'How I Can Help Me': Self-Care Priorities and Structural Pressures Among Black Older Adults With Diabetes

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Abstract

Background and Objectives: Disparities in Type 2 diabetes mellitus (diabetes) represent an ongoing public health challenge. Black older adults are at high risk of diabetes and diabetes' complications. Diet, physical activity, and medication can control these risks, yet disease rates remain elevated. Utilizing an Intersectionality framework, we seek to extend understanding of the social dimensions of diabetes through an examination of the diabetes self-care process from the perspective of Black older adults.

Research Design and Methods: This project involved a thematic analysis of diabetes illness narrative interviews with Black participants (N=41) in our National Institute on Aging-funded study of diabetes. In a narrative approach, the participant communicates the significance of actions and events.

Results: The findings suggest that diabetes self-care involves interconnected struggles across four domains of care: 1) multimorbidity management, 2) financial well-being, 3) family support, and 4) formal health care.

Discussion and Implications: Black older adult self-care reflects an active process of pursuing meaningful social goals and critical health needs. An Intersectional framework, however, reveals the ongoing histories of inequity that shape this process. Further intervention to address the racist policies and practices found in Black older adults' communities and clinical care is needed to make true progress on diabetes disparities.

Keywords: Qualitative research, Health disparities, Urban, McGill Illness Narrative Interview

Introduction

Black Americans' experiences of diabetes disparities are a public health priority (Office of Disease Prevention and Health Promotion, n.d.). The diabetes prevalence rate among Black Americans is 16.4%, compared to 13.0% for U.S. adults as a whole (Centers for Disease Control and Prevention, 2020). Compared to White Americans, Black Americans experience higher diabetes mortality (Buscemi et al., 2021) and risk of complications (Clements et al., 2020; Spanakis & Golden, 2013). Analyses of Medicare beneficiaries indicate diabetes disparities are especially high among Black older adults (CMS OMH and NORC, 2017). With type 2 diabetes representing over 90% of adult diabetes cases nationally (Centers for Disease Control and Prevention, 2020), the focus of this paper is type 2 diabetes (hereafter referred to as diabetes).

Health disparities research indicates macro-level variables, such as neighborhood and health system inequities, correlate with racial variation in diabetes outcomes (Campbell & Egede, 2020; Steve et al., 2016). This literature clearly establishes the racist urban development, housing, and health care policies and practices, to name just a few social systems, that foster these inequities (R. B. Baker et al., 2008; Williams & Jackson, 2005).

Qualitative studies of diabetes management similarly point to individual-level racism in clinical encounters and follow-up as undermining diabetes control (Ochieng & Crist, 2021; Shiyanbola et al., 2018). These examples of racist practice need to be recognized as further representations of systemic racism, i.e., as part of the "collective practices, mechanisms, and behaviors that reproduce racial domination" (Bonilla-Silva, 2021, p. 519).

Diabetes research also highlights individual-level variables such as social support (Hawkins, 2019; Hu et al., 2021), self-efficacy beliefs (Rao et al., 2020), and diet and blood glucose goals (Brewer-Lowry et al., 2010), that shape diabetes control. Thus, while macro-level systems explain

much of the variation in diabetes rates and outcomes, individual behavior is often the site of intervention.

Building on this literature, we argue that scholarship is now needed that investigates how interlocking macro-level systems, which are imbued with privilege and oppression (Collins, 2019), operate within and across race and gender categories, shaping the experience of diabetes (Naqvi et al., 2020). We seek to examine the care goals Black women and men with diabetes set for themselves and the social structures pressing upon those goals, i.e., how do Black older adults' responses to diabetes reflect the challenges of a racialized, de-industrialized U.S. city?

For this project we draw on Intersectionality theory, rooted in Black Feminist Theory, which calls for "recognizing the significance of social structural arrangements of power, how individual and group experiences reflect those structural intersections, and how political marginality might engender new subjectivities and agency" (Collins, 2019, p. 26; Collins cites Collins & Bilge, 2016, pp. 71–77). As a critical theory, Intersectionality importantly requires analysis of individual experience in relation to large scale social forces in order to both understand and challenge oppression (Aguayo-Romero, 2021; Collins, 2019; Crenshaw, 2017).

