ORIGINAL RESEARCH

All in the Family: A Qualitative Study of the Early Experiences of Adults with Younger Onset Type 2 **Diabetes**

Anjali Gopalan, MD, MS, Maruta A. Blatchins, BS, Karen K. Xu, BS, Andrea Altschuler, PhD, Cassondra J. Marshall, DrPH, MPH, Danielle M. Hessler, PhD, Alicia Fernandez, MD, and Richard W. Grant, MD, MPH

Objective: Adults with type 2 diabetes diagnosed at a younger age are at increased risk for poor outcomes. We examined life stage-related facilitators and barriers to early self-management among younger adults with newly diagnosed type 2 diabetes.

Research Design and Methods: We conducted 6 focus groups that each met twice between November 2017 and May 2018. Participants (n = 41) were aged 21 to 44 years and diagnosed with type 2 diabetes during the prior 2 years. Transcripts were coded using thematic analysis and themes were mapped to the Capability-Opportunity-Motivation-Behavior framework.

Results: Participants were $38.4 (\pm 5.8)$ years old; 10 self-identified as Latinx, 12 as Black, 12 as White, and 7 as multiple or other races. We identified 9 themes that fell into 2 categories: (1) the impact of having an adult family member with diabetes, and (2) the role of nonadult children. Family members with diabetes served as both positive and negative role models, and, for some, personal familiarity with the disease made adjusting to the diagnosis easier. Children facilitated their parents' self-management by supporting self-management activities and motivating their parents to remain healthy. However, the stress and time demands resulting from parental responsibilities and the tendency to prioritize children's needs were perceived as barriers to self-management.

Conclusions: Our results highlight how the life position of younger-onset individuals with type 2 diabetes influences their early experiences. Proactively addressing perceived barriers to and facilitators of self-management in the context of family history and parenthood may aid in efforts to support these high-risk, younger patients. (J Am Board Fam Med 2022;35:341–351.)

Keywords: Age of Onset, Focus Groups, Motivation, Parenting, Qualitative Research, Self-Management, Type 2 **Diabetes Mellitus**

Introduction

A growing number of individuals are being diagnosed with type 2 diabetes at a younger age and are at increased risk for disease-related micro- and macrovascular complications. 1-3 Concerningly, racial/ethnic minorities are disproportionately impacted by the onset of type 2 diabetes at a younger age. While differences

This article was externally peer reviewed.

Submitted 26 May 2021; revised 19 July 2021 and 17 September 2021; accepted 5 October 2021.

From the Kaiser Permanente Northern California, Division of Research, Oakland, CA (AG, MAB, KKX, AA, and RWG); University of California, Berkeley, Division of Community Health Science, Berkeley, CA (CJM); University of California San Francisco (DMH and AF).

Funding: AG was supported by a National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) grant, K23DK116968, and a Kaiser Permanente Northern California Health Policy and Disparities Research Award. RWG had support from an NIDDK grant, K24DK109114. AF was supported in part by an NIDDK award, K24DK102057. The funders had no role in the design and conduct of the study, the

completed analysis, data interpretation, or the content of the manuscript.

Conflict of interest: No potential conflicts of interest relevant to this article were reported.

IRB: This work was approved by the Kaiser Permanente Northern California Institutional Keview Board.

Prior/pending presentations: Parts of this study were presented in abstract form at the 2021 Society of General Internal Medicine California-Hawaii Regional Meeting. Parts of this study will be presented in abstract form at the upcoming 2021 American Diabetes Association Scientific Sessions.

Corresponding author: Anjali Gopalan, 2000 Broadway, Oakland, CA 94612 (E-mail: Anjali. Gopalan@kp.org).

in underlying disease physiology and the prolonged duration of diabetes contribute to this higher complication risk, younger-onset individuals (defined as <45 years) are also less likely to achieve key disease management targets, including those for HbA1c, blood pressure, and lipid control, even after adjustment for race/ethnicity.^{5,6} Age-related disparities in achieving glycemic goals are apparent within a year of diagnosis, with younger-onset individuals significantly less likely to achieve early glycemic control.4 This early difference warrants further exploration given the lasting benefits conferred by optimal early glycemic control (the so-called "Legacy Effect").7,8

Early age-related differences in glycemic control likely reflect the additional and often unique disease-related challenges faced by younger individuals. Younger-onset individuals have higher HbA1c values at diagnosis, a greater prevalence of obesity, and higher smoking rates.^{4,9} Prior research, not specific to newly diagnosed individuals, has shown that younger age at diabetes onset is also associated with higher prevalence of depression, greater diabetes distress, poorer diet, and lower diabetes self-efficacy. 10,11 Insights from human development may shed additional light on how type 2 diabetes selfmanagement—defined as the behaviors a person undertakes to care for diabetes (eg, diet, taking medications)—differs for younger adults compared with middle-aged and elderly individuals.

