

University of Louisville

ThinkIR: The University of Louisville's Institutional Repository

Faculty Scholarship

1-27-2018

Understanding Diabetes-Related Distress Characteristics and Psychosocial Support Preferences of Urban African American Adults Living With Type 2 Diabetes: A Mixed-Methods Study

Sula Marie Hood
Indiana University

Amy Irby-Shasanmi
University of West Georgia

Mary de Groot
Indiana University

Elissabeth Martin
University of Arkansas at Little Rock

Andrew S. LaJoie
Follow this and additional works at: <https://ir.library.louisville.edu/faculty>
University of Louisville, lajoie@louisville.edu



Part of the [Public Health Commons](#)

Original Publication Information

Hood S, Irby-Shasanmi A, de Groot M, Martin E, LaJoie AS. Understanding Diabetes-Related Distress Characteristics and Psychosocial Support Preferences of Urban African American Adults Living With Type 2 Diabetes: A Mixed-Methods Study. *The Diabetes Educator*. 2018;44(2):144-157.

ThinkIR Citation

Hood, Sula Marie; Irby-Shasanmi, Amy; de Groot, Mary; Martin, Elissabeth; and LaJoie, Andrew S., "Understanding Diabetes-Related Distress Characteristics and Psychosocial Support Preferences of Urban African American Adults Living With Type 2 Diabetes: A Mixed-Methods Study" (2018). *Faculty Scholarship*. 789.

<https://ir.library.louisville.edu/faculty/789>

This Article is brought to you for free and open access by ThinkIR: The University of Louisville's Institutional Repository. It has been accepted for inclusion in Faculty Scholarship by an authorized administrator of ThinkIR: The University of Louisville's Institutional Repository. For more information, please contact thinkir@louisville.edu.

Understanding Diabetes-Related Distress Characteristics and Psychosocial Support Preferences of Urban African American Adults Living With Type 2 Diabetes

A Mixed-Methods Study

Sula Hood, PhD 

Amy Irby-Shasanmi, PhD

Mary de Groot, PhD

Elisabeth Martin, BA

Andrew S. LaJoie, PhD

From Department of Social and Behavioral Sciences, Indiana University Richard M. Fairbanks School of Public Health, Indianapolis, Indiana (Prof Hood); Department of Sociology, University of West Georgia, Carrollton, Georgia (Dr Irby-Shasanmi); Division of Endocrinology, Indiana University School of Medicine, Indianapolis, Indiana (Dr de Groot); University of Arkansas for Medical Sciences College of Medicine, Little Rock, Arkansas (Ms Martin); Department of Health Promotion and Behavioral Sciences, University of Louisville School of Public Health and Information Sciences, Louisville, Kentucky (Dr LaJoie).

Correspondence to Sula Hood, PhD, Department of Social and Behavioral Sciences, Indiana University Richard M. Fairbanks School of Public Health, Office 6051, 1050 Wishard Boulevard, Indianapolis, IN, 46202, USA (sulahood@iu.edu).

Acknowledgments: This research was supported by a Signature Partnership Grant from the University of Louisville Commission on Diversity and Racial Equality and a Doctoral Scholar Dissertation Award from the Southern Regional Education Board. A special thank you to Dr A. O'tayo Lalude of the Westside Family Medical Center and Dr Gina Pariser of the Active Steps for Diabetes program for assistance with participant recruitment.

DOI: 10.1177/0145727118754325

© 2018 The Author(s)

Purpose

The purpose of this study is to understand diabetes-related distress (DRD) characteristics and identify psychosocial support preferences of urban African American adults living with type 2 diabetes (T2DM).

Methods

A 2-phase, mixed-methods sequential explanatory study design was used to gather data. In phase 1, a purposive sample of participants (N = 155) was recruited and asked to complete a written survey. The Diabetes Distress Scale (DDS17) was used to assess DRD, including subscales—emotional burden (EB), regimen distress (RD), interpersonal distress (ID), and physician distress (PD). In phase 2, a subset of phase 1 participants (N = 23) volunteered to attend 1 of 4 gender-stratified follow-up focus groups to contextualize the quantitative survey results.

Results

Survey findings indicate that on average, participants had moderate levels of DRD (aggregate), RD, and EB but had low ID and PD. During follow-up focus groups, participants described RD and EB as their primary distress types and emphasized that clinicians should prioritize the

mental health aspects of T2DM similarly to its physical aspects. Participants expressed a desire for culturally appropriate peer support groups as a psychosocial support resource for distress coping and specifically requested the development of gender-stratified groups and groups for young adults.

Conclusions

Results support the need to screen for and address diabetes-related distress among African American patients with T2DM. Findings also inform the development of culturally appropriate psychosocial support resources to facilitate diabetes-related distress coping.

.....

Diabetes is a chronic disease that affects 30.3 million people in the United States.¹ In adults, type 2 diabetes (T2DM) accounts for nearly 90% to 95% of all diagnosed cases of diabetes.¹ The burden of diabetes falls disproportionately on African Americans, with prevalence estimates indicating that 13.4% of African American adults have been diagnosed with diabetes in comparison to 7.3% of white adults.¹ African Americans have also been observed to have higher rates of diabetes complications and mortality rates than white Americans.²

The prevalence of serious psychological distress has been observed to be twice as high among individuals with diagnosed diabetes compared to individuals without diabetes.³ Many daily tasks, including carbohydrate counting, checking glucose levels, and meal-centered medication glycemic control, involved in diabetes self-management, can create diabetes distress, where individuals feel emotionally burdened. Diabetes-related distress (DRD) is uniquely associated with the diagnosis of diabetes, self-management demands, comorbidities and diabetes complications, and lack of supportive relationships.⁴ Unlike affective and anxiety disorders, which tend to be episodic, diabetes distress has been observed to be chronic in that it persists over time.⁵ Diabetes-related distress has been positively correlated with the length of diagnosis of diabetes (ie, chronicity) and the number of diabetes complications experienced.⁶ Psychological distress has also been associated with a lower quality of life among adults living with T2DM.⁷

Gender disparities have been observed in DRD, where women have reported feeling more distressed than men.⁸ Women have also been observed to have more chronic distress over time.⁵ Racial differences also exist in perceived DRD. Specifically, African American adults have reported higher levels of DRD than whites, including a greater perceived interference of diabetes with daily life and increased perceived diabetes severity.⁹ In previous studies, African American adults living with T2DM have reported feeling stressed, frustrated, and overwhelmed by the demands of diabetes self-management.^{10,11} African Americans are also more likely to express feelings of guilt, particularly guilt for an inability to care for others as they did prior to their diagnosis.¹² Additionally, perceived severity of diabetes and perceived level of diabetes self-management knowledge have been linked to DRD among African Americans. In a previous study by Spencer and colleagues,¹³ African American adults who reported their case of diabetes as being more serious and those who reported having less understanding of how to manage their diabetes were found to have increased DRD.