We focus on Black Americans' experiences of "self-care" rather than "self-management" as self-care refers to the individual's self-defined efforts to treat illness or create a sense of health, which may or may not include biomedical treatment (Jones et al., 2011; Thorne et al., 2003). In contrast, self-management tends to refer to adherence to a specific set of clinically-relevant behaviors, i.e., diet, physical activity, weight loss, medication adherence, and blood glucose monitoring (American Diabetes Association, 2021).

The data are drawn from qualitative illness narrative interviews with Black older adults living with diabetes in a mid-Atlantic city. The findings are organized around the four dimensions of self-care that emerge from participants' interviews: 1) multimorbidity management, 2) financial well-

being, 3) family support, and 4) formal health care. In our discussion, we connect participants' experiences of self-care to the larger social structures that inform, and often constrain, self-care practice. Identifying these connections suggests avenues for expanding interventions from the person with diabetes to the larger social structures that cross individual-level care approaches.

Methods

The Subjective Experience of Diabetes Study is a National Institute on Aging-funded study of older adults' experiences with diabetes. Utilizing a modification of the McGill Illness Narrative Interview (Groleau et al., 2006), interviewers asked participants to share the historic and present-day context of their diabetes, diabetes beliefs, and diabetes management. With a narrative approach, the participant guides the discussion, elaborating on elements of the illness and life context that are of personal importance (Chase, 2003). The participant provides insights into the relevance of their narration, greatly enhancing the analysis and interpretation (Chase, 2003). Illness narratives thus elicit how people make meaning and understand their lived experience with illness (Acuff & Paulus, 2016; Crabtree et al., 1992; Kleinman, 1988; Phoenix et al., 2010).

When feasible, interviews were conducted in the participant's home, which stimulated storytelling and household introductions. Interviewers completed the consent process in-person, prior to the start of the interview. Participants received US$50 honorarium. Interviews were audio-recorded and transcribed verbatim; they averaged 100 minutes in length. To encourage rapport, we sought racial congruence between the interviewer and participant. Thirty-one (76%) of the 41 interviews in this analysis were completed by a Black woman; ten (24%) were conducted by two White women. Interviewers wrote fieldnotes to capture details of the participant's home, neighborhood, and interactions. We used qualitative data management software to house transcriptions and fieldnotes, through which the authors read, sorted, and coded the interviews

(Silverman, 2011). Demographic data were analyzed using a statistical software package. The study received Institutional Review Board approval from the University of Maryland, Baltimore County. All names used here are pseudonyms; unique personal details, including distinct illnesses, also are masked.

The Subjective Experiences of Diabetes project sample was recruited from a longitudinal study of health disparities in a mid-Atlantic city (Evans et al., 2010). By recruiting through this epidemiological project, participants were community-living older adults with confirmed diabetes but may or may not have been actively seeking treatment. The study's urban context is characterized by a legacy of redlining, deindustrialization, and disinvestment in Black neighborhoods, leading to concentrations of multigenerational poverty and low levels of grocery stores and other basic services.

To select persons for recruitment, we employed a purposive sampling frame designed to fill race and gender inclusion criteria for male and female, Black and non-Hispanic White adults age ≥50. A clinical diabetes diagnosis (e.g., blood glucose >7 mmol/L, fasting) was an additional criterion for inclusion; major cognitive impairment was an exclusion criterion. For this analysis, we focused on the interviews with Black study participants (N=41) in order to gain insights into Black experience unfettered from a comparison to other groups. Demographic data are provided in Table 1. Men and women held a range of occupations, from salaried, managerial positions to hourly skilled nursing, custodial, or service work.

[Table 1 here].

The thematic analysis involved all co-authors engaging in a collaborative process of generating themes through close reading of the transcripts and discussion. The co-authors confirmed saliency of themes through additional review of the interviews and fieldnotes (Luborsky, 1994; Miles & Huberman, 1994). As a validity check, co-authors actively sought confirming and

disconfirming evidence throughout their review (Bernard & Ryan, 2010). In addition, the co-authors, who represent persons who identify as Black Women (N=2), White women (N=4), and as a White man (N=1) approached the analysis with concern for positionality.

Four broad life domains emerged as sites of self-care in the management of diabetes, which we use to organize the results: 1) multimorbidity management, 2) financial well-being, 3) family support, and 4) formal health care. Table 2 provides a summary of these themes and sub-themes. The participants and the quotes featured in each section were purposefully selected to illustrate the range of experiences within each domain.

