


The “Ups and Downs” of Living With Type 2 Diabetes Among Working Adults in the Rural South

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Abstract

The purpose of this qualitative study was to gain a better understanding of the spheres of influence on engagement in recommended diabetes preventive health services among rural, working adults. Additionally, this study sought to understand the unique factors that influence diabetes self-management among rural, working adult populations. The sample included mostly African-American, low-income females with self-reported diabetes, who scored low on the Patient Activation Measure (PAM-10). Semi-structured interviews (N = 20) revealed that most participants struggled with the “ups and downs” of living with diabetes. Four major themes emerged from the data: “the struggle,” “doing things together,” “diabetes is not the priority,” and “we’re lucky to have what we have.” Most participants were developing individual responsibility and motivation for a healthy future, but were overwhelmed by inconsistency in self-management, diabetes distress, lack of effective coping strategies, and lack of social and economic capital. The findings of this study indicate the need to further address psychological well-being among rural, working adults, yet rural populations often lack sufficient access to mental health care and formalized psychological support. Psychological support and resources are essential to facilitate engagement in diabetes self-management and preventive health services for rural, working adults.

Keywords

rural, patient activation, diabetes, preventive health services, coping

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Diabetes is an extraordinary economic and health care burden in the United States.¹ The risk of death for adults with diabetes is 50% higher than for adults without diabetes and recent trends indicate that diabetes-related mortality rates have not improved in rural areas compared to urban areas, especially in the rural South.² Diabetes complication rates are increasing among younger adults, ages 18 to 44 years, as well as disproportionately affecting those with lower income levels.³ Low-wage earners are less likely to engage in preventive care, have a 4 times higher rate of avoidable hospital admissions for ambulatory care sensitive conditions, and are more likely to experience worse health outcomes compared to top wage earners.^{2,4,5} Rural and younger adult populations are also less likely to engage in diabetes preventive health services, such as cholesterol screening and contact with an eye or foot specialist, as compared to urban-dwelling and older counterparts.^{6,7}

Individual psychological factors, such as diabetes distress and level of patient activation, can influence health behavior.⁸ Patient activation is the cognitive appraisal of

knowledge, skills, and confidence for managing one’s health, whereas engagement is actual health behavior.⁹ Rural, working adults may also experience diabetes distress, defined as significant negative psychological reactions related to the emotional burden of diabetes self-management.¹⁰ Although rural, working adults with Type 2 Diabetes (T2DM) report low levels of patient activation and diabetes distress, scant evidence exists concerning the influence of these individual factors on self-management and preventive health behaviors in this population.¹¹⁻¹³

This qualitative research study sought to identify and understand facilitators and barriers to patient activation and

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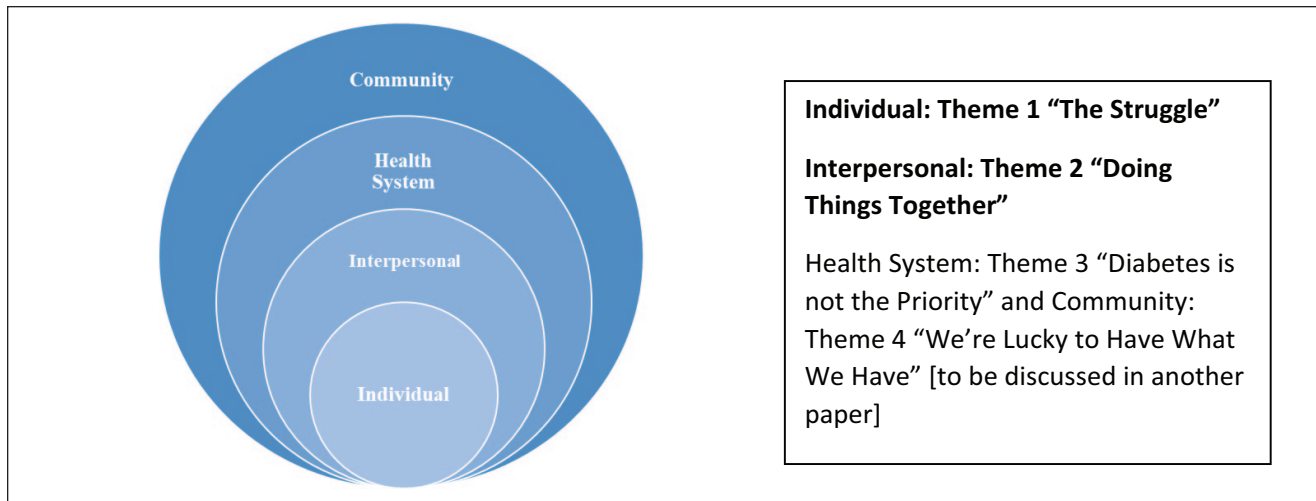


