have a tremendous impact on the ability of older Haitian immigrants to manage T2DM effectively. It is challenging to modify these barriers through individual efforts, and clinical, research, and public efforts may be necessary to address these concerns.

Type 2 diabetes mellitus (T2DM) is prevalent among older adults in the United States, affecting 26.8% of those age 65 years and older, with even higher rates among Blacks.[1–4] Disparities in factors that affect T2DM prevalence, such as access to health care, socioeconomic status, and mortality, are also higher among older adults in ethnic/racial minority populations.[1,2,4] Self-management of diabetes in older adults is complicated by

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coexisting factors such as physical disabilities, depression, cognitive dysfunction, and polypharmacy,[5–7] which may interfere with the self-management of T2DM in older adults through direct and indirect impacts on health behaviors (eg, healthy eating, taking medications, exercise, blood glucose monitoring) and health outcomes (eg, metabolic control of A1C and blood glucose levels, quality of life).[4–7]

Older adult Haitian immigrants living in the United States are among the ethnic/racial groups affected significantly by T2DM.[8] The prevalence of T2DM in Haitian immigrants is difficult to quantify, in part because they are often categorized with other Black/non-Hispanics in government census reports.[8–10] Although studies have shown that this classification may contribute to treatment errors and health disparities among Haitian immigrants,[8–10] in government surveys and labor statistics reports, the category of Black/non-Hispanic includes all persons of color.

Additionally, the perceptions and cultural beliefs regarding health and causes of disease among Haitian immigrants differ from those of other Black populations.[8,9,11,12] In the Haitian culture, a disease is viewed as a curse (eg, punishment from God or evil spells), and such a belief makes the management of chronic diseases challenging.[9,12,13] These notions regarding health and disease are related to their nation of origin and different experiences and sensibilities that shape their lifestyle.[8,12–14] Furthermore, Haitian immigrants possess a strong sense of maintaining their cultural heritage, which is considered an essential part of their well-being that is manifested in their daily lives; this has important implications for the self-management of T2DM.[8,9,12–15] Moreover, older adult Haitian immigrants are at risk of detrimental health consequences during the transitional period of adapting to their newly adopted country.[9,12–15] Subsequently, when compared with younger immigrants, for older immigrants, the process of acculturation, which may involve discrimination and acculturative stress, can be difficult because their health beliefs and barriers to acculturation, such as language (eg, limited English proficiency), differ from those of the younger generation and the natives of their newly adopted country.[12–15] There is a pressing and unmet need to identify and describe factors that may affect T2DM self-management behaviors in older adult Haitian immigrants.

In previous research involving adult Haitian immigrants with T2DM, self-management, which refers to taking medication, healthy eating, blood glucose monitoring, and adequate physical activity, was reported to be a complex ongoing challenge with corresponding suboptimal metabolic control.[8,9,12] There are differences in T2DM self-management and metabolic control between Haitian immigrants and those of other Black or immigrant populations.[8,10,11,16] A study showed that although Haitian immigrants consumed more fruits and vegetables than African Americans, their daily dietary intake contained higher amounts of saturated fats, carbohydrates, and added sugars.[10] Haitian immigrants with T2DM also have poor metabolic control when compared with African Americans and Cuban Americans with T2DM.[8,10,11,16]

Research has demonstrated a strong relationship between T2DM self-management and family support.[5–7,9,17,18] Although it is known that family and community support are critical components of Haitian culture,[8,9,12,14] there is little knowledge regarding the health

behaviors of older adult Haitian immigrants with T2DM and the influence of family, community, cultural beliefs, and environmental factors on self-management. The specific aims of this study were (1) to describe the experience of older adult (≥65 years) Haitian immigrants in managing T2DM and (2) to delineate the influences of family and community, cultural health beliefs, and social and economic status on self-management of T2DM in this population.