[Table 2 here]

Multimorbidity Management: "It's like a Merry-Go Round"

Participants' narratives reveal diabetes commonly is experienced as one of a range of conditions, from hypertension and heart disease to hepatitis C, HIV, degenerative spine conditions (e.g., spinal stenosis, sciatica), and mental illness (e.g., bipolar disorder, depression). As a result, self-care involves shifting among the needs of co-occurring conditions, hoping that unwatched illness remains stable. Co-occurring conditions such as pain and depression in particular undermine participants' ability to respond to diabetes' ongoing demands.

Louise's, age 60, illness narrative provides insight into the challenge of managing diabetes in the context of multimorbidity, defined as two or more co-occurring conditions (Goodman et al., 2016). Louise has had diabetes for over a decade; she also suffers from depression, and back and gastrointestinal conditions. She describes her diabetes is “in the gray area of control." She elaborates:

> I can only deal with one thing. So if it's the diabetes that's out of control, deal with that. But if I, you know, I have a degenerative disc in my back so I have back problems so if that's flared up, my concentration is more on the back. And when I say concentration, if the back hurts and I can't move, I'm laying down, I'm not worried about the food and I'm missing taking my medication and all of that because I'm in pain. So right now I'm in physical therapy for the back and the neck and, um, you know, so that's being handled so that I can turn my attention to something else you know. So it's like a merry-go-round, wherever it stop, whatever problem it stops on, give attention to that.

While Louise understands the importance of disease management, diabetes is "a fight because it's so many other things that's going on." This cycle was repeatedly articulated among participants: eating, exercising, and taking medication hinge on other conditions. The constant pressure provokes anxiety.

When conditions involve chronic pain, common acts of glucose control such as walking are burdensome. Delores, age 52, has severe pain from a bone spur and neuropathy. Although she tries to walk thirty minutes a day, she describes:

> that's a problem, too, you know, because I have a spur in my [foot], that's why I say I'm really conscious of my legs, that's the main problem.... Not saying, I'm not saying I can't walk or do things like, but I get, you know, pain from, even exercising but I do try to do it as much as I can.

As with Louise, Delores has strong intent, but walking is not restorative. Participants who have battled asthma for much of their life likewise are distraught when told to increase their activity by walking outside.

Louise's story additionally brings forward the challenge of mental illness in the context of diabetes (Chen et al., 2013). Louise cannot recall how many years she has been treated for depression, describing, "there are times when the medication no longer works and then the depression comes in… I am currently on disability because of the depression, so I had to stop work." Louise's providers importantly understand her depression, "they don't want to harp on the weight because they don't want me to fall into depression, you know, so in that sense they remind me but they don't push me."

Financial well-being: "It wears and tears on you"

Participants' illness narratives reveal distinct financial challenges shape diabetes self-care among both higher and lower income participants. Formal social safety net resources, including Medicaid, Supplemental Security Income (SSI), and housing subsidies, provide critical, but insufficient, aid to participants unable to work because of poor health. Participants with higher incomes, however, likewise must strategize regarding how to meet the financial demands of diabetes self-care in the context of multimorbidity. Across participants, sporadic employment and early retirement due to chronic conditions contributes to diabetes management precarity. Participants also perceive racial discrimination as contributing to forced lay-offs that further undermine diabetes resources.

Viola, age 62, lives alone and has been unable to work for over a decade due to her chronic health problems including arthritis, asthma, diabetes, high cholesterol, and hypertension. She describes the acute financial challenge of her care: "I don't really have the money to buy things that I

need to have. I only could afford to get things that I can get, so I try to eat less of it." Viola stretches her monthly income (<$800), relying on lower cost canned vegetables, eggs, and cereal in her daily diet.

Viola further noted economizing on her prescriptions, describing "sometime I don't get my medicine because I don't have the money at the time." Her preference is to space her purchases to fit her budget. The advent of electronic prescriptions has reduced her control as her provider sends all her prescriptions for filling at once. She describes:

> See, I like when they used to write you a prescription and give it to you and you take it there when you get ready for it instead of them sending it electronically. And I don't need all my medicine at one time and sometime I don't get some of the medicine I'm supposed to get.

When asked how she chooses among prescriptions, she explained, "Well, I mainly get the blood pressure medicine, the insulin, high blood, the cholesterol medicine. Stuff like that. If I get my pain medicine, I try to stretch it." Viola's rationing is striking given she is covered by Medicaid with copayments of $3.00 per prescription.