Figure 1. Resources and supports for self-management model.¹⁶

engagement in preventive health behaviors in this priority population. This study explored individual, interpersonal, health system, and community aspects of lived experiences of working adults with T2DM in the rural South. The study addressed 2 research questions:

1. What are the individual, interpersonal, health system, and community factors that facilitate, modify, or hinder engagement and use of recommended, preventive health services among rural, working adults with T2DM, and low patient activation scores (<75), as measured by Patient Activation Measure (PAM-10)?
2. How do individual, interpersonal, health system, and community factors facilitate, modify, or hinder engagement in recommended, preventive health services according to rural, working adults with T2DM, and low patient activation scores (<75), as measured by PAM-10?

Conceptual Framework

This study used a socioecological approach to guide inquiry and explore the use of social and community resources.^{14,15} Fisher et al's¹⁶ model integrates 4 spheres of influence on individual health behavior (see Figure 1). This model asserts that individual self-management skills needed for health behavior change are influenced by the services and support they receive from their environment and community.¹⁶

Methods and Study Design

Investigators used a qualitative research design to accomplish the study purpose: identify and understand the specific facilitators and barriers to patient activation and engagement

in preventive health behaviors. Data was collected using semi-structured interviews, which explored the individual, interpersonal, health system, and community factors that influence health behaviors. The interviews allowed for a collection of broad perspectives on beliefs, opinions, and behaviors within the community about diabetes.^{17,18} Through hearing and analyzing personal accounts of rural dwelling adults living with T2DM, narrative description was used as a research method to gain a better understanding of both the facilitators and barriers that impact their ability to engage in diabetes preventive health services and healthy behaviors.¹⁹ Interviews were conducted until data saturation was achieved and no new major themes emerged.

Participants

Participants recruited for this study were English-speaking adults, age 18 to 65 years, who are diagnosed T2DM, are employed for wages 20 or more hours per week, reside or work in a tri-county area in the rural South, and scored below 75 on PAM-10.²⁰ Individuals with type 1 diabetes were excluded, as were individuals who were unemployed, did not reside or work in the tri-county area, and who scored above 75 (level 4) on PAM-10. Diagnosis of T2DM was assessed via self-report by the participants.

Procedures

The PAM-10 was used as a screening tool during recruitment to identify adults with T2DM and low levels of patient activation. (ie, PAM-10 score less than 75).²¹ The PAM-10 is a well-validated measure (Rasch: 0.81) of how people view themselves as managers of their own health.²¹ Scores on the PAM-10 range from 0 to 100, corresponding to patient activation levels 1, 2, 3, and 4. Rural working adults

living with T2DM in a tri-county rural area were recruited from local employers, such as elementary schools, hospital employees, and manufacturing companies. During routine health screenings and flu clinics conducted at the worksites, information about the study was provided to potential participants and small gift incentives (less than \$10 value) were provided for completion of PAM-10. The PAM-10 was completed by 35 employees with self-reported T2DM. Out of 24 individuals that met inclusion criteria, 20 consented and participated in the study.