Adults in their 20s to early 40s are more likely to be balancing diabetes self-management with other ageappropriate endeavors, such as establishing careers, forming intimate relationships, family planning, and parenting nonadult children. 11,12 Prior work has examined the relationship between type 1 diabetes self-management and life stage and noted that many younger adults struggle to balance selfcare with life stage-related demands, such as work. 13,14 Prior interventions for adults with type 1 diabetes have incorporated insights regarding life stage-specific challenges into their designs. 15 However, similar interventions for younger adults newly diagnosed with type 2 diabetes are lacking because of the paucity of research to inform such approaches.

We conducted focus groups with younger adults recently diagnosed with type 2 diabetes to learn about barriers and facilitators to early self-management that may be distinct to the life stage of this younger population to inform the development of tailored initial type 2 diabetes care strategies. We mapped the identified barriers and facilitators to the domains of the

Capability-Opportunity-Motivation-Behavior (COM-B) framework, a well-recognized model whose premise is that behavior reflects the interactions between an individual's capability, opportunity, and motivation.¹⁶ This framework has successfully been used to inform the development of targeted and tailored interventions in a variety of settings. 17,18

Methods

Design and Study Setting

We conducted 6 focus groups with adults with younger-onset type 2 diabetes (defined as <45 years old at diagnosis). The number of groups was decided a priori based on prior research, with the option retained to conduct additional groups if needed.¹⁹ We chose focus groups to capture a greater range of perspectives and enrich the collected data via participant interactions.^{20,21} Participants were members of a large, integrated health care delivery system and the study was approved by the local Institutional Review Board. Participants provided written informed consent and received a \$40 gift card after each meeting.

Participants

Using electronic health record (EHR) data, we identified Latinx, Black, and White individuals residing in 2 disparate geographic areas in California (1 predominantly urban [East Bay] and 1 traditionally agricultural [Central Valley]). We focused on these racial/ethnic groups based on local demographics and previously established racial/ethnic differences in type 2 diabetes outcomes.²² All individuals were diagnosed with type 2 diabetes during the prior 2 years and were 21 to 44 years old at the time of diagnosis. We used 2 years to define the "early" period following diagnosis to balance the time needed to experience initial diabetes self-management with the ability to still recall these events.²³ Further, this look-back period is similar to those used in prior qualitative studies that asked participants to recount past experiences receiving a significant medical diagnosis or making health-related behavior changes.^{24–26} We selected this age cutoff based on the American Diabetes Association's recommendation to begin routine diabetes screening at age 45. We excluded non-English proficient individuals and those who had gestational or type 1 diabetes (identified via validated algorithms).^{27,28}

In accordance with our IRB's requirements, we obtained primary care provider (PCP) approval before contacting eligible participants to exclude

individuals not suitable for participation (eg, significant cognitive impairment, severe acute illness). We then mailed the remaining eligible individuals a letter that included details on declining participation. Individuals who did not opt-out were called, starting with individuals diagnosed most recently. Each focus group was assembled based on the EHR-reported race/ethnicity and geographic area of interested individuals, with a goal of 6 to 8 participants per group. This group composition strategy was based on evidence that individuals with more shared experiences may communicate more openly with 1 another.^{29,30}

Focus Group Procedures

The focus groups were conducted between November 2017 and May 2018 and led by an experienced moderator (AA, female, sociologist) with whom participants had no prior relationship. MAB, a research associate, and AG, the principal investigator, took field notes. Meetings were held in a conference room within a medical facility that was local to each of the 2 regions.

At the start of the meetings, the moderator discussed confidentiality and group etiquette (eg, listening respectfully without interrupting). Following the focus group guide, the moderator asked participants to describe how a typical day has changed since they were diagnosed, the challenges they have encountered with type 2 diabetes self-management, and things that have helped or hindered their ability to cope with these challenges. The moderator prompted further details or asked the group for thoughts, as appropriate. All participants were given the opportunity to respond to each question, but individuals were not required to share. Each focus group met for 2 60- to 90-minute meetings, held 2 weeks apart, to enhance the depth and credibility of findings (12 total sessions).³¹ The second meetings were used to revisit topics raised during the first meetings (prompted by moderator or participants) and provided participants an opportunity to correct or clarify observations recounted by the research team regarding the first meeting. No changes were made to the guide over time. Individuals who only attended the second meeting were still given the opportunity to answer the questions related to the changes and challenges they experienced. All participants completed a short questionnaire to collect demographic information. Audio-recordings of the meetings were transcribed verbatim by a professional service; participants did not review transcripts.