Despite economizing, Viola finds some months, "I run out of money. And all I can do is wait until the next month." Viola's weariness of managing an intractable situation was indicated by the frequency with which she reported being "frustrated" – she used the term eleven times, at one point explaining the significance of the emotion, "so when I get frustrated, sometimes I'll be depressed."

Higher income participants are not immune from financial constraints, particularly when multimorbidity leads to the accumulation of medical debt. Ann, age 68, for example, whose household income places her at the median for the region, has six major health conditions. Medicare does not cover her health care needs. She is in debt from hospitalizations and a rehabilitation center stay:

> Yes, I have a lot of doctor bills that I haven't paid. Yeah. I'm getting ready to try to go to work now so I can start paying some of them because after awhile they're going to start coming after me because some of them are a considerable amount, you know, like a thousand dollars or so…

Similar to Viola, Ann skips doses and refills a few prescriptions at a time to stretch funds. Ann and her husband, Sam, age 64, also a study participant, occasionally use each other's prescriptions. As Sam described, "one of us run out a little short and really don't have the funds to go get medicine, we can borrow from each other because they're identical, same medicine." Sam was without health insurance after being laid-off, having weighed the costs of the penalty for no insurance versus the premium, "Just hopefully I don't get sick before I turn 65."

Sam's lay-off also provides a window on older Black workers' experiences of perceived ageism and racism. Sam described:

> [New manager] saw me as being too old and he could get someone to do my job for half what he was paying me…We had this guy that came in, was supposed to be showing my boss how to manage his funds. I said, 'Uh-oh', because I knew. I think I

> was the highest paid supervisor in the company at that time, highest paid supervisor and Black. 'You're going out the door.'

With Ann having lost her job two years earlier as a result of her company's downsizing, the couple faced a different retirement than they envisioned. Ann described, "[we] was planning so we would have been through with the bills, you know what I mean. But we've had to buckle down and do the best we could." They now find themselves barely meeting the household's needs with Sam's part-time retail job and Ann's Social Security. Ann stocks her freezer and buys canned goods for times when money runs out. If Ann returns to work it will have a ripple effect on their extended family as the couple provides afterschool care for their grandchildren.

Geneva, age 67, who is retired and focused on her diabetes, weight loss, and asthma, also has a monthly income that places her at the regional median. Like Sam and Ann, she notes incrementally paying off medical expenses. She canceled her supplemental health insurance, noting she could not pay the premium and keep her car. Despite being unable to cover health care and household expenses, Geneva indicates that her household's income disqualifies her for a subsidized diabetes management program.

> [I]t can be discouraging because they have programs but they don't have them, like, my income I would qualify for a lot probably but then if you're married and they include your husband's income and then the other income, then you're disqualified.

Geneva reports needing her husband's support to pay out-of-pocket for a program, which he has been unwilling to give. Geneva's situation highlights the challenge, particularly for women,

when income eligiblity guidelines are built on assumptions that funds entering the household are shared and equally controlled. Thus, she reports that to make progress on her health, "I'm going to have to do research; I'm going to have to get out there and get, you know, just constantly go to anything free that I can find to find out how I can help me, you know."

The accumulation of debt, plus expenses for multiple ongoing conditions, critically shapes how participants approach self-care. For both median income participants who have worked well-paying, managerial jobs and low income participants whose careers were stymied by disease, addressing diabetes plus co-occuring conditions requires financial strategizing. As one participant described, the constant pressure of managing income elligibility guidelines, high health care expenses, and the everday expenses of the home, "wears and tears on you."

Family support: 'Hey, do you need anything?'

Black family networks have long been identified as serving as informal safety nets in the face of multidimensional inequity (Sarkisian & Gerstel, 2004; Stack, 1997). In this sample family support also is a central element of many participants' self-care. Informal care exchange is a means of asserting connection but becomes stress-filled when necessitated by structural conditions. In addition, considerable heterogeneity exists in the meaning of self-care in the context of family.

Participants described self-care as highly relational, involving exchanges with parents, siblings, adult children, and grandchildren. For example, Annette explained,

> If I find out something, I'll tell them about it. I've taught them how to change their diet and was telling them what to eat and what not to eat, so I think I played a big part, more so than them helping me, because I went out for the [diabetes] knowledge because I wanted to know how to take care of myself.

Sharing diabetes knowledge, recipes, and even food preparation, becomes a multi-directional means for expressing affection and concern.