Data Collection

Written informed consent was obtained from each participant prior to data collection. One investigator (L.G.) conducted all interviews, which were digitally recorded and averaged 60 min in length. The interviews were conducted at a mutually convenient location, such as a private meeting room in local hospital, clinic, or church. A semi-structured interview guide (see Supplemental Table 1), based on Fisher et al’s model, was used to explore the factors that influenced their engagement and use of recommended, diabetes preventive health services. Demographic data were collected using a paper and pencil questionnaire.

Data Analysis

Transcripts were transcribed verbatim and exported with NVivo 12 qualitative software for data analysis. Two investigators, one who conducted the interviews (L.G.) and another with experience in qualitative research (M.E.), analyzed the data. The 4 major categories of the socioecological model were used for a priori coding and initial themes; however, the investigators were open to emerging themes and patterns in the data.²² Transcripts were reviewed, additional codes were assigned, and predominant themes and patterns were discussed between both investigators. Themes and theme-related passages coded as code exemplars were agreed upon and reported as results. The participants’ quotations are presented in original, unedited form to reflect an accurate description of the phenomena of living with T2DM among this working adult population in the rural South.

The study was approved by the Institutional Review Board (IRB) of University of Missouri and the local institutional IRB.

Results

Participants (N=20) were rural dwelling, working adults with T2DM, ranging in age from 25 to 65 years with low patient activation scores (M=59.4). Almost half of the participants resided in the most rural of counties. Based on the Rural Urban Commuting Areas (RUCA) definitions, participants were most likely to live in areas designated as

Table 1. Demographic Characteristics of Study Sample (N=20).

Age (years)	47.3 (25-65)
Race (African American)	12 (60%)
White	7 (35%)
Other (Indian)	1 (5%)
Gender (Female)	14 (70%)
Male	6 (30%)
County of residence (classification)	
Rural (RUCA > 5)	8 (35%)
Rural (RUCA < 5)	2 (10%)
Micropolitan	9 (45%)
Metropolitan	1 (5%)
County of employment (classification)	
Rural	10 (50%)
Micropolitan	8 (40%)
Metropolitan	2 (10%)
Employment status	
Full-Time ~40 h/week.	16 (80%)
Part-Time ~20 h/week	4 (20%)
Annual income (less than \$50 000/year)	13 (65%)
More than \$50 000/year	7 (35%)
Insurance (via employee benefits)	13 (65%)
Uninsured	5 (25%)
Medicare	1 (5%)
VA insurance	1 (5%)
Patient activation score (PAM-10)	59.4 (47.4-72.1) 6.8 s.d.

Abbreviation: RUCA, Rural Urban Commuting Areas.

small-town core with urban cluster 2500 to 9999 population and small-town high commuting to small urban cluster.²³ Most participants were female (70%), African American (60%), and had health insurance (75%). However, the majority of participants had annual incomes less than \$50 000 (65%), which is lower than the U.S. 2017 median income of \$61 732 and 80% worked full-time (see Table 1).²⁴

The overarching theme, “living with the ups and downs of diabetes,” and 4 additional themes emerged from the data: the “struggle,” “doing things together,” “diabetes is not the priority,” and “we’re lucky to have what we have.” These themes reflected the spheres of Fisher et al’s model, which focused on individual, interpersonal, health system, and community resources and support. This article will specifically focus on how individual and interpersonal factors influenced engagement in diabetes self-management and preventive health services as represented by themes “the struggle” and “doing things together.”

