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“We Are All Gonna Get Diabetic These Days”:

The Impact of a Living Legacy of Type 2 Diabetes on Hispanic Young Adults’ Diabetes Care

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Abstract

Purpose—The purpose of this study was to investigate how an intergenerational legacy of type 2 diabetes affected the knowledge, attitudes, and treatment strategies of Hispanic young adults with diabetes.

Methods—Eight Hispanic young adults (ages 18–30 years) participated in a series of in-home longitudinal qualitative interviews, and 11 of their family members completed single in-home interviews, regarding their diabetes management practices. Interview transcripts were analyzed thematically by a team of researchers.

Results—Five themes emerged that characterized the influence of an intergenerational legacy of diabetes on young adults: food and family (how meal preparation and eating are shared within families), doing together (activity participation is contingent on others’ participation), knowledge and expectations (expectations for the future and understandings of diabetes are shaped by family members), miscarried helping (well-intentioned actions have negative consequences), and reciprocal support (children and parents support each other’s diabetes care).

Conclusions—Hispanic young adults’ knowledge, attitudes, and self-care practices related to diabetes are strongly influenced by the diabetes management practices of family members with diabetes, which often depart from current standards of diabetes care. Care providers should consider family members as a potentially significant influence, either positive or negative, on the diabetes self-care practices of this population.

Family relationships and the family environment have been identified as important determinants of self-care behaviors, including adherence to diabetes treatment,^{1–3} diet,^{4,5} and physical activity.^{6–8} There is a large body of research describing the impact of family environment on adherence and glycemic control in pediatric populations with type 1

diabetes,⁹⁻¹³ including specifically among Hispanic youth.¹⁴ Additionally, there have been many intervention studies targeting family relationships as a strategy to improve diabetes self-care and health outcomes in pediatric populations.¹⁵⁻²⁰ However, the literature on family environment as it relates to adults with type 2 diabetes mellitus (T2DM) is much less well developed.²¹ A limited number of descriptive studies have investigated how family factors influence diabetes care among adults with T2DM,^{2,22-25} including among Hispanic families.^{5,26} To our knowledge, only 3 family-based interventions targeting T2DM management in adults have been published.²⁷⁻²⁹ Of these, only Keogh et al²⁸ found a significant reduction in A1C in the intervention group compared with the control group; additionally, Keogh et al and Kang et al²⁷ found improvements in family support and patients' knowledge and attitude regarding diabetes.

The Hispanic American cultural context is one in which familism is acknowledged as an important value with potential health implications.³⁰ Hispanic American families are more likely than European American families to maintain close relationships, live together in extended family households, and rely on one another for social support (SS).⁵ In 2011, 22.7% of Hispanic Americans lived in households of 5 or more people, compared with 7.5% of non-Hispanic white Americans.³¹ Cultural norms in Hispanic American households are also more likely than in non-Hispanic households to promote collective decision making around health issues and to respect elders within the family unit.^{5,32}

T2DM is recognized as having strong heritability because of both shared genetics and a shared social context that may promote obesity and physical inactivity.³³ First-degree relatives of adolescents with T2DM have a high prevalence of insulin resistance and T2DM and share many risk factors for diabetes, including binge eating and a sedentary lifestyle.³⁴ The influence of a multigenerational legacy of diabetes has been explored in research by Scollan-Koliopoulos et al.^{23,24,35} One study, conducted among adults with family histories of diabetes, found that participants' recollections of their family members' diabetes care influenced their perceptions of the controllability and consequences of diabetes,³⁵ and participants' dietary behaviors were related to their recollections of the family member's dietary behavior.²³ A second study, comparing participants with and without family histories of diabetes, found that those with family histories had less understanding of diabetes and more negative emotions related to diabetes and felt that diabetes was less predictable compared with those with no family histories.²⁴

Because of the heritability of T2DM, many of the growing cohort of young people with T2DM are likely to be living with relatives who also have T2DM, perhaps especially so in Hispanic families because of the demographic factors outlined above. During the course of conducting a longitudinal qualitative study of Hispanic young adults' (YAs) strategies for managing T2DM, therefore, an emergent finding was the impact of family members' diabetes care on the YAs' own approach to diabetes. We conceptualized this as an ongoing, "living" multigenerational legacy of diabetes (in contrast to the remembered legacy described by Scollan-Koliopoulos et al^{23,24,35}). Therefore, we sought to investigate the following research question: How does a "living legacy" of diabetes influence YAs' approaches to diabetes care?

