

# US Ethnic Group Differences in Family Member Support for People With Diabetes in the 2nd Diabetes Attitudes, Wishes and Needs (DAWN2) Study

## Purpose

The purpose of the study was to describe the perceptions of family members (FM) and people with diabetes (PWD) regarding the frequency and helpfulness of FM support for PWD, including differences among US ethnic groups.

## Methods

The US 2nd Diabetes Attitudes, Wishes and Needs (DAWN2) substudy was a survey of independent samples of 238 adult FM and 540 adult PWD. Outcome measures included ratings by FM and PWD of the frequency and perceived helpfulness of 7 FM support

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behaviors and composite scores for frequency and helpfulness.

## Results

Ratings of individual FM support behaviors were strongly correlated between FM and PWD but significantly different among behaviors. FM and PWD reported most frequent support for listening, assisting, and doing activities with PWD and reporting PWD was doing poorly least frequently. Both groups reported listening, assisting, and reporting PWD was doing well as most helpful; reporting PWD was doing poorly was least helpful. PWD rated support and helpfulness of most behaviors lower than FM. Composite measures of support frequency and helpfulness were strongly correlated for both FM and PWD. Ethnic minority PWD and FM reported most support behaviors as more frequent and more helpful than non-Hispanic white Americans.

## Conclusions

FM more frequently engage in the support behaviors they view as most helpful, but PWD perceive support to be less frequent and less helpful than FM. FM support differs across ethnic groups, with ethnic minorities reporting higher support frequency and helpfulness. Diabetes care providers should consider ethnic group differences in FM support for PWD.

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**F**amily members (FM) are recognized as important allies in the care of diabetes and other chronic illnesses, and the past decade has seen a rapid growth of self-management programs that include FM.<sup>1</sup> The original Diabetes Attitudes, Wishes and Needs (DAWN) study in 2001 involved people with diabetes (PWD) and health care professionals from 13 countries but did not include FM.<sup>2</sup> This first DAWN study identified the challenges associated with managing diabetes: diabetes management was “poor,” and coordinated diabetes care was lacking. This prompted a “Call to Action” for improved coordination of person-centered diabetes care among PWD, their FM, and health care professionals.<sup>3</sup> Ten years later, the second Diabetes Attitudes, Wishes and Needs (DAWN2)

study was initiated to assess progress, with one significant addition: the inclusion of FM in the research.<sup>4</sup>

One objective of the DAWN2 study was to determine the psychosocial and educational needs of the 2057 participating FM. These findings helped to strengthen the focus on active patient and family engagement in diabetes care and self-management and to inform better practices and policies.<sup>5</sup> Quantitative results of DAWN2 revealed that approximately one-third of FM experienced a notable burden and negative impact of diabetes. Forty percent of FM reported having high levels of distress, and 61% worried about PWD experiencing hypoglycemic events. Qualitative data showed that FM wanted to do what was best for PWD and help in whatever way possible.<sup>6</sup> In addition to worrying about the day-to-day struggles of PWD, such as hypoglycemia and employment stability, FM reported that diabetes negatively affected the person with diabetes–family member relationship. FM also expressed a need for more self-management resources to deal with the burdens and lifestyle changes of diabetes. A positive impact of diabetes was that the PWD often provided inspiration to the FM and helped the FM to make positive life changes, such as eating healthier.

The importance of social support in managing diabetes has been well established in the literature.<sup>6</sup> In their review, Wiebe et al<sup>6</sup> summarized the extensive literature on social support across diabetes types and underscored that FM were the “most involved and influential sources of support.” Their summary of the adult literature indicated that behaviors representing “high warmth” and autonomy support were helpful for diabetes management, and those representing hostility or “low warmth” and control (eg, criticism, undermining, or nagging) were not helpful.<sup>6</sup> They further emphasized consistencies in the literature across diabetes types, social context, and developmental stages by noting that “high-quality social relationships characterized by warmth, collaboration, and acceptance are consistently associated with good diabetes outcomes, while relationships characterized by conflict and criticism are associated with adverse outcomes.”

