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Associations between Having an Informal Caregiver, Social Support, and Self-care among Low-income Adults with Poorly Controlled Diabetes

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Abstract

Objective: To determine whether the presence of an informal caregiver and the patient's level of social support are associated with better diabetes self-care among adults with poorly controlled diabetes.

Methods: Cross-sectional study using baseline data from 253 adults age 30–70 with poorly controlled diabetes. Participants who reported receiving assistance with their diabetes from a friend or family member in the past month were classified as having a caregiver. We used multivariate linear and logistic regression models to evaluate the associations between having a caregiver and level of social support with five self-reported diabetes self-care behaviors: diet, foot checks, blood glucose monitoring, medications, and physical activity.

Results: Compared to participants with no informal caregiver those with an informal caregiver were significantly more likely to report moderate or high medication adherence (OR=1.93, 95%CI: 1.07–3.49, p=0.028). When we included social support in the model, having a caregiver was no longer significantly associated with medication adherence (OR=1.50, 95%CI: 0.80–2.82), but social support score was (OR=1.22, 95%CI: 1.03–1.45, p=0.023).

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Discussion: Among low income adults with poorly controlled diabetes, having both an informal caregiver and high social support for diabetes may have a beneficial effect on medication adherence, a key self-care target to improve diabetes control.

Keywords

caregiver; social support; diabetes; self-care; adherence; self-management

Background

Diabetes is a common chronic condition that affects more than 29 million Americans.[1] Most people with diabetes engage in multiple self-care behaviors including taking medications, monitoring blood glucose levels, and eating a healthy diet in order to manage the condition.[1–3] Self-care can be challenging to maintain and about one in five adults with diabetes demonstrate poor diabetes control.[4] Patients with poor diabetes control are at higher risk for complications, frequently have other chronic health conditions, and are more likely to be in racial or ethnic minority groups.[4–5]

Informal caregivers - family or friends who provide unpaid help with chronic conditions or disabilities – assist with a variety of aspects of self-management and also are a source of social support for patients with diabetes. Regimen-specific instrumental support generally has been associated with higher rates of performing diabetes self-care activities,[8] and the presence of an informal caregiver has been associated with improved self-care activities, particularly medication adherence, in patients with other chronic conditions.[15–18] Social support is associated with better diabetes outcomes;[6] one mechanism is through improved self-care.[7–13] Social support includes emotional support, such as caring and showing empathy and instrumental support, such as tangible aid and services.[14] It remains unclear the extent to which having an informal caregiver helps patients manage their diabetes, and whether the influence of a caregiver differs by overall patient-level social support.

The goal of this study was to assess whether having an informal caregiver was associated with diabetes self-care in a population of adults with poorly controlled diabetes. Adults with poor diabetes control are an important patient group on which to focus given that these individuals are at high risk of diabetes complications and death and also have high health care utilization and costs.[19] We also considered whether the association was influenced by the patient's level of social support for diabetes. In order to improve diabetes control, it is important to understand whether increasing the engagement of informal caregivers for patients with poor control might be sufficient or if positive social support from these informal caregivers is necessary to change self-care behaviors.

Methods

Study Population

We used baseline data from the Peer Support for Achieving Independence in Diabetes (Peer-AID) study. This was a randomized trial of the effectiveness of in-home community health workers (CHWs) to increase self-efficacy and improve diabetes self-management among

287 low income patients with poorly controlled diabetes. Participants were recruited from the following sites in King County, WA: (1) Harborview Medical Center, a public safety-net hospital; (2) Department of Veterans Affairs (VA) Puget Sound Health Care System, a tertiary hospital that serves Veterans; and (3) Sea Mar Community Health Centers, a community-based health and human services organization that emphasizes serving Latinos. Eligibility criteria included: type 2 diabetes with a hemoglobin A1c value of 8.0% or higher during the three months before enrollment; a household income of less than 250% of the federal poverty level; age 30–70 at enrollment; English- or Spanish-speaking; and primary residence in King County, Washington. Additional details about the study design and intervention were previously published.[20] Data on participant demographics, health status, health history, self-care behaviors, and other characteristics were collected via a CHW-administered survey during the baseline visit. The trial was approved by the Institutional Review Boards at the University of Washington and the VA Puget Sound Health Care system. For this study, we restricted analyses to the 253 participants who answered questions about having a caregiver, social support, and their self-care behaviors. Participants who were excluded were older than those who were included (mean age 56.5 compared to 52.0; p=0.008); otherwise, the two groups were similar in terms of demographics, health status, and diabetes characteristics (i.e., baseline hemoglobin A1c (HbA1c), insulin use, and diabetes complications).

