Published in final edited form as:

Chronic Illn. 2016 September ; 12(3): 199–215. doi:10.1177/1742395316644303.

Family Behaviors and Type 2 Diabetes: What to Target and How to Address in Interventions for Adults with Low Socioeconomic Status

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Abstract

Objectives—Diabetes-specific family behaviors are associated with self-care and glycemic control among adults with type 2 diabetes (T2D). Formative research is needed to inform the assessments of these behaviors and interventions to address obstructive family behaviors (sabotaging and nagging/arguing), particularly among racial/ethnic minorities and low-income adults struggling most with self-care adherence.

Methods—We conducted a mixed-methods study with adults with T2D at a Federally Qualified Health Center to better understand experiences with diabetes-specific family behaviors and willingness to engage family members in diabetes interventions. Participants completed a phone survey (N=53) and/or attended a focus group (n=15).

Results—Participants were 70% African American and had low socioeconomic status (96% annual income <\$20K, 51% uninsured). Although 62% lived with family members, only 48% lived with the person providing the most diabetes-specific support. Participants' family living situations were diverse and multigenerational. Most (64%) experienced both supportive and obstructive family behaviors from the same person(s). Some participants (40%) said engaging

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Declaration of Conflicting Interests

The Authors declare that there is no conflict of interest.

Author Contributions

L.S.M. designed the study, developed research protocols, facilitated focus groups, directed analyses, and wrote the manuscript. K.J.H. managed the study, facilitated focus groups, assisted with analyses, drafted qualitative results, and edited the manuscript. C.Y.O. guided study design and edited the manuscript.

family in interventions would positively affect all members; others (27%) did not want to involve family.

Discussion—Findings can inform the design and content of interventions targeting family involvement in adults' T2D, with implications for assessing family behaviors, intervention modalities, and who to engage.

Keywords

type 2 diabetes; social environment; intervention; family involvement; social support

Introduction

Many patients with type 2 diabetes (T2D) have difficulty performing recommended self-care activities and, therefore, achieving glycemic control (HbA1C).^{1,2} This is largely because the social and environmental contexts in which patients perform self-care determines success.³⁻⁶ From a social control perspective,^{7,8} patients in contexts supporting healthy behaviors (e.g., a healthy diet, frequent exercise, medication adherence, and regular healthcare visits) are more likely to initiate and sustain self-care and achieve glycemic control via direct and indirect mechanisms. Among adults with T2D, social support indirectly affects health through better psychological well-being, including less diabetes distress⁹ and better quality of life.¹⁰ When this support is instrumental (i.e., observable behaviors that facilitate self-care) it directly affects patients' self-care adherence^{11,12} and health outcomes.¹³

Family members' obstructive or harmful behaviors co-occur with supportive behaviors¹⁴⁻¹⁷ and are just as, if not more, important for adults with T2D.¹⁴⁻¹⁹ Obstructive behaviors include sabotaging or undermining patients' efforts to perform self-care^{14,16,20} and nagging or arguing with patients about their self-care.^{14,15} Reporting more obstructive family behaviors is associated with having less adherence-related motivation and self-efficacy,¹⁸ being less adherent to diet,^{17,21,22} exercise,¹⁷ and medication taking recommendations,^{10,14,17} and having a higher HbA1C.¹⁷ Moreover, the relationship between experiencing obstructive family behaviors and HbA1C is stronger among patients reporting less supportive family behaviors.¹⁷ Compared to Whites with T2D, African Americans/Blacks (AA) and Hispanics are more likely to live in intergenerational households,²³ expect more assistance from adult children,²⁴ and report more diabetes-specific family behaviors.¹⁷ Persons with low socioeconomic status (SES) have higher rates of limited health literacy,²⁵ life stressors,²⁶⁻²⁸ and depressive symptoms,^{29,30} each of which exacerbate the detrimental effects of obstructive family behaviors on patients' self-care³¹ and glycemic control.³² Therefore, family behaviors are particularly salient constructs to understand among racial/ethnic minority adults with T2D and low SES.

Diabetes interventions including family members or focusing on family problem solving and/or behaviors may improve the context in which patients perform daily self-care and therefore enhance their ability to initiate or sustain self-care behaviors.⁶ However, exploratory work is needed to understand what family behaviors affect adults with T2D and should be targeted in interventions, and how to engage family members in interventions for adults with T2D. The Diabetes Attitudes, Wishes and Needs second study (DAWN-II™)

made significant contributions to understanding diabetes in the lived experiences of adults,⁶ particularly their family experiences and needs.³³ However, this international study did not focus specifically on the experiences or needs of patients with low SES or identify what family behaviors are perceived as helpful or harmful to patients. DAWN-II developed measures to assess family support and experiences,^{6,33} but not obstructive family behaviors from the perspective of the patients.