A review of family relations of adults with diabetes published by Rintala et al<sup>7</sup> concluded that “support from partners/spouses plays a crucial role in making and maintaining lifestyle changes and optimizing diabetes management.” The investigators noted differences in support across diabetes self-care areas, with healthy eating being the most challenging one. Diverse family relational variables associated with diabetes management were also

studied by Chesla et al<sup>8</sup> and described in the review by Rintala et al.<sup>7</sup> The work of Chesla et al<sup>8-10</sup> is particularly relevant to the current study because racial/ethnic minority groups were included. They found that family variables, particularly diabetes-related conflict resolution, were associated with measures of diabetes self-care or disease management in African Americans, Chinese Americans, European Americans, and Latino adults with type 2 diabetes.<sup>8,9,11</sup> Both the Wiebe et al<sup>6</sup> and Rintala et al<sup>7</sup> reviews underscore the complexity of family relational variables in diabetes care and the need for more research on this topic.

To the authors' knowledge, little research has examined family-support behaviors from the perspective of FM or compared these behaviors across multiple racial/ethnic groups in the United States. The purpose of this study was to describe the perceptions of FM and PWD regarding frequency and helpfulness of FM support for PWD and examine differences among US ethnic groups. These topics are assessed from the perspective of both FM and PWD.

## Methods

### Study Design

The DAWN2 study is a multinational, interdisciplinary, and multistakeholder survey. The full study design for DAWN2 has been published previously (UTN No. U1111-1123-7509; NCT01507116).<sup>4,5,12-14</sup>

Each country that participated in DAWN2 recruited a core sample of at least 120 FM (age >18 years) of adults with diabetes and a core sample of at least 500 PWD (age >18 years) stratified by diabetes type and treatment. The US study population was supplemented by independent samples of approximately 40 FM and approximately 180 PWD from each of 3 ethnic minority populations: African American, Hispanic American, and Chinese American. Participants were recruited and interviewed via the Internet, by telephone, or in person.

### Participants in This Study

This substudy included 238 FM without diabetes living with and involved in the care of an adult with diabetes: 105 white non-Hispanic (WNH) American, 47 African Americans, 46 Hispanic Americans, and 40 Chinese Americans. Also included were 540 PWD from the DAWN2 study who lived with another adult involved

in their diabetes care: 220 WNH American, 93 African Americans, 125 Hispanic Americans, and 102 Chinese Americans.

### Measures

The FM and PWD questionnaires assessed 7 support activities with a single item for each activity:

- Reporting when PWD is doing well
- Reporting when PWD is doing poorly
- Listening to PWD
- Advising PWD
- Assisting PWD
- Doing activities for PWD
- Doing activities with PWD

FM were asked about their own perceived support behaviors with this item stem: "in what ways you try to be supportive as you help the person you live with manage his/her diabetes," and PWD were asked about their perception of FM support with this item stem: "in what ways this person tries to be supportive of you in managing your diabetes." Respondents indicated the *frequency* with which each of the 7 support behaviors was performed (response options: 1 = *never* to 5 = *always*) and which of the 7 support behaviors were "most helpful" (response options: yes/no, with more than 1 choice of behavior possible).

Composite total scores for support frequency (7 items) and helpfulness (7 items) were calculated as the mean of the 7 relevant items. The alpha coefficients of interitem agreement for FM and PWD were .83/.86 for support frequency and .74/.83 for support helpfulness.

### Statistical Analysis

Analysis of variance was used to identify statistically significant ( $P < .05$ ) differences between (1) PWD and FM and (2) among 4 racial/ethnic identities: WNH American, African American, Hispanic American, and Chinese American. All comparisons among ethnic groups and comparisons between FM and PWD were controlled for age and gender of the respondent and whether the person being rated was the rater's spouse (vs other). Separate analyses are reported for each of the frequency and helpfulness support items and for the frequency and helpfulness composite scores.

To compare which item scores were reported higher, lower, or the same by each type of respondent (FM and PWD), paired *t* tests were calculated; no adjustment for

Table 1

## Characteristics of Respondents

Indicator	FM (n = 238), M ± SD or % (n)	PWD (n = 540), M ± SD or % (n)
Gender, female <sup>a</sup>	67.6 (161)	45.0 (243)
Age, y <sup>a</sup>	48.0 ± 14.9	56.1 ± 15.5
Ethnicity		
White non-Hispanic	44.1 (105)	40.7 (220)
African American	19.7 (47)	17.2 (93)
Hispanic American	19.3 (46)	23.1 (125)
Chinese American	16.8 (40)	18.9 (102)
Spouse is person rated <sup>a</sup>	51.3 (122)	80.9 (437)

Abbreviations: FM, family members; M, mean; PWD, people with diabetes; SD, standard deviation.  
<sup>a</sup>Significant difference ( $P < .05$ ) between FM and PWD.

respondent characteristics was needed since scores for the same individuals were compared with each other.

