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## Counting, Coping, and Navigating the Flux: A Focused Ethnographic Study of HIV and Diabetes Self-Management

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### Abstract

Approximately 10–15% of people living with HIV are also diagnosed with diabetes. To manage their two chronic conditions, people must undertake certain activities and adopt behaviors. Due to overlapping symptoms, complex medication regimens, and heavy patient workloads, implementing these self-management practices can be difficult. In this focused ethnography, data were collected from semi-structured interviews and limited participant-observation with a selected subset of participants to gain insight into self-management challenges and facilitators. We conducted interviews and multiple observations with 22 participants with HIV+T2DM over the period of 9 months. Participants experienced numerous barriers to self-management in the areas of diet, medication adherence, and mental health. Social and familial support, as well as consistent access to care, were facilitators for optimal self-management. At the same time participants' lives were in a unique flux shaped by the dual diagnoses, and therefore, required constant mental and physical adjustments, thus illustrating challenges of managing chronicity.

### Keywords

HIV; diabetes; self-management; focused ethnography; chronic illness

### Introduction

Approximately 10–15% of people living with HIV (PLWH) also have a diagnosis of type 2 diabetes mellitus (T2DM) (Hernandez-Romieu et al., 2017). PLWH are at increased risk of developing diabetes, due in part to low levels of chronic inflammation and mitochondrial damage from HIV treatment (Hadigan & Kattakuzhy, 2014; Sarkar & Brown, 2021). The prevalence of T2DM in PLWH is expected to increase over the next several years partially due to the aging of PLWH and general diabetes trends in the U.S. that show a growing

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Ethical Approval

This study received IRB approval by the University of Texas at Austin IRB. The study number is 2017070070.

Supplemental Material

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prevalence of T2DM as people age (Hasse et al., 2011; Kalra et al., 2011). People with both HIV and T2DM are required to manage their behavior to reduce symptoms, maintain health, and prevent disease complications and mortality (Beck et al., 2018). Self-management regimens for either HIV and T2DM are often complex, thus in combination may be even more burdensome and demanding, requiring multiple medications, dietary restrictions, regular physical activity, glucose self-monitoring, avoiding infections, and keeping frequent appointments with healthcare providers (Beck et al., 2018). For many patients, the process of sustaining effective self-management practices requires a constant learning and relearning, as they craft ways to respond to challenges and optimize health (Chrvala et al., 2016). Though there has been research on either HIV or diabetes self-management, there is a paucity of research on patients' perspectives of self-management of the dual diagnoses of HIV and diabetes.

Self-management of chronic conditions affects a person's daily life every day for a lifetime (Khairnar et al., 2019; Manderson & Smith-Morris, 2010; Mendenhall, 2019; Sangaramoorthy, 2018). A more holistic understanding of how people navigate complex self-management regimens requires recognition that long-term conditions are not stable and persons who experience chronic illnesses are often, "caught up in the ebbs and flows, cyclicity and chronicity, of their body and embodied state" (Manderson & Smith-Morris, 2010, pp. 16–17). Having two or more chronic medical conditions further complicates people's ability to navigate changing health and self-management routines. People's ability to self-manage their HIV and T2DM is affected by "patient workload" and "patient capacity" (Matima et al., 2018). Patient workload refers to the burden of a patient's tasks and responsibilities related to care for self and family. A patient's capacity is influenced by their mental health, socioeconomic status, and support, among other factors. Ultimately, these interrelated notions of workload and capacity shape a patient's ability to self-manage their disease (Matima et al., 2018).

PLWH and T2DM often struggle to achieve recommended clinical and life quality goals for both conditions and have difficulty completing self-management activities (Bosire, 2021). People are more likely to reach HIV treatment goals than that of diabetes (Zuñiga et al., 2016). In a recent cross-sectional study of PLWH and T2DM, the traditional predictors of quality of life in PLWH, such as exercise, drug and alcohol use, and medication adherence did not significantly predict quality of life in PLWH and T2DM, which suggests that there are additional variables that may affect quality of life for people with both HIV and T2DM (Zuñiga et al., 2020). Though stress and anxiety predicted quality of life, they explained less of the variance, indicating that key variables are missing (Zuñiga et al., 2020). The present study aims to address this gap, by qualitatively investigating patients' perceptions of self-management.

This study was conducted to elucidate the barriers and facilitators people experience when self-managing both HIV and diabetes. In this article, we investigate how this dual diagnosis and chronicity shape patients' experiences with self-management. We pay close attention to how participants negotiate their patient workload and its impact on the ability to self-manage. Based on our findings, we recommend possible interventions to address barriers to successful self-management of HIV and T2DM.

## Methods

Our examination of HIV and T2DM self-management involves a mixed-methods approach. The parent study also examined a large, national data set of PLWH to test a model of self-management by comparing PLWH with and without diabetes (Zuñiga et al., 2021). The qualitative arm, reported on in this article, involves focused ethnography, which is an ideal methodological framework for collecting specific data within a narrower scope of inquiry (De Chesnay & Abrums, 2015), in this case, the self-management of HIV and T2DM. This type of methodological approach is well-suited for researching the patient's perspective, or what ethnographers often refer to as the emic view. Additionally, focused ethnography is an applied methodology, which is beneficial when considering the clinical application of research findings (Cruz & Higginbottom, 2013).