The best available and most-used measure for assessing diabetes-specific supportive and obstructive family behaviors is the Diabetes Family Behavior Checklist-II (DFBC-II).²² The DFBC was developed for adolescents with type 1 diabetes³⁴ and later validated for use among adults with T2D.²² Certain items may pertain more to parent-child relationships than to adult family relationships (e.g., “How often do your family members...criticize you for not recording the results of blood sugar tests?”, “...allow you to skip taking your diabetes medicines or insulin?”, “...encourage you to participate in sports or recreational activities?”), and no data are provided about the race/ethnicities or socioeconomic characteristics of the sample used to validate the scale among adults with T2D.²² In short, it is highly unlikely family behaviors relevant to the management of T2D among adults, especially low-SES and racially/ethnically diverse patients, are adequately assessed by current measures.

Furthermore, despite obstructive family behaviors being prevalent and problematic among adults with T2D,^{14,17,18} few interventions address the negative aspects of family interactions. A recent systematic review of interventions to improve diabetes outcomes for adults³⁵ identified 26 interventions with a family component (e.g., inviting family members to intervention sessions/medical appointments, home visits, relationship-focused diabetes self-management content). Only five of these 26 interventions included content on problematic family interactions.³⁵ This is concerning because involving family members in adults’ self-care without addressing obstructive behaviors may inadvertently lead to more obstructive behaviors and worse patient adherence.^{14,17}

Therefore, we conducted a mixed-methods study to address several questions. First, we wanted to know what types of family members provide diabetes-specific family support to adults with T2D. Supportive and obstructive family behaviors co-occur at a high rate,¹⁴⁻¹⁷ but it is unclear if this is because the same family member is performing both supportive behaviors (e.g., picking up medication refills for the patient) and obstructive behaviors (e.g., nagging the patient to take their medication each day), or if different family members are responsible for different types of behaviors. Second, we wanted to know what supportive and obstructive family behaviors adults with T2D experience most. Finally, we wanted to know if adults with T2D want family members in interventions to support diabetes self-care. We anticipated knowledge gained from this study would inform interventions to improve diabetes-specific family support while reducing obstructive family behaviors among adults with T2D who have high rates of suboptimal self-care and, in turn, suboptimal glycemic control.

Methods

Participants & Procedures

In May-August of 2014, we attempted to contact 192 adults with T2D who had completed the DFBC-II in Diabetes MeASURES (**D**iabetes **M**edication **A**dherence **S**tudy in an **U**nderserved **R**acially and **E**thnically diverse **S**ample), a cross-sectional study performed 2010-2012 at a Federally Qualified Health Center (FQHC) in Nashville, Tennessee.¹⁷ Upon enrollment in Diabetes MeASURES, participants gave permission to be contacted about future research. A trained research assistant (author KJH) and medical students (participating in a summer research training program and not involved in participants' care in any way) called to ask Diabetes MeASURES participants if they would participate in a brief phone survey and an in-person focus group session about family involvement in diabetes care. Informed consent was completed verbally with phone survey participants and in writing with focus group participants. Author KJH facilitated focus groups and a medical student was the notetaker. Completion of the phone survey required 10-15 minutes and focus groups lasted one hour. Participants were paid \$5 for completing the phone survey and an additional \$20 for attending a focus group session.

Survey and focus group questions are shown in **Table 1**. We invited interested participants to attend a focus group 3.5 ± 1.7 times. We made several efforts to encourage focus group participation, including (a) conducting focus group sessions at the FQHC where participants received care, (b) offering healthy refreshments, (c) accommodating participants' preferred dates and times, (d) even weekends/evenings, and (e) making confirmation/reminder calls the day before or day of scheduled focus group session. We conducted four focus groups (with an average of three participants) and three individual interviews because on three different occasions only one participant arrived for a scheduled focus group session. Finally, we reviewed participants' medical record to obtain the number and type of diabetes medications and most recent HbA1C (%) value. The Vanderbilt Institutional Review Board approved all study procedures prior to participant enrollment.

Analysis

Analyses were conducted using Stata 13 and NVivo 10. First, we used Kruskal-Wallis tests (with Bonferroni corrections for multi-group comparisons) and Fisher's exact tests to assess the representativeness of our sample as compared to the 192 Diabetes MeASURES participants on clinical and demographic characteristics (age, gender, race, education, income, insurance status, years since diabetes diagnosis, number of diabetes medications, insulin status, and HbA1C). We also assessed differences between participants who attended a focus group/interview and participants who completed the survey only on variables in **Table 2**. Focus groups/interviews were recorded and transcribed verbatim by an external professional transcription service. KJH cleaned transcribed data by listening to focus group recordings while reading transcripts to edit and to annotate tone of voice, laughter, and sarcasm. KJH also wrote narratives describing cases after reviewing each transcript. Based on predetermined research questions four themes were identified: (a) supportive family behaviors, (b) nagging/arguing family behaviors, (c) sabotaging family behaviors, and (d) suggestions and opinions about engaging family members in diabetes self-care. As a result

of KJH's review of transcripts, a fifth theme emerged: (e) resistance to support/denial that support is needed or important. Next, authors LSM and KJH independently coded transcripts using these five themes. Inter-rater reliability was assessed by averaging kappa values for each theme across all transcripts (average kappa=0.80, range 0.66–0.91). LSM and KJH addressed and reconciled discrepancies and coded content in the “supportive family behaviors” theme into subthemes: support received, support desired, and support given to others. Percentages of participants endorsing a theme represent findings from both answers to survey questions and focus group/interview transcripts (i.e., simultaneous methodological triangulation³⁶) to give the reader an accurate depiction of the number of participants out of 53 who indicated a theme. Finally, two “exemplary, information-rich cases”^(37p.169) are profiled to portray how identified themes interacted within the experiences of individual patients, and how the same participant presented seemingly contradictory opinions on the role of family members in his/her diabetes self-care.