Living With the “Ups and Downs” of Diabetes

This group of working adults (N=20) experienced inconsistencies living with diabetes, described as an “up and down” phenomenon and portrayed as both positive and

negative experiences. The participants described both the ability and inability to make needed lifestyle changes. Adhering to healthy eating and exercise was inconsistent, as was glucose control. As explained by one of the female participants:

*Then I realize it's (blood sugar) going up again, go to the doctor and they get on me about it and then I go back to eating like I was supposed to eat. And then after a while when I feel like I'm comfortable with it again, I go eating what I want to eat. And it's just **up and down, up and down, up and down**. Diabetes is something I just don't wish on my worst enemy.*

Theme 1: The “Struggle”

This theme portrayed the struggle of living with diabetes in a predominately poor, rural community in the Southern U.S. The narratives depicted wide fluctuations in dealing with a chronic disease and contain subthemes of enabling versus challenging factors in adjustment to T2 DM (see Table 2). Some of the challenges of being engaged in diabetes self-management and preventive health services were characterized by individual factors, such as denial. Denial often led to a delay in the diabetes diagnosis. One participant, for example, said “*It don't matter. That didn't happen to me because I just **didn't have time** for that.*” Some had ignored their physical symptoms of diabetes for years before seeking a diagnosis, despite having risk factors for developing diabetes, such as a strong family history. Some of the participants struggled to recognize the classic symptoms of diabetes and experienced severe, debilitating symptoms, such as profound weakness, polyuria, and polydipsia. They felt “*surprised*” and “*shocked*.” Furthermore, denial was often typified by a minimization of their diabetes symptoms and diagnosis: “*I just looked at them and told them there was **no way possible** it could happen. . . This ain't **nothing**. It's like a cold. It'll go away.*” Many of the participants delayed seeking care, despite being encouraged to seek care by other family members:

“When I found out—I was at my mom's house and I was laying on the floor. And I kept dropping to sleep and she didn't know what was going on. And my sister said— it was unlike me. Evidently, my sugar got too high. I didn't even know I was a diabetic. . . I kind of figured something was wrong. I thought I was just tired. But then I really couldn't get up. I could hear them talking to me. But I couldn't wake up to get up off the floor.”

Accepting diagnosis of diabetes versus denial. Initially, participants described their experience of feeling overwhelmed as they struggled to accept the diagnosis of diabetes. Many described the difficulty adjusting to diabetes as “a struggle” as they fought to maintain blood sugar control and incorporate healthy eating and exercise into their lifestyle. Diabetes meant “giving up” their favorite foods such as sweets,

Table 2. Subthemes for Theme 1—“The Struggle.”

Enabling factors	Challenging factors
Acceptance	Denial
Individual responsibility and daily routine	Inconsistency in diabetes self-management
Coping strategies—self-control	Lack of coping strategies/self-control
Motivation for healthy future	Fear of complications
Emotions	Regret, guilt, tired, depressed

sodas, rice, and carbohydrates and trying to “get up” and exercise. They were trying to adhere to diabetes care, or keep “up” with diabetes, but experienced inconsistency as blood sugars kept going “up and down.” The participants reported various emotions about living with diabetes besides feelings of denial, such as regret and fear of developing diabetes-related complications. A significant proportion of the participants (n=12) had witnessed family members with diabetes-related complications. One of the young, single adults, who was recently diagnosed with diabetes, expressed the agony she endured while being the sole caretaker for her mother with fatal diabetes-related complications. She described her struggle, “*I thought that would never be me. But it **ended up being me**.*” Other common emotions were feelings of being depressed and tired, “*like you've been hit by a bus*” or “*like a dead man walking*.”

Developing individual responsibility versus inconsistency in diabetes self-management. After the initial shock of being diagnosed with diabetes, many came to realize the importance of taking individual responsibility for their health. The participants struggled, however, to develop new roles and healthful behaviors associated with diabetes and verbalized regret and frustration about their inability to make lifestyle changes: “*it's like I can't do nothing right.*” They also struggled to establish a daily routine for diabetes self-management, such as taking medications or checking blood glucose. Their daily routine was burdensome: “*somedays I feel like a pin cushion.*” In addition, participants struggled with episodes of lacking self-control in eating certain foods. For example, one participant said having diabetes is “*just like being an alcoholic, you want something that you know you shouldn't be eating, but you enjoy it,*” while another stated “*I know I am supposed to do it [eat healthier], but I don't do it.*” The ability to establish a routine and make lifestyle changes developed gradually and was an important resource for the participants.

