

# Psychosocial Impacts of Type 2 Diabetes Self-Management in a Rural African-American Population

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**Abstract** This qualitative study explored the underlying psychosocial factors and conditions that may influence type 2 diabetes (T2D) self-management among adult T2D-diagnosed African Americans in the Arkansas Delta. Listening to participants' narratives in their own voices provided meaningful insights in their real-life experiences of T2D-related psychological and emotional challenges in African American social cultural contexts. Self-determination theory was used to conceptualize the participants' motivations for making health behavior changes. Using purposive sampling, 31 participants total (16 women and 15 men) were interviewed. The study participants described their (1) concern over prescribed dietary and physical exercise guidelines as impractical and culturally not relevant to them; (2) doubts over the availability of social supports necessary to implement T2D self-management; and (3) fatalistic expectations of negative outcomes that undermined their self-motivation to follow self-management guidelines. Specific strategies for developing culturally competent T2D selfmanagement guidelines and community-based communication outreach initiatives are discussed.

**Keywords** African Americans · Rural · Type 2 diabetes · Psychosocial impacts · Self-management · Self-determination theory · Intervention

## Introduction

Diabetes mellitus is a national epidemic. In the U.S. during 2010, about 1.9 million people aged 20 or older were newly diagnosed with diabetes, whether type 1 or type 2. With type 1, the pancreas cannot produce insulin. With type 2 diabetes (T2D), the pancreas produces insulin, but the body cannot use it properly. T2D accounts for 90–95% of all diabetes cases [1]. Complications of T2D include cardiovascular disease, kidney failure, blindness, amputations, and amputation-related mortalities. Many of these complications can be prevented because T2D is a chronic but manageable disease.

T2D self-management requires all affected Americans, whatever their cultural backgrounds, to follow a healthy lifestyle that includes a balanced dietary pattern, an exercise program, medical checkups, and doctor-prescribed medications [1, 2]. However, researchers find that T2D self-management behaviors are difficult to maintain among all racial/ethnic groups and particularly among African Americans [3–9]. Nationally, compared to non-Hispanic whites, African Americans have two to four times the rates of type 2 diabetes and associated kidney failure, blindness, lower limb amputations, and amputation-related mortalities [1, 10, 11]. These findings suggest an urgent need to better understand the underlying factors and conditions that could help T2D-diagnosed people, especially but not exclusively people from hard-hit African American community.

Our qualitative study aims to (1) examine adult African Americans' psychological states and emotional feelings upon first learning their T2D diagnosis—frustration, fear, and distrust, for example; and (2) discover from their narratives the challenges they encounter in following the guidelines for lifestyle changes in terms of diet, physical exercise, and medication. We were interested in learning

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from our study participants' answers to these questions. How did they feel when diagnosed with T2D? How do their emotions affect their ability to carry out the lifestyle changes their condition requires of them? In whom can they confide? If they can confide in anyone, how so? How do they believe they can maximize their engagement in their own daily treatment routines? Are there gender differences in this process of self-engagement? Our understanding of such psychological and emotional factors may help to facilitate and sustain the involvement of T2D-diagnosed persons in their own self-management and thus improve the health and quality of life of T2D-diagnosed African Americans.

## Background

### Impact of Psychosocial Factors on T2D Self-Management Behaviors

A growing body of theoretical and empirical research emphasizes that the effectiveness of biomedical strategies depends significantly on whether and how well they address social, psychological and environmental factors that motivate individuals to change their health behaviors [12–14]. The findings from a landmark multinational study entitled *Diabetes Attitudes, Wishes, and Needs* (DAWN), highlighted the importance of enhanced psychological care, that is, counseling and psychosocial support, to the lifting of barriers to effective diabetes self-management [15–17]. Researchers in the DAWN study emphasized how urgent it is to conduct more collaborative clinical studies on the psychosocial aspects of diabetes in order to better support self-management and improve the long-term health and quality of life of people with this condition [15].

Prior researchers examined the psychosocial and cultural aspects of T2D self-management among different ethnic/cultural groups. For example, S. Brown (n.d) found that by integrating diabetes care into their everyday lives and sociocultural contexts, Mexican–American participants improved the sustainability of T2D self-management [18]. Skelly et al. [19] studied beliefs about diabetes among African American adults at high risk for it and presented an explanatory model of their views. Several studies have examined the long-term diabetes management needs of rural African Americans with T2D and recommended specific, culturally tailored interventions for this population [20–23]. Thus, for African Americans as well as others diagnosed with T2D, the importance of psychosocial and cultural issues in T2D self-management and culturally relevant intervention strategies are well-recognized. However, African Americans still suffer disproportionately from the complications of T2D, including retinopathy,

kidney failure, and amputations, adding to their overall illness burden. To address T2D self-management issues, we need to better understand the ways African Americans themselves associate cultural and psychosocial factors with self management of T2D in their daily lives. Our study among African Americans in the AR Delta partly addresses this urgent knowledge gap.