Results

As shown in **Figure 1**, 109 (57%) of the 192 patients who participated in Diabetes MeASURES were available to contact. We called these participants up to five times and were able to contact 72 participants; 5 (7%) were not interested and 67 (93%) were interested. Ultimately, 53 participants completed the phone survey and 15 also participated in a focus group/interview. Descriptive statistics for these participants are shown in **Table 2**. Participants' average age was 57.3 ± 8.7 ; 74% were female, and 70% were AA. Most (96%) had annual incomes <\$20K and were uninsured (51%) or had public insurance (45%). Half were prescribed insulin and 58% had HbA1C 7.0%. Participants in the follow-up study (n=53) were more educated than non-participants (n=139; 12.9 ± 2.9 vs. 11.7 ± 3.1 years of education, $p=.025$), but there were no other differences on observed demographic or clinical characteristics between these groups. As shown in **Table 2**, there were also no differences between survey-only participants (n=38) and focus group/interview participants (n=15) on these characteristics.

Who is involved in adults' diabetes self-care?

Of the 53 participants, 62% lived with family members, 32% lived alone, and 6% lived with a friend. Participants' family living situations were diverse and sometimes multigenerational (**Figure 2**). Most participants reported adult children/grandchildren (34%) and spouses/partners (23%) were primary sources of diabetes-specific support, followed by adult siblings (18%), friends (14%), or an older parent (11%). Nearly half (48%) lived with their support person, 45% lived in the same town (14% within walking distance), and 7% lived in another town. Only 7% said their primary source of diabetes-specific support also had diabetes but 40% provided support to a family member with diabetes (primarily adult children, siblings, or a parent), indicating diabetes-specific support was rarely reciprocal within the same relationship.

What do supportive family behaviors look like?

Participants often experienced support for medication adherence assistance and reminders and exercise. For example, participants reported family members helped them adhere to their

medication regimen by reminding them to take a dose of medicine, picking up prescriptions for them, and giving them their most often missed dose of medicine:

“Well, my granddaughter, when she get home from work, she makes sure I take my insulin...She's studying to be a nurse and she sticks real well...I will doze off and when she get off from work at 11 she comes by to wake me up.”(69 year-old AA woman, HbA1C=10.6%)

Several participants described how having someone to exercise with makes exercise a part of their regular routine:

“[My daughter] said, ‘Well, we can get out every morning, mama, and walk.’ I said, ‘Okay.’ I’ll get up and go with her.”(51 year-old AA woman, HbA1C=6.2%)

In focus groups, 8 out of 15 participants also discussed desired (though not necessarily received) support with adhering to a recommended diet, exercising, taking medications, as well as encouragement for these self-care activities. Specifically, participants wanted family members to *join them* in eating a healthier diet and/or exercising, rather than singling them out as needing a special diet or exercise routine because they are “the diabetic.” Participants also wanted family members to remind them to take medications, and two wanted family members to attend medical appointments with them.

What does nagging/arguing about self-care look like?

Almost half (49%) of participants described how someone nagged or argued with them about their diabetes self-care. The most common reason for nagging/arguing (mentioned by 32%) was to get the participant to eat a healthier diet:

“I have a grandson who's very health conscious. I hate to even be around him [because] he [nags] a lot. He'll call me, [and say] ‘I saw you eat that piece of candy’.”(69 year-old AA woman, HbA1C=10.6%)

Participants (15%) also reported being nagged about their diabetes medications:

“[My husband will] take the top off of [my Lantus] and he'll look and see if that little ball goes up and he'll say, ‘That ball is still right there, it's been like that for two days. Uh-uh (negative) that ball should have been up. You ain't took nothing.’ [I'll say], ‘Yes I did, don't you know I [may change pens] and take it out of this [pen] and then I go to another [pen] and take it out of that one.’” (57 year-old AA woman, HbA1C=6.2%)

Two participants (4%) who completed the survey indicated self-monitoring of blood glucose was a source of nagging and/or arguing with family members, but this was not discussed in focus groups/interviews.

