Understanding and Addressing Diabetes Distress in African American Adults Living with Type-2 Diabetes

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Diabetes: Disparities

- Disproportionately impacts racial/ethnic minority populations

  - Higher Prevalence rates
    American Indians/Alaskan Natives = 15.9%
    African American = 13.2%
    Hispanic = 12.8%
    *compared to non-Hispanic white population = 7.6%

  - Higher co-morbidity rates
    Renal failure, limb amputations

  - Higher mortality rates
    African Americans have twice the rate of whites

*Results from lower adherence to self-management
Type-2 diabetes

- Comorbidities
  - Heart disease, stroke, kidney disease, blindness and Neuropathy

- Mental health
  - Depression
    - Twice the rate of people without diabetes
    - 10-20% among individuals with Type-2 diabetes (T2DM)
  - Emotional distress
    - Frustration, worry, overwhelmed
    - Helplessness
Type-2 Diabetes: Self-Management

Difficult disease to manage
98% of diabetes care involves self-management

Numerous recommendations:
Diet/Nutrition
Physical Activity
Medication Adherence
Glucose Monitoring
Checking Feet
Appointment Adherence
Study: Diabetes Distress among African American Adults
Study Design

**Purpose:**
1) Understand the extent to which African American adults living with T2DM experience diabetes-related distress.
2) To identify diabetes psychosocial support resource preferences of African American adults living with T2DM.

**Study population:**
- African American men and women ages 18+ that have been diagnosed with T2DM and reside in metropolitan Louisville

**Methods:**
- Two-phase mixed-methods explanatory sequential study design was employed.
  - Phase 1-Written Survey (quantitative), N= 155, mean age 56.4
  - Phase 2-Follow-up Focus Groups (qualitative), N=4
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Male (n= 67)</th>
<th>Female (n= 88)</th>
<th>p-value</th>
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</thead>
<tbody>
<tr>
<td><strong>Family history of diabetes</strong></td>
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<tr>
<td>Yes</td>
<td>82.1</td>
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<td><strong>Length of diagnosis (yrs)</strong></td>
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<td>Insulin and pills</td>
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<tr>
<td>No medication</td>
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<tr>
<td>Nurse</td>
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<tr>
<td>Other healthcare professional</td>
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<tr>
<td>No</td>
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</table>
Main Outcome: Diabetes-related Distress

Diabetes Distress Scale (Polonsky, 2005)

- Emotional burden (EB)
- Regimen-related (RD)
- Interpersonal-related (ID)
- Physician-related (PD)

- 6-point Likert-type scale

- Distress scores ≥ 3 indicate the need for clinical attention.
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Combined</th>
<th>Male</th>
<th>Female</th>
<th>p-value</th>
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<td>Regimen-related</td>
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<td>Interpersonal</td>
<td>1.8</td>
<td>1.8</td>
<td>1.8</td>
<td>0.92</td>
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</table>
Diabetes-Related Distress: Results

- 19% of the sample had an aggregate DDS-17 score of ≥ 3.

- 30% of survey participants scored ≥3 on the RD subscale.

- 27% of the survey sample had an average score of ≥ 3 on the EB subscale.

- A smaller proportion of the sample had clinically significant scores for PD (11%) and ID (17%).
Follow-Up Focus Groups
Focus Groups (N=4), (10 males, 13 females)

**Purpose:** Contextualize survey findings

**Questions:**

1. What are the things that stress you out most about having diabetes?

2. What would you like to see in a support program for people living with diabetes?
Results: Distress

- Regimen-related distress
  - Medication
  - Diet
Results: Distress

Medication regimen

“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.”

“Sometimes I’m like, God, this is my life right here-all these pills...emotionally it could just really drain you.”
**Dietary regimen**

**Planning**

“…Annoying, frustrating…It just takes an effort for every meal for me to plan it or check what I’m eating.”

**Change in diet**

“…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.”

**Social gatherings**

“…You know, it gets stressful especially at Christmas or Thanksgiving cause you’ve got cakes, cookies, everything coming toward you.”
Results: Distress

- Emotional burden
  - Males discussed feeling depressed
  - Females discussed feeling controlled
Emotional burden of diabetes

“Depression is something else. I been depressed about this [diabetes]. I had to go to the doctor about this depression.”

“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...diabetes is like an emotional roller coaster for me. You know, I’m up and down.”
Support Needs and Preferences

What are the support needs and preferences of urban African American adults living with T2DM?

- Peer support programs
- Inclusion of family in diabetes education programs
- Address mental health needs
Support Needs and Preferences

*Peer support*

“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.”

“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.”
Support Needs and Preferences

Culturally-Sensitive Peer support

“I’m a black man- I want to be around my [black] brothers. You 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 already know.”

“I have been to 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.”
Support Needs and Preferences

Inclusion of family

“It would be nice to have your family to come along and let them see what we struggle with. They might feel our pain. Help us, you know, encourage us...It would help if I could have my sister over here.”

-Negative social support (Nagging)

Address mental health

“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.”
Conclusions

- Regimen Distress and Emotional Burden were frequently discussed.

- Mental health is an area of concern
  - Desire for clinicians to address mental health

- Desire for peer support groups

- Desire for family to be involved
Diabetes Social Support: Strategies

Family
- Educate family members
  - How they can help
  - What diabetes is
  - How it impacts the patients daily life
  - How to assist with problem solving

Culturally-sensitive
- Alternative prep for traditional foods
- Family dynamics
- Preferred activities (ex. Active Steps Program-dancing)
Thank you

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