

# EXPLORING THE LIVED EXPERIENCE OF FOOD INSECURE AFRICAN AMERICANS WITH TYPE 2 DIABETES LIVING IN THE INNER CITY

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**Purpose:** Despite evidence that food insecure African Americans with type 2 diabetes are at particularly high risk for poor health outcomes, there is currently a lack of information on their lived experience. This qualitative study aimed to identify challenges, facilitators, and barriers to effective diabetes care for food insecure African Americans with type 2 diabetes residing in an inner city.

**Methods:** In fall 2018, we conducted two focus groups attended by a total of 16 food insecure adults with type 2 diabetes residing in the inner city of Milwaukee, Wisconsin. A standardized moderator guide included questions to explore the role of food insecurity in managing diabetes, and facilitators that improve diabetes management within the context of food insecurity. Focus groups were audio recorded and recordings were transcribed by a professional transcription service. A grounded theory approach was used for analysis.

**Results:** Six major challenges existed at the individual level (diet/nutrition, exercise, diabetes knowledge and skills, complications from diabetes, a family history of diabetes, and a preoccupation with food). Five major barriers and facilitators existed both internally and externally to the individuals (access to food, medications, stress, cost of health-related needs and religion/spirituality).

**Conclusions:** This study identified multiple challenges, barriers, and facilitators to effective care for food insecure African American adults with type 2 diabetes. It is imperative to incorporate this understanding in future work by using an ecological approach to investigate strategies to address food insecurity beyond a singular focus on access to food. *Ethn Dis.* 2021;31(4):527-536; doi:10.18865/ed.31.4.527

## INTRODUCTION

Diabetes affects nearly one in 10 Americans, with type 2 diabetes accounting for 95% of diabetes cases.<sup>1</sup> Significant health disparities in the prevalence and burden of type 2 diabetes exist for minorities, with new cases being highest among African Americans.<sup>1,2</sup> Approximately 13% of African Americans are living with type 2 diabetes compared with 7% of non-Hispanic Whites, and African Americans are three times as likely to experience lower limb amputations, twice as likely to develop retinopathy, and have a five-fold higher risk of developing diabetes-related kidney disease.<sup>2,3</sup>

Major barriers to diabetes management exist at the individual,

community, and health care system levels for African Americans living with diabetes in inner city environments most affected by urban poverty.<sup>4</sup> Inner cities confer additional risk due to their historical legacies, having once served as business and industrial centers prior to employment decentralization to the suburbs and economic disinvestment in their neighborhoods.<sup>5,6</sup> Many inner cities also experienced discriminatory zoning laws and racial restrictive covenants targeting African Americans and immigrants in the 20<sup>th</sup> century.<sup>7-9</sup> These policies and practices resulted in entrenched racial segregation, high levels of income inequality, and depressed economic activity.<sup>7-10</sup> Segregated neighborhoods within inner cities

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tend to have higher unemployment rates, higher poverty, and higher rates of violent crime.<sup>11</sup> Inner city environments also create unique barriers to health care as they are more likely to have shortages of primary care physicians and quality care hospitals; historically red-lined neighborhoods have been associated with health disparities for asthma and cancer diagnosis.<sup>10-13</sup>

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ties in type 2 diabetes prevention, detection, care and outcomes for African Americans, and increased vulnerability from residing in inner city environments, access to healthy food is a particularly challenging barrier. Food insecurity is defined by the United States Department

of Agriculture as an inability to or limitation in accessing nutritionally adequate food, and the United Nations' Committee on World Food Security specified that both quantity and quality of food is necessary.<sup>14,15</sup> Food insecurity is significantly associated with increased odds of type 2 diabetes among adults, lower dietary quality and more difficulty following a healthy diet, which are important self-management factors for diabetes care.<sup>16-20</sup> In the United States, the rate of African American households with food insecurity is 21.2%, almost twice the national average.<sup>14,21</sup> In addition, food insecure individuals with diabetes report a need for culturally competent dietary counseling that accounts for their financial limitations.<sup>18-20</sup>

Despite evidence that food insecure African Americans with type 2 diabetes are at particularly high risk for poor health outcomes, there is currently a lack of information on the lived experience of food insecure African Americans at risk of or living with type 2 diabetes.<sup>22,23</sup> It has been noted that food insecure individuals with diabetes may find it especially difficult to obtain the types of foods necessary to manage their conditions, while also matching their taste and cooking preferences, and are culturally appropriate. However, limited research exists on the specific barriers and facilitators within the lived experience to address these challenges.<sup>24-27</sup> Therefore, this qualitative study aimed to identify challenges, facilitators, and barriers to effective diabetes care for food insecure African Americans with type 2 diabetes residing

in Milwaukee, Wisconsin, an inner city in the Midwest United States.