Main Predictors: Caregiver Status & Diabetes-Related Social Support

Participants were asked, “People may receive assistance from a friend or family member who helps with their health problems, long-term illness, or disability because of their diabetes. During the past month, did you receive any such care or assistance from a friend or family member?” Possible responses included yes and no. Participants who responded “yes” were classified as having a caregiver. These participants were also asked the relationship of the person who provided care to them.

We measured perceived diabetes-related social support using the four-item social support subscale of the Multidimensional Diabetes Questionnaire.[21] These questions ask respondents to rate the extent to which their spouse or significant other, family or friends, and health care team support them with or pay attention to them because of their diabetes. The rating scale ranged from 0 (not at all supportive) to 7 (extremely supportive) with higher scores indicating higher levels of support. Because two of the four items related only to a participant’s spouse or significant other and not all participants were partnered, we averaged the scores across items to which participants responded. This scale has shown adequate internal consistency and the social support subscale is distinct from other constructs measured in the Multidimensional Diabetes Questionnaire.[21]

Outcome Assessment: Diabetes Self-Care Activities

Participants were asked about the following practices related to diabetes management: diabetes-specific self-care, diabetes medication adherence, and physical activity.

We used the Summary of Diabetes Self-Care Activities (SDSCA) measure to assess the following self-care activities: (1) eating a healthy diet, (2) performing foot checks, and (3) blood glucose monitoring. Participants were asked on how many days during the past week they performed each activity, with possible responses ranging from 0 to 7 days.[22] The SDSCA has demonstrated construct validity and correlates well with interview- and diary-based assessments of self-management activities.[22]

We measured self-reported medication adherence using items developed by Morisky and colleagues.[23–24] Originally designed to assess hypertension medication adherence, the Morisky scale has subsequently been used for other conditions, including diabetes.[25–26] Scores ranged from 0 to 8 with higher scores indicating better diabetes medication adherence. We classified participants as having moderate or high adherence if they had a score of 6 or higher.[24]

To assess physical activity, we used the short form of the International Physical Activity Questionnaire (IPAQ) and classified participants in activity categories using the recommended approach.[27] This classification is based on activity-specific metabolic equivalent (MET) minutes and the frequency and duration of weekly walking, moderate physical activity, and vigorous physical activity. Because we expected physical activity to be somewhat low in this population, we collapsed the moderate and high activity categories into one group so that participants were either assigned to the low activity group or to a moderate/high activity group.

Covariates

At baseline, participants reported their age and gender. We created categories for participants' highest level of educational attainment and their marital status. Participants reported whether they had any type of health care insurance coverage (yes or no).

We asked whether participants had ever been diagnosed with each of the following health conditions: hypertension, heart disease or stroke, arthritis, bronchitis/emphysema/ chronic obstructive pulmonary disease, cancer (non-skin), and depression/anxiety. We also counted the number of these co-morbid conditions, with a maximum possible score of 6. Separately, we asked whether or not participants had ever been diagnosed with retinopathy, nephropathy, or neuropathy and also created a dichotomous variable to indicate whether participants had ever experienced at least one of these diabetes complications. Participants also reported whether or not they were currently prescribed insulin to treat their diabetes. Finally, we calculated the duration of their diabetes diagnosis by subtracting the age at which they reported being diagnosed from their age reported at the time of enrollment. We classified this as diagnosis within the past 0–5, 6–10, or >10 years.

We used the Energy and Mobility subscale from the Diabetes-39 to measure overall quality of life related to physical health.[28] The Diabetes-39 asks participants to rate how much their quality of life is affected by various aspects of diabetes on a scale from 1 (not at all affected) to 7 (extremely affected). The Energy and Mobility subscale includes 12 items relating to the impact of weakness, mobility and activity restrictions, diabetes complications and other health conditions. We scaled responses so that possible scores ranged from 0 to 100 with higher scores representing a greater effect on quality of life. The Energy and Mobility subscale scores were correlated with the SF-12 physical component summary (r=0.65 in the study sample) but were missing less frequently than SF-12 scores.