For many African Americans living with T2DM, social support from family and friends plays a critical role in their coping with the demands of self-management.^{14,15} In previous qualitative research, African American study participants have also identified peers, or other individuals with T2DM, as a source of emotional and informational support.^{10,16} In contrast, insufficient social support from other types of social network members, such as family and friends, has been associated with increased emotional distress among patients living with T2DM.¹⁷ Lack of physician support has also been observed to be a significant predictor of emotional distress among African Americans living with T2DM.¹³

Psychological health is an important determinant of diabetes coping and self-management. While a substantial amount of effort has been devoted to promoting physical health among African Americans living with T2DM, the psychological health needs of this population have received less attention. The purpose of this study was to gain an understanding of the DRD characteristics and psychosocial support preferences of urban African American adults living with T2DM.

Methods

Three overarching research questions guided this study:

Research Question 1: To what extent do African Americans living with T2DM experience DRD?

Research Question 2: What aspects of T2DM cause the most distress among African Americans living with the condition?

Research Question 3: What psychosocial support resources would African Americans living with T2DM like to have available to assist with their T2DM coping?

Design

A 2-phase, mixed-methods sequential explanatory study design¹⁸ was employed to understand diabetes distress characteristics and identify psychosocial support preferences of urban African American adults living with T2DM. In phase 1, African American adults living with T2DM were asked to complete a one-time written survey about their experience coping with and managing T2DM. In phase 2, participants from phase 1 were invited to follow-up focus groups to contextualize quantitative results. In particular, the contextual qualitative narrative data collected in phase 2 afforded the opportunity for comparative analysis, to validate and gain a more in depth understanding of the phase 1 quantitative results. All study procedures were approved by the University of Louisville Human Subjects Protection Program Institutional Review Board (IRB; protocol No. 11.0706).

Sample and Recruitment

African American adults living with T2DM were recruited between February and June 2012. Participants were recruited from community-based settings using a variety of strategies. IRB-approved recruitment flyers were posted on information boards at local hospitals, social services provider buildings, and libraries, as well as at African American beauty salons, barbershops, and churches. Additionally, flyers were posted on information boards throughout the University, to increase African American young adults' awareness of the study opportunity. A digital version of the study flyer was also included in the "research opportunities" section of the weekly electronic newsletter for University of Louisville employees. Electronic flyers were also distributed to local community health agencies for posting and sharing within their networks. As African American males have been observed to be an underrepresented group in health-related research,¹⁹ special efforts were made to recruit this population, including recruiting from African American barbershops and partnering with meetings and events hosted by local chapters of African American male

social groups, such as historically black fraternal organizations and the 100 Black Men of America, Inc.²⁰ Study participants were also recruited from local African American churches via in-person study opportunity announcements delivered by the study principal investigator (S.H.). Lastly, participants were recruited in person from local health fairs via an information table, the waiting room of a local diabetes specialist clinic, and Active Steps for Diabetes,²¹ a community-based physical activity and self-management education program for individuals living with T2DM.

Individuals were eligible to participate in the study if they were self-identified as non-Hispanic black, diagnosed with T2DM by a physician, 18 years or older, and a resident of the Louisville metropolitan area. Following the completion of the written survey in phase 1, participants were entered into a drawing for a \$100 gift card.

At the conclusion of each phase 1 survey, participants were asked to indicate their interest in being contacted to participate in a follow-up focus group (phase 2). Participants who selected "yes" were asked to provide their phone number and email on a contact form, thus comprising the phase 2 recruitment list. Eighty percent of the phase 1 survey sample (124/155 participants) selected yes to being contacted later for a phase 2 follow-up focus group. Efforts to contact phase 2 participants were delayed until the phase 1 data collection period was completed. Three contact attempts were made for each prospective focus group participant before removing them from the phase 2 recruitment list. In the event that the participant did not answer his or her phone, a voicemail was left with the study contact number. Participants who were reached were asked their availability to attend a focus group on 1 of 4 Friday or Saturday afternoons in June 2012. Two dates were designated for male focus groups, and 2 dates were designated for female focus groups. A total of 23 of the individuals (10 males and 13 females) reached were available to attend a focus group during the designated dates. Each of the 4 focus groups was comprised of 4 to 7 participants. Each focus group participant was compensated with a \$25 gift card to a local grocery store.

Data Collection

Demographic Survey

General demographic variables collected included gender, age, income, education level, employment status, marital status, and household size. Health-related demographic

information collected included self-reported length of diabetes diagnosis, medication type, diabetes self-care, perceived diabetes social support, and primary source of diabetes support. Diabetes self-care was assessed using the Summary of Diabetes Self-Care Activities²² (Cronbach's alpha = 0.79). Diabetes social support was assessed using the Diabetes Care Profile (DCP)²³ social support scale (Cronbach's alpha = 0.92).

Diabetes Distress Scale

Diabetes-related distress was the primary outcome of interest for the current analysis. The Diabetes Distress scale (DDS17)²⁴ was used to assess diabetes distress among participants in the study. The DDS17, a 17-item instrument consisting of 4 subscales, assessed perceived distress related to the emotional burden of diabetes (EB), physician-related distress (PD), regimen-related distress (RD), and diabetes interpersonal distress involving family and friends (ID). Specifically, the instrument measured the extent to which respondents perceived diabetes aspects to be a problem using a 6-point Likert-type scale. Researchers have suggested that 3 patient subgroups exist regarding DDS17 cut points: A score of <2.0 indicates little or no distress, 2.0 to 2.9 indicates moderate distress, and ≥ 3.0 indicates high distress.²⁵ The Cronbach's alpha coefficient was 0.93 for the total instrument, 0.90 for the RD subscale, and 0.88 independently for the EB, PD, and ID subscales, indicating high internal consistency for the current study sample.