Team members who attended all focus group meetings (AA, MAB, AG) met throughout the process to review field notes and discuss preliminary themes. Following the final 2 meetings, all agreed that thematic saturation was achieved, and additional focus groups were not needed. The transcripts were analyzed inductively and deductively using a thematic analysis approach.³² To minimize issues with selection bias and capture the full range of participant perspectives, we analyzed responses from all participants, including those who only attended 1 focus group meeting. Two coders (MAB, AG) read the transcripts twice. The coders met regularly to compare coding and resolved discrepancies through discussion leading to consensus. Codes were organized into themes. The themes were categorized as perceived facilitators of or barriers to type 2 diabetes self-management. Based on existing literature (not specific to younger-onset type 2 diabetes), clinical experience, and group discussion, we distinguished themes that likely reflected the distinct experiences of younger-onset individuals (eg, difficulty finding time to exercise in general vs difficulty finding time to exercise because of life stage-related barrier).^{33–36} Finally, the team mapped each theme to the COM-B framework (eg, was the theme related to individuals' capability, opportunity, or motivation for self-management?). 16 NVivo Qualitative Analysis Software (QSR International Pty. Ltd, Version 11, 2015) was used to support the analysis. Participants did not provide feedback on the codebook or identified themes.

Results

Of the 514 potentially eligible individuals identified, we called 304 regarding participation (210 were not called due to PCP disapproval [5], missing address [2], or target sample already recruited [203]). Of those called, 63 (20.7%) agreed to participate (others not interested/available [85], did not meet eligibility criteria [13], or were not reachable via phone [143]). Individuals who were not called because the sample was recruited (n = 203) did not differ by race/ethnicity from those who were called, but were more likely to be men (60% vs 50.3%) and had an average age of 39.1 (compared with 37.6 years for those called). A total of 41 individuals attended at least 1 focus group meeting, and 31 attended both (Table 1). Each of the group meetings was lively, interactive, and respectful. Among participants, 27 (66%) mentioned a history of type

Table 1. Focus Group Participant Characteristics (n = 41)

Characteristic	n (%)
Age, mean (SD)	38.4 (5.8)
Gender	
Male	21 (51)
Female	20 (49)
Ethnicity/race*	
Latinx	10 (24)
Black	12 (29)
White	12 (29)
Multiple/other	7 (17)
Academic attainment	
Less than high school	2 (5)
High school graduate or GED	8 (20)
Some college	8 (20)
2-year college	10 (24)
4-year college	6 (15)
Master's degree or higher	7 (17)
At least one family member with diabetes	27 (66)
At least one child <18 years at home (% yes)	24 (59)
Diagnosis HbA1c, mean (SD)	8.1 (2.0)
Pre-focus group HbA1c, mean (SD)	7 (1.7)
Pre-focus group HbA1c < 7% (% yes)	16 (39%)

^{*}Self-reported on survey administered during focus group meeting

2 diabetes in a biologic relative (parent, grandparent, sibling) or other adult family member (stepparent, spouse), and 59% reported having a least 1 child less than 18 years old.

We identified 9 themes that fell into 2 primary categories: (1) The influence of a family history of type 2 diabetes on self-management (3 themes), and (2) The role of nonadult children in their parents' type 2 diabetes self-management (6 themes) (Tables 2 and 3). For each theme, we include in parentheses (1) whether the identified theme was classified as a facilitator or barrier to early type 2 diabetes self-management, and (2) which COM-B domain (capability, opportunity, or motivation) the barrier or facilitator reflected.

A Family History of Type 2 Diabetes

Theme 1: Knowledge about type 2 diabetes gained from observing or speaking with family members (facilitator; COM-B domain: capability)

Having a family history of type 2 diabetes influenced participants' perceived capability for self-management because exposure to family members'

diabetes experiences made participants feel familiar with the diagnosis and necessary behavior changes. As 1 participant described, "My mom's a diabetic, so I was already kind of familiar with a lot of adjustments that I could make...so it was not a hard transition." (Participant [P] 20)

Older relatives with type 2 diabetes were further perceived as supporting participants' self-management capability by providing advice and tips regarding self-management. This guidance was distinct from other, more tangible self-management support provided by family members (eg, spouse cooking diabetes-appropriate meals) as it was directly rooted in these older relatives' personal type 2 diabetes experiences. One participant recounted his mother's reaction and advice on learning of his diagnosis and HbA1c value: "when [my mother] found out, she told me, she said, 'That is nothing.' She's like—'you know, your dad was this. You know, I am this'...she's like, 'That is nothing like compared with what it could be'. . And then she kind of gave me some ideas." (P18)

Theme 2: The diabetes-related experiences of older relatives (facilitator; COM-B domain: motivation)

The positive type 2 diabetes experiences and health outcomes of older relatives influenced participants' motivation for self-management. Some participants described parents or older relatives with type 2 diabetes who had maintained good health into their 80s and 90s and viewed these individuals as role models or reasons to be hopeful. They cited the active self-management efforts of such individuals and stated that the positive outcomes of these individuals encouraged them to adhere to their diabetes management behaviors. A participant described being driven to remain active and eat healthily based on his grandmother and great-grandmother's longevity, stating "My grandmother's still living. She's 91, she has diabetes. And my great-grandmother had diabetes and she did not take insulin or medicine. She kept just regular by walking and eating healthy." (P9)

In contrast, a number of participants cited devastating type 2 diabetes-related health complications experienced by family members, including death and end stage renal disease. These participants saw the adverse outcomes experienced by their older relatives as cautionary tales that motivated their type 2 diabetes management efforts. A participant

Abbreviations: SD, standard deviation; GED, General Education Development.