This research received approval from the designated university institutional review board. All participants provided written informed consent. Participants in the focused ethnography were residents of Central Texas who self-identified as having both T2DM and HIV and were taking medication for both conditions. Participants were recruited through convenience sampling. Recruitment methods included inviting participants from a previous study conducted by the research team and recruiting patients from both a local federally-qualified health center system that includes a clinic that specializes in treating PLWH, and from community-based organizations serving PLWH. Recruitment was conducted in person, through flyers, and via word of mouth. Participants received compensation for the interviews, follow-up interviews, and observations. Data were collected in 2018–2019.

Data consisted of semi-structured interviews with 22 participants and focused participant-observation with a selected subset of five participants. Each interview lasted between 1.5 and 2 hours with questions and probes about their daily activities (e.g., food and eating, medication-taking, housing, and transportation), and their mental health. We also asked participants about their personal histories, with a focus on their medical diagnoses and treatment, their relationships with family members and friends, family histories of illness, and how participants felt their lives changed post-diagnoses. The follow-up participant observations included visits to the local grocery store, observing medication-taking routines, and attending a lunch with two participants who are a part of the same HIV support group.

All interviews were audio-recorded and transcribed by a third-party. Interviews that were conducted in Spanish were transcribed and translated into English by a third-party. During the interviews and participant-observations, the research team wrote in-depth fieldnotes about body cues and other observations that may not have been captured in the audio-recording. Members of the research team met regularly throughout the data collection process to discuss thematic areas. Because we relied on a grounded theory framework, we discussed themes that emerged throughout the research process, and modified subsequent interviews and participant-observation based upon these findings. This type of methodological approach was implemented to gain a more in-depth understanding of our key subject areas as they pertain to self-management (Moore, 2010).

The coding process itself is analysis, as it involves deep levels of thinking about the meaning of the data and the search for broader patterns (Miles, 2014; O'Reilly, 2011). During our analytical process we used NVivo software to organize and explore the data. Members of our team coded six interviews together and generated a codebook. The members of the team then coded interviews separately, regularly checking our coding processes against one another. Once all interviews were coded, we analyzed the codes for major themes using a process of memoing, which included writing notes, reflective thinking, and further immersion into the data (Bernard, 2011) in order to understand and conceptualize the broader themes. For this article we report the themes related to our research question about the barriers and facilitators of self-management for PLWH and T2DM: eating and diet, medication management, and mental health.

## Findings

Participants were on average 56 years old (range 47–66); just over half were male, and the female participants included one transgender woman. Over half of participants were Black. Five were employed full-time and only one was employed part-time as a barber; the majority of participants were either unemployed or retired, though some served as primary care-takers for young children or aging parents. The majority of the participants were diagnosed with HIV in the 1990s and with diabetes more recently, in the past 10 to 15 years. Most participants said their doctors considered their HIV status to be in control, with non-detectable virus levels. A large majority had a history of depression or drug use. All participants had additional comorbidities besides HIV and T2DM (See Supplemental Table 1), most commonly hypertension, high cholesterol, and mental health conditions, such as depression. No participants reported having cancer. Most participants relied on various forms of support and assistance, such as food stamps, transportation vouchers, and housing assistance.

### Food and diet

Participants' self-management was focused on food and eating. Many participants continuously thought about what they eat, and when, how, why, with whom, and under what circumstances. Much of this decision-making process involved counting, cost, and consultation.

A significant part of their diabetes self-management involved counting carbohydrates, the number of sodas they drank, and portions of foods. These quantitative aspects of preparing and eating food were different than what they had done before they were diagnosed with diabetes. Most participants acknowledged that while they were encouraged to adopt certain dietary lifestyles following their HIV diagnoses, such as increasing vegetables and lean protein in their diets, the more drastic changes to their eating patterns occurred once they were diagnosed with diabetes. One participant said that because of his diabetes, he was very cognizant of his carbohydrate (carb) intake. He regularly checked nutrition labels and brands for carb content and he ate items such as low-carb bread, sugar-free jelly, and whole wheat pasta. He drank sugar-free coffee and diet soda every day. He also knew the carb count for each snack; for example, during our interview, he stated that  $\frac{3}{4}$  cup of peanuts is one

carbohydrate serving. He said, “It is never hard to eat, [but] do I like it? No...I can’t eat the way I used to.” Another participant shared that she did not realize how much sugar she usually consumed until she was diagnosed with diabetes and had to track her intake.

“I love orange juice, so and, of course if you love something, you’re gonna fix a big glass instead of a little glass. It’s just like, you gotta learn everything over again so you can keep your numbers good...Cheerios with one white sugar and one blue sugar...And animal cookies, the little animal cookies, I know I can have three and [my grandbaby] can have three and that’s it...I do a lot of fruits but I’ve learned that I can only actually have four grapes before my sugar starts lifting up.”

Another participant shared similar sentiments, when she revealed what she considered her one “bad habit.” She said,

“I like Cokes...yeah and um, I talked to the dietitian, and she told me well, you can have one [Coke] a day. So, I’ve been practicing having one a day because I used to drink like a liter a day.”