Coping with diabetes and self-control. The participants' ability to change their lifestyle was challenging and many blamed themselves for being inconsistent with statements such as, “*it's still me that doesn't take care of it*” or “*is totally my fault.*” Additionally, participants had an overwhelming

sense of stress when trying to cope with diabetes, as one of the younger participants described:

I try to go and just try not to worry about too many things because I tend to worry a lot and be all stressed up. Sometimes I don't know how to deal with it, deal with the stress and stuff like that.

Motivation for healthy future versus fear of complications. Some participants were developing individual responsibility for diabetes self-management, yet many seemed to lack personal accountability for being engaged in recommended diabetes preventive health services. Engaging in care provoked fear related to the possibility of diabetes-related or other medical complications. Fear was one of the main reasons cited for avoiding medical care, as a young working male stated, “*And they (his family) kept telling me, ‘You got to go to the hospital. Go to the hospital’. And I was scared to go.*” The participants expressed their fear of developing complications, such as having a stroke or kidney failure, and “*I don't want that to happen.*” The positive, or “*upside,*” of this fear seemed to prompt the participants to have a sense of accountability and be fearfully motivated to avoid diabetes-related complications or end “*up*” like everyone else.

Theme 2: Doing Things Together

The theme “doing things together” emerged from the interpersonal resources and support category, based on the Fisher et al’s model (See Table 3).¹⁶ Living in a rural community included a sense of social support and sense of belonging in their relationships with others. Certain relationships provided emotional support, as well as a sense of accountability and motivation for diabetes self-management. Strong social networks not only provided emotional support, but also facilitated being engaged in physical activity. However, participants explained that social and family support had little impact on being engaged in diabetes preventive health services. Participants were more likely to utilize social support for acute or emergency medical situations. The participants also felt the burden of responsibility for receipt of diabetes preventive services was left to health care providers.

Social support and sense of belonging. The sources of social support varied, and included family members, coworkers, friends, peers with diabetes, and role models in the community. One of the younger participants described a friend, who also has diabetes, which motivated him to take “*better*” care of himself and helped make it easier than “*trying to do it by yourself.*” This participant faced many stressors, including being hospitalized for a skin infection and uncontrolled diabetes, changing jobs, and experiencing family stress. Further,

Table 3. Subthemes for Theme 2—“Doing Things Together.”

Enabling factors	Challenging factors
Family and social support	You don't talk about it
Physical activity with family and friends	Feelings of shame and guilt

he felt that those without diabetes lack understanding about diabetes, as he stated, “*It's hard for people who don't understand diabetes or don't have it and is not going to realize someone else who has it and what kind of effect does it have on them because they don't have it.*”

A busy, middle-aged, working woman also described the sense of belonging and emotional support from others. She gave an account of a very supportive environment in a fitness “*boot camp*” she joined after being diagnosed with diabetes. This support, “*the best thing since sliced bread for me,*” helped the participant to start exercising and lose 30 pounds. She also described having a very stressful job and the importance of receiving emotional support from a coworker, including talking and going out to lunch together. However, others reported not knowing friends who were living with diabetes and hence, they sought diabetes-related support from other sources, such as family members. Only one of the female participants, who had been living with diabetes since young adulthood, engaged in “*virtual*” support via an online diabetes chatroom.

Family support versus “You don't talk about it.” Some interactions with family members, friends or coworkers were positive experiences, however, many were not; “*The kind of house I grew up in, certain stuff is just not—You don't talk about it.*” The “*downs*” of having diabetes included the challenge of openly discussing experiences. Overall, in conversations among family members or friends, participants avoided openly talking about diabetes itself. Being engaged in recommended diabetes preventive health services, such as doing annual eye exams, was not a topic discussed among family and friends. The participants explained that few social interactions involved talking about diabetes itself, described when one participant stated, “*very once in a blue moon it might come up.*” Although many had close family members with severe diabetes-related complications, they indicated that their family did not talk about diabetes on a regular basis and seemed to prefer to “*keep it to myself.*” Instead, they were inclined to talk about food or eating. Overall, talking about diabetes was mixed with reluctance, fear, and shame amidst close, supportive relationships with friends and family.