### African Americans, T2D, and the Arkansas (AR) Delta

Significant differences exist in the prevalence of diabetes by race/ethnicity in AR. In 2010, 12.3% of non-Hispanic Blacks had diabetes, compared to 9.3% of non-Hispanic Whites and 8.8% of Hispanics [24, 25]. In the AR Delta, T2D, although underreported, is ranked number four among the state's seven health problems with the highest mortality rates for minorities. In 2007, AR's annual rate of newly diagnosed T2D cases among adults 18 years and older was 11.2 per 1,000 population, compared to the national rate of 8.0 [1] Diabetes is well-recognized as a significantly underreported cause of death in the state of AR. Only about 10–15% of death certificates name diabetes itself, instead of a diabetic complication like stroke or heart attack, as the actual cause of death [25]. At the same time, the percentage of total deaths caused by stroke and other cerebrovascular diseases—often complications of diabetes—was 54.7% for Whites and 91.7% for Blacks [25]. The AR Department of Health Diabetes Prevention and Control Program and the Diabetes Advisory Council have identified diabetes prevention, treatment, and management as a priority area [25].

### Theoretical/Conceptual Framework

#### *Self-Determination Theory and T2D-Related Health Behavior Changes*

Self-determination theory (SDT) differentiates between an individual's intrinsic and extrinsic motivations to initiate changes. SDT highlights the effects of sociocontextual factors upon individual self-motivation [26–28]. According to this theory, the fulfillment of three basic psychological needs—competence, relatedness, and autonomy—contribute to enhanced self-motivation and mental health, which in turn, encourage individuals to become engaged with and proactive in their treatment. Competence is an individual's felt sense of confidence in one's capability to engage in behavior changes and one's perception that these changes are possible within one's own sociocultural contexts. Relatedness refers to the individual's feeling of social belonging, support, and connectedness to others. Autonomy refers to the perceived outcome of personal behavior,

which is derived from the internalized values and reasons for initiating the changes [27]. Intrinsic motivation is derived from the internal desire to seek out, explore, and learn from new experiences and challenges. Extrinsic motivated behaviors, in contrast, are instrumental to a particular consequence, such as receiving a reward or avoiding punishment. The distinction between intrinsic and extrinsic regulation and the importance of competence, relatedness, and autonomy are particularly relevant to efforts in T2D self-management to change health behaviors. For example, appealing to fear of T2D's dreadful complications is an extrinsic mechanism that may intimidate African Americans without helping them to internalize values that promote actual behavior change. A sense of hopelessness may further hinder treatment seeking. Primary reliance on extrinsic regulation thus may not lead to desired health outcomes [29, 30].

## Methods

The purpose of this qualitative, community-based study was to understand T2D diagnosed African Americans' self-management in their own sociocultural contexts and identify culturally relevant ways to promote T2D self-management in African American communities. This study's qualitative data analysis applied grounded theory to recognize themes and patterns within the participants' narratives. Our narrative data collection approach encouraged participants to reveal their experiences in their own voices and enabled them to place themselves within their own stories in their familiar sociocultural and historical contexts. Listening to the participants' narratives and paying attention to the language they used, and the contexts in which they placed their T2D, we identified both problems and strengths in the participants' T2D self-management [31]. A deeper, community-level understanding of individual-level perceptions may further help to build within-community intervention strategies [32]. For African Americans, storytelling and intergenerational oral histories preserve their collective, culturally specific spiritual practices, values, traditions, and histories, including the experiences of slavery [22, 33–35]. Researchers using a narrative approach have applied participant storytelling to improve blood pressure readings among African American patients [36] and encourage cancer-related health promotion behaviors [37].