## METHODS

### Grounded Theory Approach

Grounded theory is a research methodology that allows the identification of general concepts, development of theory, and insight into lived experiences that are grounded in qualitative data.<sup>28</sup> It uses an iterative process and constructs theory based on data collected during the research process as opposed to having developed a theory prior to beginning data collection.<sup>28</sup> In addition, grounded theory relies on constant comparisons, where responses are investigated to understand similarities and differences with similar concepts grouped together under an overarching conceptual theme.<sup>28</sup>

### Study Design and Context

Two focus groups were conducted for food insecure African American adults with type 2 diabetes who reside in the inner city of Milwaukee, Wisconsin in September and October 2018. All procedures were reviewed by the Institutional Review Board at the Medical College of Wisconsin and approved prior to study initiation. Focus groups were held at community-based sites and participants were provided a \$25 incentive for participation. Two facilitators (LEE and RJW) led the focus groups using a structured moderator guide (available from corresponding author); two note takers captured comments. Focus groups were audio recorded and transcribed by a

professional transcription service. Participants introduced themselves prior to recording to maintain confidentiality so individuals were not matched to quotations for reporting results. Indexing and comparisons were completed following each focus group by facilitators and note takers. Emerging ideas and concepts were integrated into the next session to allow constant comparison analysis in identifying emergent themes.

### Recruitment, Inclusion Criteria, and Procedures

Purposive, convenience sampling was used through targeted recruitment from food pantries, soup kitchens, and other community locations offering emergency food in the inner city. Recruitment flyers advertising the focus group events were placed in more than 30 locations throughout the city and included a phone number that allowed interested individuals to call and speak to a coordinator. In addition, food pantry, soup kitchen, and emergency food site workers were informed of the purpose of the project and asked to refer interested individuals to a sign-in sheet or to call the study team directly. Participants who signed up and those who called the study line were given information on the study and were asked questions to determine eligibility. During this pre-screening, individuals self-reported if they were African American, food insecure, and diagnosed with type 2 diabetes.

Participants were also asked to self-report if, over the prior year, they had found it difficult to obtain enough food or worried that food

**Table 1. Demographic characteristics of participants in focus groups**

	Focus group 1	Focus group 2	Overall
Men, n	4	1	5
Women, n	6	5	11
Age, range in years	40-57	30-77	30-77
Diagnosed with type 2 diabetes in prior 5 years, n	4	2	6
Diagnosed with type 2 diabetes between 10-20 years prior, n	6	4	10

would run out before they had money for more. At the start of the focus group, an informational form was reviewed to ensure that participants understood the purpose of the focus group and that they were participating in a research study. The standardized moderator guide included questions to explore: 1) challenges and barriers in managing diabetes; 2) role of food insecurity in managing diabetes; and 3) facilitators and resources that improve diabetes management.

Questions were kept open-ended with probes to draw out additional perspectives and personal experiences during the discussion. Each participant was asked to respond to the first question and then the facilitator allowed additional comment by individuals and asked clarifying questions. Facilitators wrote notes to allow follow-up on any topics that may be of interest for additional detail, asked probing questions, and ensured all participants were able to provide input. Sessions lasted 90 minutes.

### Data Analysis

Initial themes and areas for further investigation were identified following the first focus group through discussion between the two facilitators and two note tak-

ers. Following the second focus group the two facilitators and two note takers again discussed themes that emerged and if additional focus groups were needed given evidence that existed in the literature and information being heard from the participants. Themes were similar between the two focus groups, so it was decided theoretical saturation had been achieved, and no further focus groups were held.

Transcripts and field notes for each focus group were reviewed by the four co-authors, with final themes decided based on consensus. Authors read and reread the entire transcript and generated a list of codes from the data. Initial coding focused on identifying as many individual topics as possible. Codes were discussed until consensus was reached regarding a set of constructs. Further discussion focused on how concepts fit together with smaller concepts grouped into categories, and categories grouped into themes based on consensus. Authors then reviewed transcripts again to determine if topics were missed and identify quotes that reflected each of the concepts. Finally, authors discussed the relationship between the different themes.

