

LIVING WITH DIABETES IN A HISTORICALLY BLACK COMMUNITY:

Insights from Residents

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People Living with And Inspired by Diabetes

ABSTRACT

Objective: This research report shares insights gained from participants who reside in a historically black community in Florida concerning their experiences living with diabetes.

Research Design and Method: The findings in this research report draw from three focus groups undertaken to gather patient perspectives on potential causes and mechanisms related to a community setting with higher than national average levels of diabetes (both in relation to the broader population and Black Americans specifically) as part of an applied project geared toward establishing potential interventions that could benefit the community.

Results: Participants in the focus groups discussed (1) positive efforts to improve diet; (2) less successful efforts to increase exercise levels, and (3) marked differences in experiences with medical professionals and access to quality medical care.

Conclusions: These findings illustrate difficulties patients experience seeking to manage diabetes in relation to structural (i.e., racial, healthcare access, and economic) and interpersonal (i.e., medical professionals) barriers to quality care.



INTRODUCTION

In recent years, studies exploring the experiences of people living with diabetes [1] and the social factors that influence access to and outcomes related to chronic health conditions [2] have begun to gain prominence in medical and social scientific domains. Central to these studies is the recognition that social factors – such as race [3], class [4], gender [5], and sexuality [6] – often fundamentally cause and impact the experience of living with chronic health conditions. In fact, researchers have shown many ways social conditions influence everything from who develops a given chronic condition [7] to what resources – interpersonal and structural [8] – people may have when seeking to manage and make sense of chronic health conditions. As a result, medical and social researchers have emphasized the importance of both communicating with specific communities when seeking to understand health outcomes and management [9] and reporting the insights of said communities within the pursuit of better healthcare outcomes, access options, and management strategies [10].

Here, we build on these discussions by reporting insights from people living with diabetes in a historically Black neighborhood concerning the management of diabetes and their experiences with medical professionals. We focus on this community due to its demonstration of a concrete, social context wherein residents experience higher levels of diabetes and prediabetes than national averages for both Black Americans and the broader American population. As such, this research report outlines the insights of participants living with diabetes concerning two topics drawn from their own experiences. First, we outline their efforts to maintain healthy diet and exercise behaviors. Second, we outline variations in the ways these participants experience interactions with medical professionals. In so doing, this report sheds light on insights from participants living with diabetes and experiencing encounters with medical professionals that may be utilized to guide further neighborhood studies and speak to interventions in communities with lesser structural resources and higher levels of diabetes.

Before turning to the data, however, it is important to note that many scholars have outlined significant relationships between both race and health overall [3], and race and diabetes specifically [11]. Thomas and associates [12], for example, used retrospective data in Oklahoma to outline racial disparities in access to diabetic care tied to transportation, neighborhood, and care facility location while Graetz and colleagues [13] found similar racial discrepancies in

terms of the access racial minorities had to digital technology that can aid the delivery and monitoring of care for people with diabetes. Further, researchers have shown how the ways medical providers talk can influence diabetic care and have varied effects with different racial groups [14], that narratives of African American people with diabetes reveal less trust in doctors and prescriptions and more interest in behavioral changes [15], and the ways older African Americans living with diabetes evaluate their health based on comparisons to the past rather than based on a specific objective indicator [16]. As such studies request, our work here continues the process of bringing to light both the lives of African Americans living with diabetes and the issues they face as they manage diabetes over time.

METHODS

Drawing on prior expertise and literature concerning inductive qualitative methods [17, 18], this study was designed as an open-ended, exploratory evaluation of a specific community. Put simply, we sought to learn the experience of health and healthcare as well as relevant healthcare needs and resources from the members of a specific community [19]. To this end, we utilized an inductive design whereby we offered participants open opportunities to tell us “what is going on” [20] in their community rather than drawing on structured questions established via external prior research. In this way, we sought to capture the lived health experiences of participants in order to ascertain insights for professionals seeking to serve this population.

This study focuses on the reported experiences of people living with diabetes in a specific central Florida community. This focus emerged following community surveys conducted by the University of Central Florida Institute for Social and Behavioral Sciences [21, 22]. These surveys indicated that nearly 25% of the residents lived with diabetes. In terms of neighborhood context, the survey found that the community had a median income of just over \$26,000 (more than \$20,000 below the state of Florida median income), with 43% of the residents living below the poverty line (compared to 16.5% in the state). The median age of the residents was 37.2 years old and 79.9% identified as Black or African-American.

