Social determinants of managing type-2 diabetes in rural communities in the Dominican Republic: a qualitative study of stress and social support

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Abstract:
Introduction: Type 2 diabetes (T2D) is changing the burden of illness across Latin America, particularly in rural communities, where research on T2D remains sparse. Objectives: We conducted a longitudinal, qualitative study to explore experiences of living with T2D among adults in rural communities in the Cibao region of the Dominican Republic. Methods: We conducted qualitative in-depth interviews with men (n=22) and women (n=27) recruited from two rural diabetes clinics in 2015 and 2017. Interviews were audio-recorded and transcribed verbatim. We used narrative and thematic analysis procedures to inductively identify themes related to social support, stress, and coping. Results: Diabetes-related stress started at diagnosis and continued as participants managed T2D as a chronic condition. Insufficient food access, medication access worries, fears about illness injury, and the cyclical process of experiencing stress all produced stress. Sources of social support varied from T2D diagnosis through management, with more support from friends and communities when enrolling into care and more support from partners and family when managing T2D over time. Participants lacked sufficient emotional support to cope with the stress of T2D. One way participants coped was to employ the strategy of “no le doy mente”, or not thinking about T2D. Conclusions: Stress and social support are two key determinants of managing T2D. Diabetes management programs should aim to provide holistic services tailored to the unique stress and support needs of patients to achieve optimal outcomes.

Palabras clave: stress, social support, type 2 diabetes, qualitative research, Dominican Republic
I. INTRODUCTION

Latin America and the Caribbean (LAC) have experienced an epidemiological transition from acute, infectious disease to chronic conditions including diabetes and hypertension (1,2). Diabetes prevalence across LAC is 10%; in 2016, 90% of these cases were Type 2 diabetes (T2D). The rapid transition of T2D has made it one of the top causes of death and premature disability in less than 50 years (3). The estimated prevalence of T2D in the Dominican Republic (DR) ranges from 7.36% to 9.3% (3).

T2D is a complex, chronic illness that requires self-management strategies, including a healthy diet, regular exercise, medication adherence, and access to continuous medical care (2,4). These strategies may improve diabetes outcomes and avoid diabetes-related complications; however, poor coping and problem solving skills and depression can limit self-management behaviors and affect metabolic control (5,6). Social support from peers, family, and providers is an important determinant of self-management behaviours (7). In both clinic and community settings, individuals with diabetes with peer support are more likely to improve self-management behaviors than those without peer support (8,9).

Diabetes-related stress and social support are highly contextualized phenomenon that require in-depth examination to identify sources and impacts across distinct settings. Relatedly, improving diabetes management requires understanding the experiences of living with diabetes (10), particularly in the LAC region where research on this remains limited. We conducted a longitudinal, qualitative study to explore the experiences of living with T2D among adults in rural communities in the Cibao region of the DR.

II. METHODS

A. Study Setting

We conducted this longitudinal, qualitative study from June to July 2015 and in June 2017 at two non-governmental (NGO) rural health clinics in the central Cibao region of the DR. This agricultural region produces staples such as cacao, rice, and plantains, though residents purchase most their foods at colmados, locally owned neighborhood shops, and, to a lesser extent, supermarkets. We collaborated with the Dominican NGO, Institute for Latin American Concern (ILAC), and their United States (US)-based partner, Chronic Care International (CCI) in two clinics, which have delivered T2D and hypertension services since 2010. The T2D component of the program provided enrolled participants with: health talks (charlas) provided by community health workers (cooperadores) on healthy eating, increasing physical activity, and glucose management; medical screenings; and medications, all at no cost. The two clinics had approximately 900 patients. ILAC and CCI collaborated on the development of interview guides and facilitated access to clinics.

B. Participants, Recruitment and Data Collection

Individuals 18 years and older with a confirmed T2D diagnosis enrolled in the diabetes program were eligible. We purposively sampled 49 participants (n=22 men, n=27 women) across the program’s geographical catchment area in two waves of data collection, first in June-July 2015 and then in June 2017. Clinic staff provided referrals for initial participants. Thereafter, we independently recruited participants from clinic waiting rooms in both waves of data collection. We interviewed participants in private rooms within clinics, outdoors spaces, or nearby community spaces, such as schools and churches.
We obtained oral consent from participants, who received a gift bag with toiletries valued at 200 Dominican Pesos (USD $5). This study received approval by Institutional Review Board at the University of North Carolina. Interviews were conducted in Spanish and audio-recorded. Interview times ranged from 30 to 120 minutes. HG, DW, CS and two Dominican women transcribed interviews verbatim.