**Table 2. Summary of challenges identified through focus groups of food insecure adults with diabetes residing in the inner city**

Diet/nutrition
Knowing what to eat
Dealing with old eating habits
Access to healthy foods
Selecting foods
Exercise
Desire to exercise
Where to go for exercise
Access to places where they could engage in exercise
Benefits of exercise
Diabetes knowledge and skills
Lack of knowledge
Application of knowledge
Managing HbA1c
Existing comorbidities
Complications
Personal experience with other's who had complications
Sense of poor self-efficacy over preventing complications
Fear of complications
Fear of hypoglycemia
Poor circulation
Unexplained weight loss
Family history of diabetes
Experience of diabetes in multiple family member
Experience of multiple family members who had complications
Experience of poor treatment adherence in family members
Preoccupation with food
Access to food
Cost of food
Types of food (unhealthy vs healthy)
Knowledge about food
Cultural associations with food
Being around unhealthy food and people who eat unhealthy food

## RESULTS

A total of 16 individuals participated in the two focus groups. Table 1 provides participant characteristics. Six major challenges to managing diabetes that existed at the individual level were identified (Table 2), including diet/nutrition, exercise, diabetes knowledge and skills, complications from diabetes, a family history of diabetes, and a preoccupation with food. Five major barriers and facilitators to man-

aging diabetes within the context of food insecurity were identified that existed both internally and externally to the individuals (Table 3). These included access to food, medications, stress, cost of health-related needs, and religion/spirituality. Figure 1 provides a graphic of how major constructs are related.

### Challenges to Managing Diabetes

The first challenge identified was diet and nutrition, which included

knowing what to eat, dealing with old eating habits, having access to healthy foods, and selecting healthy options. For example, one participant stated their challenge was “*trying to eat right, knowing the stuff you don't have no business eating that's going to make your sugar go up.*”

The second challenge was exercise, including the desire to exercise, knowing where to go for exercise, having access to locations where participants could exercise, and understanding the benefits of exercise. One participant noted “*Exercise is a big help. Because it burns off your food. Instead of just eating and just laying down you got to exercise that stuff off. And that helps keep your blood sugar under control. I notice that.*”

A third challenge identified was sufficient diabetes knowledge and skills. There was a sense of lacking knowledge regarding diabetes, but also difficulty in applying this knowledge specifically when related to managing HbA1c, hypoglycemia, and hyperglycemia, and handling existing comorbidities, such as poor circulation and neuropathy. One participant stated, “*So that's one of my biggest stressors because I want to understand my diabetes. I want to know how to do better with myself.*” Another said “*My thing is trying to find out-- I know, at times, my blood sugar drops. I get that disoriented feeling, it's a terrible feeling. And I need to know why it does that, what am I doing wrong to make it do that.*” In regard to applying knowledge, one participant stated, “*generally, I used to be better than I am. But lately, I find myself*

*falling off more. So, I think my problem is just-- it's not that I don't care. I'm just not applying what I know."*

The fourth challenge was diabetes complications, including fear of complications, personal experience with others who had complications and poor self-efficacy over preventing both short- and long-term complications. Specific complications noted by participants included hyperglycemia, hypoglycemia, poor circulation, and unexplained weight loss. One participant said, *"And it's kind of affected my feet. I don't have neuropathy in it but I'm scared that might end up losing my feet."*

Many participants noted a family history of diabetes, including experiences of family members having complications or watching difficulties family members had in their efforts to adhere to lifestyle recommendations. One individual stated, *"And my mom is under control now but I used to work for her, and I didn't know at the time that I was like killing her by giving her so much-- whatever she wanted to eat, I'll put it like that...Right now, her sugar is very under control right now. And mine's are too."*

Finally, throughout the focus groups there was a preoccupation with food; the conversation consistently went back to access to food, cost of food, types of food, knowledge of food, cultural associations with food, and being around others who eat unhealthy food. One individual stated, *"Because, okay, you can go ahead and slip. But then you got to go ahead and go back to eating right. But then when you don't have the money what do you do?"*