Focus Groups

In phase 2, 4 gender-stratified follow-up focus groups (2 male, 2 female) were conducted to contextualize the phase 1 quantitative findings. Each focus group was held in a private meeting room at a local community organization. The study principal investigator (S.H.), who was racially matched to the participants, facilitated each focus group and was accompanied by an African American trained observer who took notes. Each focus group was audio recorded. During the focus groups, participants were asked to discuss their perceptions and experiences concerning the specific aspects of diabetes that cause them the most distress. They were also asked to discuss their preferences for community-based psychosocial support resources that would assist them with better managing and coping with their T2DM. The full set of focus

group questions is available from the corresponding author upon request.

Analysis

Quantitative

SPSS 24.0 quantitative data analysis software was used to analyze the quantitative data. Chi-square analysis was conducted to assess for significant differences in categorical demographic variables by gender. Independent sample *t* tests were conducted to assess for significant differences in continuous demographic variables by gender. Level of significance was set at $P \leq .05$ for all analyses.

Qualitative

Focus group recordings were professionally transcribed and then coded using Atlas.ti version 6.2 qualitative analysis software. Emergent themes were identified in the transcripts using inductive content analysis.²⁶ First, open codes were applied to participants' narrative statements of similar content to reveal primary themes. Next, a nested coding approach was used to identify subthemes that were contained within each primary theme.²⁷ Analyses were conducted on the aggregate focus group sample to assess common themes across all groups. Stratified analyses were also conducted on the basis of gender to identify any qualitative differences that exist between African American men and women as it pertains to T2DM distress and preferences for T2DM psychosocial support.

Phase 1 Survey Results

General demographic characteristics of the sample are presented in Table 1. A total of 155 African American adults (67 males, 88 females) completed the written survey. The average participant was 56 years old (range, 27-84 years), where most were 55 or older. Over one-third (37.7%) of the sample was married; however, a significantly greater proportion of male participants were married than female participants, who were more likely to be separated/divorced and widowed ($P < .001$). No significant differences were observed between male and female participants regarding household size, education level, and employment status. Nearly one-third (31.6%) of the sample reported that they live alone. The sample was highly educated, with 38.7% of participants having some college or technical school experience and 32.2%

Table 1

Sample Characteristics by Gender (N = 155)

Characteristics	Total (N = 155)		Male (n = 67)		Female (n = 88)		P Value
	No.	% (SD)	No.	% (SD)	No.	% (SD)	
Age (y) ^a	56.4	(10.0)	55.3	(8.4)	57.2	(11.0)	.226
Marital status ^b							<.001
Never married	38	24.7	15	22.7	23	26.1	
Married	58	37.7	37	56.1	21	23.9	
Separated/divorced	44	28.6	13	19.7	31	35.2	
Widowed	14	9.1	1	1.5	13	14.8	
Household size ^a							.696
Live alone	49	31.6	17	25.4	32	36.4	
Live with 1 other	54	34.8	25	37.3	29	33.0	
Live with 2 others	23	14.8	11	16.4	12	13.6	
Live with 3 others	18	11.6	9	13.4	9	10.2	
Live with 4 or more	11	7.1	5	7.5	6	6.8	
Education							.960
Less than high school	5	3.2	3	4.5	2	2.3	
Some high school	8	5.2	3	4.5	5	5.7	
High school or GED	32	20.6	13	19.4	19	21.6	
Some college	60	38.7	26	38.4	34	38.6	
College degree	27	17.4	11	16.4	16	18.2	
Graduate degree	23	14.8	11	16.4	12	13.6	
Employment							.460
Employed	73	47.1	35	52.2	38	43.2	
Unemployed	9	5.8	4	6.0	5	5.7	
Homemaker	1	0.6	0	0.0	1	1.1	
Student	2	1.3	0	0.0	2	2.3	
Retired	145	29.0	16	23.9	29	33.0	
Disabled	21	13.5	9	13.4	12	13.6	
Other	4	2.6	3	4.5	1	1.1	

^aMean values reported.
^bSignificant at $P \leq .001$ level.

of the sample having a bachelor's degree or higher. The most commonly selected employment status category was employed (47.1%), followed by retired (29.0%).

Diabetes-specific sample characteristics are presented in Table 2. Most of the study participants (90.3%) had a family history of diabetes. However, a significantly

greater percentage of female participants reported having a family history of diabetes than males ($P < .05$). Male and female participants did not significantly differ in the length of their diabetes diagnosis, medication type for managing their condition, diabetes self-care, or history of attending a diabetes education class. On average, most

Table 2

Diabetes-Specific Sample Characteristics by Gender (N = 155)

Characteristics	Total (N = 155)		Male (n = 67)		Female (n = 88)		P Value
	No.	% (SD)	No.	% (SD)	No.	% (SD)	
Family history of diabetes ^a							.012
Yes	139	90.3	55	83.3	84	95.5	
No	15	9.7	11	16.7	4	4.5	
Length of diagnosis (y) ^b	9.5	(8.1)	9.1	(7.1)	9.7	(8.7)	.212
Medication type							.224
Insulin only	26	16.8	14	20.9	12	13.6	
Pills only	83	53.5	30	44.8	53	60.2	
Insulin and pills	38	24.5	20	29.9	18	20.5	
No medication	8	5.2	3	4.5	5	5.7	
Diabetes self-care ^b	4.0	(1.4)	4.2	(1.4)	3.8	(1.4)	.711
Diabetes social support ^b	3.9	(1.1)	3.9	(1.2)	3.9	(1.0)	.260
Primary source of help ^a							.009
Family	54	34.8	33	49.3	21	23.9	
Friends	6	3.9	2	3.0	4	4.5	
Health care professional	54	34.8	16	23.9	38	43.2	
No one	41	26.5	16	23.9	25	28.4	
Diabetes education class							.955
Yes	113	72.9	49	73.1	64	72.7	
No	42	27.1	18	26.9	24	27.3	

^aSignificant at $P \leq .05$ level.
^bMean values reported.

participants had been diagnosed with diabetes around 9.5 years. Most participants (53.5%) managed their diabetes with oral hypoglycemic agents (OHA) only or a combination of insulin and OHA (24.5%). As a whole, the sample scored moderately in terms of diabetes self-care (mean = 3.95 on a 7-point scale). While participants reported relatively high diabetes social support from their family and friends (mean = 3.9 on a 5-point scale), males and females significantly differed in their primary source of support for their diabetes ($P < .05$). Specifically, males primarily listed family (49.3%) as their main source of help for their diabetes while females typically relied on health care professionals (43.2%) or no one at all (28.4%) to help with their diabetes. Over a quarter (26.5%) of the sample reported that no one helped them with their diabetes. The majority (72.9%) of the partici-

pants reported that they had attended a diabetes education class before.