Methods

Research Design

We used a longitudinal qualitative methodology informed by both narrative and phenomenologic approaches.³⁶ Qualitative methods are most appropriate for investigating the realm of human experience, particularly phenomena about which little is known. Narrative strategies were used in data collection and analysis as a means to understand the events that transpired in participants' lives, as well as the meanings they ascribed to those events. Phenomenology seeks to understand the essence of a phenomenon; in this case, what it means to have diabetes as a Latino YA. A longitudinal design was selected so that we would have the opportunity to observe, in real time, how contextual changes (eg, starting or leaving jobs, change of school schedules, initiating or ending romantic relationships) affected YAs' diabetes management strategies.

Participants and Setting

Study participants were recruited in 2 phases. First, YAs ages 18 to 30 years, who had been diagnosed with T2DM for a minimum of 1 year and self-identified as Hispanic or Latino, were recruited from 2 outpatient diabetes clinics in the Los Angeles County public health care system: a pediatric clinic serving children up to age 21 and a YA clinic serving individuals ages 21 to 30. These clinics serve predominantly ethnic minority patients who are uninsured or are insured through public entitlement programs. Eight YAs were recruited for the study, with purposeful sampling used to ensure representation of both genders and a range of diabetes treatment strategies.

For the second phase of recruitment, YA participants nominated 1 to 3 family members whom they considered important sources of SS. Seven YA participants nominated 15 family members as SS participants, 11 of whom completed interviews: 6 mothers, 1 father, 2 siblings, 1 spouse, and 1 cousin. Six of the 11 SS participants had diabetes themselves. Of the 4 family members who did not complete interviews, 2 declined to participate, and 2 were not available for interviews within the time frame of the study.

Data Collection

A total of 61 interviews with 19 participants were completed for the study, 50 with YA participants and 11 with SS participants. YA participants each completed a series of 4 to 8 interviews (median, 6.5 interviews), lasting approximately 45 minutes each, over a 2- to 11-month time span (median, 7 months). Interviews were terminated when the research team agreed that saturation had been reached or, in one instance, because the participant withdrew from the study. Interviews were semistructured, following an interview guide addressing participants' everyday lifestyles and routines; diabetes care strategies, knowledge, and beliefs; and SS related to diabetes. Examples of interview guide questions are provided in Table 1. YA participants also completed a demographic questionnaire, and their medical charts were reviewed to verify their diagnoses, treatment regimens, and overall health status.

The SS interviews were not planned as part of the original study protocol. However, in the course of interviews with the YA participants, we discussed emergent themes during weekly

team meetings. One frequently recurring theme was the influence of family members in shaping the YAs' diabetes management. To explore this theme more fully, we altered the study protocol to obtain the first-hand perspectives of family members through interviews. This modification was made after all YAs were recruited and 24 YA interviews had been completed. Eleven SS participants completed single interviews using a semistructured interview guide addressing the same domains outlined for the YA participants. A particular focus was on how the SS participants supported the YAs in caring for diabetes and, for the 6 who had diabetes, the SS participants' own disease management strategies.

Two bilingual research assistants who identified as Hispanic or Latino conducted interviews, primarily in participants' homes and occasionally in other locations of participants' choosing. The research assistants participated in 4 hours of training and role-playing of interviewing techniques before their entry into the field and conducted 2 interviews with the principal investigator before conducting interviews independently. The research assistants also attended weekly supervision meetings to discuss data collection challenges and strategies.