Table 2. The Influence of Family History of Type 2 Diabetes on Early Self-Management

	Themes	Representative Quotes	Mapping to COM-B
Perceived facilitators	Knowledge about type 2 diabetes from observing or speaking with family members	I guess I didn't feel overwhelmed because I've been around it so much with my parents and my siblings. So, a lot of the terminology, I was already familiar with. (Participant [P] 6) [My dad] was telling me you need to do everything that you can to avoid getting full-blown diabetesyou need to get more exercise, overhaul your diet right now. (P38)	Capability
	2. The diabetes-related experiences of older relatives	my mom's the one who start telling meshe was about 40 years old when she had diabetes, so she's now 80She never like, "Have to go to the hospital for this or need glasses, or need" I mean, she's healthier than me. (P3) I have that in mind, my great-grandfatherHe lived to be 97. Small, frequent meals walk two to three times a dayThat's what I'm gonna keep doing until I die. (P12) I really thought about doing the weight loss surgery, you know, because once I hear "diabetes"—my dad died from diabetes and I kinda got scared. (P1) [My mom] said that I was going to be fine, that I was young, that I could take control of it she just told me to take care of myself so I wouldn't end up like her. (P4)	Motivation
Perceived barriers	3. Futility/inevitability related to family history of type 2 diabetes	[My brother] said, "You knew this was coming, right?"And I was like, "Yeah. I mean I knew, but, you know, I was trying to avoid it." (P18) [type 2 diabetes] runs on both sides. So, I'm screwed. (P34)	Motivation

Abbreviations: SD, standard deviation; GED, General Education Development.

describing his desire to avoid the adverse outcomes experienced by his mother stated, "So now what am I going to do to not be like my mom?...she never took care of it, so she has a lot of other health issues related to diabetes, and I did not want to be in her shoes." (P4)

Theme 3: Futility/inevitability related to family history of type 2 diabetes (barrier; COM-B domain: motivation)

Among those with a family history of type 2 diabetes, several participants, including some who also cited a family history as a facilitator of their self-management capability, perceived this history as a barrier to optimal self-management via its impact on motivation. For these individuals, their motivation for initial self-care was impeded by the feeling that, given their family history, a type 2 diabetes diagnosis was inevitable. This perceived lack of control over developing type 2 diabetes led to feelings of futility regarding self-management efforts. As 1 participant described, "...I also just ended up feeling like it is hopeless. You know, [my father's] diabetic. My

grandmother on his side was diabetic. I am going to end up there no matter what I do...Which gave me a reason not to try." (P38)

The Role of Nonadult Children in Parent's Type 2 Diabetes Self-Management

Theme 1: Children provide encouragement, support self-management, and easily adapt to household changes (facilitator; COM-B domain: opportunity)

Some participants described being urged by their children to take care of themselves so that they would be present for future life events and not develop disease-related complications like their parents or older relatives with type 2 diabetes. Recounting her children's urgings, 1 participant stated, "...they are like, 'Mom, you cannot be like grandma' ... mom was like so extreme like not taking care of herself. She was almost blind and [on] dialysis..." (P24)

Several participants reported that their children were actively involved in their self-management. For example, some children decided to make the

Table 3. The Role of Children in Parents' Type 2 Diabetes Self-Management

	Theme	Representative Quotes	Mapping to COM-B
Perceived Facilitators	Children provide encouragement, directly support self-management activities, and easily adapt to household changes	[My kids] they tell me, too, "Daddyyou need to take care of yourself because I want you to walk me down the aisle." (Participant [P] 7)my daughter "dad, you can't get that. You can't eat that." (P25) If I bring any kind of sweets in the house, [my son] call his self saving me by eating it up. (P26) But like when I buy healthy stuff my daughter is like so into itI'll buy like yogurts or fruit, or whatever, salads and she'll say, "Oh, monmy can you buy me some of that?" Like she's interested in eating that other than cookies or ice cream or doughnuts, or stuff like that. I think it's wonderful. (P9)	Opportunity
	Desire to be healthy and present for children	I need to be healthy for my kidswhen I had kids it wasn't like oh, "I want to be the mom who sits in a park and lets my kids go off and play while I sit there and do nothing." (P8) Dude, I cannot let this take me down. I have two children, I gotta be there for both of them. I'm planning on seeing my grandchildren, I'm hoping my greatgransso I gotta handle this myself. (P18)	Motivation
	3. Desire to model healthy behaviors for children and to prevent children from developing diabetes	we walk as a family because I like to teach them, you know, that exercise is – it's good, and it's okay to do it. And I just think it's better when they see me doing it. That way, they start doing it, too. (P4)	
		no candynot in grandma's house. I'm going to give them broccoli, carrots, this and that. But no candy. No sodaI have done so many mistakes raising [my kids]if someone would've came to me and explained to meI would never gave [my kids] all that junk. (P39)	
Perceived Barriers	4. Children do not want to adapt/do not like healthier food	They don't want oatmeal. Well they will, if they put sugar and a whole bunch of crap in there. (P8)	Opportunity
	5. Insufficient time for self- management	And how do you still find time to exercise multiple times per week when you get home from work, you put the baby to sleep, and I'm ready to go to sleep, toobut I still have hours of work (P31) I'm gonna get home and [exercise]And then it never happensI've got the little one, who's running around the houseit's always the thought process and just not following through or not having time. (P19) I have like a relax appsometimes I do put that on and just try to de-stress, but it seems with kids when they see someone sitting and not doing anything (P8)	
	Prioritizing your children's needs over your own	I'm spending all of my time watching out for themI'm already done, that's the way that I see it. (P38) I did make an appointment with a nutritionist, but then in typical mom fashion a kid got sick with asthma, and that becomes a priority (P8)	Motivation