Diabetes distress outcomes for the study sample are presented in Table 3. Overall, DDS17 results indicate that our participant sample experienced a moderate level of DRD (mean = 2.1). Concerning distress subscales, our data indicate that participants experienced little or no interpersonal distress or physician distress (mean scores = 1.8 and 1.6, respectively). However, the sample was observed to experience greater (moderate) distress as it relates to managing their regimen and regarding the emotional burden that T2DM has on their lives (mean scores = 2.4 and 2.3, respectively). No significant differences in diabetes distress were observed by gender with the exception of PD, where male participants were observed to experience a significantly greater level of distress in

Table 3

Diabetes-Related Distress Outcomes for Study Sample (N = 155)

Diabetes-Related Distress (1-6)	Total (n = 155)		Male (n = 67)		Female (n = 88)		P Value
	M	SD	M	SD	M	SD	
Aggregate scale	2.1	0.1	2.0	1.0	2.2	1.0	.917
Regimen distress subscale	2.4	1.3	2.3	1.2	2.5	1.4	.078
Emotional burden subscale	2.3	1.3	2.1	1.3	2.5	1.3	.653
Interpersonal distress subscale	1.8	1.1	1.8	1.1	1.8	1.0	.689
Physician distress subscale ^a	1.6	1.1	1.7	1.3	1.5	0.9	.004

^aSignificant at the $P \leq .005$ level.

association with their physicians than female participants ($P < .005$).

Phase 2 Follow-Up Focus Group Results

Four gender-stratified follow-up focus groups were conducted with a subset of phase 1 participants. A total of 23 (10 male, 13 female) individuals participated in the follow-up focus groups. Each focus group was comprised of 4 to 7 participants. Focus group 1 consisted of 7 female participants, focus group 2 consisted of 4 male participants, focus group 3 was attended by 6 female participants, and focus group 4 was attended by 6 male participants. Focus groups lasted between approximately 1 hour and 1 hour and 20 minutes, yielding a total of 6 hours of audio-recorded data.

A list of emergent focus group themes and subthemes is presented in Table 4. When asked about the aspects of diabetes that were most stressful, participant responses primarily focused on regimen-related distress and the emotional burden of living with and managing T2DM. Very little commentary was made regarding interpersonal distress or physician distress. When asked about their psychosocial support preferences, participants primarily expressed a desire for peer support in the format of peer support groups, and they provided information about perceived benefits of peer interaction and specific attributes they would like to have available within peer support groups. They also expressed a desire for health care providers to prioritize mental health in diabetes care.

Detailed information regarding themes and subthemes is provided in the following section, along with exemplary quotes from focus group participants. Each exemplary quote is accompanied by the speaker's gender, number, his or her age, and his or her distress score.

To contextualize the survey findings regarding African Americans' experiences with DRD, follow-up focus group participants were asked, "What are the things that stress you out the most about having diabetes?"

Regimen-Related Distress

Phase 1 survey participants scored higher on the RD subscale than any other DDS17 subscales. Approximately 28.4% of survey participants had moderate RD, and 29% fell into the high RD category, indicating that self-management was a particularly stressful aspect of living with T2DM. Follow-up focus group discussions mirrored these quantitative findings as many participants shared their frustrations about their T2DM self-management regimens, primarily regarding medication and dietary regimens.

Medication Intensity and Diabetes Distress

Participants expressed that they were especially frustrated with their medication regimen as it was the most commonly discussed source of regimen-related distress. Both male and female participants indicated that they were overwhelmed by the intensity of their medication regimen requirements. In particular, they felt stressed by the amount of pills needed to manage their diabetes on a daily basis.

Table 4
List of Prominent Focus Group Themes and Subthemes

Topic	Themes and Subthemes
Distress: Regimen-related distress	Medication regimen <ul style="list-style-type: none"> • Frustration with medication intensity Dietary regimen <ul style="list-style-type: none"> • Meal preparation planning <ul style="list-style-type: none"> ○ Feeling deprived of food options • Eating during social gatherings <ul style="list-style-type: none"> ○ Feeling deprived of opportunity to partake ○ Struggling with adherence during holidays • Adjustment to suggested changes <ul style="list-style-type: none"> ○ Urgency of dietary modifications ○ Clash with individual preferences ○ Clash with cultural traditions
Distress: Emotional burden	Variety of emotions experienced <ul style="list-style-type: none"> • Anger • Denial • Frustration • Anxiety • Depression Intrusiveness of diabetes <ul style="list-style-type: none"> • Feeling controlled on a daily basis <ul style="list-style-type: none"> ○ Feeling that glucose levels dictate everything • Chronicity of diabetes <ul style="list-style-type: none"> ○ Feeling like a never-ending battle
Psychosocial support preferences	Opportunities to interact with peers <ul style="list-style-type: none"> • Peer support groups Culturally appropriate peer support groups <ul style="list-style-type: none"> • African American groups • Gender-stratified groups • Young adult groups Integration of mental health into diabetes care <ul style="list-style-type: none"> • Desire for providers to prioritize mental health

Male 1, 56 (RD = 2.8): Sometimes I'm like God, this is my life right here—all these pills...emotionally it could just really drain you.

Female 1, 62 (RD = 1.0): The biggest part is, for me anyways, is the taking of so many medications....It just stresses me out that I take so many pills every day.