Most of the dietary changes occurred after consultation with dietitians and nutritionists at healthcare providers’ offices and community centers that provided HIV/AIDS services. A few participants were also connected to housing organizations or senior citizen groups that featured nutritionists as speakers. Participants revealed that while they found the information helpful, it was very difficult to change dietary practices and incorporate new habits. One participant indicated that he had attended nutrition classes in the past, and learned new information about portion sizes, but shortly after making initial changes, he often found himself “falling off.” Similarly, another participant said she would make changes but, “it’s kinda hard to stick to it because I’m used to what I am used to and that’s fried food. You know, like I said, stuff that we shouldn’t eat.” Many participants talked about their challenges with transitioning to new ways of eating. One person shared a story with us about a trip to the store shortly after her diabetes diagnosis: “I went to the store with my friend and she was talking about, ‘you can’t have this, you can’t have that,’ I was like a kid; I threw a fit right in the store. People just looking at me. I was like, ‘ok [to myself], calm down, go on now.’” This participant said that recognizing her own creativity and learning to “add her own touch” to foods and recipes allowed her to implement changes in her diet. Similarly, we observed a different participant at the grocery store, who talked about foods for optimal self-management but also added their own creative touches to weekly meal planning and that made grocery shopping more enjoyable for them.

Many participants who said that they appreciated the dietary information they received from dietitians or nutritionists also acknowledged that cost was a significant barrier to purchasing healthier foods, which was a major obstacle to self-management. Cost was especially prohibitive given that most were not employed full-time and many relied on food assistance, such as the supplemental nutritional assistance program (SNAP) and also local food pantries offered by HIV service organizations. As one participant highlighted, “healthy foods are way too expensive,” and these costs coupled with rent costs often created what she referred to as an “impossible” situation.

While some participants felt they were able to incorporate dietary recommendations, many revealed that even with guidance, they often struggled to eat according to suggested guidelines on a consistent basis. Several discussed their eating binges that usually involved foods that were comforting or familiar, and not recommended for people with diabetes. One participant, for example, told a story about a time he purchased a bunch of candy for people at work and then ate most of it himself, “just binge [d]” as he put it. A different participant referred to himself as “hard-headed” whenever he mentioned extended periods of eating more than what he thought was appropriate. Of the participants who took insulin regularly, many knew how to adjust their medication to accommodate their binges, as shared in the following:

“Uh, I occasionally break down and my weakness is I love sweets. I’ll buy something—usually I try to buy something on markdown so I don’t spend that much on it at Walmart or something. I buy a box of donuts, I’ll eat that one and that one and that one, and maybe that one, not all at the same time. I usually try to tell myself, ‘Well, if you’re gonna do this, take the insulin, an extra little bit of it.’”

Participants often acknowledged that food played a comforting role for them but that they felt that their binges were wrong. Though one participant was aware of recommended eating plans and even counted carbs regularly, he offered that “Yeah, I comfort myself with food anyway. It’s a childhood reaction and typically it’s Colonel Sanders. I mean, [my relationship] with the Colonel is the long-term relationship in my life.” This same participant shared this with some expression of shame but offered that sometimes he just “doesn’t care.” Along similar lines, another participant also discussed feelings of shame after eating certain foods, explaining that she just “deals with it” when she overeats. “When I eat [like that],” she said, “it kills me.” While participants’ eating habits were motivated by a need for comfort, many were unsure how to change these habits. Other participants showed more apathy towards their diet. When discussing food, a participant said that she was aware of dietary recommendations for people with diabetes but she did not care to implement any changes. On the day that we interviewed her, she had just finished preparing a meal. “Macaroni and cheese, starch, I shouldn’t have it,” she said. “Fried chicken—shouldn’t have it,” she continued, laughing slightly. “Some juice too and it ain’t low-fat or low-sugar. It’s real sugar, mmhmm.”

### Medication management

Medication management plays a significant role in chronic disease management and PLWH and T2DM may be prescribed many medications that are scheduled at different times of the day. A few participants took as few as three medications per day, but others took upwards of 15 medications. Many participants also took medications for conditions other than HIV and T2DM (see Table 1 for comorbid conditions). We found that participants considered medication management to be extremely important even if they struggled to develop and maintain a consistent regimen. Participants shared about their self-management tactics, such as using a pill box or calendar to keep track of the medications they took. Others relied on strategies such as putting a glass of water in the same location in the house every time as a reminder to take medication at a particular point in their day. In addition, others had weekly rituals of refilling pill boxes at specified times. It was observed that those who had such

regimens noted the intentionality behind these practices, emphasizing that building routines requires time. Many participants who had switched from an HIV cocktail to a single pill acknowledged the ease of managing the new medication regimen.

One participant had a daily regimen for taking his 11 medications: six pills in the morning and five in the evening. We observed his morning ritual that involved carefully counting out the medications with a large glass of water, always starting with the largest pill and ending with the smallest. Though he was not able to identify what each medication was for, he said that he knew taking each one was important. This participant acknowledged that he has to perform the same ritual each day in order to maintain consistent medication practices: He shared with us the following:

I'm not very good at taking pills—it's not a pretty process. I spit 'em out. I've got a system down now. I'm good at getting them to the back of my tongue. Sometimes I would like to be on a much simpler cocktail...I'm not on a cute little one-a-day like all the kids these days. I have friends that take one pill a day and that would be nice. One [pill] would be easier for sure, especially with my grace with taking pills.

Regarding lapses in medication-taking, one participant said that she does not ever skip medications; when asked how often she misses medications in a 2-week period, she replied, “never.” She said that she cannot afford to land back in the hospital and noted that in the past there were times when she had multiple hospitalizations in 1 year. She also experienced numerous bouts of homelessness in the past, which she said made it extremely difficult to take medication. At the time of our interview, she was living in a shared residential space that was not to her liking but said, “When I tried staying outside with my granddaughter in her car, I didn't have nowhere to keep my, my insulin cool you know, and stuff like that. So, I had to take a place. That wasn't my choice.”