Abbreviation: Capability-Opportunity-Motivation-Behavior (COMB).

same lifestyle changes as their parents, helped with blood glucose measurement, or reminded their parents about what foods they should or should not eat. One participant shared how her children supported her efforts, stating, "My kids decided that they were going to be supporting me and they were going to make the same changes I do...that made me feel so great." (P39)

The adaptability of children to family diet and other lifestyle changes eased their parents' selfmanagement efforts by creating an environment more conducive to these changes. A participant described his child's flexibility, stating, "...my 14year-old daughter...we changed up everything and took the juice out and start adding more water and everything, she just went with the flow." (P19)

Theme 2: Desire to be healthy and present for children (facilitator: COM-B domain: motivation)

Children motivated their parents' type 2 diabetesself management efforts. Many participants described a fervent desire to be healthy and present for their children, both now and into the future. One participant in describing his motivation to take care of his diabetes stated, "...you want to see your grandchildren. You want to see your family...your kids get married and go finish off. Then take your butt to the doctor's yearly." (P40)

A few participants who did not have children also described the possibility of starting a family in the future as motivation to maintain good health. As 1 participant expressed, "...every time I think about just doing anything that I should not be... 'Okay, but you want kids?... Are you gonna be around for those kids?"" (P27)

Theme 3: Desire to model healthy behaviors for children and to prevent children from developing diabetes (facilitator; COM-B domain: motivation)

Several participants felt that by engaging in selfmanagement activities they modeled important healthy behaviors for their children. As 1 participant asserted, taking care of yourself can be teaching them [children] how to take care of themselves." (P31)

Many participants reported being strongly driven by the desire to prevent their children or grandchildren from developing type 2 diabetes and were cognizant of the role that lifestyle changes, like eliminating certain foods or encouraging physical activity, had in mitigating this risk. While the fear of children developing type 2 diabetes was not directly linked to participants' own personal selfcare behaviors, their experiences were colored by this worry. One individual expressed the importance he placed on his children engaging in physical activity, saying, "... I make sure that they are doing their physical and having fun... if not, they are going to have type 2." (P40)

Theme 4. Children do not want to adapt/do not like healthier food (barrier; COM-B domain: opportunity)

Unlike some participants who felt their children's easy adaptability facilitated their self-management, others cited their children's inflexibility as a barrier to their own attempts at self-management. These

struggles centered on food, such as the need to make separate meals for their children or their children's aversion to healthier foods. When discussing the idea that the whole family could eat a "diabetes friendly" diet, 1 participant disagreed, stating, "You know, I've got a family, wife, and 4 kids...the same that you cook for everybody you will be able to eat that, too. Absolutely not." (P38)

Theme 5. Insufficient time for self-management (barrier; COM-B domain: opportunity) Adding type 2 diabetes self-management tasks to their list of daily responsibilities was described by many as unattainable. Some participants explained that even when they attempted to engage in selfcare activities, they were often interrupted by their children. For several participants, there was a sense that success in certain self-care behaviors, like regular exercise or significant weight loss, was less feasible for people with children compared with those without children. One frustrated participant shared, "...I do not exercise...but I am not lazy. I do not sit on my ass. I am like busy... the stress is there. It is totally going to be there I have kids." (P34)

Theme 6. Prioritizing your children's needs over your own (barrier; COM-B domain: motivation)

A number of participants discussed that their tendency to prioritize their children's needs over their own impacted their type 2 diabetes self-management. This manifested in specific events, like missing personal medical appointments when they perceived their children had more pressing issues and, in a more general sense, that their children's well-being was more important than own. One participant described the financial sacrifices he considers to ensure his children remain healthy, stating, "...Dividing your funds to certain things...somebody has to sacrifice...I will sacrifice myself before—for my kids... you know, they are my future...so I want to make sure they go to doctors. They get healthy." (P40)

Discussion

Among adults with younger-onset type 2 diabetes, we found multiple barriers and facilitators to diabetes self-management linked to having a history of type 2 diabetes in family members or having nonadult children. These themes were present across the racially/ethnically and geographically defined

groups, suggesting they cut across these divides. While a family history of diabetes gave some individuals a sense that their situation was inevitable or "hopeless," it also increased self-management capability and motivation for self-care for individuals who reflected on their family experiences with the illness. Children were central to their parents' type 2 diabetes lived experiences and often acted as strong motivators for their parents' self-management. However, the time and priority given to children were also reported as limiting parents' opportunity and motivation for self-care.