Though participants described several examples of the ways in which nagging is an obstructive family behavior, there were differing opinions about whether nagging was helpful or harmful. In some cases, nagging and arguing were perceived as helpful because participants realized family members were *attempting* to help them:

“I find [nagging] to be helpful. You may not like it at the moment, but [my wife is] doing it out of being concerned about [me]...[my wife] tells me, ‘When I stop nagging [or] don’t say nothing, you know I don’t care.’”(62 year-old AA man, HbA1C=8.7%)

“We don’t like [nagging], but it’s for the best.”(45 year-old White woman, HbA1C=7.3%)

In other cases, patients described nagging as discouraging and annoying and felt they were being treated “like a child” (**Figure 3**). *How* family members express their concerns defined whether nagging was perceived as helpful or harmful by the patient. Harmful nagging was characterized by hostile tone of voice, “pushiness,” and/or rudeness whereas helpful nagging was characterized by gentleness and recognition of the patient’s autonomy (e.g., asking the patient what he/she needs; **Figure 3**). In addition, participants resented being “called out” in front of others, or having multiple people “gang up” on them, whereas comments made privately (e.g., quietly suggesting healthy options on a restaurant menu) were perceived as helpful “reminders.”

What do sabotaging family behaviors look like?

Sabotaging behaviors – when a family member does something that makes patients’ self-care adherence efforts difficult or impossible to achieve – were universally regarded as harmful by participants. When participants described sabotaging behaviors, they usually focused on diet. A participant who lived with her adult son described her experience with diet-specific sabotaging:

“My son was eating all them sweets. I wasn’t eating too much but I tasted every now and then because it was Krispy Kreme Donuts, that’s where he was working. I liked the taste. It was full of sugar and I just couldn’t keep eating that...Finally, he got another job doing something else and I was glad of that, he had so many of them sitting on the counter.” 64 year-old AA woman, HbA1C=6.4%)

Sometimes a lack of support was perceived as sabotaging, especially when participants had asked for a specific type of support. For example, participants reported that family members chastised them for not following a regular exercise program, but when patients asked them for help, family members refused or made promises to help, but never followed through:

“My biggest [problem] is exercising. [I asked my wife to exercise with me, but she said] ‘I don’t need to go, you take [adult son] and go.’ I had been [exercising], but I’d gotten out of practice. [The doctor asked me] ‘Are you still walking?’ I said, ‘Well, every now and then.’ My wife told him, ‘Yeah, to the refrigerator.’”(62 year-old AA man, HbA1C=8.7%)

“Well, all I get is a bunch of promises on the exercise thing. I don’t really want to exercise by myself, but I do need to get out and exercise...My daughter [says], ‘We going [to exercise] such-and-such date,’ and such-and-such date never comes... They want me to just go by myself and I don’t want to go by myself, I want somebody to go with me.”(54 year-old AA woman, HbA1C=5.7%)

Several participants described how nagging and sabotaging and/or the absence of support would converge during family gatherings and holiday meals. Despite the absence of healthy options, family members would publically criticize patients for eating unhealthy foods. When desserts were a part of a family celebration, participants described being reprimanded for indulging alongside other family members:

“They make them good old caramel cakes with the homemade icing, chocolate and stuff at Christmas and Thanksgiving...you got to go sneak and eat a piece. Lately there's been a bunch of family gatherings and so they [were] watching my plate... [saying], ‘Don't you eat that!’ [and] ‘That's too much of that!’”(54 year-old AA woman, HbA1C=5.7%)

Who performs obstructive and supportive behaviors?

Sixty-four percent of participants indicated the same person who provided the most support also performed obstructive behaviors (25% indicated a different person, 11% said no one). Often the supportive and obstructive behaviors were with the same diabetes self-care behavior. For instance, this participant stated his wife is his greatest motivator in managing his diabetes, especially for helping him eat healthfully, but later he explained:

“There are a lot of different types of foods that come in my house because of the grandkids and stuff. My wife, she goes overboard cooking this and a lot of things is not according to the diet that I should have...She cooks and kind of messes with [me] as far as really staying on a controlled diet. I'm still struggling.”(62 year-old AA man, HbA1C=8.7%)

How do patients perceive the role of family in their diabetes self-care?

Participants had varying and sometimes dissonant perceptions of the role of family in their diabetes self-care. Six out of 15 focus group/interview participants (note: these questions were only asked of focus group/interview participants) felt family should be involved in helping manage their diabetes, especially with regards to diet. Furthermore, six of the 15 focus group participants said it was in family members' best interest to support patients' efforts to manage their diabetes. They described how family members who commit to being healthier would both help patients manage their diabetes and reduce the family's diabetes risk:

“Even somebody that doesn't have diabetes, but you know it runs in your family, you kind of get to eating right yourself, so you're not in this spot [of having diabetes].”(61 year-old AA woman, HbA1C=7.5%)

“In the long run, I actually think it would lessen the risk of diabetes for everybody.” (45 year-old White woman, HbA1C=7.3%)

Others felt their diabetes was not their family members' “problem” and/or that it wasn't “fair” to ask their family members to change their own diet or exercise. Four of the 15 focus group participants said it was more important to motivate them, and didn't want to involve family members:

“It is not [about] getting [family members] involved. It is getting me involved.”(65 year-old AA woman, HbA1C=7.6%)

Sometimes the same participants expressed both viewpoints (**Figure 3**).