Field notes were dictated immediately after each interview. Interviews were conducted in the language of the participant's choosing, either English or Spanish. All YA interviews were conducted primarily in English; among the SS interviews, 7 were conducted primarily in Spanish and 4 were conducted primarily in English. All Spanish interviews, and Spanish excerpts in predominantly English interviews, were translated by a bilingual research assistant. Each research assistant carried out all interviews (YA and SS) associated with a particular participant. Interviewers maintained the confidentiality of YAs' data when conducting SS interviews and vice versa, except in cases in which participants self-disclosed information, such as when they chose to jointly complete interviews. All interviews and field notes were digitally recorded, transcribed, and deidentified for analysis. Transcription was completed by an independent contractor (subject to a confidentiality agreement) within 1 week of each interview, with deidentification completed by the research team immediately upon receipt of the completed transcripts. The study was approved by the University of Southern California Institutional Review Board, and all subjects completed informed consent before study participation.

Data Analysis

The research team met weekly during data collection to review emerging themes, discuss interviewing strategies, and adapt data collection in light of evolving findings. After the completion of data collection, the focus of weekly meetings shifted exclusively to data analysis. Each participant's transcripts were reviewed by a different member of the research team than had conducted that participant's interviews. Cross-case narrative thematic analysis was used, as outlined by Riessman.³⁷ This approach is a form of thematic analysis that seeks to discern similarities across participants' stories and experiences. It is distinct from other forms of thematic analysis (such as grounded theory) in its emphasis on stories as the unit of analysis rather than descriptive codes. It is distinct from other forms of narrative analysis in that it emphasizes the topical content of narratives (what stories are about) more so than their form and structure (how stories are told).

Each researcher highlighted significant interview passages to share with the research team. During analysis meetings, these were discussed, and significant recurring themes were organized using MindMeister software (MeisterLabs, Munich, Germany). The thematic organization of findings and review of relevant interview passages was an iterative process that continued until consensus was achieved among the research team. Finally, the themes and supporting data were reviewed and discussed with an independent researcher to enhance the trustworthiness of the findings.

Results

Demographic characteristics of the YA participants are presented in Table 2. Interviews with YA and SS participants revealed a high prevalence of diabetes and associated complications among families, as summarized in Table 3. Of the 8 YA participants, 7 had at least 1 parent with diabetes; in 5 of those families, both parents were affected. In 4 of the families in which both parents had diabetes, 1 or more siblings of the YA also had diabetes. Two participants reported that grandparents had died as a result of diabetes complications. Five parents of YA participants had diabetes complications, including renal failure, amputations secondary to diabetes, and vision loss.

At the time of the study, 7 of the 8 YA participants lived with at least 1 family member who had diabetes. We conceptualize this ongoing exposure to family members' diabetes management as a "living legacy" of diabetes, in which family members' experiences with the disease were an active and continuing influence on the YAs' diabetes care. The YAs' knowledge, attitudes, and behaviors regarding diabetes were clearly influenced by this legacy. At the same time, the YAs actively shaped their families' experiences and understandings of diabetes. We classified these influences in 5 themes, illustrated with representative passages from interviews (edited for clarity and to protect confidentiality).

Food and Family

This theme describes families' strategies for preparing and eating meals and how diabetes influenced family members' eating. The relationships of food, family, and diabetes were reflected in household dynamics that made it difficult to consistently eat home-cooked food, which was typically more healthful than the alternative (generally fast food). This was due to work or school keeping family members away from home, or the mother or cook being unable to prepare meals. In every household, the mother was identified as the primary cook, while fathers often purchased food from outside the home; when the mother could not undertake meal preparation (because of work, illness, etc), participants emphasized that whoever was performing this family function (often a daughter) was doing so temporarily. One participant summarized the challenge as such:

Jorge: Everything is changing. Now, everyone's mother, or whoever runs the kitchen, is either working all the time, or just not paying attention to what they're supposed to be doing, so I mean the fastest thing someone could eat is a burger, or pizza, or anything like that. If you're hungry, you don't want to go into the kitchen and take out all the stuff, clean the stuff, cook, and then all that, when you could just walk up to any restaurant and ask for a burger.