## Results

Table 1 reports the descriptive statistics for the sample. There were statistically significant differences between FM and PWD for gender, age, and in the proportion of those who were part of a spousal relationship ( $P < .05$ ). These factors were controlled in all comparisons of FM and PWD (and when comparing ethnicities).

Table 2 displays overall sample means for each of the support measures, as rated by FM and PWD. Within each column, tests indicate which items are rated higher, lower, or equal to the other items by each respondent type. For FM, support was perceived as most frequent for listening to PWD, assisting PWD, and doing activities for PWD. Advising PWD, doing activities with PWD, and reporting when PWD are doing well were lower, whereas reporting that PWD are doing poorly was reported as least frequent. The pattern for PWD was similar to that of FM reported frequency.

For FM, support was perceived as most helpful for listening to PWD and assisting PWD, followed by reporting when PWD are doing well and doing activities with PWD; doing activities with PWD and advising PWD were perceived as more helpful than reporting when PWD are doing poorly. The pattern for PWD was like that of FM, except that advising PWD was rated lower than reporting PWD are doing poorly (Table 2).

Table 2 also reports whether each item and the composite were rated higher, lower, or the same by FM and PWD. FM reported that each support behavior was more frequent than PWD reported; 5 of the 7 differences were statistically significant ( $P < .05$ ), as was the difference in the composite measure. FM also reported that each support behavior was more helpful than PWD did; 6 of the 7 differences were statistically significant ( $P < .001$ ), as was the difference in the composite measure. Reporting that PWD are doing poorly was the only behavior for which there was no significant difference between FM and PWD on frequency or helpfulness.

Table 3 displays FM reports of FM support for PWD in each of the 4 ethnic groups. FM in each of the 3 minority ethnic groups reported significantly more support than WNH American respondents for most items ( $P < .05$ ). Chinese American FM told PWD when they were doing poorly significantly more often than African Americans ( $P < .05$ ); other types of support did not differ among minority ethnic groups. The WNH American FM had significantly lower ( $P < .05$ ) scores than each of the minority subgroups on the composite measure, and the other ethnic groups were similar to each other.

Table 4 displays reports from PWD of FM support for PWD in each of the 4 ethnic groups. WNH Americans consistently reported the lowest frequency of support, with 1 or more ethnic minorities reporting more frequent support for PWD on all except 1 item (listening to PWD). There were significant differences among the

Table 2

FM and PWD Ratings of Frequency and Helpfulness of FM Support for PWD in Total Sample<sup>a</sup>

Support Behavior	FM-Rated Frequency, Mean	PWD-Rated Frequency, Mean	FM Versus PWD, P of delta	FM-Rated Helpfulness, % Yes	PWD-Rated Helpfulness, % Yes	FM Versus PWD, P of delta
Reporting PWD are doing well	3.54 d	3.31 c	.012	73.1 a,b	54.6 b,c	<.001
Reporting PWD are doing poorly	3.15 e	3.28 c	.671	46.2 d	44.3 d	.209
Listening to PWD	4.12 a	3.81 a	.002	78.2 a	56.5 a,b	<.001
Advising PWD	3.58 d	3.33 c	<.001	56.7 c	38.5 e	<.001
Assisting PWD	3.94 b	3.76 a	<.001	77.3 a	60.3 a	<.001
Doing activities for PWD	3.81 c	3.56 b	<.001	59.7 c	43.0 d	<.001
Doing activities with PWD	3.56 d	3.40 c	.075	69.8 b	50.2 c	<.001
All items combined	3.67	3.50	<.001	65.9	49.6	<.001

Abbreviations: FM, family member; PWD, person with diabetes.  
<sup>a</sup>Means are raw scores: 1 = *never*, 5 = *always*. In each column, values with the same letter are not significantly ( $P < .05$ ) different from other values in that column; values that do not share a letter are significantly different from other values in that column. Highest values indicated by letter "a" and lower values have consecutive letters in descending alphabetical order.  $P$  values for comparison of FM and PWD are taken from the model adjusted for gender, age, ethnicity, and target rated = spouse versus other.