When asked in focus groups, participants rarely had suggestions for how to involve family members in their diabetes self-care. When participants did offer ideas, they suggested providing information to family members about diabetes via educational reading materials or bringing them to face-to-face didactic sessions about diabetes:

“I guess with some people, hearing it from the experts in the information session is different from hearing it from [the patient] after you go. They may be more likely to listen to it and follow the directions if they hear it from someone else rather than from you.”(50 year-old White man, HbA1C=6.5%)

Some participants said family members nagged without understanding the requirements of diabetes self-care. One participant suggested didactic sessions with family members might reduce this:

“I think the more you find out about [diabetes] with your family, it educates them... I think that it'll slow down the nagging.”(45 year-old White woman, HbA1C=7.3%)

Discussion

This sample of adults with T2D and low SES had diverse living situations and received support most often from adult children/grandchildren, spouses/partners, and siblings. Less than half indicated their primary support person lived with them. Family members provided diabetes-specific support most frequently with medication adherence and exercise. Participants were infrequently engaging in reciprocal support (i.e., being both “helper” and “helpee” in the same relationship), but often gave diabetes-specific support to someone other than their primary support person(s). Participants wanted family members to engage in healthy behaviors with them, rather than singling them out as needing healthy behaviors because they are “the diabetic.”

Sabotaging and nagging behaviors were most common regarding diet and exercise. Nagging or criticizing was often viewed as helpful if the tone was gentle because participants understood family members were concerned for their well-being. However, nagging often made participants resistant to adherence, especially when they felt their family members were being pushy, critical, or treating them “like a child.” Nagging was especially frustrating and alienating for participants when it was accompanied by sabotaging (e.g., when family members brought desserts to family gatherings and then criticized the patient for partaking alongside others). Many (64%) reported the family member providing the most support also performed obstructive family behaviors, and supportive and obstructive behaviors were often experienced in the same area of self-care. Participants had disparate and sometimes contradictory opinions about engaging family members in their diabetes. Some were reluctant to ask family members to change behaviors because they felt diabetes was their “problem” and it was “unfair” to ask family members to be penalized by having to make

healthier choices. Others felt engaging family members would result in better health for all involved, and sometimes the same participant expressed both views.

Limitations

We recruited patients who had participated in a cross-sectional study to understand the role of family in their diabetes self-management. Those who did not participate in this follow-up study might have had different experiences and perspectives than those who did participate, but we found participants and non-participants were similar on all demographic and diabetes characteristics except for a one year difference in education. Our mixed methodology facilitated wide assessment with a larger sample via a phone survey and a more in-depth examination of the phenomena via focus groups/interviews. Given the number of focus group attendees was lower than desired, we were unable to reach thematic saturation in some instances. Furthermore, we sampled from a single FQHC and our results may not generalize to other patients. Most participants were AA or White, so we have not addressed the experiences of patients of other races/ethnicities. Finally, because of our small sample size, we were unable to ascertain if differences in views on the role of family in adults' diabetes management were driven by racial/cultural differences or reflect individual variability.

Implications for Interventions

Findings have several implications for interventions with low-SES adults with T2D: (a) assessments of family behaviors should be developed for intervention evaluation among adults with T2D, (b) interventions should minimize the amount of time and location requirements for participation, (c) family member involvement in interventions should be optional rather than assigned and should not require a certain type of relationship or living arrangement between the patient and family member, and (d) interventions should have patient-centered content.

Assessment of family behaviors—As mentioned previously, the DFBC-II²² items are not based on the experiences of adults with T2D and several items imply a parent-child relationship (e.g., “allow you to skip taking your diabetes medication”) or use language relevant to adolescents (e.g., “sports or recreation”). Based on our results, we identified additional weaknesses of the DFBC-II²² for use among adults with T2D. First, only two of the nine items in the DFBC-II²² obstructive behavior subscale focus on sabotaging, and no items acknowledge the absence of promised support as sabotaging (e.g., cancelling scheduled exercise with the patient). Second, the remaining seven obstructive items assess nagging, arguing or criticizing behaviors, but participants in this study found it difficult to characterize nagging as helpful or harmful. We suggest measures replace the word “nagging” with more nuanced descriptors about the characteristics of the interaction such as tone of voice, public versus private, and asking how to support versus telling patients what to do. Based on our findings, this language may be more aligned with what patients consider obstructive or harmful than items using the term “nag.” Finally, as a result of the DFBC-II being developed for adolescents,³⁴ several items assume patients live with their family members (e.g., “How often do your family members...eat at the same time you do?”, “...plan activities around your self-care routine?”, “...eat foods that are not part of your healthy

diet?”) and therefore seemed nonsensical or irrelevant to participants living alone or with a friend, roommate, or adult child.