**Table 3. Summary of barriers and facilitators identified through focus groups of food insecure adults with diabetes residing in the inner city**

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Access to food
Eating right (avoiding salty and sweet food, low/no sodium canned food)
Hard to stay away from soul food
Inadequacies of food pantries (expired food and limited fresh food)
Having money to buy fruits and vegetables
No healthy food options
Unfamiliar food
Medications
Skipping medications
Cost of medications
Lack of knowledge about equivalency of doses
Lack of knowledge of mechanism of action
Concerns about side effects
Concerns about being on too many medications
Concern over insulin versus pills
Stress
Competing needs (including caregiving)
Distrust of providers
Being able to make appointments
Stress from people in environment
Lack of social support
Cost of health-related needs
Lack of insurance
Cost of needles
Cost of medicine
Cost of insulin
Cost of copays/office visits
Challenges based on area of residence
Religion and spirituality
Reliance on God
Importance of scripture/spiritual food
Biblical guidelines on clean foods
Prayer as a solution to stress
Prayer to bear the burden of disease
Religion improves quality of life
Personal responsibility

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**Barriers to Managing Diabetes Within the Context of Food Insecurity**

The first barrier noted by participants was access to food. Specific barriers included: eating right by avoiding salty foods and sweets; using low/no sodium canned foods; finding it hard to stay away from soul food; experiencing the inadequacies of food pantries (eg, expired food); having limited access to fresh food;

having money to buy fruits and vegetables; not having healthy options at pantries for people with diabetes; and having foods that are unfamiliar or unsure of how to cook. One participant stated, *"For one, when you go into the pantry some of the things they put in there for you is not some of the healthy things in there. So you getting Ramen noodles. That's not healthy for you for diabetes, high cholesterol or high blood pressure... You*