Table 3

FM Report of Frequency of FM Support for PWD by Ethnicity (Mean Score, 1 = never, 5 = always)<sup>a</sup>

Support Behavior	White Non-Hispanic American (n = 105)	African American (n = 47)	Hispanic American (n = 46)	Chinese American (n = 40)
Reporting PWD are doing well	3.34 <sup>§</sup>	3.65	3.84 <sup>†</sup>	3.62
Reporting PWD are doing poorly <sup>a</sup>	2.81 <sup>§  </sup>	3.02 <sup>  </sup>	3.45 <sup>†</sup>	3.88 <sup>†‡</sup>
Listening to PWD	3.97	4.36	4.34	3.99
Advising PWD*	3.11 <sup>‡§  </sup>	3.73 <sup>†</sup>	4.08 <sup>†</sup>	4.10 <sup>†</sup>
Assisting PWD*	3.58 <sup>‡§  </sup>	4.17 <sup>†</sup>	4.35 <sup>†</sup>	4.13 <sup>†</sup>
Doing activities for PWD	3.38 <sup>‡§  </sup>	4.02 <sup>†</sup>	4.36 <sup>†</sup>	4.04 <sup>†</sup>
Doing activities with PWD	3.34 <sup>  </sup>	3.64	3.72	3.89 <sup>†</sup>
All items combined	3.36 <sup>‡§  </sup>	3.80 <sup>†</sup>	4.02 <sup>†</sup>	3.95 <sup>†</sup>

Abbreviations: FM, family member; PWD, person with diabetes.  
<sup>a</sup>Means and significance levels taken from model adjusted for gender, age, and target rated = spouse versus other.  
<sup>\*</sup>Significant ( $P < .05$ ) interaction of ethnicity with FM/PWD (compare to Table 4).  
<sup>†</sup>Significantly ( $P < .05$ ) different from white non-Hispanic American.  
<sup>‡</sup>Significantly ( $P < .05$ ) different from African American.  
<sup>§</sup>Significantly ( $P < .05$ ) different from Hispanic American.  
<sup>||</sup>Significantly ( $P < .05$ ) different from Chinese American.

ethnic minority groups for 3 behaviors, with African and Hispanic Americans reporting more frequent support than Chinese Americans ( $P < .05$ ).

When comparing Tables 3 and 4, there was a statistically significant ( $P < .05$ ) difference in the pattern across ethnicities for FM versus PWD on reporting when PWD

Table 4

PWD Report of Frequency of FM Support for PWD by Ethnicity (Mean Score, 1 = *never*, 5 = *always*)\*

Support Behavior	White Non-Hispanic American (n = 220)	African American (n = 93)	Hispanic American (n = 125)	Chinese American (n = 102)
Reporting PWD are doing well	3.03 <sup>‡§  </sup>	3.65 <sup>†</sup>	3.53 <sup>†</sup>	3.32 <sup>†</sup>
Reporting PWD are doing poorly**	2.90 <sup>‡§</sup>	3.75 <sup>†§</sup>	3.71 <sup>†§</sup>	3.12 <sup>‡§</sup>
Listening to PWD	3.74	3.98 <sup>  </sup>	4.00 <sup>  </sup>	3.59 <sup>‡§</sup>
Advising PWD**	2.85 <sup>‡§  </sup>	3.88 <sup>†  </sup>	3.84 <sup>†  </sup>	3.29 <sup>†§</sup>
Assisting PWD**	3.58 <sup>§</sup>	3.79	4.04 <sup>†</sup>	3.76
Doing activities for PWD	3.29 <sup>‡§  </sup>	3.69 <sup>†</sup>	3.83 <sup>†</sup>	3.70 <sup>†</sup>
Doing activities with PWD	3.13 <sup>‡§  </sup>	3.57 <sup>†</sup>	3.67 <sup>†</sup>	3.48 <sup>†</sup>
All items combined	3.22 <sup>‡§  </sup>	3.77 <sup>†  </sup>	3.80 <sup>†  </sup>	3.48 <sup>†§</sup>