Methods

Design

This study employed a descriptive qualitative design, the tenets of which include acknowledgment of various shared experiences of individuals and the interactive, inseparable nature of human interactions.[19,20] Hence, the design enabled the older adult Haitian immigrants to describe their experiences in managing T2DM.

Inclusion/Exclusion Criteria and Setting

A purposive sampling method was used to recruit older adult Haitian immigrants from 3 dispersed Haitian community-based churches in the northeast region of the United States. The final sample size was based on data saturation.[19] The inclusion criteria were (1) self-identified Haitian immigrants age 65 years and older, (2) T2DM for at least 1 year, (3) living in the United States for more than a year, (4) willing and able to participate in an individual interview, and (5) able to speak Haitian Creole or English. The exclusion criteria were (1) diagnosed with type 1 diabetes mellitus and (2) unable to comprehend, consent to, or fully participate in the study.

Recruitment

To recruit potential participants, flyers that described the study in both English and Haitian Creole were posted on the bulletin board of each church's bulletin board. Eligible and interested participants were instructed to contact the first author directly, and those meeting the inclusion criteria were invited to participate.

Data Collection

Demographic information and clinical history, including self-reported A1C, were collected using a brief survey. Based on a semistructured interview guide, face-to-face in-depth audio-recorded individual interviews were conducted from November 2018 to November 2019. The interview guide was written in English and translated to Haitian Creole. The process of translation was followed as indicated by Châvez and Canino.[21] Each interview lasted 40 to 90 minutes. Field notes were written for each interview. Participants received a $20 gift card on completion of the interview. Thematic saturation of coding categories occurred after 14 interviews; however, we interviewed an additional 6 participants to ensure that no new information or concepts emerged. In this manner, the final sample size of 20 was determined. The audio-recorded interviews were transcribed verbatim by an experienced transcriptionist who was fluent in both English and Haitian Creole. The transcribed data were analyzed using NVivo 12 software (Version 12, QSR International).

Data Analysis

Demographic data were analyzed using IBM SPSS Statistics for Windows, Version 26 (IBM Corp, Armonk, NY, USA). To ensure the credibility of data analysis, we used a modified iterative 7-step descriptive data analysis method[22–25] to examine data, compare codes, challenge interpretations, and develop themes inductively. The steps were (1) reading the transcripts several times to gain a broad understanding of the text, (2) meeting as a group to identify key quotations and discuss key codes related to the research question, (3) combining the coded quotations into 1 file and confirming the accuracy of the code and quotation, (4) carefully analyzing quotation files and identifying major themes by collating key coded quotations for each research question, (5) meeting as a group to review major themes and engaging in active dialogue to resolve any discrepancies, (6) reviewing the transcripts and validating the structure of themes alongside interview data, and (7) conducting multiple discussions until consensus was achieved about each aspect of the process of data analysis. Efforts were made to differentiate and compare each individual's experience with careful selection of the text illustrating the essence of the experience.[26,27] Essential themes were identified to illuminate the experience and factors that impede or promote T2DM management among older adult Haitian immigrants.

Rigor and Trustworthiness

Four criteria to assess the trustworthiness of this qualitative research were applied to ensure the rigor of the study: credibility, transferability, dependability, and confirmability.[20] Credibility was achieved through reflective journals, field notes, and verbatim transcriptions. It was further ensured by listening to the recording of each interview while checking against the transcripts to guarantee accuracy. Transferability was supported by detailed descriptions from participants. There was strong evidence of dependability because of the emergence of similar data from different participants. Confirmability was achieved by member checking and interrater reliability. Finally, the researchers discussed the analysis and arrived at a consensus regarding the results.

Ethical Considerations

This study was approved by the Yale University Institutional Review Board (Protocol ID: 2000023745). A thorough description of the study was provided to all participants, including the right to withdraw at any time. After explaining the study purpose, goals, and process of the study, written informed consent was obtained in English or Haitian Creole based on the participant's preference. Privacy and confidentiality were maintained. Pseudonyms were used to report the study results.