### Participants

The Institutional Review Board, Arkansas State University-Jonesboro, approved this study. The data was collected between March and July 2010. We recruited both adult

African American men and women who were age 25 or older; lived in AR Delta, and self-reported a T2D diagnosis for a minimum of 6 months before their interview date. We recruited study participants using a purposive data collection method that included outreach activities and flyers. The PI, a woman with extensive applied behavioral science research experience, contacted two African American community leaders, one male and one female. These leaders mentioned the study in community meetings and urged others to contact the PI. In addition, another African American woman very active in community organizations discussed the study in informal community get-togethers and collected the names and telephone numbers of people who were interested. Flyers were put up in stores and places where all communities but especially African Americans visited. The community advocate also visited the stores and collected information about anyone who expressed an interest in the study. Although the PI intended to have as broadly representative a range of participants as possible in regard to socioeconomic status (SES), occupation, age, and medical insurance status, the eventual sample lacked such variation in the areas of SES and medical insurance status.

### Measures and Data Collection

A thematic semistructured guide was developed for the interview (Table 1).

However, we focused upon encouraging the study participants to narrate their psychological and emotional feelings about T2D diagnosis in their own life experiences. All participant interviews were face-to-face and based upon this open-ended guide. To evaluate the appropriateness of the themes in our interview guide and identify any new ones that we needed to include, the PI conducted a pilot study with 6 participants, 3 women and 3 men. The PI conducted all the interviews. Each interview, including those during the pilot study, lasted 60–90 min.

### Analysis

This qualitative study used grounded theory. Grounded theory is a method of inquiry into social processes that can help identify links among the participants' life events. As social processes are always changing, the experiences, circumstances, and identities of the study participants may also change. A grounded theory approach allows the researcher to capture the dynamic character of the participants' lives [38]. We qualitatively analyzed the data, applying a grounded theory approach to recognize themes and patterns in the participants' narratives of T2D-related life changes. The PI and two other researchers together read the transcripts, agreed upon systematic, open coding

**Table 1** Psychosocial and emotional issues on being diagnosed with type 2 diabetes

*Broad themes for interviewee narratives/stories: Adult African Americans in Rural Arkansas*

1. Emotions upon type 2 diabetes (T2D) diagnosis (Probe: distress, concern, helplessness, challenge, fatalism, hopelessness)
2. Psychosocial aspects of attempting to follow T2D self-management guidelines (Probe: diet patterns, physical activities, medication adherence)
- 3a. Feelings about perceptions of the interviewee's T2D diagnosis among the members of his or her social networks
- 3b. Health problems over the years
4. Expectations regarding self-care and post T2D social supports from family, peers, and community members
5. Psychosocial constructions/meanings of health, illness and T2D in sociocultural context
6. Spirituality/religiosity and T2D
7. Perceptions regarding societal discrimination

procedures, and applied these to analyze each participant's stories about T2D self-management adherence and its challenges. The data analysis team included psychological and emotional perceptions of T2D diagnosis in the consensus list of codes and concepts that recurred in the participants' narratives regarding T2D self-management. The team applied an axial coding procedure to explore and identify the conceptual dimensions of the participants' emotions. Then we employed a selective coding procedure to analyze each participant's description of his or her intrinsic and extrinsic motivations and their influences upon his or her T2D self-management. Next, we identified broad patterns and themes that illuminated any links among their psychological and emotional feelings and to T2D self-management. As we read and discussed each transcript multiple times, the research team reframed these links as needed. We ensured intra-coder reliability by comparing each coder's data to that he or she gathered at different points in time throughout the coding process. In each meeting of the coding team, the PI discussed the coding categories with each coder. We ensured inter-coder reliability through an iterative process, achieving inter-coder agreement of 85% with the final list of codes and definitions. To place the participants' individual experiences in the overall context of African Americans living in the AR Delta, we examined each case on its own and as a part of the entire data set.

The PI improved the rigor of this qualitative study with three strategies: audit trails, triangulation of data, and member checking [39]. Audit trails include the use of journal entries, writing memos, field notes, and transcribed interviews to determine intra-rater reliability. Triangulation of data involved several forms of data that the PI and team members utilized to corroborate or challenge our findings. Our transcription of the interviews and our reading of relevant documents and literature added to the soundness of our data. The PI also sought out expert opinion through attendance at appropriate conferences and discussions with African American scholars. All of these strategies to improve our data quality reflected our determination and commitment to understand the life experiences of African

Americans diagnosed with T2D. In addition, the PI conducted member-checking interviews, during which she asked participants to comment on specific themes arising from their interviews.

## Results

Thirty-one African-American adults—15 men and 16 women—with a diagnosis of Type 2 diabetes participated in this study. 56% of the female participants and 60% of the men were in the age group 45–64. More than 30% of each gender group was 65 years or older. Majorities of both the women (75%) and men (67%) attended high school. Twice as many of the women as the men had college degrees. Table 2.