Abbreviations: FM, family member; PWD, person with diabetes.  
\*Means and significance levels taken from model adjusted for gender, age, and target rated = spouse versus other.  
\*\*Significant ( $P < .05$ ) interaction of ethnicity with FM/PWD (compare to Table 3).  
† Significantly ( $P < .05$ ) different from white non-Hispanic American.  
‡ Significantly ( $P < .05$ ) different from African American.  
§ Significantly ( $P < .05$ ) different from Hispanic American.  
|| Significantly ( $P < .05$ ) different from Chinese American.

are doing poorly, advising PWD, and assisting PWD but not for other individual items nor the composite measure.

Table 5 displays FM-perceived helpfulness of FM support for PWD in each of the 4 ethnic groups. WNH American FM rated all support behaviors, except listening to PWD and assisting PWD, as significantly less helpful than did 1 or more ethnic minorities ( $P < .05$ ). Among ethnic minorities, Chinese American FM rated support helpfulness significantly higher than Hispanic Americans for reporting when PWD are doing poorly, advising PWD, and assisting PWD and higher than African Americans for the latter 2 behaviors ( $P < .05$ ).

For the composite measure of support helpfulness, WNH American FM had significantly lower scores, and Chinese Americans had significantly higher scores than African or Hispanic Americans; the latter 2 groups were not significantly different from each other.

Table 6 shows PWD-perceived helpfulness of FM support for PWD in each of the 4 ethnic groups. WNH American PWD rated all support behaviors, except listening to PWD and doing activities with PWD, as significantly less helpful than did 1 or more ethnic minorities ( $P < .05$ ). Among ethnic minorities, Chinese Americans rated support helpfulness significantly higher than Hispanic Americans for reporting when PWD are doing

poorly and higher than African Americans for advising PWD ( $P < .05$ ).

For the composite measure of support helpfulness, WNH American FM had significantly lower scores than all ethnic minorities ( $P < .05$ ). Chinese Americans had significantly higher scores than Hispanic Americans ( $P < .05$ ); African and Hispanic Americans were not significantly different from each other.

When comparing Tables 5 and 6, there was a statistically significant ( $P < .05$ ) difference in the pattern across ethnicities for FM versus PWD (ie, an interaction between respondent status and ethnicity) on doing activities for PWD and doing activities with PWD but not for other individual items nor the composite measure.

The composite scores for support frequency and support helpfulness were correlated .38 for PWD and .54 for FM (results not shown in tables). Correlations of scores for matched individual support frequency and support helpfulness items ranged from .23 to .35 (median = .27) for PWD and .28 to .52 (median = .39) for FM; correlations of scores for unmatched individual support frequency and support helpfulness items ranged from .08 to .27 (median = .17) for PWD and .10 to .36 (median = .23) for FM (results not shown in tables). Thus, there was a general tendency for frequency of support to be

Table 5

FM Report of FM Support Behaviors for PWD as Helpful by Ethnicity (% Yes)<sup>a</sup>

Support Behavior	White Non-Hispanic American (n = 105)	African American (n = 47)	Hispanic American (n = 46)	Chinese American (n = 40)
Reporting PWD are doing well	64.3 <sup>  </sup>	80.7	73.0	90 <sup>†</sup>
Reporting PWD are doing poorly	29.1 <sup>†§  </sup>	58.7 <sup>†</sup>	48.0 <sup>†  </sup>	74.3 <sup>†§</sup>
Listening to PWD	78.3	79.6	74.1	80.8
Advising PWD	39.3 <sup>†§  </sup>	58.3 <sup>†  </sup>	65.7 <sup>†  </sup>	90.2 <sup>††§</sup>
Assisting PWD	74.9	73.8 <sup>  </sup>	73.4 <sup>  </sup>	92.2 <sup>†§</sup>
Doing activities for PWD*	43.9 <sup>†§  </sup>	65.3 <sup>†</sup>	73.0 <sup>†</sup>	78.9 <sup>†</sup>
Doing activities with PWD*	60.0 <sup>  </sup>	70.9	75.7	87.2 <sup>†</sup>
All items combined	55.7 <sup>†§  </sup>	69.6 <sup>†  </sup>	69.0 <sup>†  </sup>	84.4 <sup>††§</sup>

