ORIGINAL ARTICLE

Patient Understanding of Diabetes Self-Management: Participatory Decision-Making in Diabetes Care

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Abstract

Objective:

Our aim was to determine whether patient participation in decision-making about diabetes care is associated with understanding of diabetes self-management and subsequent self-care practices. We also identified issues that would impact messaging for use in mobile diabetes communication.

Research Design and Methods:

A cross-sectional observational study was conducted with type 2 diabetes patients ($n = 81$) receiving their care at the University of Maryland Joslin Diabetes Center. A convenience sample of patients were eligible to participate if they were aged 25–85 years, had type 2 diabetes, spoke English, and visited their physician diabetes manager within the past 6 months. In-person patient interviews were conducted at the time of clinic visits to assess patient understanding of diabetes management, self-care practices, and perceptions of participation in decision-making about diabetes care.

Results:

African Americans reported fewer opportunities to participate in decision-making than Caucasians, after controlling for education [mean difference (MD) = -2.4, $p = .02$]. This association became insignificant after controlling for patient–physician race concordance (MD = -1.5, $p = .21$). Patient understanding of self-care was predicted by having greater than high school education (MD = 3.6, $p = .001$) and having physicians who involved them in decision-making about their care. For each unit increase in understanding of diabetes self-care, the mean patient self-care practice score increased by 0.16 ($p = .003$), after adjustment for patient race and education.

Conclusions:

Patient participation in decision-making is associated with better understanding of care. Participation in decision-making plays a key role in patient understanding of diabetes self-management and subsequent self-care practices. Patients with limited education need specific instruction in foot care, food choices, and monitoring hemoglobin A1c.

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Introduction

Diabetes patients who report discussing their treatment goals and management strategies with their physicians tend to have better clinical outcomes than those who do not.[1,2] Effective patient–physician communication can promote behaviors such as daily monitoring, which is an important part of the patient role in diabetes self-management.[3,4] Patient–physician communication has been shown to significantly affect patient decisions about their health practices and the behaviors that are associated with health outcomes. Effective communication about diabetes often provides patients with clear information, emotional support, opportunities for shared decision-making, and agreement on the nature of their medical problems and the need for follow-up.[5–8]

Patients who receive information, instructions, and guidance during medical appointments are more likely to accept their health problems, understand their treatment options, follow treatment plans, and modify their compliance behaviors.[9,10] Satisfaction with this type of communication improves when the physician takes into account the patient's perspective on health.[9] Overall, patients of physicians who are involved in participatory treatment decisions report being more satisfied with their medical appointments and are more successful at self-management and compliance with treatment.[11–13] Kaplan and colleagues[12] first described the practice of participatory decision-making among physicians and their patients during medical encounters in 1995. They found that physicians who involved their patients in participatory decisions were likely to present treatment options to them and engender in them a sense of personal responsibility for their medical care.

Participatory decision-making (PDM) has been investigated among diverse groups of patients. In several studies, minority patients have reported poorer quality of interaction with their physicians.[13,14] African American patients, for example, report receiving less information and fewer opportunities for PDM during their medical appointments than their Caucasian counterparts.[9,12–14] They recall shorter office visits and lower satisfaction with physicians who are race discordant.[15–17]

Communication between patients and providers is an essential element in PDM and important to the success of automated messaging, telehealth, or mobile technology diabetes management. The exploration of Internet and telehealth communication barriers have focused on the influence of literacy, sociodemographic factors, and cultural appropriateness.[18–24]

This study was designed to investigate and compare patient participation in decision-making about their diabetes self-care in samples of African American and Caucasian diabetes patients at an urban medical center. We explored the patient side of the patient–physician communication equation by race. We hypothesized that diabetes patients who reported greater involvement in participatory decision-making about their diabetes care would demonstrate better understanding of guidelines for diabetes self-care, more complete self-management practices, and better self-reported glycemic control. This hypothesis was investigated for the study sample overall and by racial subgroups.

Research Design and Methods

Procedures

Ten-minute in-person interviews were conducted with patients with type 2 diabetes while waiting for their care at the University of Maryland Joslin Diabetes Center clinics during July and August of 2005. Patients were interviewed verbally one time and given a printed copy of the survey so that they could follow along with the interview for this cross-sectional study. Those eligible to participate were 25 to 85 years old, were diagnosed with type 2 diabetes, were African American or Caucasian, spoke English, had not participated in the self-management educational program offered by the Joslin Diabetes Center, and visited their diabetes physician at least once within the past 6 months. Approval for this study was obtained from the University of Maryland Institutional Review Board.