Dietary Regimen and Diabetes-Related Distress

While the phase 1 survey findings suggested that participants were moderately adherent to T2DM dietary

self-management recommendations (mean = 4.1 on a 7-point scale), dietary self-management was observed to be a primary area of concern among the follow-up focus group participants and a significant source of stress and frustration. In particular, they expressed concerns about meal preparation, dietary adherence in social settings, and adjustments to suggested dietary changes. Participants frequently discussed their dietary frustrations in the context of perceived limitations regarding foods that they were allowed to eat such that they felt deprived of food options.

Difficulty of preparing meals was a common topic of discussion primarily among female focus group participants, where some women were stressed by the amount of effort and problem-solving skills needed to plan appropriate meals.

Female 2, 51 (RD = 2.6): Annoying, frustrating....It just takes an effort for every meal for me to plan it or check what I'm eating.

Female 3, 57 (RD = 1.8): Not being able to cook all the food is stressful. You stand there and try to figure out what you gonna do.

Additionally, several female participants indicated that they were stressed by perceived limitations of their dietary regimen during social outings at restaurants as well as special social gatherings, such as holidays.

Female 1, 62 (RD = 1.0): The eating out part is really hard... 'cause you see all this good food and you're like "I can't do that."

Female 4, 44 (RD = 1.4): You know, it gets stressful especially at Christmas or Thanksgiving 'cause you've got cakes, cookies, everything coming toward you.

Lastly, both male and female participants discussed being frustrated by the immediate necessary changes in dietary behaviors, which created a sense of urgency due to the seemingly abrupt modification of their usual eating habits and preferences. In particular, participants stated that the T2DM dietary regimen clashed with their food-related cultural traditions, routine, and overall identity, as noted by one man and one woman with moderate RD scores.

Male 2, 59 (RD = 2.0): All of a sudden you've got diabetes.... You've got to change everything about food and eating.... You can't eat like you used to, you can't eat what you used to.... Change it or you'll die.... So that's my frustration,... trying to make that change.... Trying to learn, relearn something that

you've done for 49 years. . . . You can't gradually slide into it. No, you need to change it now.

Female 5, 55 (RD = 2.0): Food makes me happy. Now you're telling me I gotta give it up and I've got to give it up in such a way, I've got to go to things that are foreign to me. My mother never cooked zucchini and all that other different vegetables that you're telling me that I need.

Emotional Burden

The EB subscale was the second highest average subscale score among phase 1 survey participants. A quarter (25.2%) of the phase 1 survey sample met the criteria for moderate EB, and another quarter (25.8%) reached the cut point for high distress, indicating the need for clinical attention. To contextualize the EB survey responses, the facilitator asked follow-up focus group participants, "What types of feelings and thoughts do you have about having diabetes?" Participants provided a variety of responses regarding their emotions related to diabetes, including feeling *angry* about their diagnosis, feeling in *denial* about the reality that they have diabetes, and feeling *frustrated* and *anxious* about the demands of self-care. However, of all the topics related to the emotional burden of diabetes, participants mostly frequently discussed *depression*.

Depression and Diabetes

Several male participants reported feeling depressed because of living with T2DM.

Male 3, 69 (EB = 2.8): Depression is something else. I been depressed about this [diabetes]. I had to go to the doctor about this depression.

Male 1, 56 (EB = 5.6): [You have] depression at times. . . . because of the fact that you know this is a every day, day in and day out thing. Nothing change about it every day.

Similarly, one female participant described the comorbidities that result from having diabetes as being as cause of depression.

Female 6, 38 (EB = 2.4): It's just the other problems that come along with it [diabetes] or aside from it, and then just being able to function. It's depressing. You become really depressed.

Intrusiveness of Diabetes

A more common observation among female participants was the sense of feeling controlled by diabetes, which in turn made them feel helpless. In some instances, the perceived control of diabetes influenced participants' motivation to manage their condition so that they could avoid the guilt of nonadherence. Additionally, some women discussed their frustrations with the fact that diabetes is a *chronic*, long-term condition.

Female 5, 55 (EB = 3.8): Sometimes I feel helpless, because I am no longer in control of my life. . . . I wake up in the morning and stick myself and this little meter dictates how I am going to run the rest of my day. . . . If I slip, I got to deal with all of that guilt. . . . So emotionally I am not in control of my life. So, diabetes is like an emotional roller coaster for me. You know, I'm up and down.

Female 1, 62 (EB = 2.6): Just knowing that it's a lifetime thing. That it's not going to go away. You could lose weight, you could do everything right and everything. It's still not going to go away. It's going to always be there. I think that's the thing that gets to me the most.

One male participant who had a high EB score described his frustration with the *controlling* and *intrusive* nature of diabetes comorbidities and self-management in his daily life.

Male 4, 60 (EB = 6.0): What I find most disturbing about diabetes is, I mean, it upsets everything. I get absolutely no sleep at night because I go to the bathroom about 6 times. . . . And with the diabetes, my circulation is just gone. . . . so I get numb, all in my hands and my arms, my feet, my legs. . . . It's a night and daymare, really. . . . they say 5 small meals, that's really very hard to do. . . . And it's not always at the opportune time but I have to consider what my numbers are. . . . It's just not good.

Psychosocial Support Preferences

Over a quarter (26.5%) of the phase 1 survey sample reported that no one helps them with their diabetes, and nearly a third of the sample lived alone. Reflective of the phase 1 quantitative findings, follow-up focus group participants emphasized their desire to have more support available for improving their T2DM coping. At the conclusion of the focus group interview, the facilitator asked

participants, “What would you like to see in a support program for people living with diabetes?” in an effort to inform the development of psychosocial support resources for African Americans living with T2DM. A frequent response among both male and female participants was the desire to participate in peer support groups. Interestingly, at the conclusion of *every* focus group, several participants asked the facilitator when the next “support group” would be scheduled. While the focus groups were being conducted for research purposes, participants benefitted from the focus groups in that they afforded the participants the opportunity to be in the presence of others with whom they share the experience of living with T2DM.