However, most participants did acknowledge missing doses, at least occasionally. The reasons that people missed doses of their medications varied, from memory lapses, lack of time or regular routine, or failing to refill the prescription on time. As can be seen in the following interview extract, changes to routines and transportation barriers are two factors that affect medication regimens:

“[I miss medicines] maybe once or twice a month...I just get up rushing because I'm late, you know. And then [I live] way out there, the later the bus I catch, the later I'm gonna be wherever I'm trying to go...like I said, I try not to [miss medication] because the pills I'm taking now, they [doctors] done told me that's it. They don't have nothing left for me if I mess this up. So, I'm trying my darndest not to mess this up. I don't wanna get cut off at the knees”.

At numerous times during his interview, this same participant stressed the importance of prioritizing his diabetes medication over medication for his other ailments, as indicated by his comment of fearing a leg amputation if he was not able to control his diabetes. Overall, it was observed that most participants felt differently about their diabetes medications than their HIV medications. Some expressed beliefs that diabetes was more serious and difficult to manage than HIV. One participant shared the following:

“The HIV to me is not an issue because I know what to do, I know to take my medicine, eat right, exercise, all that. I know about that. It’s just the diabetes. It’s funny...[Diabetes] is serious. To me, it felt more serious than the HIV because the HIV, I never had any complications with HIV. I’ve never been hospitalized; I’ve never been sick—anything behind it. I started HIV medicine in 2010, [but] I was diagnosed in 2000...That’s why I say the HIV to me has been much easier to manage than the diabetes.”

Similarly, another participant shared that his family was more concerned about his diabetes than HIV:

“...and my parents, they—they know about the HIV, they know about the diabetes, um, they know that H-I—the HIV can be controlled with the medications. They’re more concerned, which is, you know, funny for me—they’re more concerned for me because they can say, you’re gonna be okay with HIV, but you can—you can die faster from the diabetes.”

Despite perceiving diabetes as a more serious disease with frightening complications, participants had a difficult time managing their insulin injections. The participant who was afraid that diabetes complications could lead to amputation revealed that until recently, he had experienced obstacles in establishing a routine for taking insulin. This was largely shaped by his history of drug injection and the similarities he felt with “shooting insulin” as he referred to it. He quit using insulin altogether, because he associated the syringes with drug injection, and this was a trigger for him.

“I just quit using insulin. And my first lab, he didn’t know I had quit using it, my doctor. And when they did the next lab, and he was telling me how my numbers were, he said, “I haven’t gotten any refills on your insulin.” I said, “Because I ain’t been doing it.” He said, “Huh?” I said, “I stopped. I got tired of sticking myself.” ...Having them syringes around. You see that’s why I got sick, shooting dope...and having them needles around me every day, you know, I took it for three and a half—like I say, like three and a half years, but after that, the temptation started getting a little stronger, and so I just quit using them...I was scared it was gonna trigger me.”

Many others also noted the extra difficulty of remembering insulin shots. One participant shared different strategies to ensure that insulin was taken each day:

“I have a big sign between my bedroom and my bathroom and I start drawing on it in colors and I take it down and turn it around, so I keep noticing it again. As soon as I recognize that I’m not noticing it or that I’ve missed too many shots, you know, I—I refresh my sign, trying to remind myself to take my insulin. The shots are not clicking with me all the time yet, but the pills I’m pretty good with.”

Another element that emerged in our findings was the practice of participants regulating their own medication doses, or what two participants referred to as to “doctor myself.” Participants often made their own determination of how much medicine to take and when to stop taking medicine based upon side effects or how their bodies responded to medication. They made changes to their diabetes medication, more than they did their HIV medications.



This was especially true for the diabetes medication Metformin. A common practice that participants described was to cut their Metformin pills in half or to stop taking the drug altogether because of common side effects like diarrhea. One participant, who had been prescribed Metformin at several different points, says that he stopped and restarted the medication as he saw fit:

“Yeah, as a matter of fact, I went on a long road trip and then I had a friend come in town for a week so and before all that was the holidays, so I actually haven’t seen my numbers where I like them, for a while...So, I actually I haven’t talked to the doctor about it, but I put myself back on Metformin again.”

Another participant added the following:

“And the lady, the diabetes lady that I saw this morning, she got on me because I’ve been taking extra Metformin...Because I—my blood sugar’s been so high, and so I took another half...She said, ‘You can’t do that.’...I—I—I literally doctor myself. [Laughs] And I have been [doing this] for a long time.”

Several participants also revealed that they adjusted their dosage to make up for medications that they had missed during previous days, as demonstrated by the following:

“Yeah. I missed the [medications] at night. Sometimes, I’ll eat, and I don’t know I miss them, but I’ll miss them, and when I look the next day, the pills are still in the bottle—in the container—so I know I missed them. So, what I do is I try to work them in the next day—and I don’t know if I should do it or not. But I’ll work them in, maybe take my medicine in the morning, a little bit earlier, then work the ones that I missed in the next day. Now, I don’t know if that’s right or not, I never told my doctor I did that, so... I don’t know if you should do that or not. I don’t know.”