Although the PI intended to also recruit people who had private health plans or who were uninsured, all the men and women participants were on Medicaid/Medicare. All took prescription medications for T2D and were diagnosed with T2D by laboratory tests in addition to clinical assessments. The length of time between the T2D diagnosis and the date of interview ranged between 2 and 15 years. The following themes emerged from our participant's narratives about their perceptions of their lifestyle changes on being diagnosed with T2D.

### Fear of Failure at Following Guidelines

A majority of the participants (75% of the women and 80% of the men) revealed their doubts about their ability to make the lifestyle changes prescribed by the guidelines they received after their T2D diagnosis. They described the required lifestyle changes as "big." As a 62 year old man commented: "*Changes? Are you kidding? It is like learning how to live all over again.*" The participants were concerned that adopting the T2D self-management guidelines regarding diet, physical exercise, and medication adherence all at the same time was the most difficult challenge for them. Their sense of incompetency made

**Table 2** Study Participants Characteristics (N = 31)

Characteristics	Female (n = 16) %	Male (n = 15) %
Sex	51.6	48.4
Age (years)		
<25	0	0
25–34	6.3	6.7
35–44	6.3	0
45–54	6.3	13.3
55–64	50.0	46.7
>65	31.3	33.3
Education		
Elementary	12.5	26.7
High school	75.3	66.7
College degree	12.5	6.7
Medical insurance		
Medicare/medicaid	100	100

them feel hopeless, fearful of inevitable failure, and depressed.

#### Food Pattern

Thirteen female (81%) study participants and nine male (60%) participants revealed their concern that dietary guidelines for T2D were difficult and impossible to follow. As African Americans, they felt distressed that their culturally relevant foods are “not healthy, no good” and immediately experienced a disconnection between their community and the self-management guidelines. Both men and women described several major issues: “no potato,” “no fried foods—particularly not chicken,” “no sweets,” and “always stay on [the] diet”. When the interviewer inquired about the barriers to following these dietary prescriptions, they responded as follows. “It is my heritage, we eat fast food and fried food” (66 year old woman). A 50 year old woman divulged: “We were taught what to eat, raised on fatty, fried foods, maybe not that healthy.” At the same times, as a 55 year old man noted, there was “no money to buy fresh fruit, good food.”

We particularly wished to listen and learn from the 6 men and 3 women who did not find the dietary changes challenging after they were first diagnosed with T2D. Their responses, if any, were very general: “got to do what I got to do”, “nothing special for me”, or “I can do it all if I need to.”

Many of the participants described that in their community, they share dinner in their churches about two or three times per week. Generally they have potlucks with a “huge” spread of food served according to the buffet system. The participants were worried that attending these big dinners would be mentally stressful and emotionally

tense for them because they should not eat “forbidden foods.”

#### Physical Exercise Patterns

The majority of the women participants (75%, 12 of 16 total) were overwhelmed with the thought that they could not possibly engage in physical exercise at least 3 days a week as required after T2D diagnosis. They narrated the “big” chasm between the guidelines and the practical reality of their lifestyles in their community. Gyms were not available in their area and even if available, would be unaffordable. In fact, this disconnect between the T2D self-management guidelines and the realities of their lives caused some of the women participants to experience their doctors as “disrespectful.” However, 14 of the 15 men in our study stated that they did not feel physically fit to play the high-intensity games (such as soccer or baseball) they perceived as required for T2D self-management.

One critical aspect of the participants’ built environment came up frequently in the narratives. A 62 year old single woman narrated her concern over “where to walk? The roads are no good. I’ll fall and break my hips. Then surgery and a walker!” A 72 year old man told the interviewer, “We walk once in a while to go to friends’ houses. No one walks in the countryside. Exercises for elderly people? My parents did not do them. They lived 90+ years. Old age symptoms caught up obviously.”