Peer Interaction Reduces Feelings of Isolation

Focus group participants described peer support groups as opportunities to provide informational support to peers. They also discussed how peer support group participation reduces feelings of isolation by allowing individuals to interact with others who are also living with T2DM. Several focus group participants spoke about the peer support that they received through their participation in the focus group.

Male 5, 51 (DDS = 1.5): Listening to other people, like we’re doing now is helpful. Finding out more insight about it...I don’t feel so odd about it no more.

Female 7, 31 (DDS = 4.4): It makes you feel like you’re not the only person dealing with this, and, you know, some things that I may have experienced...maybe can help her. Or things that she’s talking about...[are] things I may be thinking about.

Peer Interaction Facilitates Empowerment

Additional benefits of peer interaction were also discussed among the focus group participants, where several participants suggested that the experience of sharing with and listening to other focus group participants living with T2DM empowered them to them to better manage and cope with their T2DM.

Male 6, 44 (DDS = 3.1): Until today...I mean I thought I was [confident], but to hear these gentlemen...Mr. [name removed] here, he does exercises and everything and I do nothing. And it’s given me an opportunity to take a look at it and see how a terrible job...that I’ve been doing to save my own life.

Female 8, 54 (DDS = 2.4): Just listening to everybody’s actual thoughts and stuff, this is motivating me. I’m learning something and I think I can work with it. If they can do it I can do it too.

Culturally Appropriate Peer Support

Focus group participants also provided insight about their support group composition preferences. Both male and female participants indicated that they preferred to participate in a peer support group comprised of individuals with whom they share common characteristics, including gender, race, and age. Specifically, individuals suggested that such commonalities would allow them to feel even more connected to their peers and receive information in a relevant context.

Male 7, 45 (DDS = 1.2): I’m a black man—I want to be around my [black] brothers. You [other races] may have the same disease but for many of us it’s just not physical, it’s social. You know, there’s a social element to that...one thing is, we always have a common thread that binds us all together...our faith and our family. And that’s comforting to know...We know what’s going on, you know.

Female 9, 27 (DDS = 3.2): I know I have been to these...diabetic classes and all of this stuff, but I find myself being the only person of color and the youngest...And my issues, and the things in my lifestyle is totally different...I would love to hear, you know, about the others, you know, who [are] kinda like me...and hear what they’re doing.

While participants primarily expressed peer support groups as preferred psychosocial support resource, some participants also wanted to gain the support of health care providers. In particular, they discussed the need for health care providers to make mental health a priority in diabetes care.

Making Mental Health a Priority

Despite having a low distress score, 1 male participant emphasized the importance of addressing psychological aspects of diabetes in addition to physical health aspects. This suggestion was met with agreement by other focus group participants who were present, as some shared that they had previously sought out help for diabetes-related mental health complications, such as depression.

Male 7, 45 (DDS = 1.2): I wish that health insurance companies and health care practitioners would expand upon [mental health] and they don't... They always look at the physical illness or the physical side of things, but they don't address the psychological.

Discussion

Findings from this study fill an important gap in the extant literature concerning the mental health impact of T2DM on African American adults. Compared to the physical health aspects of diabetes, such as complications and comorbidities, the psychological aspects of diabetes have been largely underexplored and consequently unaddressed. Findings from the current study offer important insights regarding the specific aspects of T2DM that are especially stressful for African Americans and provide important culturally appropriate suggestions for how to best assist them with distress coping.

Collectively, the quantitative and qualitative findings in this mixed-methods study highlight the importance of addressing mental health among African Americans living with T2DM. Historically, mental health has been viewed as a highly stigmatized topic among African Americans, including older adults²⁸ and males.²⁹ However, both male and female participants in the study openly discussed the mental health impact of living with T2DM as well as expressed a desire for their emotional support needs to be met. It is widely acknowledged that T2DM regimens are stressful to manage; however, the emotional burden of the condition has been less acknowledged and consequently is less addressed in diabetes support programs.³⁰ Instead, traditional diabetes support programs have primarily focused on providing education about self-management.

Results from the current study suggest that psychosocial support efforts for African American adults should incorporate traditional peer support groups, where individuals have the opportunity to openly share their feelings about living with T2DM as well as share information. Though participants in the current study reported receiving relatively high levels of social support from family and friends, they specifically expressed a desire to receive support from others who also live with T2DM. Thus, they emphasized a preference for T2DM support programs that offered peer support components that would maximize their opportunities to interact with others who are living with T2DM and consequently empathize with their experience. Recent pilot study research has

shown that African Americans living with T2DM can be feasibly trained to facilitate peer-based diabetes support interventions.³¹

Peer support groups have been utilized as effective strategies to improve coping and self-management in several conditions, including breast cancer³² and HIV/AIDS.³³ While peer support resources are available for these and other conditions, peer support groups do not appear to be as accessible to African American individuals living with T2DM. Several participants in the current study indicated that they were frustrated and disappointed by the fact that peer support groups are not available for people living with T2DM to the same extent that peer support programs are available for individuals living with other chronic conditions. This frequent observation emphasizes the need for support programs to be developed for African Americans living with T2DM in locations where this type of resource is not currently available.

Similar to focus group participants in the current study, African American participants in other studies have expressed interest in attending peer support groups.³⁴ For African Americans in particular, peer support groups provide a culturally sensitive safe space to vent about the frustration of managing T2DM day in and day out as well as learn from others. Participants' expressed desire for culturally sensitive diabetes support resources closely mirror findings in a recent focus group study by Lehrer and colleagues,³⁵ where African American participants of a resilience-based diabetes education program highlighted the benefits of interacting with similar others in support groups. Similar to the current study, participants in the Lehrer et al³⁵ study indicated that African American peer support groups provide an empathetic environment, where attendees are reminded that others also live with T2DM and face similar difficulties when it comes to managing the condition. Participants in the current study also emphasized the importance of offering gender-specific support groups, a request primarily voiced by male focus group participants where they noted that men and women might experience distinctly different T2DM stressors that affect their mental health. For example, 1 male focus group participant discussed erectile dysfunction, a common T2DM complication among men, mentioning that men may be embarrassed to discuss this issue in the presence of women. Similarly, women often fulfill the unique role of being a caregiver to multiple others and "wearing multiple hats" while still having to manage their T2DM.^{30,36} Finally, several

participants who were in their 20s requested the development of support resources that are tailored to their age-specific needs as they are still managing school, employment, and being socially accepted among their peers. These findings support a growing body of literature highlighting the unique experiences and needs of young adults who live with T2DM.³⁷⁻³⁹