Intergenerational practices of self-care also speak to the hereogenity of self-care experiences within gender categories. Some men embrace self-care as a generative activity, a way to provide life lessons to sons and daughters (Chard et al., 2017). Anthony, age 62, talked at length about assisting relatives, explaining, "I try to help where I can, you know. Hopefully it'll bless me in the end. If it don't, hey, I'm satisfied in my heart that I did the right thing."

In the absence of opportunities for personally meaningful connection, however, participants opted for isolation as a form of self-care. Leroy, age 72, prefers religious rather than social gatherings because of his histories of addiction and heart attack. With the passing of friends who would debate scripture, he finds, "I don't associate with no one. I have become a recluse...under the circumstances, that's the way the game is played."

These narratives additionally highlight the fluidity of support networks. Social connection can retract with the loss of jobs or age-mates, and expands with newfound passions or the aging of grandchildren. Housing policies also shape networks: the conversion of subsidized older adult apartment buildings to multi-age units undermined older men's networks. Men described a lack of shared interests when apartments rented to younger families.

The heterogeneity of women's self-care within family also deserves highlighting. Louise, introduced at the start, describes life features that are consistent with the strong Black woman motif (Beauboeuf-Lafontant, 2009). She is the support provider across her relatives, including a sibling who has advanced cancer. She explained the emotional and instrumental work:

> [M]aking sure that he has food and, you know, pay for his medications which is not all the time but the stress is, does he have it and will he tell me, you know, because not so much as pride but looking after me. Sometimes he won't say that he has,

> that he hasn't eaten, you know, so trying to find a nice way to, you know, get around to saying, 'Hey, do you need anything?'

If he has not eaten, she will bring him food before she herself eats, representing a pattern of prioritizing his needs.

Yet, as agents of self-care, women do negotiate this cultural script (T. Baker et al., 2015). Annette, for example, realized she needed to be more attentive to the impact of stressors on her blood glucose. As mornings and evenings are difficult times, she told her family, "I said don't call me before 9 o'clock and don't call me, uh, after 9 o'clock at night. I said, 'Because I don't want to hear all y'alls problems. I want to go to sleep." When family expressed dismay, she was firm, "I said, because if it's irritating me or messing with my health, I will do anything I can to try to keep myself together this time." One of Annette's adult children was recently incarcerated; she insists he will not live with her again: "He had to get away from here because he was like messing with my health again. Each time I, I started trying to be nice to him, my [blood] pressure would go up….That's when I said, I can't do this, I can't do this."

When structural conditions require participants to accept help from children, such exchanges can painfully transgress parent-child hierarchies. Continuing with Annette, whose spine injury makes walking and lifting difficult, she described wanting to move to a different subsidized apartment that had laundry,

> 'cause that way everybody won't have to be coming to my rescue when I need to go to the laundromat and everything…making me feel like I'm the child and they the parents again, you know what I mean? Although I appreciate it.

Viola similarly can only walk short distances. She notes the absence of nearby services like laundry or stores requires her to schedule her self-care with others:

> And when I can't, um, get certain places and, and then I have to, like I said, wash my clothes, so I have to wait for somebody to take me because the closest laundry mat around here is up the Village. And I have to wait for somebody to take me to the market, my son he works a lot so I have to be on his schedule for the laundry and the market…

These obstacles to completing basic activities of daily life greatly impact Viola and Annette's dignity and level of activity, key to diabetes control.

Similar instances of both needing and resisting help from children occur among higher income participants. Sam and Ann are fortunate to own a home and a car. They were grateful for their adult children's help with a recent emergency, but explained, "that's something that we don't want to do." Sam later noted that his son offered to pay his health insurance premium, but Sam declined, "I didn't want him to take that kind of money out of his," preferring to "struggle it out" until he becomes eligible for Medicare. Their rationale is that their children's own needs should take priority.

Formal health care: "I'm not just a patient"

The final domain of care centered on formal health care providers. Participants viewed their health care providers as mediators in their self-care "fight," to borrow Louise's term. Participants' high rates of multimorbidity necessitated engaging numerous providers. Following up on recommendations involves considerable time and energy.

Participants describe provider visits as a means of regaining control of their self-care and their diabetes. Leroy, for example, noted a series of upcoming appointments, "I have an appointment with the eye doctor and the dentist and, uh, my regular heart doctor, you know. So I'm, I'm trying to get on top of that because I'm really afraid of the harm that this sugar is doing to me, you know."