We measured self-efficacy using the Diabetes Management Self-Efficacy Scale, calculated the sum of scores on 20 items with a maximum of 200 and higher scores indicating greater self-efficacy.[29]

Statistical Analysis

First, we compared characteristics of participants with and without a caregiver using chi-square tests for categorical variables and t-tests for continuous variables. We also compared mean scores on diabetes self-care, medication adherence, and physical activity among participants with and without a caregiver. We compared both overall scores and items; our purpose in comparing individual items was to identify specific areas where caregivers might be more or less influential.

We used three separate linear regression models and two logistic regression models to evaluate the cross-sectional association at baseline between having a caregiver and each of the five self-care behaviors. We ran crude (unadjusted) models and also two sets of adjusted models. In adjusted models, we included participant age, gender, educational attainment, and physical health status as *a priori* covariates in all five models, and we added Hispanic ethnicity as a covariate in all models because it significantly differed between participants with and without caregivers. In addition, we expected blood glucose monitoring and medication adherence might be influenced by health care costs and insulin prescription and included indicator variables for each of these characteristics in these two models. We considered social support as an aspect of the support provided by informal caregivers but also were interested in understanding whether social support alone – independent of caregiver presence – was associated with diabetes self-care and therefore ran the adjusted models both with and without social support. We considered potential interactions between caregiver presence and gender and between caregiver presence and education in each model and considered $p<0.05$ for the interaction term to be statistically significant.

We calculated power using Stata's power command with $\alpha=0.05$, a standard deviation of 2.5 for continuous measures, and the observed sample sizes of participants with and without informal caregivers. We used independent sample t-tests to estimate power and effect sizes for continuous outcomes and likelihood ratio tests for differences in proportions to estimate measures for categorical outcomes. All analyses were conducted in Stata 14.0 (College Station, TX).

Results

The study included 253 people, most of whom had at least one comorbid chronic condition (90%), fair or poor general health (60%), and a high school education or less (60%). Participants were from diverse racial and ethnic groups (45% white, 25% black, and 43% Hispanic). Ninety-four participants (37%) reported receiving care from a family member or friend in the past month for their diabetes. Among these, 35 caregivers were the participant's spouse (37%). Other caregiver relationships included the participant's child (23%), sibling (12%), parent (3%), other relative (2%), and non-relative (22%).

Participants with a caregiver had higher educational attainment than those with no caregiver, but poorer physical health based on comorbidity burden and Diabetes-39 Energy and Mobility scores (Table 1). Respondents with a caregiver had significantly higher overall social support ($p<0.001$), including higher support from their spouse/partner and from family and friends. Social support from health care providers was similar regardless of caregiver presence. Age, HbA1c, prevalence of a diabetes complication, diabetes duration, insulin prescription, and self-efficacy were similar among people with and without a caregiver.

In unadjusted analyses, participants with a caregiver were more likely to have moderate or high medication adherence (63%) than participants with no caregiver (50%, p=0.04; Table 2). Specifically, participants with a caregiver were less likely than participants without a caregiver to report they did not take their diabetes medications in the past two weeks (31% versus 44%, p=0.04), they cut back on their medications because they were feeling worse (13% versus 23%, p=0.04), or they stopped taking their medications when their diabetes was under control (12% versus 23%, p=0.02). Foot care, blood glucose monitoring, healthy eating, and physical activity were similar across groups. For continuous measures, we had about 80% power to detect a 0.9-point difference in self-care scores between participants with and without caregivers. For categorical outcomes, we had about 80% power to detect an odds ratio of 2.1 or greater when comparing respondents with and without a caregiver.

After adjusting for covariates, the association between having a caregiver and medication adherence remained. There was no evidence of effect modification by gender or education in any models. Participants with a caregiver were significantly more likely to report having moderate or high medication adherence than participants with no caregiver (OR=1.93, 95%CI: 1.07–3.49, p=0.028; Table 3). When we added the level of social support to the model, respondents with a caregiver had an attenuated odds of greater medication adherence than respondents without a caregiver but the association was no longer statistically significant (OR=1.50, 95%CI: 0.80–2.82, p=0.21). However, social support score was associated with better medication adherence in this model: for every one-point increase in social support, the odds of having moderate or high medication adherence increased by 22% (OR=1.22, 95%CI: 1.03–1.45, p=0.023). There were no significant differences in healthy eating, checking feet, checking sugar, or physical activity across participants with and without a caregiver. Higher social support was associated with healthy eating (B= 0.20, 95%CI: 0.02–0.38, p=0.029).