Findings from this study provide evidence for the growing clinical interest of incorporating mental health care into the treatment of patients with diabetes in an effort to provide care that is more comprehensive. Pouwer⁴⁰ has suggested that patients with T2DM should be screened for emotional distress, and several other studies promote the integration of psychological and physical health treatment for patients living with T2DM.⁴¹⁻⁴³ As one participant in the current study alluded to, it is just as important to address the psychological impact of diabetes as it is to address its physical effects. Other participants also expressed the desire to have psychological treatment integrated into their diabetes care. These observations mirror similar qualitative work by Egede,⁴⁴ where depression treatment was perceived to be beneficial among African Americans living with T2DM. Together, these results indicate that African Americans living with T2DM are open to discussing and having their diabetes mental health issues addressed, even to the extent that it involves clinical treatment. The American Diabetes Association's (ADA) Standards of Medical Care in Diabetes⁴⁵ emphasizes the importance of comprehensive medical evaluation and assessment of comorbidities and recommends that patients with diabetes have an interprofessional health care team that includes mental health professionals. The ADA standards of care also directly addresses the issue of DRD, advising providers to regularly screen people with diabetes for DRD.^{45,46} To overcome the barrier of mental health stigma, it is imperative that health care providers initiate conversations about any possible psychological effects that African American patients with T2DM may be experiencing as previous research has shown that African Americans with T2DM are less likely than whites to discuss mental health concerns with their primary care provider.⁴⁷

Strengths and Limitations

There are several notable strengths to this study. By employing a mixed-methods study design with complementary quantitative and qualitative data, the study provided a comprehensive perspective of African Americans'

experience with diabetes distress. An additional strength of the study was the inclusion of a considerable number of African American males. African American males have been recognized as an underrepresented group/perspective in health-related research.¹⁹ By gaining the perspective of African American males, researchers are able to better meet the needs of this important population. The study also has limitations worth noting. The quantitative and qualitative study sizes are relatively low and thus warrant caution for generalizability. However, the authors are confident that study findings provide useful insight regarding diabetes distress and African Americans as the findings are consistent with the extant literature.

Study Conclusions and Implications for Diabetes Educators

The current study findings are especially beneficial to practitioners and scholars who seek to improve psychosocial care among African Americans who live with T2DM. Overall, the study findings support the need for health care providers to prioritize mental health in diabetes care among African American patients by incorporating psychological health prevention and treatment strategies such as screening for and addressing DRD. The study findings also point to the desire and need among African American men and women to have social forums available to discuss their disease experience with their peers. The voices of participants underscored the importance of providing culturally sensitive psychosocial support resources to assist African Americans in coping with the psychological aspects of T2DM. As a preferred and cost-effective approach to addressing diabetes distress and improving coping, diabetes educators and other practitioners can assist in the development and implementation of peer support groups that can be held in private, community-based spaces for African Americans.

ORCID iD

Sula Hood  <https://orcid.org/0000-0002-9607-5714>

References

1. Centers for Disease Control and Prevention. *National Diabetes Statistics Report, 2017*. Atlanta, GA: Centers for Disease Control and Prevention, U.S. Department of Health and Human Services; 2017.