Results

Characteristics of the Participants

Twenty older adult Haitian immigrant men (n = 8) and women (n = 12) with T2DM who resided in urban neighborhoods of the northeast region of the United States were enrolled in this study. The mean age of the participants was 69 years (65–75). On average, the participants had lived in the United States for over 30 years. Among the 20 participants, 45%

met the recommended guidelines for glycemic control in older adults (7.5% [58 mmol/mol]) without hypoglycemic events.[3] Table 1 presents demographic and clinical characteristics of the participants.

Essential Themes

Older adult Haitian immigrants described their experience of being diagnosed with T2DM as "a life-changing experience" and expressed that day-to-day T2DM management "takes over your life." Susane, age 66 years, remarked, "It was a life-changing time for me. Things have not been the same." Participants described being stressed by the intensity of day-to-day disease management and being worried about physical symptoms (eg, frequent urination, issues related to eyesight) and the likelihood of negative disease consequences (eg, amputation, cerebrovascular accident), even among participants who reported adequate glycemic control (self-reported A1C of 6.5 ± 0.5% [47 ± 5 mmol/mol] to <7% [<53 mmol/mol]). Their perception that T2DM affected every aspect of their lives provided context for the 3 essential themes that emerged: enduring financial hardship, facing isolation outside the Haitian community, and creating and maintaining good community relationships among themselves. Table 2 presents the essential themes and representative quotes.

Enduring Financial Hardships

"Having T2DM requires a lot of work and money. It is not a poor man's disease," Joseph, a 67-year-old man, emphasized. Out of the 20 participants, 15 characterized T2DM as "it is not a poor man's disease." The participants reported that they had to carefully allocate their funds to effectively manage T2DM. The majority of the participants were frustrated with having to "skip medications and miss doctor appointments" and worried about "buying food" although they were aware and concerned about the negative health outcomes of "not taking medications" or "seeing doctors." All participants recognized the importance of medications to manage T2DM; however, quite often, they struggled to pay for them. Odette, age 71 years, who has managed her diabetes for over 30 years, remarked, "I did not take insulin for a month. I could not pay for it. I used to take it, but it was too expensive. It [insulin] worked well, but it was too expensive." Participants were also frustrated by the limited resources available to help them. Veronica, a 66-year-old woman, was frustrated with her medical issues and the lack of aid to help. She shared, "Six months ago, there were a few months in which I was only able to pick up some of the medications because the kids could not help in paying for them."

Participants were also aware that a healthy diet was key to managing T2DM; nonetheless, they struggled to pay for "good food." Evelyne, a 65-year-old woman, emphasized, "For many other older Haitian people like me in church, it is very difficult for them to buy good food, you know, like vegetables, fruits, and paying for their expensive insulin regimen." Although the participants recognized the significance of having the necessary resources that could help achieve better glycemic control, they also felt that being Black and Haitian deprived them of these resources. Nancia, age 66 years, noted, "I go back and forth based on the amount of money, and limited resources are available to people like me, you know, Black and Haitian."

Facing Isolation Outside the Haitian Community

In response to the questions regarding challenges of having and managing T2DM, the participants emphasized the experience of being isolated outside of their Haitian community. Despite feeling well connected within their community, they perceived “a lack of tolerance” and an absence of connection with their “American neighbors.” The participants viewed this feeling of disconnection with their non-Haitian neighbors as a form of what they called “home-based” isolation arising from their “foreign accent and broken English,” specifically, on a lack of connection with their American neighbors. This feeling of isolation was a daily affair, which was in contrast to the support of their own church community. Participants used the phrase “isolation among people I should be closely connected with.” Despite efforts to engage with their non-Haitian neighbors, most faced a strong sense of rejection from non-Haitian communities. Joseph, a 69-year-old man, who has managed diabetes for over 15 years, emphasized, “We are isolated. Even more now. Our neighbors do not really talk to us because we are different.” Marie, a 68-year-old woman, who has managed her diabetes for over 20 years and has been living in the United States for over 30 years, commented, “I am beyond frustrated. I feel neglected, isolated by all of this. English, not enough English, no neighbor friends. Many of us are the same age. I think because I am Haitian and most of them are White, they do not want to talk or invite me to some of their fun stuff.” Pierre, a 67-year-old man, who has been living in the United States for over 20 years and managed diabetes for over 10 years, echoed, “I feel alone at times, you know, because of my accent; they do not think I speak good English. My kids cannot always come and stay with me, my neighbors do not know me, and I do not know enough English to reach out to them.”