Prior work has examined the role of family in type 2 diabetes self-management. However, this work has primarily focused on the family's influence in promoting or deterring specific self-management activities, like adhering to diabetes-specific diet recommendations, and less on how a family history or "legacy" of type 2 diabetes affects the self-care capability or motivation of newly diagnosed individuals.^{37,38} Though some participants described their fears related to family members' negative diabetes experiences as galvanizing, the effectiveness of fear as a motivator of sustained behaviors, like those required of type 2 diabetes self-management, may be limited as fear is a better motivator of single actions than persistent changes.³⁹ Understanding other potential self-management barriers related to a family history is also vital. If the feeling of inevitability regarding the onset of type 2 diabetes becomes a belief that diabetesrelated complications are also inevitable, self-management efforts could be stymied. Prior work has shown that diabetes fatalism, the sense that the course of type 2 diabetes is out of one's own control, is associated with worse self-care, glycemic control, and quality of life. 40 Given the limits of fear-centered motivation and the consequences of diabetes fatalism, care interventions that leverage more positive aspects of a family diabetes history, including a greater baseline of disease-related knowledge and access to the advice and hopeful experiences of older relatives, may hold greater promise.

The role of nonadult children in their parents' type 2 diabetes self-management is largely unexplored. In a 2010 publication, Laroche et al. found that nonadult children supported and hindered their parents' self-care efforts. However, the research focus was more on specific activities, such as assistance with meal preparation, and not on how nonadult children more holistically influence their

parents' diabetes self-management. A recent study on type 1 diabetes found that nonadult children were not involved in their parents' self-care, unsurprising given that type 2 diabetes self-management is arguably more centered on changes that impact the whole family (eg, diet, physical activity) than type 1 diabetes self-management.⁴²

The responsibilities of child-rearing may contribute to the higher diabetes distress seen among individuals with younger-onset type 2 diabetes. ¹¹ Given the links between greater diabetes distress and suboptimal self-care and glycemic control, care strategies that address diabetes distress for these younger-onset individuals with children may facilitate improvements in early self-management efforts and better outcomes. ⁴³

Our results must be interpreted within the context of the study design. The research was conducted in a relatively small sample of insured, English-proficient individuals who were all members of the same health care delivery system. The research team members are all employees of the health care delivery system which could have resulted in some social desirability bias in participants' responses. The study design does not support between-group comparisons based on race/ethnicity or geography. For example, any observed differences may reflect specific group member characteristics and group dynamics rather than race/ethnicity- or geography-based differences. Participants may not be representative of other patients; they may have been more engaged with care or may have had specific care experiences that motivated study participation. Our lower recruitment rate may reflect distinct characteristics of participants (eg, different work schedules, available childcare). Not all participants had a type 2 diabetes family history or children; still the themes noted were present in all groups. Finally, the focus groups were conducted pre-COVID; thus, we cannot comment on the potential influence of the pandemic on early self-management experiences.

Conclusions

Individuals with younger-onset type 2 diabetes may represent a "sandwich" generation whose disease self-management may be simultaneously influenced by their family's prior diabetes experiences and by the specter of diabetes in their children.

Understanding the context in which these individuals navigate a new type 2 diabetes diagnosis can inform tailored diabetes care strategies. These strategies can begin with the disclosure of the diagnosis. 44 For instance, initial diagnosis disclosure conversations for individuals with significant family experiences can dispel myths about the inevitability of disease-related complications, highlight treatment advancements, build patients' self-efficacy, and emphasize the possibility of preventing diabetes in subsequent generations (supporting capability and motivation). Strategies to ameliorate diabetes distress triggered by the struggle to balance self-care and the time demands of parenting include choosing treatment regimens that minimize treatment burden (eg, minimizing selfmonitoring of blood sugars) and identifying or creating health system- and community-based self-management resources that address the needs of the racially/ethnically diverse younger-onset population (eg, convenient times and locations, low- or no-cost, culturally responsive approaches, onsite childcare, inclusion of family and friends, community health workers/care navigators; increasing opportunity). 45,46 Interventions that acknowledge that parents may be more driven by their children's health and future diabetes risk may hold potential for shifting behaviors in this patient population (leveraging motivation and increasing opportunity). Examples include public health and health system interventions targeting high-risk families (eg, adults with diabetes, prediabetes, or a history of gestational diabetes) that promote healthy behaviors in both adults and their children and care strategies linking parents' diabetes care (eg, HbA1c testing) with their children's well-child visits.