The 2015 interview guide explored participants’ understanding and management of T2D as well as descriptions of the context and environment in which they lived. The 2017 interview guide followed-up on the emotional burden and stress of managing T2D and, a major theme identified in the 2015 interviews.

C. Study team and reflexivity

Our primary interviewers (HG, DW, CS), were graduate public health students at the University of North Carolina. Our principal investigator (CB) is a US-born public health researcher with over 20 years of experience in the DR. The team resided in one of the clinic communities during fieldwork. As researchers from a US university, we were cognizant of the social and class power dynamics that existed between the participants and ourselves. We did our best to facilitate a relaxed and open environment where participants felt comfortable sharing their experiences. Although we conducted interviews in Spanish, the diversity of our team led to regional and stylistic differences in accents, and the use and interpretation of words, phrases, and ideas. Conscious of this, and when appropriate, we probed participants to define unfamiliar words and phrases to ensure we understood and interpreted their descriptions as accurately as possible. We also tried to define and explain unfamiliar words or expressions we used so participants understood us clearly.

D. Data Analysis

We conducted an inductive, data driven analysis of the data using both connecting and categorizing approaches (11). During the fieldwork, we produced field notes on initial impressions of patterns and emerging themes of interest after each interview and debriefed daily as a team. This process led to refining of probes in response to emerging themes. During the transcription and data quality control processes we also noted key themes and relationships for further exploration. Following the completion of data collection and transcription, we wrote analytic summaries to capture each participant’s “diabetes story” (12). Through these early analysis processes, we identified mental health and social support as key themes in the diabetes experience, which informed the focus of the analysis for this paper. We then developed a codebook to examine the emotional and mental health aspects of living with diabetes, including inductive codes such as “worry”, “sadness”, and “stress”, and “no le doy mente” (I don’t think about it). We used ATLAS.ti software to systematically code transcripts (13). Finally, we conducted a second in-depth analysis of stress and diabetes, where we refined our focus to “diabetes-related stress”, and identified sources of stress and associated coping behaviors.

We used Heaney & Israel’s (2008) (14) definition of social support as ‘aid and assistance exchanged through social relationships and interpersonal transactions’, to guide our analysis. We followed their categorization of four types of support: emotional, instrumental, informational, and appraisal. We then developed matrices to organize text by types and sources of social support at specific stages of the patient’s diabetes journey, as described in the interviews. Next, we developed a codebook comprised of descriptive codes using the four types of social support and sources of support.
III. RESULTADOS

A. Sources of Diabetes-Related Stress

Stress at diagnosis
Diabetes diagnosis was an acutely stressful experience for most participants, especially for those surprised by their diagnosis. Participants described feeling sadness, uncertainty, and fear at diagnosis. Juana, 55, felt simultaneously scared and sad learning she had diabetes, an illness she viewed negatively, saying, “I was sad, sad, I was, because I heard that it was big – being a diabetic, that it was bad.” In addition to sadness, participants also experienced fear of morbidity and mortality, as expressed by Pedro, 37, “Damn it! I am going to die soon; I am going to die young.”

Participants’ initial stress at diagnosis caused disruptions in sleep, appetite, and their desire to be social. A motorcycle taxi driver, Marcos, 53, animatedly explained the physical toll of his stress, “I didn’t sleep, I didn’t eat…” He worried his diminishing vision was associated with diabetes. Sophia, 60, said she felt lethargic when diagnosed and had little desire to leave her house. “Yes, when it started, the diabetes, I lasted a month where I did nothing...”. The acute stress caused by both internal and external reactions to the diagnosis caused a combination of physical, emotional and social effects that disrupted participant’s lives.

Food access and availability
The limited availability of healthy foods in the communities where participants lived was a salient source of chronic stress. Many felt they had few options to control their diet in a nutrient-poor food environment. Foods such as whole-grain rice were only available in supermarkets and could be twice the cost of white rice, a common staple in the local diet. Lucia, 52, described her stress accessing healthy food, “There are people who can follow their diet, but many cannot. We often must eat things that we should not eat because [living with] hunger is hard. … [Diabetes] is harder for the poor… I would say it is much harder. I feel bad for those of us that suffer from this illness. Sometimes I go to sleep hungry, and more so when one lives in the countryside. Things in the countryside are very difficult. Participants also expressed little control over foods options available to them, and participants with dependents often lamented on their struggles to put enough food on the table.