Discussion

We found that low-income patients with poorly controlled diabetes who had a caregiver had about twice the odds of moderate or high medication adherence compared to those with no caregiver. In particular, caregivers helped patients take their medications more consistently: patients with a caregiver were less likely to report they had stopped taking their medication because they felt worse or because their diabetes was controlled. The association between having a caregiver and medication adherence was attenuated and no longer statistically significant when we also included social support in the model; instead, greater social support was associated with higher odds of medication adherence. These results are consistent with previous studies of both caregiver involvement and social support in diabetes and other chronic conditions.[7–12, 15–18] For example, Nicklett and Liang found that people with diabetes-related social support had higher odds of medication adherence (OR=1.59).[11] Also, Trivedi and colleagues found – among patients with chronic obstructive pulmonary disease – long-acting beta agonist and antihypertensive medication adherence was higher among participants with a caregiver (81%) than among those with no caregiver (68%).[15] However, our findings diverge somewhat from those of Rosland and colleagues in which social support and social connectedness were associated with improved lifestyle self-care behaviors – physical activity and diet – but not medical behaviors including medication adherence.[13] It is possible that this difference is a result of our focus on adults with poorly controlled diabetes: these patients may need additional supports to make substantial lifestyle changes, but having diabetes-specific care and support may be adequate for changing daily medical behaviors.

We also found that study participants infrequently reported receiving assistance from a family member or friend in spite of the fact that all patients had poorly controlled diabetes and about half had experienced a diabetes complication. Participants who did have an informal caregiver rated their support from both significant others and other family members or friends more highly, on average, than people with no informal caregiver, consistent with our expectation that caregivers might improve self-care by increasing social support and through other mechanisms. Given the positive impacts caregivers and/or others providing social support to people with diabetes can have, this result highlights a potential need to increase the availability of informal supports for low-income adults with poor diabetes control. One approach may be recruiting friends or family members from outside the home, since several recent studies demonstrate that engaging these informal caregivers is a promising approach for improving self-care and disease outcomes.[30–32] Another strategy to improve self-care among people with existing in-home caregivers is to provide additional information or skills training to help them support patients with poorly controlled diabetes in improving their self-care. Scarton et al. found that caregivers expressed substantial needs for more information about helping their care recipient with diabetes self-care, particularly around diet and blood glucose monitoring.[33]

This study is subject to several limitations. First, as in all assessments of self-reported self-care behaviors, the possibility of social desirability bias exists, though we have no reason to believe this would have differed between participants with and without a caregiver or by the level of social support. Second, our definition of having a caregiver was broad; therefore, we may have classified people who received only periodic or minimal assistance from a spouse in our group of respondents with a caregiver. Third, we did not collect information about how long the caregiver had provided assistance, what types of support the caregiver provided, the quality of care, or the caregiver's confidence in promoting self-care. These additional details would be helpful in understanding whether caregiver characteristics modify or explain the association with self-care. Likewise, we did not collect information about the caregiver's or participant's perception of the relationship quality. Mayberry and colleagues found that patients with diabetes reported obstructive family behaviors about as often as they reported supportive behaviors, and obstructive behaviors were associated with poorer self-care while supportive behaviors were associated with better self-care.[34] Third, the cross-sectional nature of the data make it unclear whether having a caregiver and high social support is causally related to self-care behaviors. Longitudinal studies of caregiving, social support, and diabetes self-care will be vital to clarifying the direction of the association and to understanding how changing support can change outcomes. We plan to use the final study data to conduct a longitudinal analysis in this sample. Finally, our ability to detect significant differences was limited by the small number of participants who had a caregiver.

The strengths of this study include its use of well-validated measures of diabetes self-care activities and its focus on low-income adults with poorly controlled diabetes, a patient group that is at high risk for diabetes complications. We also identified some potential mechanisms through which caregivers help with medication adherence, namely by increasing social support for diabetes and by helping patients take their medications consistently. Given the diversity of educational attainment, race/ethnicity, age, and gender among participants, we expect the results would be generalizable to the population of low-income adults with poorly controlled diabetes.