Participants also described family conflicts around eating: parents disagreed about how to feed their children, children resisted parents' efforts to provide healthy meals, family members without diabetes undermined the healthy eating efforts of those who had diabetes, and family members conspired to eat unhealthy foods behind others' backs. For example, Javier described how he and his father (who both had diabetes) ate less healthfully when his mother was away:

Javier: [Interviewer: So, when your mom's not here, who does the cooking?] We don't cook, we just—we go out to eat. We're too lazy to cook. ... We just go to a restaurant, hamburgers, chicken, tacos and stuff like that, just go out and eat.
[Interviewer: So, when you guys are eating out, do you think about your diabetes?] We do, but then we're like, "I'm just hungry" ... I'm like, oh, who cares, because [my dad] tells me always, "I'm just hungry, I'm just going to eat." When my mom comes back, I'll watch my diet.

The mother was often the arbiter of nutrition in the household. This role was a source of conflict between spouses, or between mothers and children, when they disagreed on food choices:

Leticia: I used to eat junk food. I didn't really like house food, but now, I've got to eat house food. Yeah, because it's too much fat, what I used to eat. Like, oh, wow. I used to call my dad when I was small, "Dad, bring me a hamburger. Bring me something, anything. I don't want to eat at the house." So, he would bring it to me, but then my mom's like no, we can't give her that.

[Interviewer: Did you argue over what's healthy? What did you say?] Javier's mother: Yes, but they got mad at me and said, "We don't want that." And so, there were some times that my husband watched them when I was working. ... [He] would take them to get hamburgers.

Pamela's mother: Look, my husband drinks a soda and then starts drinking soda. And then when my kids see this, they want it too. And then I tell him that if you don't drink, then no one will drink. And then if my kids drink it, and then as a result my mom drinks it, and then I drink it. ... And even though it's a little, we are drinking it. And so I tell him that if he didn't drink, no one would drink.

Doing With

This theme describes how participants' engagement in health-related activities such as exercise, following a healthful eating plan, or regularly attending medical appointments, were often contingent on the availability of other people with whom to share those activities. Many participants expressed clearly that they did or did not participate in certain activities because of the choices of people in their social circles. This was sometimes for logistical reasons, but in other instances, it was attributable to the individuals' preferences, as exemplified by Leticia: "I always like doing stuff with my family. I don't really like doing anything by myself. It's rare the time when I'm doing something by myself."

Participants frequently reported being more likely to exercise if they had someone with whom to share this activity.

Jorge: I just really enjoy going [to the gym]. Like, I have my friend. She goes with me. My cousin goes. Another friend sometimes goes... I would go on my own, yeah, but it is a lot easier to have someone. ... It's just like, it makes time go faster. It's motivation, kind of like, "Oh, you have to go because they want to go." Or, "Oh, yeah, we're all going."

When an activity partner became unavailable, it could derail efforts to exercise for lengthy periods of time, as illustrated by a participant who did not anticipate exercising until her walking partner, who was pregnant, had her baby:

[Interviewer: Why do you think it was that you weren't walking, or doing other exercise, then?] Leticia: Well, no one wanted to, and since my sister-in-law, she didn't even know she was pregnant, and now she's huge. And she gets tired if she hurts right here or something, so now I can't. ... Maybe when she's not pregnant anymore and she has to walk, then I'll take her with me.

The theme of "doing with" also related to food choices, as illustrated in the quotation from Javier in the previous section, who described being more likely to dismiss his diabetes as guiding his food choices when eating out with his dad. The timing of meals was also influenced by others, as Erica and her husband discussed:

Erica: Right now I'm still kind of on a diet. I don't eat that much during the day. He always tells me, why don't you eat? No, I don't eat because I wasn't hungry.

Erica's husband: It's better to eat in the day than it is at night. In the day you burn more calories and then in the night don't eat anything. But you are in reverse—like a vampire.

Erica: Well, yeah sometimes I'll eat in the night—when he comes I'll eat with him. I'll eat what I didn't eat through the whole day.

Shaping Knowledge and Expectations

This theme describes how YAs' observations of how others manage their diabetes influence their knowledge and expectations regarding diabetes. This theme is divided into 2 subthemes: future expectations and persistence of misinformation.