Creating and Maintaining a Good Community

Creating and maintaining a good community was recognized as the most important strategy for the participants to manage their T2DM. In response to questions regarding what helped participants manage T2DM, all the participants shared their stories of managing T2DM in relation to God, family, and their own community. Julene, age 69 years, commented, “You have to create and maintain a good community.” Participants described that “having a good relationship with God” served to guide the daily management of their condition. Previlon, age 69 years, said, “When diabetes bothers me, I pray and ask my sisters from the church to pray with me and for me, and it works. I do not know where I would be without God.” Older adults also expressed that their belief in God and their church community was a major source of strength for them to cope with their disease and sustain the day-to-day management of T2DM. Odette, age 71 years, stated, “To tell you the truth, without my family and my sisters from the church, I do not know where I would be with this disease. I am glad I was able to create this support network and happy I have a good family to help me manage my diabetes.”

In conjunction with having a good relationship with their church community, the participants also acknowledged that strong support from family and health care providers was essential for T2DM management, particularly “in the face of financial constraint.” By creating and maintaining a strong support system, participants were able to sustain the daily management of their disease even while enduring financial hardships and experiencing isolation outside their community. The examples in the following represent such experiences. Berly, age 69

years, remarked, “I do not know what I would do without support from the church and my kids. They check on me, call, pray for me and my family.” Evelyne echoed, “The nurse in the church helped me make some changes to the food I eat, and I started feeling better. She also connected me with another dietician who had worked with Haitians before. It was a very scary time for me.”

Discussion

To the best of our knowledge, this is the first study that explores the experiences of older adult Haitian immigrants in daily management of T2DM in the context of family, community, cultural health beliefs, and living environment. Participants in the study perceived T2DM as a complex chronic disease with possible detrimental consequences if the condition was not carefully managed, which differs from the traditional Haitian health belief that a disease is a curse. Additionally, they recognized the importance of medication and “good food” in managing T2DM. The lack of resources is recognized as a risk factor in managing T2DM and meeting the targets for glycemic control in racial/ethnic minority groups with diabetes.[28–30] The details of experiences furnished by our study participants provide evidence of the real-life impact of financial hardships on their ability to effectively manage T2DM. They were forced to choose between competing financial responsibilities of basic needs and health care (eg, food vs medications) and sometimes had to forgo medications or seeking medical advice. Our study findings support the fact that the cost of ongoing medical management and financial constraints are significant barriers to achieving glycemic control and quality of life, especially for patients with low socioeconomic status or those who are unable to meet financial obligations.[9,28,29]

Furthermore, the impact of social isolation among Haitian immigrants with T2DM was noted. Social isolation is known to have a negative impact on all-cause mortality, cardiovascular mortality, and self-reported quality of life.[31,32] Immigrants may experience isolation after arriving in their new communities, thereby putting them at risk of facing adverse health outcomes. The older adult Haitian immigrants in our study expressed feelings of being socially isolated from their neighbors of different race/ethnicity even though many of them have lived in the United States for several decades. The participants particularly noted that their neighbors who were ethnically different from them did not include them in social activities, causing acculturative stress in addition to social isolation.