#### T2D Medication Compliance

On being diagnosed with T2D, the study participants described their immediate reaction that they would have the status of sick persons for the rest of their lives. All the women in the study (15 of 16 total) expressed their certainty that they would be on T2D-related medications all their lives. Out of the 15 men, 12 men (80%) were very sure and the remaining 3 (20%) were somewhat sure that they would take T2D medication permanently. The thought of needing “shots” in the future made the men feel troubled and fearful. Both men and women participants worried about “taking pills/meds everyday”, “keep it [blood sugar] under control”, “constant watch, cannot eat like before”, “careful of diabetes attacks [too low or high blood glucose]”. The majority of the participants, both men and women, divulged their worries about blindness. “I have eye problems—losing vision—could be old age.” The men disclosed an additional anxiety: “I see so many lost their limbs, what I mean [is that] I see so many leg amputees. I am scared of not be able to walk around.” The majority of the participants revealed that their doctors advised that T2D needs consistent maintenance and self care, including regular monitoring of blood sugar (“pricking fingers”), and

ultimately they may require “*insulin shots*.” They felt nervous and helpless about what they perceived as the inevitable, final health outcomes. They had witnessed people in the community with “*loss of legs*” (lower limb amputations) and more often “*blind[ness]*.”

#### Uncertainty of Social Support to Make T2D Changes Happen

The men and women participants differed significantly in their ideas about how to make the required T2D self-management changes happen. Compared to 7 men (47%), only 3 (20%) of the women described feeling alone in their daily efforts to follow the guidelines regarding food patterns, physical exercise, and medication compliance. Men not only felt depressed because they felt alone in making these changes; they expressed more concern that their family would treat them as lifelong sick persons. To better understand the nature of expected social support, we wanted to listen to the study participants’ own voices about who could help them effectively self-manage T2D and how.

#### Ambivalence About Family Support

All women study participants except one, along with 7 (47%) of the men, mentioned that their first thought after T2D diagnosis was that their families would be their main supports. All 31 participants disclosed that their households included extended family members. For example, they were living with spouse, children, grandchildren, and their sister’s family. When this interviewer asked them to elaborate the ways in which family can be supportive, the participants were clear that family help meant preparing food, taking care of medication, and advising on physical exercises.

We were interested to learn from the 8 male participants who did not think about family as the first source of their support. Their main concern was how their special diet, medication and regular physical exercise needs will be perceived by other family members. Mainly the men participants were ambivalent. As a 67 year old grandfather stated: “*How can I say I am now sick for my whole life? They will think who will take care of this man?*” We asked a 56 year old man in this group about his thoughts: “*My family is young—young kids, wife. They may not say much but think I am a sick person.*” On second thought, this man continued: “*I have some money—it would help me for a while, I guess.*” A 68 year old single man who was recently T2D-diagnosed and lived with his daughter’s family sadly summed up: “*You are lonely—when no family, and alone—within your own family especially when you are old and sick.*”

#### Feeling of Alienation from Peers

Only 4 women (of 16 total) and one man (of 15 total) reported that they indeed thought about their peer support when first diagnosed with T2D. Both female and male participants were distrustful about disclosing their T2D status to their peers. “*It is a rural community, word will spread, and all will look at me with sympathy,*” reported a 62 year old woman. When the interviewer asked if they know any of their peers were diagnosed with T2D, the participants responded affirmatively. But at the same time, they also divulged that they learned about it “through the “grapevine” and not directly from their peers.

#### Role of the Church and Church Members

In the U.S. South, churches are central to the lives of many African Americans. We encouraged our participants to narrate their feelings about the church’s role in their own lives upon their T2D diagnosis. A majority of the participants—13 (81%) of the women and 13 (87%) of the men shared the belief that the church should not have any supportive role to play in their T2D self-management. “*I do not believe church can do anything for my diabetes care. Church is the sacred place to worship God. I come to the church to pray to God. I do not want to bring up my problems, worries, and anxieties in the church. I want peace and quietness in the church to be with God-spiritually.*” Indeed, they expressed the guilty feeling that they would violate church sanctity if they discussed their own T2D with other church members. Among the remaining 3 women and 2 men, we explored their personal thoughts about whether the church had supportive roles for them as people diagnosed with T2D. They felt very depressed because they did not know why they developed T2D when they followed God faithfully. However, they described their feeling of continued faith in “*God to take care of them*”. Their feelings of helplessness may have further undermined their capacity to adhere to their T2D regimens.

#### Lack of Belief that T2D-Related Lifestyle Changes Could Benefit Them

Beginning with their own descriptions of feeling fear, hopelessness, and depression when they were first diagnosed with T2D, the participants revealed their doubt about the benefits of medically recommended lifestyle changes.