One of the male participants talked a lot about his mother, who had faced much adversity as a child, and later suffered diabetes-related complications as an adult. He described her as endearing, conveyed authority, yet she

rarely talked with him about diabetes. He lacked support for healthy eating at family gatherings and had to “*mentally set myself up.*” In contrast, he was a source of support for healthy lifestyle to his students and fellow coworkers, led yoga exercises at his workplace, and enjoyed exercise as way of “*socializing.*”

Another participant, having diabetes more than 30 years, talked about her family experiences. She has a living brother with diabetes, who suffered a stroke, and her mother died from end-stage renal disease and heart failure. She explained that her mother was reluctant to talk about diabetes with others. However, she encountered social support for diabetes self-management in her community, namely from a role model at church:

And my spiritual mother, we would talk all the time. And anytime she would come up with something like the carrot juice, she would fix carrot and celery. She'd fix that in one and we'd drink that. . . She was as healthy as a mule. I just enjoyed talking with her. And we would talk when she would find different things. And books, she would give me books—good lord, to read, and I would just read, read, read. And that's how I found a lot of different things.

Feelings of shame and guilt. Many participants encountered shame in their social interactions with family members, while exercising in gyms, with health care providers, and at their workplaces. Participants described feelings of guilt and shame or “being embarrassed” or being judged as a diabetic. One of the participants talked about the stigma associated with diabetes at her workplace, stating “*She made a mistake of letting other people know she had it. So, when she wants to cheat, she can't cheat because they'll say, 'No, you can't have it.'*”

Many participants felt frustrated and ashamed about having uncontrolled blood sugars and being overweight. Furthermore, engaging in health care was often described as a negative experience and provided little support for dealing with the challenges of diabetes. One of the male participants expressed his frustration about the challenge of juggling the responsibilities of diabetes and being a store manager, tirelessly working more than 60 to 80 h a week. He felt “*tired of going to the doctor. . . tired of being preached at. . . tired of hearing the same thing.*”

Physical activity with family and friends. The participants spent much of their leisure time with family and expressed enjoyment in social interactions. The “ups and downs” of diabetes manifested as the inconsistent social support for healthy behaviors, such as being physically active. Physical activity with family was sporadic and challenging to sustain: “*I love to play kickball, and I would always go out and play ball with my kids, especially on Saturdays, but during the week, it was just hard because I'll be tired.*” One participant talked about an exercise and healthy eating program at

work, “*So me and my other co-worker talked about it, signed up for it, but haven't really done it.*”

Discussion

Overall, the participants struggled with their adjustment to living with diabetes and achievement of sustained behavior change. At the individual level, some of the participants were developing responsibility, yet many seemed to lack personal accountability for being engaged in diabetes self-management and recommended diabetes preventive health services. Those who had a “routine” in diabetes self-management and who were developing a more consistent pattern of being engaged in diabetes care reflected a higher level of patient activation (or level 3 and PAM-10 scores 56 or greater out of 100). Conversely, those with inconsistency in diabetes self-management and a pattern of health care avoidance represented lower levels of patient activation (or level 2 and PAM-10 scores below 56 out of 100). On average, this group of participants had lower levels of patient activation ($M=59.4$, $SD=6.8$), which has been associated with being poorly engaged in diabetes care and preventive health services.²⁵ On an interpersonal level, the level of patient activation can be influenced by the availability of social support and economic resources.^{26,27} Their social support did not facilitate being regularly engaged in preventive health behaviors. Social support has been associated with positive diabetes health outcomes; however, the existing literature is unclear whether social support can have a positive impact on engagement in diabetes preventive health services.²⁷