Leroy's description also illuminates the number of doctors patients have and the days spent on specialized care. Louise similarly noted, "If I could just stop going to the doctors. Because most of my week is this doctor, that doctor, the other doctor, so many different doctors, you know, so next week I think I got about four doctor's appointments. That gets in the way."

In addition to the time involved with appointments, Olivia, age 63, lamented having to remind each specialist of her history:

> I know you specialize in certain things because I know everybody can't have everything but every, every, every doctor got a different part and you have to go to every, every, you know, and this, it boggles my mind sometimes. And they always tell me, 'Miss Olivia, you're a good patient, um, you keep all your appointments.' I just would look at 'em, I would just, 'Look, you know, y'all just don't know. You just don't know.'

While the various specialists know and manage their 'part' well, Olivia is noting *she* must manage each provider and appointment, a facet of care that few providers realize.

Participants attending clinics with rotating providers confront even further time spent on repetitive medical history reviews. Lamont, age 65, for example, questions advice that is not built on a sustained relationship:

> [T]hey're not helping me because it ain't like I see the same doctor that know my medical history...this doctor gave me new blood pressure medicine for 30 days, 'come back in 30 days.' I go back in 30 days, a different doctor, he give me something different. I said, 'I don't know, y'all keep doing it this a way,' I said, 'I ain't no damn guinea pig. Y'all just trial and error.'

His use of the term "guinea pig" also powerfully evokes medicine's history of experimentation on Black bodies (Washington, 2006).

Participants' illness narratives repeatedly emphasize the provider's approach is essential. For example, Evelyn, age 58, is troubled by memories of a provider who was "so mean" and "nasty to Black people. Every Black person." She described, "He'll tell you in a minute, 'You want to die? You want to die? If you don't take the medicine, you want to die?'" Her subsequent doctors, who talk "real nice" and are "patient" are much further away, but worth the effort:

> It would be more convenient but why be treated bad. I don't like to be treated bad. I don't like nobody talk to me in that kind of way. I don't like to be talked to any kind of, even though I'm sick and stuff but I got feelings, too.

Similarly, Louise's doctor's willingness to "take time and explain things" became pivotal in Louise's acceptance of insulin.

Positive relationships do not mean that providers never critique a patient. Participants distinctly noted their providers "fuss" at them in respectful and caring ways. Leroy, age 73, said of his younger, female doctor, "She treat me like I'm her father and it make me feel so good because she really cares, you know, she really cares. I have a good relationship with her. But I got to go for an appointment to see her… She's going to fuss me out when she sees me." Delores, age 52, similarly said that her doctor, "was mad at me last time." When asked to explain, Delores reported, "Well, not really, really mad. We got a relationship, we joke, she was just telling me you're going to have to do better than this…I know one thing I'm not just a patient or a number to her…" Delores's statement that she is "not just a patient" succintly captures participants' desire to be recognized as their full selves in their provider interactions.

Discussion

Participants' illness narratives suggest diabetes care involves a negotiation of physical, psychological, and financial needs, family priorities, and health care providers. Participants' experiences also highlight how social structures related to employment, neighborhood investment, and health care, among others, shape the construction of care goals and the time, money, and energy for this care work. With our grounding in Intersectionality theory, we seek in this discussion to make the links between self-care and social structures explicit.

Consistent with national data on multimorbidity among Black Americans (Lynch et al., 2015), participants experience diabetes as one of many chronic conditions. Narratives such as Viola's show inequities in access to wealth accumulation (Pfeffer & Killewald, 2019) and

disinvestment in Black neighborhoods shape both disease status (Hill-Briggs et al., 2021; Williams & Jackson, 2005) and responses, e.g., rationing medication and food and reliance on family for groceries and laundry. Louise's metaphor of a merry-go-round aptly describes the resulting acute approach to self-care. The serious, synergistic relationship between poverty, depression, and diabetes also must be underscored (Mendenhall et al., 2017).

While adding to the call for attention to wealth mobility and neighborhood structure as healthy equity issues (Hill-Briggs et al., 2021), participants' experiences also represent compelling cases for policies to expand comprehensive care coordination (McGilton et al., 2018). Participants' narratives additionally illustrate that in the absence of formal care coordination, with each provider comes the strain of another set of orders, prescriptions, and time spent. Systems of rotating providers risk adding a psychological burden as participants must repeat their histories and there is little means for establishing trust.