Future expectations—The first subtheme describes how witnessing others' health problems first-hand shapes expectations for the future for YAs with diabetes. Observing their family members' struggles led some YAs to fear diabetes and wonder whether they would ultimately experience the same fate:

Pamela: When they told me "you have to take [diabetes] pills," I couldn't accept it. I'm like, no. [Interviewer: What was it about pills that you don't want to do?] I didn't want to take the diabetes pills. [Interviewer: Why?] Because—well, I've seen my parents, like—and I don't want to end up like that.

In other cases, it was not direct observations of living family members that produced fear but stories of grandparents or others who had passed away from diabetes complications:

Jorge: My grandpa had it. He never took care of it, so they had to amputate both his legs, and he eventually died of having diabetes [Interviewer: So, when they told you that you had diabetes, what kind of things did you think about?] I was thinking, “What am I going to do now? This is the worst thing that could happen to me. Why me?”

Leticia’s mother: [My father] was used to the way he ate and didn’t change anything, and then he would say “I’m going to die of something someday anyway” and he didn’t try to take care of himself. People here semi take care of themselves. I’m not saying that we do everything right; at least, I’m not able to do so. I try [laughs], but sometimes I can’t.

Additionally, there was a perception among YA participants that diabetes was “for old people” or that their diagnoses came at a time out of sync with their expectations, changing how they imagined their future. Because many YA participants were diagnosed with diabetes at significantly younger ages than their parents or grandparents had been, they expressed concern about whether they would experience health problems earlier in life:

Erica: I was finding it pretty hard. . . . [My mom is] diabetic and I just look better and, my mom—my mom was, whoa. And, I looked at her and I was, like, “What is my life going to be like 20 years from now? Am I going to be the same as my mom or worse?” That would be my thinking. . . . I was scared and, at the same time, I would feel down. I feel like, “What’s going to go on with my life? Is it going to be the same as before?”

In other instances, YAs responded to their diabetes diagnoses with complacency because they did not have the same outward symptoms or health problems as family members. They interpreted this absence of symptoms as meaning that their diabetes was less severe and did not require the kind of proactive management that they saw as appropriate for people who had more advanced disease:

Javier: I don’t feel sick or nothing, but people say—like my parents say that I look sick, but I don’t feel sick. [Interviewer: So, what do you think it means to have diabetes? How do you think someone feels?] I don’t know, like how I see my parents, they feel something, like headaches, sick, all broken down, but I don’t know, I don’t feel that.

In some families, diabetes was so prevalent that it was viewed as inevitable. Therefore, family members encouraged acceptance and reinforced the normality of developing diabetes. As Erica shared, “Sometimes my mom tells me, ‘Don’t get sad.’ Like, you know, ‘Everybody’s diabetic. We are all gonna get diabetic these days. Sooner or later, you’re not sure when.’”

Persistence of misinformation—The second subtheme describes how family members share information and misinformation regarding diabetes, leading, at times, to untrue and potentially damaging misinformation that persists within a family. Misunderstandings regarding nutrition were frequently expressed, in particular the carbohydrate content of particular foods. One YA participant with an infant son illustrated how such

misunderstandings (specifically, regarding the sugar content of different beverage choices) can shape behavior across generations:

Erica: [My husband and I] are both losing weight. Whatever we eat, we kind of—we try not to eat a lot of bread. We try not to drink soda. We'd rather make Kool Aid or *agua fresca*. [Interviewer: *Or agua fresca?*] Yeah. That's what I give [the baby]. Sometimes I give that to [him] in his sippy cup, *agua fresca*. He likes that. He likes watermelon water, or strawberry water.

In addition to misconceptions about nutrition, misunderstandings of diabetes were frequent. Participants sometimes classified diabetes according to treatments or complications. For example, people on insulin, or who had complications, had “bad” diabetes, whereas those who only took oral medications had “good” or “normal” diabetes. However, as in the below example, even those with “normal” diabetes could experience sequelae such as delayed healing:

Javier: My mom, every time she gets a cut, it doesn't heal as fast as when it was normal or healthy. ... I've seen it on her and my dad. [Interviewer: *Because they're both diabetic, right?*] Yeah. They got the same as me, type—not the bad one, the normal one. ... My uncles have the—one has the bad one. [Interviewer: *When you say the bad one, what do you mean?*] I heard the one that we have, it's not as bad as the other one. The other one gets you more sick. You have more problems. ... My uncle is always in the hospital.