#### Distrust of Medical Care

Although the majority of the study participants—12 (75%) of the women and 14 (93%) of the men—generally maintained some trust in their doctors as individual persons,

however, they were skeptical of the medical care system. They were suspicious of medical recommendations about regularly taking medication. *“My doctor told me to take pills regularly. Doctors always say that! I can take care of myself. If I do not feel good, I’ll take pills. (53 year old woman). They were also doubtful of the procedures followed in the doctor’s office for taking the fasting blood test and then being asked to give their personal medical history, revealing in detail their family medical history. “Doctor asked me about my family history—my parents, grandpa, grandma, about all of them. They lived a long life...don’t know how many years but did all normal things!! These questions make me feel uncomfortable!” (58 year old man).*

#### Fatalistic Attitude Upon T2D Diagnosis

A majority of the participants—14 (88%) of the women and 13 (87%) of the men—acknowledged their individual responsibility to take care of their T2D diagnosis. However, they also revealed their perceived helplessness over controlling their diabetes and their fatalistic attitudes about diabetes-related health consequences. As a 65 year old man described, *“I worry a lot about my diabetes and losing legs, and maybe earlier death. Doctor told me to prick myself three times a day to test blood sugar. But I believe in destiny. I left it to God. When He thinks it is my time to leave this world, I will be ready to go!”* The majority of the women and men trusted that God is their healer. Who always takes care of them in their challenging life situations. This belief in destiny reduced their self-motivation to make changes by themselves. As a 55 year old man explained: *“I have faith in the Lord, my wellbeing is in His hands. He saved me all the time. If you have faith in the Lord, the Lord will show you the way.”*

## Discussion

Numerous studies have documented across all cultural groups the severe consequences of non-adherence to T2D self-management [5, 16, 19, 20, 22, 29, 32] but especially among African Americans, who disproportionately bear the societal burden of the illness. These studies highlighted the importance of understanding emotions and other psychological factors that can help or hinder sustained T2D management. The current study examined the process by which psychological and emotional factors can influence the ability to self-manage T2D among adult African Americans living in the AR Delta. Using the Self Determination Theory, the following discussion conceptualizes several psychological and emotional issues with the basic psychological needs—competence, relatedness, and

autonomy—three criteria that can impede making health behavior changes. Both possible barriers to and facilitators of T2D self-management emerged from the participants’ narratives. Gender-specific differences are discussed. The study identified the following barriers.

#### Lack of Self-Competency to Follow Guidelines

According to the SDT, the felt sense of self-competence is a critical intrinsic factor that contributes to enhanced self-motivation to initiate health behavior changes. In our study, both male and female participants indicated their lack of self-confidence to follow the guidelines on being diagnosed with T2D. For example, they asked what was wrong with their food and dietary pattern they have practiced from their grandmothers’ time. Although physical exercise activities are critical for T2D management, our study participants were unsure how to follow this prescription realistically in their daily life. The emotional disconnect they felt between their real life daily routines and the recommended lifestyle changes could have contributed to feelings of helplessness. This feeling of helplessness could have led to the perceived failure of positive behavior changes outcome (i.e. autonomy), and that hampered their self-motivation to make changes.

The recommended guidelines for taking medically prescribed T2D medication and monitoring blood glucose made all participants worry that they may need to take medicine for the rest of their lives. Thus the participants had an internalized sense that they lacked “autonomy,” meaning that negative outcomes seemed inevitable to them from the time of their T2D diagnosis onward. They were thus predisposed to visualize themselves as lifelong sick persons. They divulged that health beliefs in African American social cultural contexts connect using medicine with illness. Moreover, the men’s fear of “losing limbs” as the final stage of the disease made them anxious from the time of diagnosis onward. Helplessness and fear may have impaired their intrinsic motivational expectancies and made them less willing to follow the medication guidelines.

#### Concerns About Unavailable Social Support During T2D Self-Management Initiation

Relatedness, meaning the individual’s feeling of social support and connectedness, is essential to boosting his or her intrinsic belief in the capacity to make health behavior changes. Upon their T2D diagnosis, the participants recognized their need for lifelong overall lifestyle changes that would be difficult to maintain by themselves. They recognized that family support could help them to follow the prescribed health behavior guidelines. At the same time,

they felt apprehensive that their families would perceive them as additional burdens because of their T2D disease. Indeed, their guilt over putting additional hardships upon their families may further influence their feeling of self-competence, determination to initiate changes, and decision not to follow the T2D guidelines.

