



LIVING

With Type 2 Diabetes

Black American Patient Insights

PRESENTED TO
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Methodology.

Nine people participated in two 90-minute focus groups. Group one= four people. Group two = five people. They were:

- Male and female Black American adults, 32-59 years old
- Type 2 diabetes patients
- Users of oral or injection diabetic medication
- Roughly 50% have had a stroke, heart attack, artery disease, or other types of heart cardiovascular events or diseases.



What We Learned.

Living with Diabetes Reveals Two Dichotomous Mindsets

1 // Living a Healthy Lifestyle

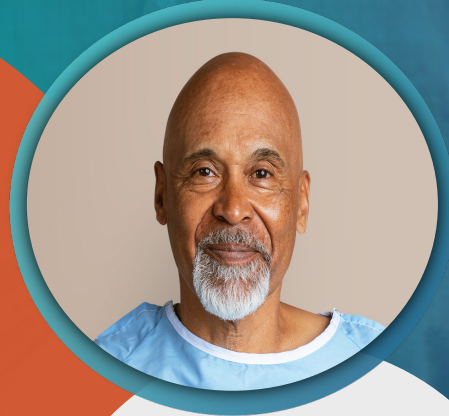


“ I can eat what you eat, but I have to do it in moderation or in a different way.”

–Group 1, Female, Age 32

- These respondents live optimistically. They are fully engaged in their T2D management and embrace a “can do” attitude.

- Some participate in healthy lifestyle programs (group walks, nutrition classes, clinical trials, and volunteer with heart and healthcare organizations).
- A few also claim to be an example to friends and family who don't have the disease yet are admired for practicing a healthy lifestyle.



“ “Some of my friends see what I eat and they say, ‘well, I should have what you’re having’... maybe hanging around you will make me pick up better habits.”

–Group 1, Male, 57

Living with Diabetes Reveals Two Dichotomous Mindsets.

2 // Living a Lifestyle of Limitations

These respondents perceive the disease as inconvenient and burdensome

They often describe their lifestyle as "limited" and are likelier to share what they "can't do."

“

“...it's an adjustment where, you know, you have to check the sugar, watch what you eat, and balance out the medication... to make sure you're okay.”

“

“I can't eat what I want.”

Most Patients Say They Are Knowledgeable About Many Aspects of T2D.

- Most respondents say “Know your numbers” is the doctors’ overarching standard advice. Respondents claim to know their numbers; weight/BMI, blood sugar, blood pressure, and cholesterol and say they consistently track them.
- During a group exercise, respondents were asked to rate their knowledge of risk factors, cardiovascular events, and medications that prevent cardiovascular events. Respondents used a scale between 1-10, where 10 is very knowledgeable, and 1 is not very knowledgeable.
- Many respondents, especially optimists, keep up to date with diabetes information and rate their knowledge of risk factors and cardiovascular events between 7 and 10.
- Respondents with heart issues or those who have experienced cardiovascular events are likelier to say they know about medications that prevent cardiovascular events. Others who are less aware say regular checkups and tests show no indication of heart issues. If the doctor says they are OK, they don’t press to learn anything more.
- They also admit to not knowing everything about diabetes.
 - *Certain things have been explained, but I feel like there’s more to know.*
 - Group 1, Female 32



Yet, Diabetes Education Typically Follows An Episode or Cardiovascular Event

Learning about their diabetic condition shocked most respondents. Before being diagnosed, many were unaware that episodes like blurred vision, frequent thirst, and urination were symptoms of diabetes.

Respondent's understanding of diabetic conditions, and cardiovascular events associated with diabetes were learned by default. The education came after the event.

"...I knew once I had the stroke how this stuff and diabetes could affect everything and make everything else go real bad.

—Group 2, Female, Age 49

Diabetes information is also learned via diagnosed family members and those who had a cardiovascular event or lost a limb:

- ▶ *(My mother) had high blood pressure, and it (diabetes) happened later in her life. It got me thinking about...getting information*
—Group 1, Male 57
- ▶ *The only thing I really know about cardiovascular is from my dad when he had heart issues. I hear it can be associated with diabetes. But I never really dug that much into it.*
—Group 1, Female 37
- ▶ *I had great aunts, like my grandmother's aunt, they all had their legs and stuff cut off, but as a kid, they would always say they had sugar.... So I thought it came from sugar...*

—Group 2, Female, 49

Doctor/Patient Relationships are Working.

- ▶ Most respondents identify endocrinologists as their primary healthcare providers.
- ▶ Many listen to their doctor and make scheduled office visits, and before being diagnosed with T2D, had annual checkups.
- ▶ Importantly, doctors are the trusted primary source for diabetes information, associated risk factors, and cardiovascular events.
 - ▶ *I learned more about my diabetes, and I also learned about different things that come from diabetes through my doctor... - Group 1, Female Age 37*
 - ▶ *I get positive reinforcement tools weekly from the clinic and the doctor. –Group 1, Male, Age 57*
 - ▶ *The doctor did go over the risk factors with me. — Group 2, Female Age 36*



However, Doctor/Patient Relationships Need Improvement.