Miscarried Helping

This theme describes circumstances in which a family member tries to support the YA with diabetes but does so in such a way that produces negative consequences, such as frustration or conflict. One example of miscarried helping was parents' nagging or warnings of future health problems, without specific suggestions on how to avoid those problems. This often led to anxiety or confusion on the part of the YAs, as when Francisco articulated,

My dad, he tells me like, oh, try not to eat a lot, and this and that, and your mother, she's going blind, and be careful. He talks about it. I get scared. Like I said, it's hard to be on a diet.

Miscarried helping also took the form of overprotection. Jorge's cousin described how he and Jorge had stopped participating in a physical activity that they had previously enjoyed together:

Jorge's cousin: [After Jorge was diagnosed] there would be certain things we wouldn't really do. [Interviewer: *Like what?*] Like before, we would do all kinds of crazy things, you know? We would be on a bike, or whatever—anything before. And then after we found—after, it's, like, “Oh, well, we can't do it because if you hurt yourself, you could go to the hospital and it could be bad.”

Another form of miscarried helping was mixed messages. In some instances, this took the form of incongruence between an SS participant's advice and his or her own behavior. Other times, mixed messages were conveyed through enabling a “forbidden” behavior, followed by scolding when the YA carried out the behavior, as Leticia shared: “My mom, she's like,

‘Oh, just get [a Frappuccino].’ But then she’ll be like, ‘You shouldn’t ever drink that.’ [Interviewer: *After you finish it?*] Yeah, after.” Finally, tough love was a strategy enacted by some family members, as in the following example. This approach produced hurt feelings and a lack of trust among family members:

Erica: [When I was first diagnosed], I wouldn’t eat. I would just be locked up in my room. ... My mom would be like, “Let her eat whatever she wants.” I’m telling you, my mom is really hard. She’s hard with us and my dad’s not. My dad’s sweet. ... [My mom said] “Well, it’s going to be on her. If she wants to die, she’s going to die.”

Parents’ efforts to support their YA children were often fraught. For example, Javier did not articulate many details about how his mother provides support, but his mother provided a rich description regarding her efforts to encourage her son to care for himself and the difficulty she experiences in doing so:

Javier: She just tells me, like, to take care of [my diabetes] because it will affect me later on in life.

Javier’s mother: Sometimes I talk to him about it and he says, “Enough, Mom, enough.” And so I stop because if not, we’ll start to fight. [Interviewer: *Do you fight a lot over this?*] Sometimes yes, when I tell him things or make him see things. He doesn’t like that I tell him anything. He gets mad and says, “Enough mom, don’t tell me anything” and so I don’t tell him anything. ... It’s not the same as when he was little and I told him, “You’re going to eat this because you have to eat it.” He’s 20, and I can’t tell him, “You have to eat this.” I can serve him, but if he doesn’t like it, he won’t eat it.

Reciprocal Support

This theme describes the exchange of diabetes-related SS across generations. Support was not only provided from parent to child; YAs shared many examples of supporting their parents or family members with diabetes. In instances in which parents and children shared a diagnosis of diabetes, their support of one another included emotional support, informational support, and instrumental support:

Leticia: I learned [from] my mom, as well. When she tells me stuff, I’m like, “Oh, I didn’t know that.” Okay, now I know. Or I tell her stuff at the doctor, and she’s like, “Over my 24 years of diabetes, I didn’t know.” [Interviewer: *So, you guys share information.*] Yeah, we tell each other, “Okay, this could help us out.” I put the paper on the refrigerator. Okay, this is how our meals are going to be.” Yeah, but she’s always been there.

Pamela’s mother: Since my husband and I are diabetic, we told [Pamela] for her own good that she needed to do more exercise ... because she is the product of two diabetic parents. ... And yes, since the time they diagnosed her, she started walking with her father. They walk for about an hour or half hour daily, daily, daily.