Another example comes from a participant who said that they regularly look up information online when their body feels different. During our interview, they noted:

“Because by the time you try to get in with the doctor system here and the insurance and all that, by the time you get in, they’re so booked, you can’t [get] in until two weeks later...so I just do a lot of stuff online and see. And then I’ll just jot it down and keep it so when I do go see him, I’ll bring it back up to let him know.”

This same participant also shared that on one occasion they were having trouble sleeping and kept complaining of insomnia to their roommate. They decided to search the Internet for information, “and when I googled it, it said that sleeplessness was one of the side effects of the diabetes medication I was taking and I was like, ‘That’s it. We’re done with this.’”

Participants expressed an aversion to taking large amounts of medications, in particular their diabetes medications. For example, one participant said that her family would often ask her, “Why are you taking all of this medicine?” or would regularly make comments about her seemingly high number of medications. As a result, she said that she began to take control of her diet and exercise with the hope of getting off of medications altogether. Another participant shared that she believed her doctors at one point prescribed too much of the wrong medications for her. Reflecting on a visit with her doctor, she told her doctor, “Yes, I’m going to Mexico, and when I come back, you’re gonna see I’m better.” She says that

she has not seen that doctor since this particular encounter. Instead, this participant relies on guidance from her sister, a doctor in Mexico, as well as herbal remedies and teas that she makes herself:

“I take moringa a lot. In teas. I prepare my morning tea. If my sugar levels are particularly high, [over 100], I’ll take moringa throughout all of the day...I drink a tea and I also eat the leaves...there’s this lady that owns a shop of everything moringa...not only do I take moringa, I also take cinnamon and turmeric tea, turmeric, and ginger. I take it as if it was water. I have a bottle in my car. Like water...Every day, I’ve got my tea pot.”

This participant said that she regularly consumes her special tea because of high blood sugars and pain, but also said that when she followed medication prescriptions from US doctors, the medicine “made [her] go crazy.” These feelings prompted her to visit Mexico, where she said:

“I couldn’t even walk, I couldn’t shower, cook, clean my house. I wasn’t able to do anything. Until I went to Mexico and the doctor was like, ‘What happened to you? This medicine you’re taking is killing you! All this medicine’s gonna kill you! You don’t have to take all of these medicines. You don’t need these medicines.’”

Some participants discussed taking “medication vacations,” particularly with their diabetes medication. One participant referred to this type of behavior as “being a renegade.” At the same time, these participants discussed shame about their renegade practices, making statements about beating themselves up when they miss medications. The participant who referred to herself as a renegade offered the following: “I’m the person,” she stated, “I beat myself up more than I let anybody else beat me up.” Other participants expressed apathy about taking medication. This was the case with the aforementioned participant who also expressed a great deal of apathy towards following a recommended diet. While she usually took her HIV medication daily because she did not “want to go back into AIDS,” she acknowledged that she did not take her insulin or other diabetes medications as instructed, and said that sometimes she was just tired of taking medicine, similar to her being tired of following recommended diets.

At the end of each interview, we asked participants about the advice they would give to someone newly diagnosed with HIV and T2DM, and almost every participant mentioned that medication and medication management are extremely important, including those persons who did not consistently manage their medications. One participant remarked, “I would tell [newly diagnosed persons] to find the medications that work for you. Everybody’s different. Stay on your regimen. Any missed days can potentially be catastrophic.”

### **Mental and Emotional Health**

The third broad theme that arises from the interviews is the participants’ mental and emotional health. As noted in the table, the majority of study participants were diagnosed with mental health conditions such as depression and many were taking medication for these conditions. These conditions were frequently discussed during interviews, particularly when participants talked about recovery, addiction, grief, and loss. A majority of participants

revealed that they experienced some form of depression shortly after learning they were diagnosed with HIV, as they assumed that this was an “automatic death sentence,” as one participant described it. “I thought I would not wake up the next day.”

Over half of the participants also reported seeing a psychiatrist or other mental health professional in the past year. Visits with mental health professionals varied, with some participants having only two to three interactions and obtaining medications such as lithium, while others met with psychiatrists monthly. Those who saw psychiatrists regularly had more consistent access to medication and some even received assistance to qualify for service and support animals. One participant had a formal diagnosis of bipolar disorder, but he did not regularly see a psychiatrist. He noted that seeing a psychiatrist was one of the things that was, “in his control” and that he would make a plan to find one. Three of the participants participated in the same support group and as a result had built a sustained friendship. We observed two of them having breakfast together and both participants acknowledged that meeting up and sharing meals could pose dietary challenges regarding portion control, but these moments of connection provided necessary mental and emotional support.

While not every participant was formally diagnosed with depression or anxiety, about 80 percent of participants discussed experiencing some form of depression or anxiety that shaped their self-management. Examples include participants linking depression and food choices, such as binging a pint of ice cream when experiencing depressive thoughts. As one participant stated, she did not “believe in that depression medicine” but did discuss her experiences with anxiety as something that was, “in [her] body.” She continued, “It was in my mom’s body and my son has it too.” When speaking of depressive thoughts, another participant offered the following:

“I have depression—I go through depression, but it ain’t like the suicidal kind...It be like—it’s like I want to quit. I don’t want this feeling. (Softly crying) You know? I just don’t want that feeling. I don’t want it no more. But it’s like the Devil choking you. You know, it’s stronger than I am.