Seeking to “qualitatively fill out” [18] the information gained via these surveys, the first author of the current work presented here undertook a series of focus groups with participants who lived in the community. The results of these endeavors make up the data presented in this report. Specifically, data for this study draws from three focus groups conducted with residents in a historically Black neighborhood in Central Florida. The focus groups were conducted within the span of a week, and 28 people took part in the conversations. These participants were all residents of the community, which is a neighborhood within a major urban area.

The focus groups were designed, organized, and conducted by the first author – a cisgender, white woman who has worked in the community in relation to the ongoing survey and healthcare delivery efforts over the past decade. In fact, she utilized her connections from her time working in the area to facilitate both recruitment and the operation of the focus groups.

The first focus group was the largest with 14 participants. This focus group was designed specifically for people that had been diagnosed with diabetes who, from their own self reports, were not handling or managing it well. The second focus group included 6 participants. This focus group was designed for people who were prediabetic or who have a family history of living with diabetes but are not yet diagnosed themselves. The third focus group had 8 participants. This focus group was designed for people who have been diagnosed with diabetes and are, from their own self reports, managing or handling it well. This study was approved by the Institutional Review Board at the University of Central Florida.

All of the focus groups were held at a church in the community. Participants were recruited via flyers that were placed in commonly visited places in the community including a community center and other churches. Only participants who lived in the community were in attendance and thus included in the study. Participants were paid \$20 at the completion of the focus group. As noted above, the first author moderated each focus group. The participants’ age and gender within the focus groups, though not intentionally accomplished, were proportionate to the above noted demographic characteristics of the community found in the prior surveys.

There were guiding questions designed for each focus group and followed throughout the process. Following other scholars seeking to inductively learn from communities [17, 18, 19, 20], these questions were open-ended. The first author would ask, for example, “What are some issues you face managing diabetes in your daily life,” and then probe participants in the focus group for detailed examples concerning whatever initial issues they might disclose. This “iterative process” of questioning [17] was carried out throughout the focus groups. The focus groups lasted about one and one-half hours each. The focus groups were audio recorded, and two trained note takers composed detailed notes during the focus groups themselves. After the sessions were finished, each note taker utilized audio files to enhance their notes and produce transcripts for review. These transcripts were combined into one final transcript, which provides the source of the quotes and discussions throughout this report.

We analyzed the transcripts utilizing an open-coded method [17, 18, 23]. Specifically, we read through the transcripts in their entirety outlining common patterns and themes reported by the residents. As is common in much qualitative socio-medical analyses [17, 18, 19, 23, 24], we sorted these themes into categories that we present in the following results section. In so doing, we focus on the most salient points or insights offered by participants in order to capture their own lived experiences managing life with diabetes and interactions with medical providers.

RESULTS

Overall, the focus groups reveal that diabetes is not something openly discussed by participants with family members, friends, or co-workers. Rather, it is often a subject that remains quiet outside of medical settings. Participants as a whole report that they are generally managing diabetes on their own without any support from others. While there are variations among the participants in terms of diet and exercise and interactions with medical professionals, there are also clear patterns alongside the overall pattern where most experience and manage diabetes on their own. These clear patterns reveal that most participants have made changes to their diets, but even though participants agree with the importance of exercise, most have not actively incorporated it into their routines. In terms of medical care, overall the participants report variation in access and treatment, and note that those with private insurance and Medicare are doing better than those without these options. Further,

they outline concerns about education and medication that limit their abilities to manage their conditions effectively.

Diet and Exercise

Participants across the three focus groups have made some changes to their diets. They are limiting carbohydrates, “white” foods, fried foods, and red meat. This has been harder for some than others, and participants suggest it needs to start with the children. In fact, they cite the difficulty of changing their diets after becoming accustomed to primarily eating certain foods during adulthood as a factor limiting their adjustments post-diagnosis. Participants expressed frustration with the cost of healthy foods, such as fresh fruits and vegetables or brown rice. They suggest there needs to be a greater focus on making healthy food options more affordable, more plentiful, and accessible to people at different income levels. A middle aged participant who was a lifelong resident of the community and living with diabetes admitted that they are not managing diabetes well and offered the following example:

I had to change my eating habits. All the white stuff ain't right. It's not just the sugar. It's the French fries, baked potatoes, macaroni and cheese, spaghetti. And the problem is that when you go get the stuff, the brown food is always higher priced. I'm just being honest.

Another participant put it succinctly:

It takes money to eat right.

Although the costs of healthy food are a major concern for participants, overall, they argued they were doing what they could to eat well despite the limitations. They agreed with their doctors that eating in a healthy way was integral to manage their conditions in the best ways possible, and overwhelmingly, they stressed the importance of food options, access, and selection. As one summarized, they stressed that:

If you don't change your diet, you die.