2. US Department of Health and Human Services Office of Minority Health. Diabetes and African Americans 2016. <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=18>. Accessed July 21, 2017.
3. Li C, Ford E, Zhao G, et al. Association between diagnosed diabetes and serious psychological distress among U.S. adults: the Behavioral Risk Factor Surveillance System, 2007. *Int J Public Health*. 2009;54(suppl 1):43-51.
4. Gonzalez JS, Fisher L, Polonsky WH. Depression in diabetes: have we been missing something important? *Diabetes Care*. 2011;34(1):236-239.
5. Fisher L, Skaff MM, Mullan JT, Areal P, Glasgow R, Masharani U. A longitudinal study of affective and anxiety disorders, depressive affect and diabetes distress in adults with Type 2 diabetes. *Diabet Med*. 2008;25(9):1096-1101.
6. Kasteleyn MJ, de Vries L, van Puffelen AL, et al. Diabetes-related distress over the course of illness: results from the Diacourse study. *Diabet Med*. 2015;32(12):1617-1624.
7. Dismuke CE, Hernandez-Tejada MA, Egede LE. Relationship of serious psychological distress to quality of life in adults with diabetes. *Int J Psychiatry Med*. 2014;48(2):135-146.
8. Verhaak PF, Heijmans JWM, Peters L, Meike R. Chronic disease and mental disorder. *Soc Sci Med*. 2005;60(4):789-797.
9. Hausmann LR, Ren D, Sevick MA. Racial differences in diabetes-related psychosocial factors and glycemic control in patients with type 2 diabetes. *Patient Prefer Adherence*. 2010;4:291-299.
10. Chlebowy DO, Hood S, LaJoie AS. Facilitators and barriers to self-management of type 2 diabetes among urban African American adults: focus group findings. *Diabetes Educ*. 2010;36(6):897-905.
11. Akindana A, Owens-Gary M, Williams A. When it all gets to be too much: addressing diabetes distress in African Americans. *AADE Pract*. 2016;4(4):44-49.
12. DeCoster VA. The emotions of adults with diabetes: a comparison across race. *Soc Work Health Care*. 2003;36(4):79-99.
13. Spencer MS, Kieffer EC, Sinco BR, et al. Diabetes-specific emotional distress among African Americans and Hispanics with type 2 diabetes. *J Health Care Poor Underserved*. 2006;17(suppl 2):88-105.
14. Hawkins J, Watkins DC, Kieffer E, Spencer M, Espitia N, Anderson M. Psychosocial factors that influence health care use and self-management for African American and Latino men with type 2 diabetes. *J Mens Stud*. 2015;23(2):161-176.
15. Jones RA, Utz SW, Williams IC, et al. Family interactions among African Americans diagnosed with type 2 diabetes. *Diabetes Educ*. 2008;34(2):318-326.
16. Anderson RM, Barr PA, Edwards GJ, Funnell MM, Fitzgerald JT, Wisdom K. Using focus groups to identify psychosocial issues of urban black individuals with diabetes. *Diabetes Educ*. 1996;22(1):28-33.
17. Schiøtz ML, Bøgelund M, Almdal T, Jensen BB, Willaing I. Social support and self-management behaviour among patients with Type 2 diabetes. *Diabet Med*. 2012;29(5):654-661.
18. Creswell JW, Plano Clark VL. *Designing and Conducting Mixed Methods Research*. 2nd ed. Los Angeles: Sage Publications; 2011.
19. Byrd GS, Edwards CL, Kelkar VA, et al. Recruiting intergenerational African American males for biomedical research studies: a major research challenge. *J Natl Med Assoc*. 2011;103(6):480-487.
20. 100 Black Men of America, Inc. "What They See is What They'll Be." Retrieved from <https://100blackmen.org>. Accessed December 19, 2017.
21. Pariser G, Hager K, Gillette P, Golemboski K, Jackson K. Active steps for diabetes: a community-campus partnership addressing frailty and diabetes. *Diabetes Educ*. 2013;40(1):60-67.
22. Toobert DJ, Hampson SE, Glasgow RE. The summary of diabetes self-care activities measure: results from 7 studies and a revised scale. *Diabetes Care*. 2000;23(7):943-950.
23. Fitzgerald JT, Davis WK, Connell CM, Hess GE, Funnell MM, Hiss RG. Development and validation of the Diabetes Care Profile. *Eval Health Prof*. 1996;19(2):208-230.
24. Polonsky WH, Fisher L, Earles J, et al. Assessing psychosocial distress in diabetes: development of the diabetes distress scale. *Diabetes Care*. 2005;28(3):626-631.
25. Fisher L, Hessler DM, Polonsky WH, Mullan J. When is diabetes distress clinically meaningful?: establishing cut points for the Diabetes Distress Scale. *Diabetes Care*. 2012;35(2):259-264.
26. Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs*. 2008;62(1):107-115.
27. Saldaña J. *The Coding Manual for Qualitative Researchers*. 2nd ed. Los Angeles: Sage Publications; 2013.
28. Conner KO, Copeland VC, Grote NK, et al. Mental health treatment seeking among older adults with depression: the impact of stigma and race. *Am J Geriatr Psychiatry*. 2010;18(6):531-543.
29. Ward E, Wiltshire JC, Detry MA, Brown RL. African American men and women's attitude toward mental illness, perceptions of stigma, and preferred coping behaviors. *Nurs Res*. 2013;62(3):185-194.
30. Penckofer S, Ferrans CE, Velsor-Friedrich B, Savoy S. The psychological impact of living with diabetes: women's day-to-day experiences. *Diabetes Educ*. 2007;33(4):680-690.
31. Tang TS, Funnell MM, Gillard M, Nwankwo R, Heisler M. Training peers to provide ongoing diabetes self-management support (DSMS): results from a pilot study. *Patient Educ Couns*. 2011;85(2):160-168.
32. Stang I, Mittelmark MB. Social support and interpersonal stress in professional-led breast cancer self-help groups. *Int J Ment Health Promot*. 2008;10(2):15-25.
33. Lennon-Dearing R. The benefits of women-only HIV support groups. *J HIV/AIDS Soc Serv*. 2008;7(1):27-45.
34. Crabtree K, Sherrer N, Rushton T, et al. Diabetes connect: African American men's preferences for a community-based diabetes management program. *Diabetes Educ*. 2015;41(1):118-126.
35. Lehrer HM, Dubois SK, Brown SA, Steinhart MA. Resilience-based diabetes self-management education: perspectives from African American participants, community leaders, and health-care providers. *Diabetes Educ*. 2017;43(4):367-377.
36. Samuel-Hodge CD, Headen SW, Skelly AH, et al. Influences on day-to-day self-management of type 2 diabetes among African-American women: spirituality, the multi-caregiver role, and other social context factors. *Diabetes Care*. 2000;23(7):928-933.
37. Aghili R, Ridderstrale M, Kia M, et al. The challenge of living with diabetes in women and younger adults: a structural equation model. *Prim Care Diabetes*. 2017;11(5):467-473.
38. Hessler DM, Fisher L, Naranjo D, Masharani U. Young adult African American patients with type 2 diabetes: a high risk patient sub-group with few supports for good diabetes management. *J Health Psychol*. 2012;17(4):535-544.

39. Miller ST. Diabetes and psychological profile of younger rural African American women with type 2 diabetes. *J Health Care Poor Underserved*. 2011;22(4):1239-1252.
40. Pouwer F. Should we screen for emotional distress in type 2 diabetes mellitus? *Nat Rev Endocrinol*. 2009;5(12):665-671.
41. Feifer C, Transman M. Promoting psychology in diabetes primary care. *Prof Psychol Res Pr*. 1999;30(1):14-21.
42. Bogner HR, de Vries HF. Integrating type 2 diabetes mellitus and depression treatment among African Americans: a randomized controlled pilot trial. *Diabetes Educ*. 2010;36(2):284-292.
43. Egede LE. Disease-focused or integrated treatment: diabetes and depression. *Med Clin North Am*. 2006;90(4):627-646.
44. Egede LE. Beliefs and attitudes of African Americans with type 2 diabetes toward depression. *Diabetes Educ*. 2002;28(2):258-268.
45. American Diabetes Association. Standards of Medical Care in Diabetes—2017. *Diabetes Care*. 2017;40(suppl 1):S1-S135.
46. Young-Hyman D, de Groot M, Hill-Briggs F, Gonzalez JS, Hood K, Peyrot M. Psychosocial care for people with diabetes: a position statement of the American Diabetes Association. *Diabetes Care*. 2016;39(12):2126-2140.
47. Wagner JA, Perkins DW, Piette JD, Lipton B, Aikens JE. Racial differences in the discussion and treatment of depressive symptoms accompanying type 2 diabetes. *Diabetes Res Clin Pract*. 2009;86(2):111-116.

For reprints and permission queries, please visit SAGE's Web site at <http://www.sagepub.com/journalsPermissions.nav>.