Many participants discussed their mental health as shaped by having multiple medical conditions. One participant referred to having both HIV and T2DM as “the flux” and said it required constant mental and physical adjustment. Similarly, another participant described his current state as in a type of “funk” that was marked by confusion and feelings of being overwhelmed. Participants stated that having both chronic conditions was frustrating. One participant said that he would often get mad at his doctor because he was unsure which condition was causing particular symptoms, resulting in a feeling of constantly trying to determine whether it was the HIV, T2DM, or both trying to “attack [him] and make [him] worse.” Others listed fatigue among their primary symptoms, often made worse by the dual diagnoses. “Due to having both issues,” one participant said, “the fatigue has set in. Fatigue has set in on me and I can’t do anything.”

The subject of loss repeatedly emerged in interviews, with just over half of participants expressing grief about the loss of significant others and loved ones. For some participants, their mental health was shaped by separation from their children. One participant said

that her depression intensified after the death of her son, and noted that she experienced recurring dreams about his death. Participants additionally discussed loss as it was tied to periods of homelessness, periods in which they lost their homes, their forms of shelter, and loss of themselves, as one participant framed it. Every Black participant had experienced at least one period of homelessness or extreme housing insecurity. One participant experienced an extended period of homelessness after he separated from his ex-husband. This included periods of living in shelters while recovering from substance use. He also experienced a significant loss with the death of a family member. He said that eventually he “got himself together” and began the process of getting to Austin where he could access more resources for his multiple conditions. He recounted:

But I just—my drug habit started consuming me, and my grief started consuming me, and then a guy that I was friends with on the street killed himself, and some other people died of AIDS/HIV. And it was extremely—extremely—just sent me into the loony bin, basically; so, it was horrible. So, and then it got worse after that, and then living on the street, and trying to kill myself.

One participant’s interview largely centered around grief, as he shared about his partner who passed from HIV complications. Most interview questions about self-management seemed to trigger thoughts about his partner’s passing from chronic diseases, and the participant continually referred to his partner when talking about diet and medications. Throughout the interview this participant shared numerous photos and mementos, and specifically named grief as a reason why he was unable to carry out recommended self-management tasks.

The overwhelming majority of participants had some history of drug and alcohol use, and many identified as being in recovery. One participant had been in recovery for more than 20 years and credited her recovery with her ability to better manage her chronic illnesses. Several other participants offered similar sentiments. At the same time, some participants noted that substance use directly shaped their inability to manage medication and dietary practices. One participant was actively seeking a 90-day treatment program at the time of our interview. Having had experience with unsuccessful 30-day programs in the past, this participant wanted to get into a longer treatment program at an “inside” facility, as she referred to it, indicating her desire for an inpatient rather than an out-patient program. She felt that she was not going to be able to successfully manage either her HIV or T2DM if she did not find a way to be fully sober.

## Discussion

The 22 participants in our study largely reflect the population of PWLH and T2DM (Cowie et al., 2010; Geter et al., 2018). They are predominantly male, middle-aged, non-White participants with multiple chronic conditions. The dual diagnoses of HIV and T2DM uniquely shape their challenges and difficulties and the three thematic areas (eating, medication taking, mental health), illustrate several key barriers and facilitators to participants’ self-management of HIV and T2DM.

## Food and diet

Our findings reveal that dietitians and nutritionists, along with community food pantries, serve as facilitators of self-management of HIV+T2DM. At the same time, cost, maintaining consistency, and eating for comfort are critical challenges that affect how patients relate to food and their dietary habits. Cost of healthier foods was often noted as a barrier for maintaining recommended dietary practices, which is frequently cited in studies of disease prevention and self-management (Berkowitz et al., 2015; Bosire, 2021; Horowitz et al., 2004; Jerant et al., 2005; Palar et al., 2017; Wang et al., 2010). For example, food costs can lead to food insecurity for people with T2DM (Ippolito et al., 2017; Seligman et al., 2011; Wang et al., 2010). Several participants in our study relied on local food pantries where they had little choice in food selection. Few participants were able to regularly purchase healthier foods because close to two thirds of the study participants did not work full-time and many had experienced periods of homelessness and housing insecurity. Thus, the participants were not able to devote much of their income to obtaining vegetables and lean meats that were recommended by dietitians, nor were they able to obtain recommended foods consistently. PLWH and T2DM may experience more socioeconomic hardships because of the costs of having both conditions, which would further affect their ability to access healthy food and medications.

Consistency was also a key factor for diet management. Participants' workloads often involved an eating learning curve, and despite the fact that some participants developed consistent counting and cooking routines, many felt burdened by the dietary aspects of their self-management workload, and as such, their capacity to manage their diets was significantly reduced. This was illustrated by those participants who mentioned regularly "falling off." These periods of falling off would often happen when patients used food as a form of comfort, such as a coping mechanism for dealing with mental and emotional health. Our findings additionally draw attention to the ways that prolonged periods of apathy shape dietary self-management. Even when participants were aware of what they should and should not eat, there were times when they just did not care to implement the recommended guidelines.

## Medication Management

The findings indicate that most participants prioritized medication management. Though several participants sometimes forgot to take their medications or did not have their medications in their possession when it was time to take them, they viewed taking medication as a critical and necessary task. When we asked participants for advice that they would share about managing HIV and T2DM, nearly everyone mentioned the importance of taking medication. Items such as pill boxes and material reminders played a significant role in optimal medication management. These forms of low technology were consistently referenced as facilitators during interviews.