Individuals with type 2 diabetes diagnosed at a younger age represent a distinct population with unique care needs. In addition to medical needs, health care providers and systems need to consider this population's distinct social and emotional needs.² Recognizing the family and life context in which these individuals receive this life-altering, chronic diagnosis can inform more tailored and effective type 2 diabetes care strategies and potentially improve the illness course of this high-risk patient population.

To see this article online, please go to: http://jabfm.org/content/ 35/2/341.full.

References

- 1. Centers for Disease Control and Prevention. United States Diabetes Surveillance System. Available from: https://gis.cdc.gov/grasp/diabetes/ DiabetesAtlas.html#.
- 2. Wilmot E, Idris I. Early onset type 2 diabetes: risk factors, clinical impact and management. Ther Adv Chronic Dis 2014;5:234-44.
- 3. Nanayakkara N, Curtis AJ, Heritier S, et al. Impact of age at type 2 diabetes mellitus diagnosis on mortality and vascular complications: systematic review and meta-analyses. Diabetologia 2021;64:275–87.
- 4. Gopalan A, Mishra P, Alexeeff SE, et al. Initial glycemic control and care among younger adults diagnosed with type 2 diabetes. Diabetes Care 2020;43:975-81.
- 5. Kazemian P, Shebl FM, McCann N, Walensky RP, Wexler DJ. Evaluation of the cascade of diabetes care in the United States, 2005-2016. JAMA Intern Med 2019;179:1376.
- 6. Wang L, Li X, Wang Z, et al. Trends in prevalence of diabetes and control of risk factors in diabetes among US adults, 1999-2018. JAMA 2021; 326:704.
- 7. Holman RR, Paul SK, Bethel MA, Matthews DR, Neil HA. 10-year follow-up of intensive glucose control in type 2 diabetes. N Engl J Med 2008;359:1577-89.
- 8. Laiteerapong N, Ham SA, Gao Y, et al. The legacy effect in type 2 diabetes: impact of early glycemic control on future complications (The Diabetes & Aging Study). Diabetes Care 2019;42:416–26.
- 9. Bo A, Thomsen RW, Nielsen JS, et al. Early-onset type 2 diabetes: Age gradient in clinical and behavioural risk factors in 5115 persons with newly diagnosed type 2 diabetes-Results from the DD2 study. Diabetes Metab Res Rev 2018;34:e2968.
- 10. Zhao W, Chen Y, Lin M, Sigal RJ. Association between diabetes and depression: Sex and age differences. Public Health 2006;120:696-704.
- 11. Hessler DM, Fisher L, Mullan JT, Glasgow RE, Masharani U. Patient age: a neglected factor when considering disease management in adults with type 2 diabetes. Patient Educ Couns 2011;85:154–9.
- 12. Lally M, Valentine-French S. Lifespan Development: A Psychological Perspective: College of Lake County; 2019. Available from: http://dept.clcillinois. edu/psy/LifespanDevelopment.pdf.
- 13. Ramchandani N, Way N, Melkus GD, Sullivan-Bolyai S. Challenges to diabetes self-management in emerging adults with type 1 diabetes. Diabetes Educ 2019;45:484-97.
- 14. Markowitz B, Pritlove C, Mukerji G, Lavery JV, Parsons JA, Advani A. The 3i conceptual framework for recognizing patient perspectives of type 1 diabetes during emerging adulthood. JAMA Netw Open 2019;2:e196944.
- 15. O'Hara MC, Hynes L, O'Donnell M, Irish Type 1 Diabetes Young Adult Study Group, et al. A

- systematic review of interventions to improve outcomes for young adults with Type 1 diabetes. Diabet Med 2017;34:753-69.
- 16. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci 2011;6:42.
- 17. Handley MA, Harleman E, Gonzalez-Mendez E, et al. Applying the COM-B model to creation of an IT-enabled health coaching and resource linkage program for low-income Latina moms with recent gestational diabetes: the STAR MAMA program. Implement Sci 2016;11:73.
- 18. Alexander KE, Brijnath B, Mazza D. Barriers and enablers to delivery of the Healthy Kids Check: an analysis informed by the Theoretical Domains Framework and COM-B model. Implement Sci 2014;9:60.
- 19. Guest G, Namey E, McKenna K. How many focus groups are enough? Building an evidence base for nonprobability sample sizes. Field Methods 2017; 29:3-22.
- 20. Coenen M, Stamm TA, Stucki G, Cieza A. Individual interviews and focus groups in patients with rheumatoid arthritis: a comparison of two qualitative methods. Qual Life Res 2012;21:359–70.
- 21. Guest G, Namey E, Taylor J, Eley N, McKenna K. Comparing focus groups and individual interviews: findings from a randomized study. International Journal of Social Research Methodology 2017;20: 693-708.
- 22. Haw JS, Shah M, Turbow S, Egeolu M, Umpierrez G. Diabetes complications in racial and ethnic minority populations in the USA. Curr Diab Rep 2021;21:2.
- 23. Stull DE, Leidy NK, Parasuraman B, Chassany O. Optimal recall periods for patient-reported outcomes: challenges and potential solutions. Curr Med Res Opin 2009;25:929-42.
- 24. Robinson N, Fuller JH. Role of life events and difficulties in the onset of diabetes mellitus. J Psychosom Res 1985;29:583-91.
- 25. Rankin NM, York S, Stone E, et al. Pathways to lung cancer diagnosis: a qualitative study of patients and general practitioners about diagnostic and pretreatment intervals. Ann Am Thorac Soc 2017; 14:742-53.
- 26. Penn L, Moffatt SM, White M. Participants' perspective on maintaining behaviour change: a qualitative study within the European Diabetes Prevention Study. BMC Public Health 2008;8:235.
- 27. Schroeder EB, Donahoo WT, Goodrich GK, Raebel MA. Validation of an algorithm for identifying type 1 diabetes in adults based on electronic health record data. Pharmacoepidemiol Drug Saf 2018;27:1053-9.
- 28. Klompas M, Eggleston E, McVetta J, Lazarus R, Li L, Platt R. Automated detection and classification