Other residents, especially women, noted the importance of diet in managing weight as well as overall health. A woman in the community living with prediabetes in her seventies who had lost thirty pounds after changing her lifestyle when concerns about diabetes were expressed by her doctor two years prior explained:

There is family history, because my mother also has it. My sister also has it. But, my doctor's advice was that I have the conditions to prediabetes. But then I started losing weight, and I did lose weight. And I managed my diet to be careful, ya know? Be careful of the carb intake and the sugar. And so, the blood work testing and my supplemental visit does not indicate that I need any type of treatment or medicine now. So, just the change in lifestyle. And so, I don't have to lose anything else, just keep it monitored to make sure nothing changes about it.

At the same time, as illustrated by the next quote from a younger woman in her twenties, changing one's diet can be a major struggle even when other family members living with diabetes have made changes to their diets.

Well, now my mom has gone organic crazy. Some of the food is pretty good. Like, the stuff that you would normally eat. Like, grilled veggie burgers or whole-wheat past. It's just that what she brings to eat is different from what me and my brothers eat. We like Pizza Hut and McDonald's. She is doing this because she is diabetic. She is trying to get the weight off and eat right. She is trying to influence me because I'm the only girl.

Despite difficulties, residents stressed ongoing attempts to adjust their dietary patterns in relation to potential or post-diagnosis diabetic status. In fact, most participants have already made at least some changes to their dietary patterns and food intake, and each one expressed desire to make such adjustments over time.

Turning to exercise, however, we found a different story. Whereas participants reported being generally active, they were not devoted to incorporating exercise into their lives in the same way they were in relation to dietary changes. In fact, they were much less likely to increase their activity levels even if they noted changing their eating habits. As one participant noted while summarizing many other comments, they often found it hard to fit exercise into their existing work and other daily requirements:

When I am working it is hard to get that exercising in.

At the same time, however, participants noted that while there were some resources in the community to assist with incorporating physical activity into their lives, there needed to be more options and resources to ease the process. For example, they pointed out that while there was a gym in

the area, it was in an old, sparse building and did not offer much in terms of usability. In fact, only a couple participants noted ever using it.

Overall, the only consistent form of exercise participants noted was walking. However, their levels of walking varied from once or twice a week to every day, and did not include any specific goals or lengths that they regularly tried to meet. As one person living with prediabetes put it in the focus group:

I walk my dogs, but sometimes it's hard, but I get up and do it anyways. It feels good to get out of the house and get some fresh air.

While participants wanted to walk and walk more, they also reported structural barriers to doing so. In a Florida city, for example, participants noted the combination of heat and physical issues served as deterrents to walking or other types of exercise.

At the same time, participants did focus on the ways exercise itself could help the development of healthier diets and habits. As one explained to the room during a focus group:

The first thing is the exercise. Because as soon as you can check that, you instantly change what you eat. Because you say 'ok, I spent an hour and a half working out and I eat that.' Between the diet and the exercise, for me, it's the exercise.

In fact, participants suggested they wanted to utilize diet and exercise together, but in many cases, the decision between the two was more likely to leave exercise aside. Even so, participants noted, as shown in the next excerpt, the importance of exercise to building better quality of life:

I just wanna live. Because when you are sick and stuff you can't live. I just want to live.

Another said:

Just continue to be able to be happy and active and enjoy life. That's my motivation.

Another added:

I agree. I want to live life. I am young. I am 29. Live life and be happy.

In each case, they wanted to live well and noted the importance of exercise, but at the same time, they were more likely to accomplish dietary adjustments while not being able to as consistently work in more exercise within the confines of their daily lives and schedules.

Interactions with Medical Professionals

Alongside experiences and concerns about diet and exercise, the other primary theme throughout the focus groups concerned the experiences participants had with medical providers and healthcare access in general. They noted variety in terms of care, treatment options, medication accessibility, knowledge and information, and the coverage options related to both doctors and insurance plans. Overall, for example, participants with private insurance or Medicare were faring much better than the ones without insurance who were relying on clinics.

The following illustrations offer some typical examples of such experience:

I got a primary doctor he doesn't give any details about it. He looks at the blood work. 'Oh ok. Don't drink any soda.' I said I gotta do stuff on my own and take my health into my own hands. That's a good thing, but he need to be more active. Some doctors just treat you like a number.

Others, like the one quoted next, echoed this sentiment:

Usually when you do your blood work, they'll send you this paper in the mail. It says 'normal' or whatever you got. I always get that paper. I don't just want that paper. I want the whole report.