Although they viewed medication-taking as crucial, there were times that some participants chose not to take their medications. Participants said they "go renegade" by taking a vacation from their medication, a practice that is common among other PLWH, particularly given the complexity of the medication regimen they needed to adhere to in order to manage

the condition (Cook et al., 2015; Lynch et al., 2012). Some participants expressed apathy, noting that they were tired of taking so much medicine, which often resulted in medication stoppage. Other participants did not want to take as much medicine as they did, and as such, they implemented practices to try and reduce the level of medication. In addition, as was observed by the participant who felt dismissed by her doctor's insistence on pharmaceutical treatments, some participants sought other forms of treatment, such as those from Mexico.

Cultural factors also shape medical beliefs (McQuaid & Landier, 2017). Our participants' reluctance to take many medications were clearly influenced by their families and friends. Such findings expose gaps in patient-provider beliefs and communication about medication adherence, suggesting a need for research into how to help patients adhere to medication regimens more consistently and to how to dialog with providers about making changes to the regimen. Providers should be aware that patients might titrate their own medication dosages without healthcare providers' guidance. Providing a non-judgmental clinical milieu will encourage patients to be honest and open about the reasons for the changes.

Medication beliefs are also illustrated by patients' practice of "doctoring themselves," which our findings suggest occurs more often with diabetes medication. This was demonstrated by one participant who consistently takes her HIV but at times alters her diabetes medication because she is, "pretty sure about when [her] sugar is and it ain't right." We also saw that patients took more liberty with changing diabetes medication, taking themselves off medications or putting themselves back on, like the example of metformin. This is similar to findings from Maneze et al. who found that patients with T2DM will at times develop "their own way" of managing their conditions when they do not feel heard or understood by healthcare providers (Maneze et al., 2019). Rather than frame medication practices solely along lines of adherence and non-adherence, these types of practices, in which patients are able to express expertise of their illnesses, provide an opportunity for healthcare providers to ensure medications are managed in optimal ways. At the same time, participants did not always discuss their medication modifications with providers, which suggests a lack of openness on the part of providers to cede medication decision-making to patients. Healthcare providers must establish communication practices which patients' self-knowledge is respected and honest conversations about medication management are encouraged. Otherwise, providers cannot accurately evaluate their prescribed regimen nor partner with patients on the safest and most effective medication prescriptions.

Though both HIV and T2DM can involve complex regimens, we found that many participants found ways to consistently manage their HIV medication while simultaneously struggling to achieve the same consistency with their diabetes medication and also dietary practices. This is similar to findings from Henry et al. who found that patients with HIV and T2DM may have better control of their HIV compared to diabetes (Henry et al., 2011). Our study demonstrates that not all patients have the same relationship with their diabetes medications as they do their HIV medications. Many expressed fears about potential consequences of not managing diabetes medications, such as an amputated limb. Even though participants stressed the need to take HIV medications consistently to keep viral load low, the unique chronicity of diabetes and HIV resulted in different medication

behaviors because of beliefs that diabetes was more serious and difficult to manage than HIV.

In a study that evaluated the national economic burden of comorbid TD2M in PLWH, researchers found that compared to PLWH without comorbid T2DM, those with comorbid T2DM had higher hospitalization costs, outpatient costs, Medicare costs, and total medical costs on average (Chinaeke et al., 2020). Though participants in our study primarily mentioned costs as a barrier to healthy food, a few discussed increased hospitalization costs. Many participants additionally discussed the care and wrap around services that they receive through community-based clinics focused on HIV, AIDS community centers, and local hospital safety net programs as facilitators for self-management. As such, findings from our study may illuminate the important role of local healthcare infrastructure to support people with multiple chronic illnesses.

### **Mental health**

Poor mental health, related to the frequently shifting disease status and treatment regimens, profound experiences of grief and loss, and alcohol and substance use and recovery significantly impacted participants' self-management behaviors. Research across numerous disciplines has drawn attention to mental distress and psychosocial ailments experienced by PLWH (Burgess & Campbell, 2014; Emlet, 2006; Farmer, 1992; Herek et al., 2013). PLWH and people with diabetes are more likely to be diagnosed with major depression compared to individuals without HIV (Mendenhall, 2012; Semenkovich et al., 2015; Sherr et al., 2011). Consistent with other studies of people with chronic conditions (Stenberg & Furness, 2017), our study findings highlight how diminished mental and emotional health hinder participants' self-management. Apathy shapes decision-making about diet and medication. Among people with T2DM diagnosed with mental illnesses such as depression and anxiety, those required to manage multiple chronic disease management regimens often show less consistent self-management practices or none at all (Cimo & Dewa, 2018).

Participants in our study described having multiple major losses and this grief seemed to significantly impact their self-management practices. While there is little research about how grief and accumulated losses affect diabetes self-management in particular, it is known that depressive symptoms hinder engagement in consistent self-management practices (Jerant et al., 2005). It is also likely that grief from frequent and accumulated losses could produce an inflammatory response that worsens diabetes and HIV control. Similarly, our participants' experiences with substance use were often the result of or contributed to grief, loss, and trauma. Substance use and recovery, or lack of recovery, contributed to daily challenges. In addition, some participants strived to attain and maintain sobriety and find solutions to homelessness in order to establish consistent self-management practices.