Time and location requirements—When asked how to best involve family members in patients’ T2D self-care, participants either resisted the notion that family members should be involved (because patients were responsible for this themselves), or recommended family members attend didactic face-to-face intervention sessions. Even in well-resourced samples, family interventions for adults with diabetes requiring face-to-face meetings struggle with low attendance and attrition.³⁸⁻⁴¹ Patients with fewer resources often have difficulty attending and/or bringing their family members to interventions due to competing priorities and challenges with changing work schedules, transportation accessibility, and childcare.⁴²⁻⁴⁴ In this study, attendance was consistently difficult. We invited 10-12 participants to each focus group, with an average of five confirming attendance for each group. However, one scheduled group was not conducted because no one arrived and three were conducted as interviews because only one participant attended. Focus groups scheduled on weekends were not better attended. Day-before or day-of confirmations didn’t predict attendance. We contacted participants after they missed a scheduled focus group to invite them to the next available focus group that aligned with their schedule, and to ask if there were specific reasons they missed their scheduled session. Participants’ stated reasons included a lack of transportation, forgetfulness, or last minute schedule changes. Our experience getting participants to attend focus groups underlines how challenging scheduled face-to-face intervention sessions might be for low-SES patients, especially if asking patients to also coordinate with family members’ schedules to attend.

Family member involvement in interventions—Given the diversity of the family types and living situations among adults with T2D, in this study and in DAWN-II,⁶ it is untenable for interventions to assume a spouse/partner or a shared living situation between the patient and his/her support person(s). While face-to-face family interventions may be successful for adolescents,⁴⁶ such interventions for adults must be flexible in content and design to accommodate different types of family relationships. Alternative methods of delivering intervention content, which do not require patients live with or near family, should be explored. Technology-delivered interventions hold promise, and more work is needed to learn how to engage adults and their family members via different forms of technology (c.f.^{45,47,48}), especially technologies available to underserved patient populations such as cell phones. Study designs which exclude patients who cannot or do not want to attend with a family member may mean interventions fail to reach those who need the most support.^{33,45}

Patient-centered content—Finally, interventions must maintain the autonomy of the patient, and respect a patient’s views about whether a family behavior is helpful or harmful. Participants described how important it was for family members to ask them what would be helpful rather than to assume or dictate what the patient should be doing. We echo Kovacs Burns et al.’s³³ statement that family members want patients to involve them and/or give them direction on how to be helpful and not harmful. Interventions should avoid didactic formats about what family members should/should not be doing to support the patient, but instruct and empower the patient to decide what support they do/do not want.

Conclusion

This study contributes to the growing recognition among researchers, providers, and policy makers that adult management of T2D occurs in contexts, which can be supportive or disruptive to self-care and glycemic control. Most notably, this study follows the international DAWN-II study of psychosocial needs adults with diabetes⁶ and family members.³³ However, our approach and findings are distinct in that we focused on (a) racially diverse, low-SES patients in the U.S. and (b) diabetes-specific supportive and obstructive family behaviors. This is a particularly critical gap to fill because diabetes-specific supportive and obstructive family behaviors have recently been identified as significantly and independently associated with adherence to self-care behaviors^{14,17} and glycemic control^{17,32} among adults with T2D and low SES. Furthermore, DAWN-II³³ found over a third of family members wanted to be more involved in patients' diabetes care, and our study explores adult patients' perspectives on that involvement.

In addition, this paper begins to address the need for adult-specific family assessment tools. Behaviors (i.e., tangible or instrumental support) are the most important type of support for adults' adherence,^{11,12} but the DFBC²² is the only validated instrument assessing both supportive and obstructive behaviors. Measures capturing the types of behaviors discussed by our participants should be developed to assess the efficacy of family interventions in changing family behaviors for adults with T2D. In our own work, these findings have informed/are informing two studies currently underway: development of an instrument assessing supportive and obstructive family behaviors among adults with T2D and a cell phone-based family-focused intervention for low SES adults with T2D.

We recognize successful family interventions take many forms. Our recommendations are intended to guide the development and design of family interventions for low-SES patient populations, specifically, and therefore focus on their unique needs and characteristics. Interventions in racially diverse populations with low SES must be responsive to several characteristics, including: time and scheduling demands, cultural and individual variation in perceptions of the role of family, and varied family structures.

Acknowledgements

The authors would like to acknowledge Bradley Harrison & Sujata Ghosh for their contributions to participant recruitment and focus groups. The authors would also like to thank the participants for their contribution to this work.

Funding

This study was funded with support from the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) through Dr. Mayberry's National Research Service Award [F32DK097880] and through the Vanderbilt Center for Diabetes Translational Research [P30DK092986, PI: Elasy], and with support from the Agency for Healthcare Research & Quality [K12HS022990, PI: Penson]. L.S.M was also supported by a Career Development Award [K01DK106306] from NIDDK. C.Y.O. was supported by a career development award [K01DK087894] from NIDDK. The parent study (Diabetes MeASURES) was supported by the National Center for Advancing Translational Sciences [2UL1TR000445-06]. The content is solely the responsibility of the authors and does not necessarily represent the official views of the funders.

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Figure 1. Recruitment and participation flow chart

Depicts how many participants did and did not participate (and reasons why) of the original sample from the parent study, Diabetes MeASURES.

Figure 2. Venn diagram depicting participants' family living situations

Depicts living arrangements of 33 participants who lived with a family member (not in figure: 17 participants lived alone and 3 lived with a friend).