Medication stress
Although participants had access to free medication through the diabetes program, worry about their reliance on medication to stay healthy was another source of chronic stress. Antonio, 57 and living with diabetes for over 20 years, firmly considered diabetes as one of the “worst diseases of the century”, “If you have AIDS, HIV, you have treatment. Done. If you are in treatment, you can live 100 years and die of something else – you will not die of that [HIV]. But with diabetes, a person without treatment can be sure that one day, he will lose his vision. Through diabetes comes the famous diabetic foot or kidney problems. It is a tragedy for them and their family because now you have lost everything.” Antonio’s comparison to HIV, also referenced by other participants, reflects two important points. The first relates to Antonio’s statement that with HIV “you have treatment”, which reflects the perception that there is greater access to anti-retroviral treatment in the DR than diabetes medication. The reliance on donated medication among study participants created a sense of vulnerability and, subsequently, stress
due to the central role of medication in diabetes management. The second was the perception that medication alone is enough to control HIV while controlling diabetes requires medication and lifestyle changes in diet and exercise.

**Injury Susceptibility**

Participants worried that diabetes-related complications could result in injury that could compromise their earning potential. Beto, a 78-year-old retired agriculture worker living with diabetes for 50 years, still worried about his diabetes,

“It worries me a lot and I sometimes do not sleep; if I have something [a health complication] I cannot work. I sometimes worry, you see.”

Although retired, Beto worried about his ability to contribute to his household, reflecting the intersection of diabetes-related stress, economic stress, and male gender roles to be providers.

Other participants worried that diabetes-related symptoms were already affecting their economic productivity, as expressed by Laura, 44, who operated a colmado from her home.

“It is hard. I have days where I work and I have days where I do nothing. When I have that [prickly feeling] in my feet, I do nothing. I do what I can and what I cannot do, I do not.”

The possibility of sustaining a diabetes-related injury translated into participants’ worries about maintaining their physical ability to work and support themselves and their families.

**Stress-Induced Stress**

While participants described general feelings of stress associated with diabetes self-management and control, they also believed stress and the negative emotions it induced could increase blood pressure and affect sugar levels, increasing their risk of other health complications. According to many participants, stress made people with diabetes more susceptible to pique, or irritability. Martin, 52, described his beliefs on the relationship between stress, pique, and negative health outcomes:

“Well, that’s where the [blood] pressure comes from, from not being tranquil. Having high stress causes the [high] pressure, and then a lot of illness results.”

Marcos continued explaining how he believes excessive worry could destabilize a person’s health and even result in depression,

[Living with diabetes] is worse... when you think about it. It is worse because you can even die of depression if you think about that, and [it can affect] your heart and all that.

Marcos believed that excessive worry could result in nervios (nerves), a term we interpret as a general negative emotion in a person’s body that could result in poor health. Perceptions of accelerated susceptibility to early mortality illustrated how participants viewed diabetes-related mortality stemming from diabetes directly and indirectly through excessive worrying about diabetes.

**B. Social Support**

We identified types and sources of support across the three stages of the diabetes journey. Most participants described learning about their diabetes indirectly through a routine check-up or going to medical appointments for other conditions. Direct support for diagnosis from friends and neighbors was commonly described, usually in the form of appraisal support regarding perceived changes in the participant’s physical appearance. Juan, 53, described how a neighbor encouraged him to seek care because he looked ill and seco, which translates to dry and describe excessive weight loss.
She told me, ‘you’re sick, your clothes are loose and falling off of you.’ I agreed. I had a t-shirt that I no longer fit in. Dry, I was getting drier, [...]to the point that a man told others ‘be fearful of that man, he could have AIDS.’ And I heard that, you see? I went to my partner and told her that I felt ill.

After that a neighbor took me to the see a good doctor to see about my condition...

Juan’s neighbor played a critical role by appraising Juan’s health through her perception of his weight loss. While most participants described getting diagnosed through an indirect process, as reflected in Juan’s experience, appraisal and informational support served prompted participants to seek out care.

Compared to the diagnosis stage, themes of support were more salient among participants at the enrollment stage, particularly informational and instrumental support from friends and neighbors to get to the clinic. Some friends and neighbors, regardless of whether or not they too were enrolled in the diabetes program, provided information on how to get to the clinic and what services were provided. Participants described friends and neighbors providing support such as accompanying them to appointments and/or providing them transportation. Pedro, 53, shared that a neighbor from his community took him to his first clinic appointment and provided him and others ongoing transportation support.

When asked ‘Who supports you with your diabetes?’ cohabitating partners were often the primary supporters referenced. Partners played many roles, sometimes as a source of emotional support such as being available for participants to talk to when needed. Partners, mostly female, also provided instrumental support by buying recommended foods, preparing meals, monitoring medication schedules, and organizing transportation to appointments. Maintaining the same level of responsibilities they had before having diabetes coupled with reporting little support in the home led to narratives depicting stress and frustration among women, as explained by Lucia, 52:

No one supports me, no one. How do I say this, even if I feel bad no one pays attention. Not even my sisters come to visit and lend me a hand. But God gives me strength, because no one else helps me.