Sometimes children sought to help their parents with diabetes but encountered resistance. YAs who had made healthful lifestyle changes for themselves felt frustrated by their inability to facilitate similar changes for family members:

Pamela: I started changing my [diet]—like eating salads. ... I would [tell my mom], eat some of it, but she would eat, like, small portions of it. Like if I make a salad for me and my dad, she will only take a little bit. ... It makes me want to tell her, you—that's what's getting you to the hospital, and that's what's getting you worse and worse and worse. But I don't really want to be that mean.

At times, the emotional and instrumental support that participants provided to their family members interfered with their own diabetes care:

Leticia: [My mom] has her good and her bad days. We just don't like those bad days. She just—she sleeps a lot, like she's really, really tired. ... I took my mom to the emergency room and I saw one of the nurses. She was like, "How come you haven't gone [to your appointment]?" I was like, "Because it's either I'm working or I take my mom to the doctor." I was like, "I could wait. My mom is really, really ill so I prefer her going instead of me." [The nurse] said, "Just take care of your mom."

Family members' investment in each other's health served as a source of emotional highs and lows. When Pamela succeeded in controlling her diabetes to the point at which her physician discontinued her oral medication, it inspired the rest of her family:

Pamela: They were really excited for me. They were really happy. ... Right after I got out of the appointment I'm like, "Guess what? They took me off the pills." [My dad] got all happy for me. Then when I got home he gave me a hug and stuff. ... My sister was like, "If you got off the pills I can get off the pills too."

The family's investment in each other could be a source of significant worry and concern. This occurred in both directions: the parent worrying about a child with diabetes, and the child worrying about a parent with diabetes:

Jorge. The faster I lose weight, the faster I can get off medication, control my diabetes, and not have my parents worry about me all the time. My dad is always worrying, trying to get me to do exercise. Worrying just all the time. ... I don't want him to always just be thinking about me like that. I just want him to be able to relax.

Discussion

In 2004, Scollan-Koliopoulos^{38(p223)} noted that "it is possible that [health care providers] will care for entire families with diabetes in the near future." Among the families in this study, this future has materialized. As illustrated in this article, understanding the family context of a person with diabetes has the potential to shed significant light on the mind-set and strategies an individual is likely to use in managing his or her diabetes.

Although the identified themes were presented separately in this article for clarity, in the lives of participants, these themes interacted to influence participants' beliefs and behaviors

regarding diabetes. For example, the themes of future expectations and persistence of misinformation were often compounded, in the sense that participants had inaccurate ideas of what to expect in the course of having diabetes. YAs frequently expressed that their ongoing diabetes care was less urgent or important than that of older family members who were experiencing complications, because they had “good” or “normal” diabetes or did not physically feel ill. This lack of urgency manifested in the YAs’ being relatively unconcerned about missing doctors’ appointments, running out of medications, or failing to adhere to other diabetes self-care recommendations.

An alternate explanation for YAs’ lack of urgency is that it is an adaptive strategy of accepting diabetes and its complications. It is possible, as discussed by Scollan-Koliopoulos et al.,²⁴ that knowing previous generations’ health history can lead to a fatalistic mind-set among people with family histories of diabetes. Because diabetes care has improved greatly in recent decades, it is possible that young people with diabetes have an unnecessarily pessimistic view of the future, shaped by knowledge of diabetes complications experienced by their parents or grandparents. Fatalism has also been identified as a prevalent outlook among Hispanic Americans, attributed to religious and cultural beliefs but also to structural inequalities and socioeconomic circumstances that limit resources and opportunities to pursue health goals.^{39,40} A challenge in this context is that fatalism may create a self-fulfilling prophecy, wherein accepting diabetes complications causes YAs to be complacent in their diabetes care, which in turn leads to poor glycemic control and a high risk for developing complications.

A limitation of this study was the strategy of assessing diabetes prevalence among families through interviews with the YA participants. This may have inaccuracies (either over- or underreporting), because of YAs’ incomplete knowledge or recall errors. However, the YA participants’ reports are likely to accurately reflect their *awareness* of diabetes and related complications in their families, which is probably a more significant influence on their diabetes care than the family members’ actual medical histories. An additional limitation of the study is generalizability. The sample was recruited from public health care facilities in urban Los Angeles and was limited to Hispanic and Latino participants, many of whom were first- or second-generation immigrants. Therefore, these findings are most likely to be applicable to populations with similar demographic profiles.