This study adds to a growing body of literature that suggests informal caregivers are helpful in facilitating medication adherence among adults with chronic conditions. We found this to be true among low-income adults with poorly controlled diabetes. It also suggests, as have other studies, that social support improves self-care. Engaging informal caregivers and increasing social support from family and friends may be effective strategies for improving diabetes self-care, particularly medication adherence, a key self-care target for poorly controlled diabetes. Improving medication adherence has the potential to result in diabetes control, which in turn reduces the risks of diabetes complications, hospitalization, and death.[19]

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Table 1.

Characteristics of participants with and without an informal caregiver who assists with diabetes-related illness or disability.

Variable	Category	No Diabetes Caregiver Presen (n=159)	Diabetes Caregiver Present (n=94)	p-value*
Age	Mean (SD)	51.1 (9.6)	53.5 (9.1)	0.06
Gender	Female	44.7%	55.3%	0.10
Marital status	Married/ partnered	37.7%	51.1%	0.04
	Divorced/separated	34.6%	22.3%	0.04
	Widowed	5.7%	5.3%	0.91
	Never married	22.0%	21.3%	0.89
Educational attainment	Grade 8 or less	28.3%	12.8%	0.006
	Some high school	13.8%	7.5%	
	High school or GED	20.1%	35.1%	
	Some college	27.7%	33.0%	
	College or beyond	10.1%	11.7%	
Race	White only	46.5%	42.6%	0.54
	Black or African American only	21.4%	31.9%	0.06
	American Indian or Alaska Native only	6.3%	5.3%	0.75
	Asian or Pacific Islander only	6.3%	5.3%	0.75
	Other race only	10.7%	6.4%	0.25
	Multiple races	6.9%	7.5%	0.87
	Refused	1.9%	1.1%	0.61
Spanish, Hispanic, or Latino ethnicity	Yes	48.4%	34.0%	0.03
Hemoglobin A1c	Mean (SD)	8.9 (1.8)	8.8 (1.8)	0.71
Prescribed insulin	Yes	63.5%	73.4%	0.11
Diabetes duration	0–5 years	34.6%	26.6%	0.23
	6–10 years	27.0%	24.5%	
	>10 years	38.4%	48.9%	
Co-morbid chronic health conditions	Cancer	5.0%	7.5%	0.43
	COPD, emphysema, asthma, or bronchitis	19.5%	38.3%	0.001
	Heart disease or stroke	13.8%	20.2%	0.18
	Arthritis	30.2%	50.0%	0.002
	Depression or anxiety	50.3%	58.5%	0.21
	High blood pressure	67.9%	77.7%	0.10
	Mean count (SD)	1.9 (1.2)	2.5 (1.4)	0.001
Diabetes-related complication (Retinopathy, nephropathy, neuropathy)	At least one	45.9%	51.1%	0.43
	None	50.9%	42.6%	0.20
	Missing	3.1%	6.4%	0.22

Variable	**Category**	**No Diabetes Caregiver Presen (n=159)**	**Diabetes Caregiver Present (n=94)**	**p-value**[*]
Health insurance coverage	Any	66.7%	76.6%	0.10
Energy and mobility, Diabetes-39	Mean score (SD); range 0–100	34.5 (24.7)	47.8 (28.2)	0.001
Social support for diabetes (items and summary score)	Spouse/significant other help or support (N=135)	5.5 (2.1)	6.2 (1.4)	0.03
	Other friends/family help or support	3.5 (2.9)	5.0 (2.4)	0.001
	Spouse/significant other pays attention (N=135)	5.2 (2.5)	6.3 (1.6)	0.004
	Doctor/health care team help or support	5.9 (1.8)	6.1 (1.7)	0.50
	Mean score (SD); range 0–7	4.7 (1.8)	5.7 (1.3)	<0.001
Self-efficacy	Mean score (SD); range 0–200	149.9 (31.8)	144.1 (40.3)	0.21

[*] P-value for difference between participants with and without a diabetes caregiver at baseline based on a chi-square test for categorical measures or a two-tailed t-test for continuous measures.

Table 2.

Mean self-care summary scores and item scores by caregiver presence.