Mary	John
<p>Mary is a 55 year-old African American woman who is prescribed insulin for T2D. Her most recent HbA1c was 12.9%. She lives with her husband. She receives support for diabetes self-care from her husband, her adult children, her grandchildren, and her co-workers.</p> <p>Mary receives a lot of support from her grandchildren, who will attend medical appointments with her and help her take her insulin:</p> <p><i>"When my grandkids [are] there, [they'll say] 'Nanna, have you had your diabetes medicine today?' And they'll run and get the needle and...the insulin. They know how much I'm supposed to take and they know what I take because I taught them [what to do] if my sugar drops or if my sugar is up."</i></p> <p>Mary's husband often nags her, and she appreciates that he's trying to help, but finds that his nagging doesn't help her be more adherent:</p> <p><i>"I don't think [nagging is] a harmful behavior. I just think they are concerned but they shouldn't just keep criticizing you about it because a lot of times when people continue to criticize you about stuff, it makes you not want to do it. It makes you just, [not] want to do it. That's just the bottom line."</i></p> <p>Mary describes how her perception of nagging as helpful or harmful depends on the approach used by the family member:</p> <p><i>"I think when people come to you it seems like in a hateful way, a demanding way or like they're trying to push you...I don't like that kind of stuff because I like for somebody to come to me and say 'Well, have you taken your diabetic medicine today,' in that [calm and gentle] tone of voice...It ain't the matter of what a person say to me, it's just how they say it. I'm not [a] child, I don't need nobody to treat me like [a] child."</i></p> <p>Mary described her internal conflict about how to feel about family members' behaviors. She doesn't want to limit her husband's food choices:</p>	<p>John is a 52 year-old African American man who is prescribed oral medications and insulin for T2D. His most recent HbA1c was 13.4%. He lives with his fiancé. He receives support for diabetes self-care from his fiancé and his adult siblings.</p> <p>John explained how family support was critical for him when he was first diagnosed with diabetes:</p> <p><i>"When I was diagnosed with it, one of my brothers had it, so him and myself was on the phone, along with my fiancé. I asked him what's going on? Why am I urinating a lot? I finally went to the doctor. His wife and myself and my fiancé, all 4 was on the phone. He was educating me about diabetes. I took that in. Like [another focus group participant] say, 'I've been to a clinic where the family can come.' I think it would really work out because he educated me a lot. Back then, it wasn't as bad as it is now, but now, I've pretty much got control of my diabetes right now. Pretty much, I'm not where I want to be, but I'm getting there. Family helps."</i></p> <p>When another brother was diagnosed, John tried to support him like the other brother had supported him when he was diagnosed:</p> <p><i>"My oldest brother just found out about 2 months ago he was diabetic. I pretty much educated him on things to do like the best foods for us to eat is the grilled foods. It's got all our fats falling in the grill."</i></p> <p>His fiancé helps him remember his medications:</p> <p><i>"Like she asks me have you took your night shot? I'll be looking at TV. I said no and I get on up and go on. A reminder helps. That really helps."</i></p> <p>But she also sabotages his efforts by bringing sweets into their home:</p>
<p><i>"My husband is not a diabetic and he loves his potato chips and he loves his sweet stuff and I don't want to take that away from him."</i></p> <p>But she struggles with how to feel about his decisions:</p> <p><i>"A whole lot of times, you know I want to blame him but I can't blame him because he ain't a diabetic. I need to keep my diabetes under control because I know what I can't have and what I can have, you know."</i></p> <p>Mary described how she wishes her family would support her:</p> <p><i>"Sometimes I just wish they would say well okay, we going to learn how to bake something that you can eat too, instead of always baking something and they know that if they bake it, I'm going to eat it. That's just me. I'm going to eat it, even though I know it's going to hurt me, I still eat it...My biggest problem is that I just wish my family would say, 'You know what, just for this family reunion or whatever, we going to have some cakes or something that she can eat.' You know...it don't hurt them to try to eat some different foods too so they won't become diabetic...a family [should come] together and say 'Well, you're a diabetic [so] we are all going to try to eat properly... because when [everyone eats] healthy in the household, and [is] not all about eating all the junk food and all that, then the person who is diabetic can benefit [from] that."</i></p> <p>However, she also feels resistant to inviting family members to interventions or to trying to engage them in her self-care. When asked how to engage family members in adults' diabetes, she says:</p> <p><i>"I got some good family members...They will help me, but first I got to help myself. It's all about self."</i></p>	<p><i>"I'm in a household where my fiancé is a sweet fanatic. God, man, it's so much temptation there but I'm pushing myself to avoid it. Why is you up there eating this cake and ice cream and I'm up here drooling at the mouth, wanting some?"</i></p> <p>John has tried asking his family members to make healthier choices to accommodate his efforts to eat a healthier diet:</p> <p><i>"I'll say, 'Hey, let's go to Subway.' [They'll say] 'I don't want that.' That's not fair to me. I think, I don't want to be less fair to me because I prefer Subway over McDonald's. If we're going to eat out, eat something fast, I prefer Subway over McDonald's. That's my whole thing."</i></p> <p>However, later John stated it is unfair to ask family members to make healthier food choices because of his diabetes:</p> <p><i>"One thing I don't agree with. Family members [should be able to] eat foods that are not part of your diabetic diet. That's not fair to them if you ask me. I got to do what I got to do and they're going to do what they want to do. What I have to do is, if they eat fried foods, then I'm going somewhere to find me something baked myself."</i></p> <p>Oftentimes, John prepares special meals for himself rather than ask his family members to change their diet:</p> <p><i>"I prefer, for example, I like baked fish and they don't. Guess what? I bake my own fish. I like baked chicken. Sometimes they do, sometimes they don't. I just bake me enough chicken. That's on them. I try to encourage them that it's better for you."</i></p>

Figure 3.
Information-rich cases with illustrative quotes from two focus group participants (names changed).