Respondents identified some areas where doctors fall short on treatment:

▸ **Sharing medication side effects with the patient**

▸ *They won't really talk about the side effects that much because its gonna scare away the patient. —Group 2, Female 36*

▸ **Adequate testing**

▸ *I really need him to do more testing to make sure this medicine is actually working and the doses that he is giving me are working. He might give me some medication... he needs to test me in 30 days. My sugar could be 200 a day and 800 next week. —Group 2, Female 49*

▸ **Showing more allegiance to pharma companies vs. patients**

▸ *I know pharmacy reps push certain drugs.*

—Group 2, Male 58

▸ *...I think that, unfortunately, in this country, our pharmaceutical and healthcare companies are in cahoots. It's all politics. —Group 2, Female 36*

▸ **Sharing patient information with patient's other doctors**

▸ *I like the team approach ...it also helps with the medication that they provide. Now they can see the whole scope of everything that I take. —Group 2, Male, 58*

▸ **Sharing more information about clinical trials**

▸ **Getting the combination of patients' total meds correct/balanced**

▸ **Understanding cultural differences between Black and white diabetes patients**

Barriers to Successful Diabetes Management.



Maintaining a Healthy Weight and BMI Controversy

- ▶ It is one of the most often mentioned topics and, for many respondents, one of the most challenging steps for managing diabetes.
- ▶ At the same time, weight loss is predicated on how patients and the medical industry define healthy weight. In fact, many respondents believe Black Americans are naturally heavier than whites. Thus, they say the BMI is incorrect and does not apply to them.
 - ▶ *I definitely heard that there are different charts for Black people in terms of weight and how they weigh us. – Group 1, Female Age 32*
 - ▶ *Weight loss comes up a lot. Every last one of my doctors told me to lose between 30-35 pounds." –Group 1, Female, age 37*
 - ▶ *As far as losing weight, if you're African American and you're 5'5, they (doctors) say you should be 112. –Group 2 Female, Age 44*
 - ▶ *...the charts are different for African Americans...that chart is not gonna work for me because we don't eat the same foods. We don't come from the same bloodline. –Group1, Female, Age 59*



Barriers to Successful Diabetes Management (cont'd).



Side effects from a single prescription and various combinations of medicine.

Respondents are taking a variety of medications to treat their diabetes. Metformin, Ozempic, Victoza, long-acting, short-acting rapid insulin, etc. A couple of respondents also shared stories of some new diabetic meds that are not working with other medications.

- *...I would rather have the doctor look at you, your history, your labs, and say, here's this. This is gonna work for you because they have experience and they've done clinical trials. Group 2, Female 44*
- *...one of the things that makes me concerned is that some of these new medicines...are good for diabetes... but has 27 side effects. You're gonna cure me or kill me. Group 2, Female 49*
- *After every advertisement, the last (side effect) they mention is death. It's so prevalent. Group 2, Male 58*

Some insurance companies won't pay for additional office visits or particular medications.

- *I think they should come up with a law or some type of regulation that if a doctor prescribes something, the insurance should cover it. —Group 2, Male 58*

Needle pricks

- *I hate poking myself. Basically, I cry when I poke myself. I don't even know where to poke myself anymore. Group 1, Female 32*

Where's the Black Representation in Diabetes Information?

Some respondents say there is not enough Black representation in diabetes literature. These respondents want images of Black people in collateral materials and videos. They want to see Black healthcare providers treating Black patients and hear Black patients talking with other patients and sharing diabetes information with the Black community at large.

- *There's always been a place where you can get information for everything, but they haven't made one for us. ...There is not enough representation of people of color telling us about research studies and healthy nutrition...* Group 1, Male 57
- *African American doctors will be able to identify with you with your questions.* Group 1, Female 59
- *There needs to be information at festivals and cultural events where Black people are in the community. (We need to see Black people) handing out information to let other Black people know it is available.* Group 2, Female 44

Personal Responsibility, Personal Patient Advocacy is a Must

Several respondents agree that patient self-advocacy is critical for better health. They believe conducting research, listening to doctors, speaking up about their needs, and learning from their experiences and other patients are important contributors to the best healthcare plans and decisions.

- ▶ *I found a research study that was able to help me with my progress....I told my doctor this is something I think I should check out.... Group 1, Male 57*
- ▶ *...I do a lot of research. I reached out to certain people I know who are diabetics, too, to see what they're taking and how they're doing. Group 2, Male 59*
- ▶ *...As patients, we have internet access. We have our healthcare (resources), different government sites that break down certain medications, and everything you could get your information from. - Group 2, Female 32*
- ▶ *You have to advocate for yourself cause nobody's gonna advocate better for you than you. – Group 1, Female 59*



Sources of Information



In addition to acquiring information from their doctors, searching the Internet for T2D information is a frequent practice by most respondents. They describe entering words like diabetes medicines, alternative medicines, and the names of diabetes medications in the search engine and YouTube search boxes. Some respondents prefer YouTube searches because they can see and hear diabetes patients share stories about their T2D journey.

- ▶ *YouTube has actually been one of the best things that I've seen. I actually see people who've taken medication, and they're sharing their personal experiences. Sometimes they'll even do it as a diary where they do day-to-day (entries), and you can track it. Group 2, Male 58*

Other sources of information include:

- ▶ WebMD
- ▶ National Diabetes Association
- ▶ Mayo Clinic
- ▶ Instagram and Facebook Diabetes Groups
- ▶ Medications' websites
- ▶ American Heart Association
- ▶ California Black Nurses Association
- ▶ Association of Black Cardiologists