Self-care behavior category and items	No Caregiver Present (n=159)	Caregiver Present (n=94)	p-value[*]
General diet			
Summary score (range: 0–7)	3.9 (2.3)	4.0 (2.5)	0.91
Followed a healthy eating plan last week, mean (SD)	3.8 (2.7)	4.0 (2.7)	0.64
Followed a healthy eating plan last month, mean (SD)	4.1 (2.6)	4.0 (2.7)	0.77
Foot care			
Summary score (range: 0–7; mean (SD))	4.1 (2.2)	4.2 (2.4)	0.56
Checked feet, mean (SD)	5.0 (2.6)	5.0 (2.6)	0.83
Inspected inside shoes, mean (SD)	3.2 (3.2)	3.4 (3.3)	0.52
Blood glucose monitoring			
Summary score (range: 0–7; mean (SD))	3.4 (2.9)	3.4 (2.9)	0.93
Tested blood sugar, mean (SD)	3.8 (3.0)	3.9 (3.0)	0.91
Tested as recommended by provider, mean (SD)	3.0 (3.2)	3.0 (3.1)	0.96
Diabetes medication adherence			
Moderate or high adherence category	49.7%	62.8%	0.04
Sometimes forget	54.4%	43.0%	0.08
Did not take in past 2 weeks	44.0%	30.9%	0.04
Cut back because felt worse	23.3%	12.8%	0.04
Forget to bring meds	30.2%	27.7%	0.67
Did not take yesterday	15.1%	8.5%	0.13
Stop taking when diabetes controlled	23.3%	11.7%	0.02
Feel hassled by treatment plan	45.9%	44.7%	0.85
Difficulty remembering			
All the time	2.5%	4.3%	0.54
Usually	2.5%	1.1%	
Sometimes	16.4%	11.7%	
Once in a while	28.3%	24.5%	
Never/rarely	50.3%	58.5%	
Physical activity			
Moderate or high physical activity category	37.1%	34.0%	0.62
Days/week of moderate activity, mean (SD)	1.3 (2.1)	1.1 (2.0)	0.32
Days/week of vigorous activity, mean (SD)	0.6 (1.7)	0.5 (1.3)	0.51

[*] P-value for difference between participants with and without a caregiver at baseline based on a chi-square test for categorical measures or a two-tailed t-test for continuous measures.

Table 3.

Association between participant characteristics and self-care behaviors by caregiver presence and by caregiver presence and social support categories in multivariate linear (general diet, foot checks, blood glucose monitoring) and logistic (medication adherence, physical activity) regression models.[*]

Category	Self-care behavior				
	General diet	**Foot checks**	**Blood glucose monitoring**	**Moderate or high diabetes medication adherence**	**Moderate or high physical activity**
	B (95% CI)	**B (95% CI)**	**B (95% CI)**	**OR (95% CI)**	**OR (95% CI)**
Models excluding social support					
Caregiver	0.04 (−0.59 – 0.66)	0.20 (−0.40 – 0.81)	−0.35 (−1.03 – 0.34)	1.93[1] (1.07 – 3.49)	1.22 (0.68–2.19)
No caregiver	Ref	Ref	Ref	Ref	Ref
Models including social support					
Caregiver	−0.24 (−0.60 – 0.65)	0.22 (−0.43 – 0.87)	−0.37 (−1.10 – 0.37)	1.50 (0.80 – 2.82)	1.44 (0.77 – 2.71)
No caregiver	Ref	Ref	Ref	Ref	Ref
Social support score	0.20[2] (0.02 – 0.38)	−0.02 (−0.20 – 0.15)	0.01 (−0.19 – 0.22)	1.22[3] (1.03 – 1.45)	0.88 (0.74 – 1.04)

Ref: reference category

[*] General diet, foot checks, and blood glucose monitoring were scored on a scale of 0–7 days per week; more positive βs represent better self-care. All models included age, gender, educational attainment, Hispanic ethnicity, and physical health status (Energy and Mobility score from Diabetes-39). Models for blood glucose monitoring and diabetes medication adherence also included health insurance coverage (yes/no) and insulin prescription (yes/no).

[‡] Social support scores ranged from 0 to 7 with higher values representing more support. Regression coefficient represents change in self-care behavior associated with a one-unit increase in social support score.

[1] P=0.028

[2] P=0.029

[3] P=0.023