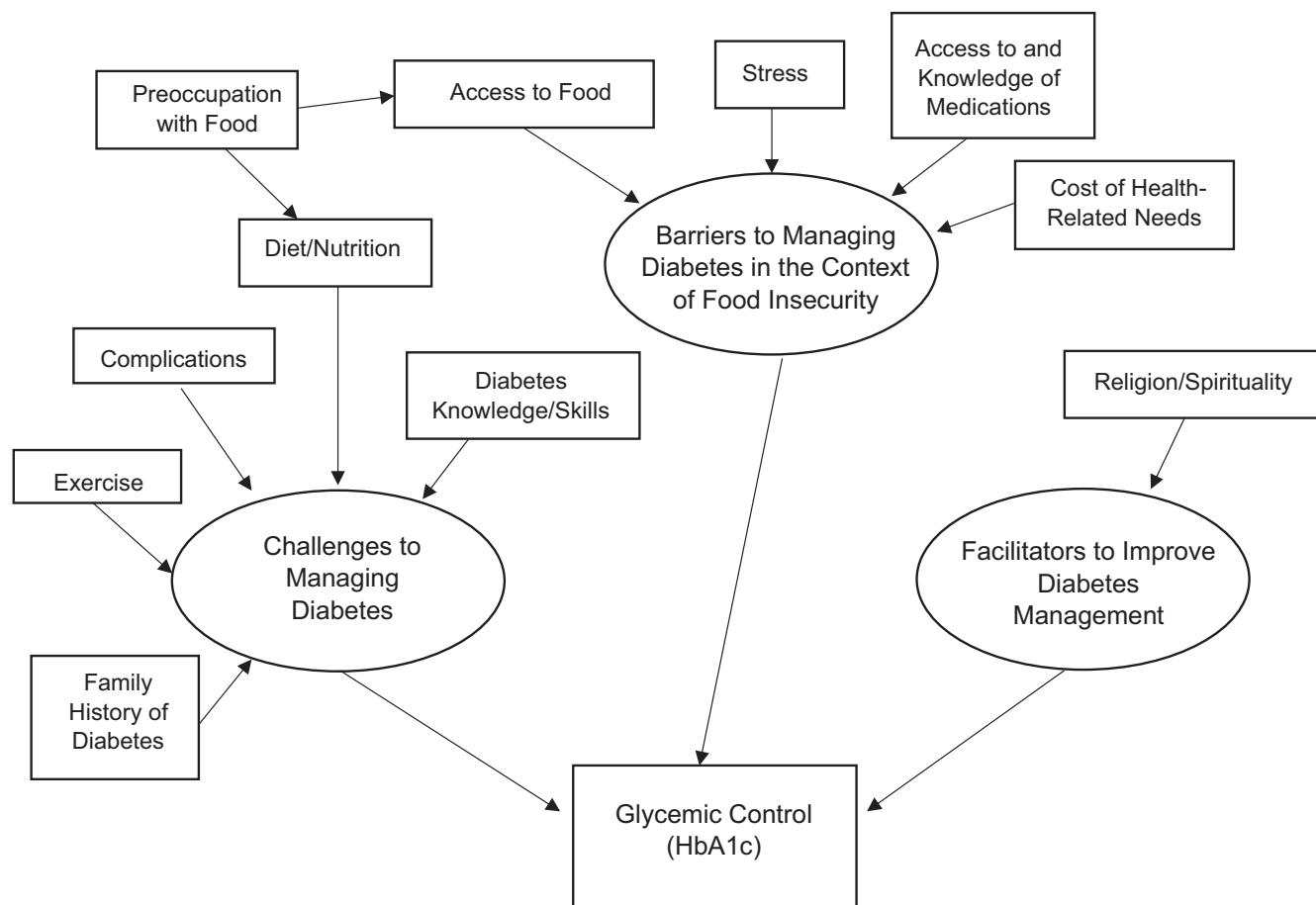


Figure 1. Relationship between themes identified in focus groups and glycemic control in food insecure adults with diabetes living in the inner city

getting canned fruit. To me, canned fruit is not healthy. Fresh fruit is more healthy to me than any canned fruit. So you not getting anything in those pantries that are healthy. So you got to take it with a grain of salt and go with it even though you know it's not healthy for you. But what do you do?"

The second barrier to diabetes care within the context of living with food insecurity was adhering to medications. There was significant conversation regarding skipping medications because of cost, lack

of knowledge regarding equivalency of doses or mechanism of action within the medication, and concerns regarding side effects, being on too many medications, and not wanting to switch to insulin. One participant said, "And then classes on kind of to maybe reducing your medication intake because every time I go to the doctor, they're presenting to me different medications, and before you know it, you've got a box full of medication. And that right there makes me feel a certain type of way..."

The third major barrier to diabetes care within the context of food insecurity was stress. Individuals noted competing needs with taking care of themselves, including caregiver burden, distress related to medical encounters including distrust of providers and being able to make appointments, and stress from people in their neighborhood and living environment, or a lack of social support. Participants related stress surrounding office visits, such as, "What stresses me out is not having

*the right doctor. Going to the doctor, I keep all of my appointments, however, my doctor just basically touch here and there and they don't take the time to listen to you and what you're going through and what you want to understand."* The stress of decisions was also noted, such as, *"you ain't probably going to live that long if you ain't got the right stuff to take care of your situation. That stress you out."*

The fourth major barrier was costs related to health care, including lack of insurance, cost of needles/test strips, cost of medicine, cost of insurance, cost of copays for office visits, and the challenges resulting from poverty and where one lives. They noted the compounding of costs, for example one participant said, *"Especially when you on a set income that's what makes it hard. And then you got to use that income to pay your bills. Then trying to pay for your medicine. And then you got co-pays when you go to the doctors. And then when they sending you to a specialist. And then when you don't get other help from the state to buy groceries or whatever, you got to come to these different pantries and stuff like that. That's even worse."*

### **Facilitators to Managing Diabetes within the Context of Food Insecurity**

There was one primary facilitating factor noted by focus group participants, which was religion and spirituality. Participants stated that faith and belief helped, and that prayer was an important part of their lives. They also noted the importance of reliance on God, seeing scripture as spiritual food, and fol-

lowing Biblical guidelines on clean food. Multiple participants stated prayer was a solution to stress, that prayer helped them bear the burden of disease, and that religion improved their quality of life. Despite the focus on God, participants also noted their own personal responsibility and did not see religion or spirituality as a reason not to take care of themselves. One individual stated, *"Spiritual food is the best food. And I wouldn't be here if it wasn't for talking to God because I have to rely on Him...I'm trying to work on that now, eating right."* A second individual noted, *"Well, with spiritual food. I intake that spiritual food all day long. I get full off that free spiritual food."* And finally, a third participant stated *"Well, we know that God, it is in his hands, but we got a responsibility to do something ourselves. We can't let God do everything. And you've got to be real faithful and believe he will take care of you, but you got things to do yourself to help him along. He loves us, but we got to love ourselves by not doing the stuff that's defiling the temple, the body."*