Participants' discussions of their formal care additionally reveals perceptions of provider discrimination (Shiyanbola et al., 2018). These experiences bolster the call for attention to how structural racism is "covert," and also "normative and routinized" (Bonilla-Silva, 2021, p. 524) in everyday clinical practice (Golden, 2021). Of particular concern is the way medicine's history of racist experimentation, exclusion, and inhuman practices shapes providers' approaches (Washington, 2006). Lamont's perception that he was treated like a "guinea pig" references this history and contributes to his distrust of medication changes. The alienation that arises from such interactions stands in stark contrast with participants' goals for the clinical encounter: visiting a provider represents the participant's health intervention, aimed at putting illness in check. Participants hold in high esteem providers who acknowledge their proactive health behavior and the complexity of their self-care.

Diabetes self-care also often requires a negotiation of social roles and relationships. Participants' descriptions are consistent with the literature suggesting Black social networks offer

emotional, financial, spiritual and physical support in response to structural inequities (Brown, 2008). Yet, participants' descriptions also highlight heterogeneity in the experience of social exchange in the context of diabetes. For men like Anthony who are quite active, helping others with physical tasks is generative. For Leroy, his weakness and the passing of friends makes social exchange fraught. Shifts in public housing policies that allow younger families to rent in senior housing buildings limits his ability to make new connections.

Among both men and women, diabetes care exchanges that upend age and role hierarchies can threaten dignity and risk burdening one's adult children. Much of participants' dependency, i.e., the inability to do laundry or shop, stems from the disinvestment in housing, business, and transportation in Black neighborhoods throughout the city.

When discussing social support among Black families the personal costs of support networks to Black women also must be noted (Abrams et al., 2019; T. Baker et al., 2015; Beauboeuf-Lafontant, 2009). Older Black women with chronic illness report relatively little time off from social roles (Hughes et al., 2014). Evidence of this strain occurs across participants and is perhaps most poignantly illustrated in Annette's description of the need for limits, which included not having her adult son live with her. She finds herself asking, "Why me all the time, why, why can't he go stay with somebody else. I'm the sickest but yet I always end up with him."

Annette's case also specifically illustrates the tax on Black women's self-care stemming from the policing of Black men (Williams & Perry, 2019). The system of incarceration-release-and-reincarceration that targets young Black men drains the emotional and physical energy for self-care. This was a particularly salient theme among Black mothers in our study; further research is needed to explore the impact on Black fathers and other family members with diabetes. We note too that while we provide one case example, it is tragically not unique. Improving diabetes disparities involves addressing the upstream production of Black older adults' stress, i.e., attending to the

forces perpetuating hyper-racially segregated neighborhoods and New Jim Crow Laws (Alexander, 2010).

Finally, participants' narratives also highlight the role of institutional workforce practices in undermining self-care. Sam ties his lay-off to discriminatory practices in hiring and firing. The resulting economic precarity forestalls his retirement plans and directly impacts the funds available for diabetes care. Sam also lost the health insurance subsidizing his self-care. Sam's experiences are consistent with findings elsewhere on job discrimination and health insurance among older Black adults with diabetes (Moody-Ayers et al., 2005; Sohn, 2017).

Limitations

While study participants held a range of occupations, few attended college. The experiences of persons with post-secondary degrees and white-collar professional positions may be under-represented. However, we note that Black Americans, regardless of socioeconomic status, experience high levels of discrimination (Bleich et al., 2019), suggesting the cases described here may be highly relevant. The sample also is drawn from a mid-Atlantic city, which shares similar concentrations of poverty, racial segregation, and losses in manufacturing to other cities in the mid-Atlantic and mid-West regions. Further research is needed to understand diabetes self-care among rural Black older adults (Brewer-Lowry et al., 2010).

Conclusion

A self-care lens reveals that for Black older adults, diabetes care involves negotiating priorities across multiple domains of care. As Geneva states, this is an active process that includes identifying "how I can help me" and a strong commitment to the self and family. Participants' illness narratives also demand recognition of the ongoing racism in urban development, employment practices, and health care that shapes those self-care processes (Torres, 2020). Participants' narratives reveal these and other structures directly contour care in the context of diabetes: from Louise's focus on her back and her sibling's illness to Ann's approach to stocking her freezer and sharing prescriptions. Further intervention to address the racist policies and practices found in Black older adults' communities and clinical care is needed in order to make sustained improvement on diabetes disparities.