Abbreviations: FM, family member; PWD, person with diabetes.  
<sup>a</sup>Percentages and significance levels taken from model adjusted for gender, age, and target rated = spouse versus other.  
<sup>\*</sup>Significant ( $P < .05$ ) interaction of ethnicity with FM/PWD (compare to Table 6).  
<sup>†</sup>Significantly ( $P < .05$ ) different from White Non-Hispanic American.  
<sup>‡</sup>Significantly ( $P < .05$ ) different from African American.  
<sup>§</sup>Significantly ( $P < .05$ ) different from Hispanic American.  
<sup>||</sup>Significantly ( $P < .05$ ) different from Chinese American.

Table 6

PWD Report of FM Support Behaviors for PWD as Helpful by Ethnicity (% Yes)<sup>a</sup>

Support Behavior	White Non-Hispanic American (n = 220)	African American (n = 93)	Hispanic American (n = 125)	Chinese American (n = 102)
Reporting PWD are doing well	43.5 <sup>†§  </sup>	61.8 <sup>†</sup>	56.1 <sup>†  </sup>	70.2 <sup>†§</sup>
Reporting PWD are doing poorly	28.7 <sup>†§  </sup>	58.0 <sup>†</sup>	51.2 <sup>†</sup>	56.7 <sup>†</sup>
Listening to PWD	53.5	59.5	52.9	64.6
Advising PWD	23.7 <sup>†§  </sup>	42.9 <sup>†  </sup>	46.7 <sup>†</sup>	56.4 <sup>††</sup>
Assisting PWD	56.4 <sup>  </sup>	61.4	59.8	68.7 <sup>†</sup>
Doing activities for PWD	35.5 <sup>†  </sup>	50.7 <sup>†</sup>	41.7	53.7 <sup>†</sup>
Doing activities with PWD*	46.3	53.7	50.9	54.6
All items combined*	41.1 <sup>†§  </sup>	55.4 <sup>†</sup>	51.3 <sup>†  </sup>	60.7 <sup>†§</sup>

Abbreviations: FM, family member; PWD, person with diabetes.  
<sup>a</sup>Percentages and significance levels taken from model adjusted for gender, age, and target rated = spouse versus other.  
<sup>\*</sup>Significant ( $P < .05$ ) interaction of ethnicity with FM/PWD (compare to Table 5).  
<sup>†</sup>Significantly ( $P < .05$ ) different from White Non-Hispanic American.  
<sup>‡</sup>Significantly ( $P < .05$ ) different from African American.  
<sup>§</sup>Significantly ( $P < .05$ ) different from Hispanic American.  
<sup>||</sup>Significantly ( $P < .05$ ) different from Chinese American.



positively associated with perceived helpfulness, and this tendency was stronger when considering ratings of individual support behaviors.

## Discussion

The data regarding diabetes support by FM for PWD reveal both parallels and differences between PWD and FM. In terms of the different support behaviors, PWD and FM rate both frequency and helpfulness similarly. For frequency, both PWD and FM rated listening to PWD as highest, followed by assisting PWD and doing activities for PWD; they rated reporting PWD are doing poorly as lowest. For helpfulness, both PWD and FM rated listening to PWD, assisting PWD, and reported PWD are doing well as the 3 most helpful behaviors; they rated reporting PWD are doing poorly as (among the) least helpful. Despite these parallels for individual items, PWD rated the combined measures, as well as most individual behaviors, as less frequent and less helpful than FM rated them. Notably, the frequency and helpfulness scores of the lowest-rated behavior (reporting PWD are doing poorly) were similar.

Despite the differences between PWD and FM in ratings of support frequency and helpfulness, there is general agreement between them regarding which specific behaviors are more or less frequent and helpful. The more frequent and helpful behaviors involve emotional (listening to PWD) and instrumental (assisting PWD) forms of autonomy support,<sup>15</sup> with each leaving the PWD in the lead role (ie, these behaviors are empowering rather than disempowering). A parallel finding is revealed when comparing doing activities for PWD and doing activities with PWD; the latter is more empowering than the former and is regarded by both FM and PWD as more helpful. However, both PWD and FM report that doing activities for PWD are more frequent than doing activities with PWD. This suggests that the less empowering support strategy may be perceived as easier and/or more appealing than the more empowering strategy. Alternatively, it may simply be that there are more opportunities to do something for another person than with them because the latter requires mutual availability and coordination. Nevertheless, it is important to recognize that the more empowering strategies are regarded as more helpful.