### **DISCUSSION**

This study identified six major challenges and five major barriers and facilitators to effective care for food insecure African American adults with type 2 diabetes. One of the primary findings was that while there was a preoccupation with discussing topics surrounding food, when asked about specific barriers and facilitators to managing type 2 diabetes within the context of

food insecurity, access to food was not the only barrier discussed by participants. Additional barriers included being able to afford and use medications, stress associated with living with type 2 diabetes and food insecurity, and the cost of health-related needs. The primary facilitating factor noted by participants was a reliance on religion and spirituality. Based on these findings, future research should investigate strategies to address food insecurity beyond a singular focus on access to food.

While access to food was not the

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only barrier noted by participants, the importance of increasing access to healthy food, and specifically diabetes friendly food, for food insecure individuals is crucial for the emergency food industry. As noted by participants, there is great variability in the types and quality of food since availability depends on the types of foods donated to and/or purchased by food banks and emergency food sites.<sup>20,21,29,30</sup> This can result in food insecure individuals'

ability to access food but inability to maintain a diabetes appropriate diet.<sup>23,24,27,30</sup> Continued work examining how to support and encourage healthy food choices at emergency food sites will be worthwhile.

Using the United Nations definition of food and nutrition security as a guide,<sup>15</sup> in addition to providing physical access to food, it is necessary to improve social and economic access as well. It is important for individuals with type 2 diabetes to have access to diabetes-friendly foods from supermarkets, pantries, farmers markets, and other food outlets within their communities. Additional barriers noted by participants, including the cost of health-related needs, stress surrounding competing needs for financial resources, and stress from individuals in their neighborhood or their living situation, identify that food insecurity is not a single experience focused on food access. This is especially salient for inner city residents given challenges posed by living in this environment, including limited access to health care facilities, high prevalence of housing instability, crime, and unemployment, and limited access to pharmacies and supermarkets.<sup>31,32</sup> Future work on integrating community resources across sectors, including the food sector, will be important to provide comprehensive support to food insecure African American managing type 2 diabetes.

An important finding to highlight is that religion and spirituality was noted as an important coping mechanism for food insecure African Americans with type 2 diabe-

tes. Religion is generally defined as an organized belief system involving practices, a shared community, and typically a public place of worship, while spirituality is defined as feelings of connectedness, peace, hope, and meaning.<sup>33-37</sup> It is believed that the mechanism for this observation is that religion/spirituality fosters a sense of hope and motivation in managing diabetes.<sup>33-37</sup> Of significance in the current study is the concept of “spiritual food” and the reliance on religious scriptures to identify appropriate diets for optimal health, and to provide upliftment, guidance, and encouragement for managing diabetes. Furthermore, participants were more likely to have an internal locus of control, thereby acknowledging their role in managing their diabetes along with God’s help, as opposed to diabetes and diabetes complications being exclusively a divine will.

## CONCLUSION

In conclusion, it is imperative to incorporate an ecological approach to future work in food insecurity by addressing the individual, interpersonal, community, organizational, and policy-level factors leading to food insecurity. Based on insights from food insecure, inner city African American adults with type 2 diabetes, future research should investigate strategies to address food insecurity beyond a singular focus on access to food. It is imperative that future programs consider the intersection between race and place and address individuals in a holistic manner.

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## CONFLICT OF INTEREST

No conflicts of interest to report.

## AUTHOR CONTRIBUTIONS

Research concept and design: Rebekah Walker, Renee Walker, Mosley-Johnson, Egede; Acquisition of data: Rebekah Walker, Renee Walker, Mosley-Johnson, Egede; Data analysis and interpretation: Rebekah Walker, Renee Walker, Mosley-Johnson, Egede; Manuscript draft: Rebekah Walker, Renee Walker, Mosley-Johnson, Egede; Statistical expertise: Renee Walker; Acquisition of funding: Rebekah Walker, Renee Walker, Egede; Administrative: Mosley-Johnson; Supervision: Rebekah Walker, Egede

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## Lived Experience of Food Insecure African Americans - Walker et al

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