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Table 1. Demographic Characteristics of Study participants

	Women (*n*=26)		Men (*n*=15)		Total (*N*=41)	
Characteristic	**Mean(SD)**	***N*(%)**[**]	**Mean(SD)**	***N*(%)**	**Mean(SD)**	***N*(%)**[**]
Age	61.2(5.3)		62.3 (6.1)		61.6 (5.6)	
Education (years)	12.2(1.9)[*]		12.3 (2.0)		12.3 (1.9)[*]	
Household income US$ (monthly)	$1,772($1,539)[^]		$1,850($1,363)		$1,804($1,451)[^]	
Diabetes duration (years)	11.3 (7.1)[*]		15.8 (8.0)[**]		12.8 (7.6)[***]	
Marital status						
Single		9(38)		6(40)		15(38)
Widowed/divorced/separated		10(42)		4(27)		14(36)
Married/live-in significant other		5(21)		5(33)		10(26)

[*]missing=1; [**]missing=2; [***]missing=3; [^]missing=4

Table 2. Summary guide to themes and sub-themes with representative quotes

Themes	Sub-themes	Representative quote
Multimorbidity management: *It's like a merry-go-round*	Multimorbidity requires shifting among conditions	*I can only deal with one thing [at a time]. It's like a merry-go-round; whatever problem it stops on, give attention to that.*
	Chronic pain & asthma challenge diabetes control activities	*I get pain from, even exercising but I do try to do it as much as I can.*
	Diabetes self-care with depression	*[My doctors] don't want to harp on the weight because they don't want me to fall into depression…*
Financial well-being and self-care: *It wears and tears on you*	Stretching resources with a concern for one's health	*Sometime I don't get my medicine because I don't have the money at the time.* *… If I get my pain medicine, I try to stretch it.*
	Frustration and stress due to financial barriers to self-care	*I run out of money. And all I can do is wait until the next month…*
	Lay-offs and resources for self-care: challenges of middle-income workers	*I think I was the highest paid supervisor in the company at that time, highest paid supervisor and Black. [I thought to myself:] 'You're going out the door.'…* *… we've had to buckle down and do the best we could.*
	Self-care resources, gender and income eligibility	*I would qualify for a lot probably but then if you're married and they include your husband's income and then the other income, then you're disqualified.*
Family support: *'Hey, do you need anything?'*	Relational sharing of diabetes knowledge	*If I find out something, I'll tell them about it. I've taught them how to change their diet and was telling them what to eat and what not to eat.*
	The intrinsic value of supporting others	*I try to help where I can, you know. Hopefully it'll bless me in the end. If it don't, hey, I'm satisfied in my heart that I did the right thing.*
	Social isolation as self-care/ Change in support networks among older adults	*I have become a recluse...under the circumstances, that's the way the game is played.*
	Women and self-care: prioritizing others	*[M]aking sure that he has food and, you know, pay for his medications which is not all the time but the stress is, does he have it and will he tell me…*
	Contesting role expectations and inverted social roles	*I don't want to hear all y'alls problems. I want to go to sleep.* *…coming to my rescue when I need to go to the laundromat and everything…making me feel like I'm the child and they the parents.* *I didn't want [my son] to take that kind of money out of his.*
Formal health care: *I'm not just a patient.*	Seeking formal care as a self-care intervention	*I have an appointment with the eye doctor and the dentist and my regular heart doctor. So, I'm trying to get on top of that because I'm really afraid of the harm that this sugar is doing to me.*
	The strain of fragmented care	*If I could just stop going to the doctors. Because most of my week is this doctor, that doctor, the other doctor, so many different doctors.* *[I]t boggles my mind sometimes and they always tell me, 'Miss Olivia, you're a good patient, um, you keep all your appointments.' I just would look at 'em, I would just, 'Look, you know, y'all just don't know. You just don't know.*
	Medicine's history frames the clinical encounter	*I go back in 30 days, a different doctor, he give me something different. I said, 'I don't know, y'all keep doing it this a way,' I said, 'I ain't no damn guinea pig. Y'all just trial and error.'*
	Implicit racism / provider approach matters	*[My old doctor was] nasty to Black people. He'll tell you in a minute, 'You want to die? You want to die? If you don't take the medicine, you want to die?' I don't like nobody talk to me in that kind of way, even though I'm sick and stuff but I got feelings, too.* *[My doctor] treat me like I'm her father and it make me feel so good because she really cares, you know, she really cares. I have a good relationship with her. But I got to go for an appointment to see her… She's going to fuss me out when she sees me.*