Another interesting item-to-item comparison can be made between reporting PWD are doing well and reporting PWD are doing poorly. The wording of these items was designed to avoid bias and thereby permit a more

valid and meaningful comparison (as opposed to “praising PWD” vs “criticizing PWD”). Negative reporting was viewed as less helpful than positive reporting by both PWD and FM, and negative reporting was the only behavior that FM did not perceive as more helpful than PWD. Negative reporting also was the only item that FM reported as less frequent than PWD (albeit not significantly less). This suggests that FM either seek to avoid this behavior and/or that they are more reluctant to report it than other support behaviors, perhaps because they perceive it as less helpful.

It is comforting that PWD and FM have a similar perception of which items are more (or less) frequent and helpful. However, it should be noted that this similarity exists at the aggregate level (comparison of independent samples of PWD and FM), and the perception of these behaviors within any specific PWD/FM dyad might differ substantially; ultimately, the within-dyad (in)congruence in perception can influence the impact of these behaviors.<sup>16</sup> The differences between PWD and FM ratings of FM support behaviors are easy to understand. One simple explanation is optimistic bias on the part of FM (ie, they see most of their behaviors as more helpful than PWD do), which may lead them to report it as more frequent than PWD do. Alternatively, FM are more likely to be aware of the frequency of their own activities than are PWD because they have access to their motives for engaging in behaviors while PWD are at most aware only of the behaviors themselves.

There also are distinct patterns when comparing ethnic groups. At the most general level (ie, looking at the composite measures), WNH American PWD and FM rate FM support as less frequent and less helpful than all 3 ethnic minorities. Results are less consistent for comparisons among the ethnic minority groups. FM ratings of support frequency did not differ by ethnicity, but Chinese American PWD rated FM support frequency lower than the other 2 ethnic minority groups did. However, both Chinese American PWD and FM rated FM support helpfulness as the highest of the ethnic minority groups (although this difference was not significant for African American PWD). Despite the results for WNH Americans, it appears that ethnic group differences in frequency of support do not account for the group differences in perceived support helpfulness (ie, the differences in perceived helpfulness are not a result of support behaviors being performed more or less frequently). Conversely, ethnic group differences in



perceived support do not seem to account for the observed differences in frequency of support.

When examining the patterns across specific support items by (1) PWD versus FM and (2) ethnicity, the results mostly follow the pattern observed for the composite measures. One exception is for listening to PWD; unlike other support behaviors, there are no significant differences between ethnic groups for helpfulness and only a marginal difference for frequency (and only for PWD ratings) that does not conform to the pattern for other support behaviors. Another exception involves reporting PWD are doing poorly. Among PWD, Chinese Americans report the frequency of this behavior as lower than African Americans, while among FM, Chinese Americans report it as higher than African Americans. In terms of support helpfulness, only among Chinese Americans do FM report this behavior as more helpful than PWD. Thus, it seems that negative reporting is perceived differently by Chinese Americans than other ethnic groups.

There were also other differences between the patterns across specific support items by PWD versus FM and ethnicity. For support frequency, there was a significant interaction for advising PWD (Chinese American FM reported the highest frequency, while Chinese American PWD reported the lowest frequency among the ethnic minority groups). For support helpfulness, there were significant interactions for doing activities for PWD (Hispanic American FM reported higher helpfulness than WNH Americans, while Hispanic American PWD reported helpfulness that was similar to WNH Americans) and doing activities with PWD (Chinese American FM reported higher helpfulness than WNH Americans, while Chinese American PWD reported helpfulness that was similar to WNH Americans). Thus, it seems that, among some ethnic minority groups, PWD do not attribute the same elevated helpfulness to some support behaviors as FM do.

## Limitations

Measures of support frequency are subjective (participant self-report) rather than objective (eg, direct observation by an impartial rater). Thus, it is difficult to know if observed differences are real or due to different perspectives (PWD vs FM or among ethnic groups) or to bias (eg, social desirability). The questionnaires attempted to minimize bias by using value-neutral item wording, but this may not have been sufficient. Because of the limited sample size (especially for FM), the participants in this

study may not have been representative of the ethnic populations from which they were drawn.