Numerous participants shared how they grapple with the ways that chronicity impacts their mental health. The "flux", as it was named by one participant, speaks to the persistence of mental health challenges and how they shape the experience of living with T2DM and HIV. This flux is produced by the unique experience of chronicity, patient capacity, as well as the side effects of treatment. In order to effectively self-manage their health, PLWH and T2DM must fluctuate in all aspects of their lives. Their medications change. Their

diets change. Their occupational status changes. Their housing changes. Their intimate relationships change. In the pursuit of comfort, many often oscillate between restrictive diets and behaviors to diets with no regard for diabetes or HIV management. This flux is marked by continuous changes in their multiple conditions and movement between self-management routines. It can be difficult for people to know the source of a particular symptom or ailment. As patients with HIV+T2DM negotiate this back and forth, many are simultaneously impacted by socioeconomic factors shaped by race, gender, and sexuality. These precarious and intersecting forms of social and structural inequality can shape patients' workload and their capacity to respond to their dual diagnoses (Fritz, 2015; Geter et al., 2018). Therefore, the notion of a flux provides a framework to examine both the movement between overlapping chronic conditions and the syndemic nature of T2DM+HIV. By employing this type of syndemic analysis, we could learn more how forms of social inequality drive the "mutual exacerbation of concurrent epidemics at the population level" (Mendenhall, 2012, 2019; Mendenhall et al., 2015), and how forms of inequality also shape self-management practices. While our findings illustrate that social support groups, family support, and mental health treatments are facilitators that can address mental and emotional distress, we propose that a more comprehensive understanding of this flux shaped by dual chronicity could yield more insight into further tactics that could enable more optimal self-management.

Finally, the results of this study illuminate shame as an overarching theme. We know that shame and stigma can prevent individuals with HIV from presenting all relevant facts about their sexual history with healthcare providers, such as higher-risk sex practices or having same-sex partners (Hutchinson & Dhairyawan, 2018). In a similar manner, the dual diagnosis of HIV and T2DM may compound feelings of shame and stigma in all aspects of self-management including what and how PLWH and diabetes eat, how they manage their medications, and how they navigate various mental health diagnoses. PLWH have to negotiate when and how they disclose their diagnoses and how they get support. As Webel and Higgins have noted, such stigmatization impacts self-management tasks (Webel & Higgins, 2012). Our findings reveal participants' difficulties in reporting their eating and medication behaviors, and the feelings of shame that emerge when they discuss being "hard-headed," "going renegade," or discouraged when they do not meet desired clinical outcomes. At the same time, our findings do not draw attention to gaps in education about chronic disease management, as most participants were familiar with their conditions and recommendations regarding food and medication; rather, we found that many participants experienced challenges as shaped by socio-economic factors, and mental and emotional aspects shaped by comfort, loss, and shame. Further research should explore how these mental and emotional factors operate in terms of other self-management practices, the various ways that different people experience shame in the context of chronicity, and potential strategies that can be used to address shame and stigma for persons with HIV and T2DM.

There are numerous clinical applications that emerge from the study's findings. Recent literature on the subject of self-management has demonstrated the significant impact that the patient-provider relationship has on a patient's self-management practices (Franklin et al., 2019). Provider interaction styles influence patients' decision-making and goal setting



(Franklin et al., 2019), and our findings demonstrate the ways that participants experienced positive and negative provider interactions, and how it impacted decision-making about medication management and dietary practices. As such, clinical providers should adopt more person-centered approaches that encourage patients to share their medication and dietary experiences in a non-judgmental and more equitable communicative process (Franklin et al., 2019).

Another example derives from the participant who stated that due to his past history of intravenous (IV) drug use, he was often triggered by insulin needles. For patients with a history of IV drug use, health care providers should advocate for them to obtain a continuous insulin pump instead of insulin that is self-administered by needles. Patients without insurance would need assistance in covering the costs of insulin pump therapy. In addition, patients with HIV and T2DM are more likely to obtain glucose level goals if they are using insulin than oral anti-diabetic medication (Zuñiga et al., 2016). Yet many people are concerned that being on insulin implies their diabetes is beyond control and they are reluctant to use needles (Byrne et al., 2021). It is imperative that clinicians help patients have access to and be comfortable with the route of insulin administration that is needed to achieve diabetes glucose level goals and their personal goals, and improve long-term health outcomes (Byrne et al., 2021; Saboo & Talaviya, 2012).

Though most participants stated they consulted with a dietitian or nutritionist at the time of T2DM diagnosis, most participants reported they were unable to follow their advice because the foods or meals were too expensive or did not match their cultural dietary habits. As such, dietary instruction should be given in the preferred language, be culturally relevant, and community-based in order to have positive outcomes (Perez et al., 2013). Further, nutrition specialists could adopt methods that promote critical thinking and evidence-based decision making for addressing multiple forms of food insecurity (Wetherill et al., 2018).

## Conclusion

In this study, we describe the barriers and facilitators of self-management of HIV and T2DM. The results demonstrate that participants often strive to implement self-management tactics but experience numerous challenges, particularly in the areas of diet, medication management, and mental health. The findings reveal that while routines, low medication technology, familial and social support, and consistent provider-patient communication are facilitators to optimal self-management, participants often face obstacles when it comes to food cost and access, medication regimens, and mental distress. At times participants also employ their own strategies and tactics for medication dosage, even those not prescribed by health care providers. Providers, therefore, need to ensure that their communication is patient-centered and equitable. The dual diagnosis of HIV+T2DM can produce a unique flux in which participants feel like they are in a constant back and forth between conditions, which ultimately impacts the ability to self-manage. Continued research on this dynamic will yield greater insight into potential facilitators to address this flux.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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