As another one put it, medical professionals were often more focused on protocol than what the people needed in terms of care and information:

Basically they just wanna give you a pill and then you gotta come with a list of the questions to ask the doctor.

The perceived lack of concern or active care was a source of frustration among participants in all three focus groups.

This type of experience was especially salient when other participants brought up their experiences with specialists. Participants who had access to specialists reported much better health care experiences and much more positive interactions with doctors. What set them apart was the way specialists involved their patients in every aspect of

their care and made sure that patients understood what was happening and what was necessary. In fact, one local endocrinologist, as the following quote from one of their patients illustrates, emerged as the best case among residents:

That's my doctor. He's fabulous. You get a printout of your sugar levels. And you get a graph, different styles of graphs that you are going to get in color.

Participants without this kind of specialist or attention from doctors, however, all sought more information on their conditions and potential interventions. In fact, prediabetic participants reported that their condition was generally not taken seriously by the healthcare providers they had access to at the time.

Alongside interactions with doctors themselves, participants also reported issues with medications. Specifically, they noted trouble affording medications they were prescribed, and trying to figure out how to get them on tight budgets. As one put it:

The hardest thing is getting the medication. It is hard to get the help to get medication. The insulin is expensive. If it wasn't for my doctor giving me the shots of insulin, I don't know where I'd be at right now.

Another added:

I went to go pick up my medication on Saturday, and they told me it was \$143 for the insulin. So, I said, 'I guess we gotta leave it.' I don't have it, but I went to the hospital and they gave me some for 5 days, but I'm not on any now.

As suggested in these examples, participants noted experiences being prescribed medications they could not afford to acquire regularly or even at all. This was especially salient in relation to pre-loaded insulin pens that are more convenient and much more expensive. In fact, they noted this as a primary problem both in relation to healthcare access and in relation to medical professionals who were primarily interested in providing prescriptions without much other care or engagement concerning the resources or experiences of the participants themselves.

Participants were also deeply interested in information concerning diabetes, prediabetes, and management strategies and options. They noted their efforts to educate themselves by attending workshops, reading brochures, and studying other materials online or in doctor's offices. Participants, however, wanted to learn more even as they noted that not

all of them would take similarly proactive approaches all the time. Part of the education aspect, however, was that they (1) wished healthcare professionals would focus on making things more affordable and available via information sessions about how to manage conditions, and (2) that medical professionals should, as one put it,

Make all medical recommendations to African American people that they do to whites [because] in the real world it doesn't happen.

In fact, participants in each focus group highlighted both of these concerns repeatedly as they discussed the need to both know more about the conditions and management options and find better interactions with medical doctors and practices.

DISCUSSION

The primary themes in these focus groups present some key findings for further development in research and treatment for people living with diabetes. First, our participants were primarily managing diabetes and prediabetes by themselves. Next, our participants were seeking to incorporate and adjust diet and exercise, but having more success doing so with diet than with exercise. Third, our participants report variation in experiences with medical professionals, and specifically note the importance of insurance coverage and education and access concerning medications and treatment protocols. In each of the following paragraphs, we expand on these findings in relation to existing literature and possibilities for further research.

Our participants, like older African Americans in other studies, were primarily managing diabetes and prediabetes conditions by themselves [15], which automatically suggests the need to ascertain how to foster and create social support networks and mechanisms within communities with fewer resources and high levels of chronic conditions [16]. Especially since social support, alongside resources and access [11], has been repeatedly shown to impact health outcomes and experience as much or more than any other factor [2], this finding alone points to an important area of research for ongoing studies of diabetes management as well as management of other chronic health conditions within communities [16].

Beyond this overall pattern, our findings, echoing some other studies [12, 15], point to both the commitment of people to engage in practices that will help manage diabetes, and barriers they may face when they occupy marginalized social and economic positions. In the focus groups, for example, the importance of dietary practice and management was an emphasis, which suggests this message coming from research and clinical literatures [19] is getting through to the population. However, problems arise for our participants due to social factors that stand in the way of following such guidelines as well as possible. While they have made changes in diet, they also note significant cost and other barriers to transforming dietary practice when inhabiting low income social statuses and lacking the economic resources for healthier, and more costly, foods [3, 4, 11, 12]. Future research and intervention efforts should seek to ascertain options for communities without access to affordable healthy foods when seeking to create and maintain healthy eating habits related to diabetes, prediabetes, and other outcomes.