Implications for Diabetes Educators

Cohabiting families with diabetes have a high likelihood of influencing one another’s knowledge, beliefs, and behaviors related to diabetes, which often depart from current medical understandings and the standard of care for diabetes. Young people with T2DM are especially likely to have prior exposure to the disease through family members, and their understanding of diabetes is likely to be shaped by this exposure before they are diagnosed with the disease. Understanding how family members of a newly diagnosed young person with T2DM manage the disease may be a critically important opportunity to correct potentially damaging misunderstandings of the disease. Additionally, this issue is an important consideration when developing interventions to improve diabetes management in this population; family-based interventions that address the health beliefs and self-care

practices of the family unit may be more efficacious than interventions aimed at individuals. Further research is needed to better understand how such a “living legacy” of diabetes shapes self-care among both younger and older generations with diabetes and the implications for clinical care among this population.

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Table 1**Sample Interview Guide Questions**

Everyday habits, routines, and lifestyle

What activities do you typically participate in (such as work, school, housework, childcare)?

What are your most valued activities—the things you love to do?

How do you feel about the balance of activities in your life—such as work, school, household responsibilities, and things you do for fun?

Walk me through what you did on a recent day, from morning until bedtime. What did you do? Were these the kinds of things you usually do or was this day different?

[SS interviews] How often are you and [YA] together? What kinds of things do you do with [YA]?

Family and social engagement

What are your most important relationships—friends as well as family members?

Who do you currently live with? Tell me about the people in your household.

What kinds of things do you do to help the important people in your life? How do they help you?

[YA] How does your family influence how you take care of your diabetes?

[SS] Do you think you have influenced how [YA] manages his/her diabetes? How so?

Diabetes management

Tell me the story of when [you/YA] were first diagnosed with diabetes.

How have [you/YA] taken care of diabetes in the past? How [do you/does YA] take care of it now?

Can you tell me about a time when [you/YA] had trouble taking care of diabetes? What happened?

[SS interviews] How is your health now? [If SS has diabetes, follow up with YA diabetes management questions.]

Illness beliefs

What do you think causes diabetes? How did [you/YA] get it?

What do you think will happen as [you/YA] gets older with diabetes?

When you compare what you have been taught about diabetes, and what you have experienced in everyday life, what is the same? What is different?

Table 2

Young Adult Participant Demographics

Variable	Value
Age (y)	20.6 ± 3.5
Age at diagnosis (y)	16.8 ± 3.0
Duration of diabetes (y)	3.9 ± 4.8
A1C (%)	7.4 ± 1.7
Female/male	5/3
Treatment regimen	
Metformin only	3 (37.5%)
Metformin and sulfonylurea	1 (12.5%)
Metformin and basal insulin	2 (25%)
Basal and bolus insulin	2 (25%)

Table 3

YA Participants' Family Histories of Diabetes

Pseudonym	Parents With Diabetes	Siblings With Diabetes	Other Relatives With Diabetes	Family Members' Health Status
Erica	Yes: one	No	Uncle	No known diabetes complications
Francisco	Yes: both	Yes	Grandparent, aunt	Parent 1 reports high blood glucose Parent 2 has vision problems
Javier	Yes: both	No	Aunts and uncles	Parent 1 reports high blood glucose Both parents on insulin
Jorge	No	No	Grandparent	Grandparent died from diabetes complications
Leticia	Yes: both	Yes	Grandparents	Parent 1 has renal failure Grandparents died from diabetes complications
Marta	Yes: one	No	Grandparent	No known diabetes complications
Pamela	Yes: both	Yes	Grandparent	Parent 1 had lower-extremity amputation Parent 2 had kidney transplantation after dialysis Grandparent "had diabetes and would sometimes get very sick"
Vanessa	Yes: both	Yes	Grandparent	Parent 1 has vision problems