It was noted above that the different perspectives of PWD and FM may affect their reporting of support and that the aggregate similarity of PWD and FM reports across support behaviors may disguise substantial within-dyad differences in perception of support. Moreover, an objective determination of whether FM support for PWD is helpful in terms of diabetes self-management would require analysis of the association of support with self-management behaviors and outcomes. Analysis of data from linked dyads would allow more insight into the nature of the findings.

## Implications

Diabetes self-management education and support (DSME/S) is the cornerstone that empowers PWD to make their daily self-management decisions. Diabetes self-management support refers to behavioral, educational, psychosocial, or clinical activities that assist PWD in implementing and sustaining the behaviors needed to manage their condition on an ongoing basis.<sup>17</sup> It has been increasingly recognized that, while the initial DSME/S is typically provided by a health care professional, ongoing support can be provided by a variety of sources, including FM. This study's findings across ethnic groups have shown that no single support activity by FM was considered universally helpful, despite the best intentions of FM. Emotional support provided by FM, such as listening to PWD and assisting PWD, was perceived as more helpful than doing things for PWD. Thus, an important message for health care professionals to share with FM is to focus more of their efforts on these empowering strategies to better support PWD.

PWD rated most support behavior as less frequent and less helpful than FM rated them. This mismatch in perception can be an obstacle to providing effective support for PWD. In addition, since FM support effort was not acknowledged to the same degree by PWD, FM may feel unappreciated, as previous findings from the DAWN2 study have shown that higher FM diabetes involvement was associated with negative psychological outcomes for FM; however, this negative impact was offset by a positive impact of the perceived helpfulness of their involvement.<sup>14,18,19</sup> Similarly, there is a positive association between PWD well-being and their perception of FM support.<sup>13,20,21</sup> To further bridge the divide in the perception

of support behaviors offered by FM, health care professionals should encourage frequent and honest communication between PWD and FM regarding what is helpful and focus on the activities that PWD consider helpful. This is important for reporting when PWD are doing poorly, the least helpful support behavior in this study. Special attention should be used in considering whether and when this behavior might be helpful and in developing a shared understanding of how this strategy should be implemented in any given situation.

These findings also have important implications regarding ethnic diversity in support for living with diabetes. WNH American PWD and FM rate FM support as less frequent and less helpful than all 3 ethnic minorities. The behavioral pattern in WNH Americans is consistent with an individual-oriented Western culture, in contrast to family-oriented and community-oriented cultures common in the other ethnic groups. However, there are distinct differences among ethnic groups. For example, only among Chinese Americans do FM rate reporting of PWD doing poorly as more helpful than PWD. This exception may be explained in the cultural context, where values tend to be family centered and important life decisions, including medical plans, are often decided with FM.<sup>10</sup> FM often have a strong sense of obligation to care for other members who are ill. The cultural norm is further reinforced in a predominantly immigrant population in which more than two-thirds of Chinese Americans are foreign born.<sup>22</sup> Among immigrants who may not have access to community resources and support available to other members in the general society, FM tend to share each other's responsibilities and rely on one another for support.<sup>23</sup> Under these social circumstances, FM who are eager to help may overestimate their helpfulness even as they execute their familial obligation through "tough love." However, it is important to note that the interactions of a FM as a caregiver with a PWD may be strongly affected by external factors such as immigration history, education level, and exposure to Western culture and could evolve with acculturation. To the authors' knowledge, studies regarding FM interactions with PWD in Chinese American patients are limited.

In summary, this study has demonstrated the complex interactions between FM and PWD in their perception of frequency and helpfulness of FM support for PWD. Better communication between FM and PWD regarding their expectations for offering or receiving support behaviors has the potential to improve well-being and

health outcomes for both groups. Furthermore, FM support profiles differ across ethnic groups. Health care professionals should consider these differences when treating individuals of culturally diverse backgrounds. Cultural respect or competency is defined by the National Institutes of Health as the ability of a health care professional to "deliver services that are respectful of and responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients."<sup>24</sup> Empathy and appreciation for the cultural values of PWD will enhance the provider-patient relationship, potentially leading to better health outcomes for people living with diabetes.

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