Race is a sociopolitical construct that is strongly inter-twined with socioeconomic status, and their interconnection accounts for substantial racial/ethnic differences in health.[33,34] The essential themes of financial hardship and social isolation as the major barriers to T2DM management reflect the impacts of structural/social racism and discrimination on the ability of older adult Haitian immigrants to achieve financial independence, which is crucial to effectively manage T2DM. Having just enough would grant our participants financial freedom and eliminate the burden of having to choose between purchasing basic items for survival and medications for T2DM. The findings of our study depict how financial hardships limit the ability of older adult Haitian immigrants to effectively manage T2DM. Furthermore, their perception of being isolated by the ethnically different neighbors reflects the ongoing social discrimination against Black/Haitian immigrants. Moreover, our

study participants viewed social isolation as a major barrier to T2DM self-management and quality of life, and their descriptions provide a better understanding of the impact of societal racism and health care discrimination in immigrant populations.[34] Regardless of the availability of community-based health programs in the localities of our participants, their lack of interaction with neighbors of a different race might have prevented them from the knowledge of or access to freely available public health services. Subsequently, decreased access to healthy food and increasingly sedentary lifestyles would lead to poor medical outcomes and health inequities. A previous study report showed that mortality is more strongly associated with social isolation than loneliness,[35] and our study findings underscore the importance of addressing the problem of social isolation among older adult Haitian immigrants.

Although facing financial hardship and social isolation, our study participants described how creating and sustaining strong networks within their Haitian communities helped them gain strength and support, which allowed them to manage their chronic T2DM better. Strong support provided by family, community, and health care providers is essential in T2DM management.[5–7,9,18–36] Despite the numerous challenges and barriers associated with social isolation and low levels of education, the participants had found strategies to successfully maintain normal A1C levels.

Limitations and Strengths

The study has a few limitations. First, this is a qualitative research study with the goal of achieving a deeper understanding of a phenomenon and not generalization.[19,20] Second, attention was focused on people dwelling in northeast cities of the United States with established Haitian communities and churches to facilitate access to the older adult Haitian immigrants, and the barriers they face may be different from those of other populations. Third, although the findings of the study may be similar to those of others, they should be considered with caution because of geographic limitations. Therefore, future studies in different geographic areas of the United States are warranted. Furthermore, future studies on distinct populations of African descent should be considered and begin to move away from categorizing Black people into one homogeneous group in research studies, which overlooks the considerable diversity within populations.

A strength of the study lies in the qualitative approach, which yielded rich data. Furthermore, the primary researcher was of Haitian origin, and this aided in gaining the trust of the study participants. Although self-reported A1C values may not be accurate, the overall good level of control suggests that the participants whose data we sampled are engaged in the self-management of diabetes reasonably well despite the identified stressors and barriers; there may be other barriers for those who are less engaged in self-care. Finally, the study emphasizes the need to address the impact of racism and discrimination as well as acculturative stress to improve T2DM self-management among older adult Haitian immigrants.

Conclusion

The older adult Haitian immigrants in the current study described financial hardship and social isolation from their neighbors of different race/ethnicity as the major barriers that limited their ability to effectively manage T2DM. Financial constraints meant prioritizing basic day-to-day needs over medications and doctor appointments. These barriers are challenging to modify through individual efforts.[34,36,37] Solutions may be found in training and empowering lay church leaders to provide information, resources, and support to their congregants with T2DM. Nevertheless, older adult Haitian immigrants found strength and support by creating and maintaining strong social ties within their own community that allowed them to self-manage T2DM. It is important to recognize that clinical, research, and public efforts are necessary to address these barriers that lead to T2DM disparities among older adult Haitian immigrants. Future cross-sectional studies are needed to examine societal factors that support T2DM self-management in older Haitian immigrants.