What happens is that when my sugar levels go up, I cannot sleep well and sometimes I get scared. Sometimes my family does things I don’t like, which makes me feel ill, like I have high blood pressure. I don’t know. Listen, those who have diabetes have to be careful and so they need someone who will support them so that they feel better.

Lucia described her desire for support and the emotional and physical repercussions in not receiving it. Among the few men who did mention limited support after enrolment, it was usually a lack of emotional support from a cohabitating partner. Other family members were also mentioned as sources of support such as older children, parents, and extended family. Similarly to partners, extended family members provided instrumental support with transportation, medication and diet adherence.

Once enrolled, instrumental and emotional support from family was important, especially from partners. Healthcare providers and cooperadores provided informational and instrumental support to help participants manage their diabetes. Friends and neighbors were less salient in this stage compared to the diagnosis and program enrollment stages. Although participants reported a greater variety of social support sources in this stage, participants also described the negative effects of limited or no support to manage their diabetes.

C. Coping with the Stress of Diabetes

Beyond the benefits of social support, participants identified two main ways of coping with diabetes-related stress: (1) the diabetes program, a significant external factor that reduced stress; and (2) no le doy mente (I do not think about), as an internal stress-reduction technique.
The diabetes education and self-management techniques provided by cooperadores at the clinic and their providers alleviated participants’ stress by reducing uncertainties they had about their illness. While support from cooperadores was appreciated, it was the free provision of diabetes medications that was the primary, stress-reducer. Participants believed US-imported diabetes medications obtained through the program were superior in both quality and efficacy compared to medications sold locally. Receiving diabetes medications at no cost also reduced the economic burden of diabetes, though some expressed concern about the sustainability of the program’s model.

No le doy mente was a popular phrase that encompassed how participants internally coped with diabetes and reduced their stress. Participants sought to actively ignore or avoid negative thoughts or feelings associated with diabetes to cope with stress by focusing on managing their illness the best they could, as described by Rosalie, 43:

*I do not pay attention to [diabetes] because imagine life - I am not going to dedicate myself to worry about that because... one has to take care of themselves, ... as much as you can. If I start worrying, it will be worse. If I focus on only that, it will not be controlled because that is how the sugar also rises, because of [worrying].*

Rosalie echoed normative beliefs about the need to avoid stress to prevent additional health complications. When asked what she does to worry less about diabetes, Rosalie concisely responded, “*I take my pill and do not worry about the rest.*”

Related to not thinking was about diabetes was fatalism, described as “the tendency to believe that events are predetermined or determined by external events” (15). Fatalism in the DR has religious component that often includes relinquishing control to a central theological authority (15). Ana, 53, described her reactions to her diabetes diagnosis, “*I took it well because one shouldn’t take it [the diagnosis] with a lot of pressure because God gives things and one has to accept it.*” The role of fate was also reinforced by Oscar, 59, “*Everything that God does is perfect. He never makes a mistake. And the things that are going to happen will happen. We are talking today due to pure chance, we’re talking because the Lord accepted it.*” Both examples illustrate how fate helped facilitate no le doy mente by seeing their diagnosis as something they cannot change. Participants also talked about giving their worries, fears and medical complications to God to do his will. For example, Guadalupe, 70, said, “*When I feel depressed, I grab onto God. I say, ’Lord Jesus, I am in your hands, that my will be not done but yours.’*” In these examples, religion seems to serve the purpose of helping participants not dwell or think not about their diabetes.

IV. CONCLUSION

We found that diabetes-related stress began at diagnosis and persisted as participants worried about injury, access to healthy foods and medications, and economic productivity. Worry about avoiding stress, perceived by participants as harmful to their health, was a source of stress itself. Social support facilitated participants’ diagnosis and management of T2D. Beyond social support, participants coped with diabetes stress by attending clinic and adhering to medication, which alleviated uncertainty and diabetes-related symptoms. Internally, participants coped with diabetes by not thinking about their diabetes (“*no le doy mente*”), which appeared to facilitate fatalistic attitudes about living with diabetes among some participants. Holistic, integrated T2D services that provide social support and asset-based, problem solving strategies to reduce stress could improve sustained clinical outcomes and overall wellbeing among
adults living with T2D. Structural level interventions to improve access to healthy foods and access to health services are also needed.

V. REFERENCES

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