The majority of the participants, both men and women, expressed their reluctance to ask for social supports from their peer and church communities. They did not disclose their T2D to their peers because they did not want to be perceived as sick people for the rest of their lives, possibly because of something they did not directly articulate during the interview: the stigma attached to T2D. Our study participants disclosed that it is psychologically painful and emotionally stressful to keep their T2D diagnosis secret. This sense of social isolation and lack of relatedness negatively influenced their internalized motivation and hindered them from exploring new things and making changes. An overwhelming majority of both men and women in our study totally opposed the idea of discussing their T2D diagnosis with other church members. They disclosed strongly their beliefs that the church is the place to worship and be thankful to God and not a place to bring up personal problems.

#### The Negative Outcome Expectancy for T2D Self-Management

It is important to note that the length of years an individual has been diagnosed with T2D impacts the trajectory of his or her illness (for example, symptoms and consequences) and thus influences how much or little he or she “accepts” the disease [40]. In our study, the interval between T2D diagnosis and date of interview ranged from 2 to 15 years. Two critical issues emerged from the participants narratives. First, the participants distrusted that they could gain benefits from following the recommended lifestyle changes. The majority of the participants appreciated their doctors as a human being. However, T2D management recommendations such as blood glucose testing and the detailed family history questionnaire raised suspicion. The PI conceptually offers two issues that may have contributed to this suspicion. One, the participants’ preference not to disclose family medical history and “pricking fingers” may be connected to African American suspicion, especially in the South, of the formal medical system— a suspicion shaped by historical experiences of racial discrimination in health care. In the rural, Southern African American community, “research” reminds elderly of the experiences and consequences of the Tuskegee experiments. This history often is passed down along younger African Americans and linked to ongoing discrimination. Because of these suspicions, the participants could be doubtful that

following the guidelines can have tangible benefits and this sense of doubt and suspicion could promote a lack of intrinsic self-motivation. Thus social conditions arising from social historical contexts could impact upon personal values and intrinsic self-motivation which will negatively affect outcome benefits from T2D self-management. However, the author emphasizes that concrete evidence is needed for these explanatory speculations and their implications for health behavior changes. Second, our participants associated outcome consequences of T2D diagnoses with fatalistic outcomes. At the same time, complete faith in spirituality gave them confidence that God will take care of their T2D.

#### Implications for Intervention Strategies

Drawn from our participants’ narratives, our study findings suggest new directions for T2D intervention strategies. Although self-motivation to pursue lifestyle change guidelines is essential, our participants’ own stories about their own lives show that socialcultural conditions and environments can facilitate or forestall intrinsic self-motivation. According to self-determination theory, health behavior changes happen when people internalize the values necessary to make the changes, expect positive outcomes for those changes, and integrate and implement these changes in their daily lives. At the same time, specific paths to self-determination and motives for following T2D self-management guidelines can vary according to gender.

The PI highlights two critical concerns regarding the development of T2D self-management intervention strategies that apply available knowledge to practice. First, medically recommended guidelines for lifestyle changes must relate to the lifestyles that people with T2D actually pursue [21, 22, 41–44]. This is because people’s social, cultural, and environmental contexts, including the effects of community history, influence self-motivation. Dietary guidelines may be more acceptable to an individual if they address his or her own “food subculture”—that is, what the “family” eats, cooks, and shops for, and how they perceive the effects of food upon the individual’s and family’s health. The replacement of the “food pyramid” with “MyPlate” (<http://www.choosemyplate.gov/>) [45] may help people with T2D more easily understand than the biomedical components of healthy dietary patterns. However, health workers need to explain food substitutions and portion sizes in terms of people’s real-life experiences. While regular physical exercises are also essential to T2D self-management, our study findings suggest that physical activities are affected by the built environment. The activity guidelines can become more effective by learning from the community what conditions and situations will

allow for easier implementation. Cooking demonstrations with community members—both men and women—in community centers, including churches, could be combined with food sharing events. Fostering community connectedness in such ways may help T2D diagnosed African Americans to dispel their feelings of alienation. This feeling of connectedness may help T2D diagnosed African Americans themselves to recognize their own capabilities and competency to make changes, internalize the guidelines, and practice them in daily life.