A key finding in this study was the emotional burden of living with diabetes (see Figure 2). Having a lack of self-control, worrying about future diabetes complications, having feelings of fear, guilt, shame, and depression, as well as lacking honest conversations about diabetes clearly exemplified diabetes-related distress. The participants exhibited signs of diabetes-related distress, which is common among rural, African American populations.²⁸⁻³⁰ A lack of effective coping strategies among this group of rural, working adults with low patient activation levels highlight the need for targeted efforts to help persons to cope with the psychological impact of chronic disease. These efforts can improve health outcomes, such as reductions in diabetes-related distress and A1C.^{10,31,32} The need for psychological support is a priority, as access to mental health providers disproportionately impacts rural areas compared to urban areas, although rates of depression and diabetes-related distress are similar.^{10,28} Furthermore, fear and anxiety related to COVID-19 has compounded the level of diabetes distress in this population.³³ Other sources of support might be needed, such as from churches, employers, and family/friends. The psychological impact of living with diabetes also highlights the crucial need for rural clinicians to monitor for signs of

behaviors. Worksites proved to be a feasible point of access for screening potential study participants. Collaborating with a local institution's employer relations department was a good point of contact that facilitated access to potential study participants at their worksites. There were some challenges to conducting research activities at worksites due to corporate policies and some of the PAM screenings had to be conducted via telephone due to time constraints at worksite health screenings. Engaging with other community leaders, such as a local diabetes educator and a local health coalition, and assisting with the local hospital's diabetes fair, also enhanced recruitment.

This study had limitations that must be considered when interpreting the results. As this was a qualitative study with a small number of participants, the results are not generalizable to other rural populations. Further, researcher bias could have influenced the interview data, as the researcher conducting the interviews was familiar with the local community as a health care provider. Finally, while data saturation was achieved, the majority of the participants had PAM-10 scores at level 3 and may not adequately represent poorly engaged, working adults living with T2 DM.

Conclusions

The findings from this study show that living with T2 DM was characterized by various "ups and downs" and inconsistency. Taking individual responsibility, having a routine for diabetes self-management, having social and family support, and engaging in physical activity with others facilitated engagement in diabetes self-management and preventive health behaviors. In contrast, feelings of denial, regret, guilt, fear, lack of self-control, inconsistency, and lack of honest dialog about diabetes hindered diabetes self-management and engagement in preventive health behaviors. Individual and interpersonal factors had both positive and negative influences; some of these factors modified how rural, working adults with T2 DM engaged in preventive health behaviors. The significance of the other themes "diabetes is not the priority," representing health system factors and "we're lucky to have what we have," representing community factors that influence diabetes preventive health behaviors, will be discussed in a later manuscript.

The results have implications for research, health policy, and clinical practice. The results from this study will inform future development of interventions designed to enhance patient activation in poorly engaged, rural, and working adult populations. Adults with T2 DM, who are not engaged in self-management and preventive care, might benefit from interventions aimed at enhancing patient activation and lead to better glucose control and diabetes health outcomes.⁴⁷ Novel evidence-based psychological interventions are needed to address the unique needs of working, rural dwelling adults living with T2 DM. Community-based participatory

research might be particularly amenable to addressing issues that working, rural dwelling adults with T2 DM face.⁴⁸ In community-based participatory research, an important strategy is to emphasize the strengths and resources within a community, instead of focusing on community needs and problems.¹⁷ Utilizing identified strengths, such as having strong social networks, could enhance health in this rural community. Recruitment and participation in the research study proved to be effective at the workplace setting for this population. Hence, this population may also benefit from integrating telehealth into workplace settings to facilitate access to health services and diabetes management.

Decreasing the diabetes-related health disparities among vulnerable populations should remain a priority. Rural health policy should enhance telemedicine infrastructure, support, and mental health resources to rural communities. Finally, clinicians can help facilitate engagement in diabetes care by assessing the individual, interpersonal, health system, and community support and resources that are available to their patients.

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Supplemental Material

Supplemental material for this article is available online.

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