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Table 1

Demographic and Clinical Characteristics of the Study Participants

Variable	
Age, y	**Mean ± SD (Range)** 69 ± 7.3 (65–75)
Years of being diagnosed with T2DM	**Mean ± SD (Range)** 12.6 ± 7.0
Self-reported A1C (% [mmol/mol]) range[a]	**Mean ± SD (Range)** 7.2 ± 0.8 [55 ± 9] 5.75 ± 0.3 [39 ± 3] to 8.0 ±1.5 [64 ±16)
Sex	**n (%)**
Female participants	12 (60)
Male participants	8 (40)
Marital status	**n (%)**
Single	4 (20)
Married	8 (40)
Divorced	4 (20)
Widowed	4 (20)
Education	**n (%)**
Lower than high school	5 (25)
Some levels of high school	8 (40)
High school	3 (15)
Some levels of college	1 (5)
College graduate	1 (5)
Master's or other advanced degrees	2 (10)
Meeting financial obligations	**n (%)**
Yes	5 (25)
No	15 (75)
Health care coverage	**n (%)**
Yes (including Medicare, Medicaid)	18 (90)
No	2 (10)
Comorbidities	**n (%)**
Hypertension	12 (60)
Hyperlipidemia	8 (40)
Feeling sad/frustrated about their situation	**n (%)**
Yes	15 (75)
No	5 (25)

Abbreviation: T2DM, type 2 diabetes mellitus.

[a]Unverified A1C levels. The SI unit conversion for 7% A1C is 53 mmol/mol.

Table 2

Essential Themes and Representative Quotes

Essential themes	Representative quotes
Enduring financial hardship	Susan: “Lack of money, money to pay for healthy food, good health care is not enough.” John: “Money is never enough. I have my car insurance, family members in Haiti are included on my monthly bill, and I have a lot of my own bills. The medicines are pricey, and I have to spend $20–$25 when visiting the doctor.” Evelyne: “For many other older people like me in the church, it is very difficult for them to buy good food, you know, like vegetable, fruits, paying for their expensive insulin.” Veronica: “I am frustrated with all my medical issues and lack of resources to help. I have more money to pay for my medications because of my newly added MassHealth insurance. Six months ago, there were months in which I was only able to pick up some of the meds when my kids could not help paying.” Pierre: “Lack of resources for people like me make it hard to manage T2DM.”
Facing isolation outside Haitian community	Joseph: “We are isolated. Even more now. Our neighbors do not really talk to us because we are different.” Marie: “I am beyond frustrated. I feel neglected, isolated by all of this. English, not enough English, no neighbor friends. Many of us are the same age. I think because I am Haitian, most of them are White, they do not want to talk or invite me to some of their fun stuff.” Pierre: “I feel alone at times. You know, I do not speak good English, my kids cannot always come and stay with me, my neighbors do not know me, and I do not know enough English to reach out to them.” Previlon: “I used to be very frustrated and isolated given the culture is different. I am used to French or Haitian Creole languages. When I came here, for a good period of time, I did not have a voice. Without the language you feel isolated and like a man with his head cut off. You know, no one respects you, they think you are not educated at all and that is frustrating.” Berly: “I feel sad, frustrated, and isolated; sad from losing my wife, frustrated with all my medical issues and lack of resources, and finally, my neighborhood. I do not know what it is; older people who are different get isolated. They do not like to have us around and socialize with us much.”
Creating and maintaining a good community	Previlon: “When diabetes bothers me, I pray and ask my sisters from the church to pray with me and for me, and it works. I do not know where I would be without God.” Berly: “I do not know what I would do without the support from the church and my kids. They check on me, call, pray for me and my family.” Evelyne: “The nurse at the church helped me make some changes to the food I eat, and I started feeling better. They also connected me with another dietician who had worked with Haitians before.” Odette: “To tell you the truth, without my family and my sisters from the church, I do not know where I would be with this disease. I am glad I was able to create this support network and happy I have a good family to help me manage my diabetes.” Julene: “Make sure you have people to support you.”

Abbreviation: T2DM, type 2 diabetes mellitus.