Another critical aspect of T2D intervention is outreach. Outreach efforts need communication strategies relevant to their audiences, with targeted/tailored messaging and exposure to messages via appropriate channels. The audience in our study consisted of adult African Americans living in AR Delta who distrusted the medical system, especially regarding the issue of “pricking” fingers. Though home blood glucose testing is scientifically sound, the participants were suspicious of it, perhaps because of their real-life social historical experiences of unethical medical experimentation. A deeper understanding of the participants’ characteristics must be the first step in developing improved communication strategies that promote self-competence in T2D self-management. The message needs to be tailored so that the audience can truly internalize the positive consequences of following the treatment guidelines. At their initial T2D diagnosis, our study participants felt worried and depressed thinking about the supposedly inevitable physical disability—limb loss—that they would face in the future. This fatalistic attitude made them immediately fearful, and less determined to change their health behaviors. A health promotion behavior approach that inspires individuals to foster their well-being and quality of life seems more personally meaningful and conducive to internalizing self-competence than a biomedical disease model of T2D which often highlights the severe consequences of non-adherence to this chronic but manageable condition [46–48]. Health promotion messages need to identify community-strengths. For example, considering the importance of faith and spirituality to our study population, messages about self-care could be communicated through scriptures affirming it as a way to honor God’s creation. It must be noted that even with a well-tailored, effective message, it is critical to thoughtfully analyze and identify the mechanisms by which that message reaches its audience. For example, T2D diagnosed African Americans may view hospital-based diabetes counselors as a part of the formal medical system and may hesitate to share own concerns with the counselors. Individual T2D spokespersons from the community or community-based health workers (also mentioned as *promoter*s) may be more acceptable to discuss their individual concerns.

Future research needs to explore two issues in this context. First, African Americans in rural communities may face somewhat different issues than urban African Americans. Confidentiality concerns may be more pronounced in rural communities. Second, the participants’ narratives clearly revealed some gender differences and similarities. Both the men and women shared concerns, for example about physical exercises and dietary patterns, but expressed different feelings about family support and adherence to the treatment guidelines.

Our findings may have the following implications for individual counseling and community outreach. For individuals and families who were comfortable with it, counseling after initial T2D diagnosis appeared to help them realize the chronic but manageable nature of the condition. Following T2D diagnosis, individuals and their families can benefit from encouragement to sustain post-diagnosis quality of life and to apply tailored treatment guidelines as a means to that end. Indeed, addressing the psychological and emotional aspects of behavior change is just as important as addressing the biomedical ones. Counselors need to offer sensitive, individualized attention to the needs of clients with T2D. At the community level, *promoter*s—men and women who have been diagnosed with T2D and have learned to manage it—could be highly effective community spokespersons and role models. For example, they could help newly diagnosed community members with barriers to self-disclosure. The *promoter*s could also tell stories about their real life experiences in the local environments to show the usefulness and applicability of clinical guidelines. The resort to *promoter*s must be a sustained, community-based health promotion strategy.

Our current study is unique because our qualitative methods allowed African Americans to relate their experiences at the time of T2D diagnosis. The greatest strength of our study was its narrative approach centered on listening and learning from adult African Americans diagnosed with T2D about their psychological distress, emotional stress, and efforts at self-management. Our findings are meaningful to the development of better, more culturally competent intervention strategies. Other strengths of our study pertain to our recruitment strategies. We successfully recruited adult African American participants, whom health care researchers have often described as a typically “hard to reach” population [49]. Because this study was conducted in the AR Delta, it presents invaluable information regarding the socialcultural contexts of geographically underserved populations in health care research.

This study qualitatively identifies psychological and emotional feelings that may impact self-determination, but it does have potential limitations. First, a qualitative cross-sectional study such as ours cannot capture causal links.

Second, the participants retrospectively narrated the psychological and emotional feelings that they experienced at the time of their initial T2D diagnosis. Their recall memory loss seemed to be minimal, considering the details in which they narrated their feelings of helplessness, incompetency, and fatalism at the time of diagnosis. Nevertheless, the data may still have this particular limitation. Third, we purposively sampled African Americans in the AR Delta. Our findings may thus not be generalizable to all African Americans or African Americans from other geographic locations.

## Conclusion

T2D self-management is often associated exclusively with following guidelines for lifestyle changes and described in terms of individual responsibility. Non-adherence is framed as an entirely personal failure. Our study provides critical information from the real-life experiences of T2D diagnosed African Americans, both men and women, namely the barriers they themselves identify to following T2D management guidelines. By listening to the participants' narratives, we gained meaningful insights into social-cultural and historical influences upon their self-determination and their motivation to self-manage T2D. Our study identifies some of the gender-specific psychological and emotional challenges to and their implications for the development of intervention strategies in African American social cultural contexts. Long-term T2D self-management is a critical issue for all Americans, but especially for the disproportionately affected African American community. Future research needs to examine whether other ethnic/cultural groups face psychosocial barriers to T2D self-management like those we have identified among African Americans. Such critical information will help to address the challenges that people of all cultural groups face with T2D self-management.

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