- of type 1 versus type 2 diabetes using electronic health record data. Diabetes care 2013;36:914-21.
- 29. Leask J, Hawe P, Chapman S. Focus group composition: a comparison between natural and constructed groups. Aust N Z J Public Health 2001;25:152-4.
- 30. Greenwood N, Ellmers T, Holley J. The influence of ethnic group composition on focus group discussions. BMC Med Res Methodol 2014;14:107.
- 31. Patton MQ. Enhancing the quality and credibility of qualitative analysis. Health Serv Res 1999;34:1189-
- 32. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology 2006;
- 33. Adu MD, Malabu UH, Malau-Aduli AEO, Malau-Aduli BS. Enablers and barriers to effective diabetes self-management: A multi-national investigation. PLoS One 2019;14:e0217771.
- 34. Ahola AJ, Groop PH. Barriers to self-management of diabetes. Diabet Med 2013;30:413-20.
- 35. Breland JY, McAndrew LM, Gross RL, Leventhal H, Horowitz CR. Challenges to healthy eating for people with diabetes in a low-income, minority neighborhood. Diabetes Care 2013;36:2895-901.
- 36. Shultz JA, Sprague MA, Branen LJ, Lambeth S. A comparison of views of individuals with type 2 diabetes mellitus and diabetes educators about barriers to diet and exercise. J Health Commun 2001; 6:99-115.
- 37. Maillet NA, D'Eramo Melkus G, Spollett G. Using focus groups to characterize the health beliefs and practices of black women with non-insulin-dependent diabetes. Diabetes Educ 1996;22:39-46.
- 38. Chlebowy DO, Hood S, LaJoie AS. Facilitators and barriers to self-management of type 2 diabetes among urban African American adults: focus group findings. Diabetes Educ 2010;36:897–905.
- 39. Tannenbaum MB, Hepler J, Zimmerman RS, et al. Appealing to fear: A meta-analysis of fear appeal effectiveness and theories. Psychol Bull 2015;141: 1178-204.
- 40. Asuzu CC, Walker RJ, Williams JS, Egede LE. Pathways for the relationship between diabetes distress, depression, fatalism and glycemic control in adults with type 2 diabetes. J Diabetes Complications 2017;31: 169–74.
- 41. Laroche HH, Davis MM, Forman J, et al. Children's roles in parents' diabetes self-management. Am J Prev Med 2009;37:S251-61.
- 42. Krall J, Helgeson VS, Tracy EL, Campbell MS, Korytkowski M, Berg CA. Perspectives of parents with type 1 diabetes: role of children in self-management and support. Diabetes Educ 2020;46:552-8.
- 43. Fisher L, Mullan JT, Arean P, Glasgow RE, Hessler D, Masharani U. Diabetes distress but not clinical depression or depressive symptoms is

- associated with glycemic control in both crosssectional and longitudinal analyses. Diabetes care 2010;33:23-8.
- 44. Gopalan A, Blatchins MA, Altschuler A, Mishra P, Fakhouri I, Grant RW. Disclosure of new type 2 diabetes diagnoses to younger adults: a qualitative study. J Gen Intern Med 2021;36:1622-8.
- 45. Flores-Luevano S, Pacheco M, Shokar GS, Dwivedi AK, Shokar NK. Impact of a culturally
- tailored diabetes education and empowerment program in a Mexican American population along the US/Mexico Border: a pragmatic study. J Clin Med Res 2020;12:517-29.
- 46. Islam NS, Wyatt LC, Taher MD, et al. A culturally tailored community health worker intervention leads to improvement in patient-centered outcomes for immigrant patients with type 2 diabetes. Clin Diabetes 2018;36:100-11.