Our findings also point to similar barriers and struggles related to incorporating regular exercise into daily life [12]. Participants noted the lack of available places in their community to go for exercise options, and noted the difficulties of finding time for more physical activity in relation to pressing work and other demands. Especially in communities where monetary and occupational resources are scarce and often without fixed schedules [13, 14], it may be more difficult for the exercise component of diet and exercise suggestions to find place in the everyday practices and routines of the populations [24, 25, 26]. What might be done to facilitate better access to exercise settings, options, and opportunities or to create physical activity space within schedules tightened by pressing economic and occupational needs? These questions could form the basis of more community intervention and outcome studies, and in so doing, potentially provide answers and options for communities with similar characteristics in different locations.

Echoing some concerns raised by the American Diabetes Association in recent years [25, 26], our findings also point to struggles people living with diabetes may face interacting with medical professionals and institutions. Especially for low income and racial minority patients [12], the reliance upon Medicare, Medicaid, and public clinics often means that a general physician, rather than a specialist, handles the diagnosis and treatment of diabetes. In fact, as noted by the American Diabetes Association more broadly [1], our participants with prediabetes experienced the fact that

too many physicians do not treat prediabetes aggressively. Alongside these issues, participants struggled with the ability to access the medications necessary for proper treatment and management of their conditions. In fact, they often had to forego medication simply because of cost, and this was especially common for those prescribed more expensive pre-loaded insulin pens. These findings suggest the need for more research into the ways people living with diabetes experience interactions with medical providers.

This is especially relevant considering that this study draws from a community of people living with diabetes situated within a major urban area. This particular context is important because this means that these are participants living with diabetes who are in a major city that has certified diabetes educators (CDE) through the major area hospital, and clinical and other educational programs offered via the hospital and CDE in the area. Even so, lacking the structural resources (i.e., time, transportation, and / or insurance, for examples) to access such options, patients like those in our focus groups, may not gain benefit from the existence of such options even when it is theoretically possible to do so [3, 15, 16]. Such a scenario directs our attention to the importance of not only establishing programs, like CDE offerings, but also creating avenues where all who would benefit from such options may access them.

Overall, the findings from our focus groups suggest that better serving communities with limited resources and high levels of diabetes and prediabetes will require systematic attention to the ways these people experience their health, daily lives, and access to food, medical providers, and exercise options [15, 16, 26]. As our participants suggest, it is vital that patients can gain access to quality education about their conditions, management options, and possibilities for accessing care, more information, and medication. At the same time, it is equally vital that providers, clinicians, and researchers, as Nowakowski [7] notes in relation to chronic conditions more broadly, collect and learn from the insights of the people – and especially the more socially marginalized people [17, 20] – living with diabetes and prediabetes. As researchers have noted in relation to cancer treatment protocols [9], this type of reciprocal community is necessary for any chance of providing patients with the best chances for not just living with, but thriving with conditions while managing resources, access options, and community needs.

Strengths and Limitations

Finally, it is important to note that the current report has both strengths and limitations for furthering research into the ways varied communities live with diabetes and prediabetes. In terms of strengths, we offer insights here from patients who are less represented in the literature and able to speak freely beyond medical establishments and protocols [17]. Whereas much research into living with and experiencing diabetes and other chronic conditions utilizes surveys of various sizes or clinical interpretations and structured questions, here we utilize the impressions of people offered in their own words, from their own perspectives, and without any limitation or constraint upon what they may say [19]. This allows for a view of the concrete experiences and thoughts of a particular community in a particular social context [20]. In so doing, as medical and social ethnographers have noted [7, 19, 23, 24], our findings here offer a snapshot into the empirical realities of the people managing and interpreting health beyond what we may expect, hypothesize, or interpret outside of the lived experience of health and illness.

This important strength of ascertaining and reporting patient lived experience, however, also reveals a significant limitation of the study. Put simply, this is a case study of a specific community in a specific social context. As such, the findings here cannot be automatically generalized to other communities. Rather, our findings here provide possibilities for future research in similar and different communities as well as opportunities to ascertain and evaluate how common the experiences of these patients may be more broadly through other research methods. We thus caution against extrapolating these findings directly onto other communities, and rather, suggest future studies utilize the patterns here as a baseline for exploring the ways other communities – similar and different in demographic content – make sense of and experience living with diabetes and prediabetes. Our findings thus join others calling for more in-depth qualitative and quantitative research into the many ways people experience, live with, and manage diabetes in the context of their ongoing lives, varied social contexts, and varied connections to medical and other health-related resources.

CONFLICT OF INTEREST DISCLOSURES

The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. Dr. Donley reports grants from University of Central Florida during the conduct of the study. Dr. Sumerau has no conflicts to disclose.

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