Table 1**Survey & Focus Group Questions**

Survey Questions		Focus Group/Interview Questions	
1	Who lives with you?	1	Introduce yourself, say how long you have had diabetes and who you consider to be your family. You may include close friends who you consider to be part of your family.
2	What is your relationship with the friend or family member who provides the most support or help with your diabetes? - Does [this person] also have diabetes? - How far does [this person] live from you? - What is the most helpful thing [this person] does to support your diabetes management? - Does [this person] ever do anything that is not helpful for your diabetes management? (If yes, what?)	2	What kinds of help with your diabetes do you get from your family?
3	What is your relationship with the friend or family member who gets in the way of your efforts to manage your diabetes?	3	What types of family behaviors have you found most helpful for managing your diabetes?
4	What is your relationship with the friend or family member who nags you or argues with you the most about your diabetes management? - What about your diabetes management does [this person] nag you about the most or what do you argue about most often?	4	Is there anything in particular your family could do that would help you manage your diabetes?
5	Do you provide support or help to any of your family members who have diabetes? - What is your relationship to this/these person(s)? - What are some things you do to help this person/these persons with their diabetes management?	5	Sometimes family members get in the way of patients' efforts to eat a healthy diet. Have you experienced this? Tell us about your experience?
		6	Sometimes family members get in the way of patients' efforts to exercise. Have you experienced this? Tell us about your experience.
		7	Sometimes family members get in the way of patients' efforts to take their diabetes medications. Have you experienced this? Tell us about your experience.
		8	Sometimes family members nag patients or argue with them because they are worried they are not taking good care of their diabetes. Have you experienced this? What was that experience like for you?
		9	What would help family members to give the best kinds of support for patients with diabetes?

Table 2

Participant characteristics.

Mean $\pm$ Standard Deviation or n (%)	Survey-Only n=38	Focus Group n=15	All Participants N=53
DEMOGRAPHIC CHARACTERISTICS			
Age, years	56.7 $\pm$ 9.0	58.7 $\pm$ 8.1	57.3 $\pm$ 8.7
Women	28 (73.7)	11 (73.3)	39 (73.6)
Race			
White	12 (31.6)	3 (20.0)	15 (28.3)
African American/Black	25 (65.8)	12 (80.0)	37 (69.8)
Other race	1 (2.6)	0 (0.0)	1 (1.9)
Education	13.0 $\pm$ 2.6	12.7 $\pm$ 1.9	12.9 $\pm$ 2.4
< High school degree	6 (15.8)	2 (13.3)	8 (15.1)
High school degree	26 (68.4)	11 (73.3)	37 (69.8)
College degree	6 (15.8)	2 (13.3)	8 (15.1)
Income ^a			
<\$10,000	13 (38.2)	7 (53.8)	20 (42.5)
\$10,000 – \$14,999	11 (32.4)	4 (30.8)	15 (31.9)
\$15,000 – \$19,999	8 (23.5)	2 (15.4)	10 (21.3)
\$20,000	2 (5.9)	0 (0.0)	2 (4.3)
Insurance Status			
Uninsured	20 (52.6)	7 (46.7)	27 (50.9)
Public insurance	16 (42.1)	8 (53.3)	24 (45.3)
Private insurance	2 (5.3)	0 (0.0)	2 (3.7)
Live Alone	11 (29.0)	6 (40.0)	17 (32.1)
DIABETES CHARACTERISTICS			
Diabetes duration, years	10.3 $\pm$ 6.9	13.4 $\pm$ 10.7	11.2 $\pm$ 8.2
Type of diabetes medications ^b			
Oral agents only	18 (50.0)	7 (50.0)	25 (50.0)
Insulin only	7 (19.4)	2 (14.3)	9 (18.0)
Both	11 (30.6)	5 (35.7)	16 (32.0)
Glycemic Control (HbA _{1C} , %) ^b	8.0 $\pm$ 2.0	8.0 $\pm$ 2.6	8.0 $\pm$ 2.2
Suboptimal ($\geq$ 7.0%)	24 (63.2)	8 (53.3)	29 (58.0)
Optimal (<7.0%)	14 (36.8)	7 (46.8)	21 (42.0)

Note: Kruskal Wallis and Fisher's exact tests compared survey-only and focus group participants on all variables in Table; no differences.

^a 6 participants did not report their income

^b 3 participants did not have medications or an HbA_{1C} in their medical chart