Measures

Patient and Physician Characteristics

Age, gender, education level, income, health insurance, and race/ethnicity were self-reported by patients during study interviews. Patients also reported the gender and race of the physicians who provided their diabetes care.

Glycemic Control

Glycemic control was assessed by patient self-reports with the question, "In your last visit to your regular doctor, did he/she tell you that your blood sugar levels were

controlled?" Possible responses were yes, no, or not sure/don't know.

Diabetes Self-Management Practices

Diabetes self-management practices were assessed with five items adapted from a valid scale developed by Heisler and associates.[4] Participants were asked, "How often do you do the following things to take care of your diabetes: take diabetes medication, daily physical activity, follow eating plans, check blood sugar, and check feet for changes?" Response options on a four-point Likert scale were none of the time (0), some of the time (1), most of the time (2), and all of the time (3). Responses on the five items were added to produce a total self-management practices score for each participant, ranging from 0 to 15.

Understanding of Diabetes Self-Care

Understanding of diabetes self-care was assessed with nine items adapted from a scale developed and validated by Heisler and associates.[4] Participants were asked "How well do you understand how to care for your feet, how to take medications, what to do for symptoms of low blood sugar, how to make food choices, how and when to test your blood sugar, diabetes complications, glucose control (daily target glucose range), glucose control [three-month hemoglobin A1c (HbA1c) test], and what to do for symptoms of high blood sugar?" Response options on a four-point Likert scale were not at all (0), somewhat (1), mostly (2), and completely (3). Responses on the nine items were added to produce a total understanding of diabetes self-care score for each participant, ranging from 0 to 27.

Participatory Decision-making during Medical Appointments

Participatory decision-making during medical appointments was assessed with four items from a valid survey that asked, "How often does your primary doctor (a) offer you choices in your diabetes treatment, (b) discuss pros and cons of each choice with you, (c) get you to state which choice or option you like best, and (d) take your preferences into account when making diabetes treatment decisions?"[4,12] Response options on a four-point Likert scale were from none of the time (0), some of the time (1), most of the time (2), and all of the time (3). Responses on the four items were added to produce a total PDM scale score for each participant and ranged from 0 to 12.

Preferred Role in Medical Decision-making

Preferred role in medical decision-making was assessed with preference statements that were developed and validated by Degner and Sloan.[25] Patients were asked to select one of the five statements that best described their preferred way of making medical treatment decisions. Two statements indicated an "active" preference in which the patient preferred to make treatment decisions herself/himself, one statement indicated a "collaborative" preference in which the patient preferred sharing treatment decisions with her/his physician, and two statements indicated a "passive" preference in which the patient preferred the doctor to make the treatment decisions.

Statistical Analysis

Univariate analyses were used to describe participant characteristics, overall means, and standard deviations of study measures. Bivariate tabulation and t-tests examined the mean differences (MDs) of continuous variables within racial subgroups. Chi-square tests were used for comparing proportions among groups. Self-management practices and understanding of diabetes self-care scales were dichotomized using the 75th percentile as a cut-off point (excellent self-management practice or understanding of diabetes self-care was the 75th percentile or higher). The same was done for PDM. Logistic regression models were used to estimate adjusted odds ratios (ORs) of reporting excellent self-management practice, excellent understanding of diabetes self-care, or glycemic control. The independent variables included in each model were race, excellent PDM, and more than high school education. Separate models were constructed for each of the domains of the self-management practices and understanding of diabetes self-care. Participants were considered to have excellent self-management practices or understanding of diabetes self-care in separate domains if their responses to the domain questions were most of the time (2) or all of the time (3) for practice domains or mostly (2) or completely (3) for understanding domains.

Results

Participant and Physician Characteristics

Eighty-five patients were recruited to participate in this study, and 81 agreed to complete a study interview (95% response rate). The study sample included 49 African American and 32 Caucasian diabetes patients between 26 and 83 years of age. **Table 1** shows participant and physician characteristics that were estimated and compared by patient race. More than 60% of the sample were 50 years or older, 60.5% were African American, 48% were male, 44% had greater than a high school education, and almost all had health insurance (95%). Approximately 65% had been diagnosed with diabetes more than 5 years earlier, 41% of the participants had at least one complication related to their diabetes, and

54% were receiving insulin. African Americans were significantly less likely to report racial concordance with their physicians than Caucasian patients (23% versus 84%, $p < .0001$).

Table 2 presents the overall and race-specific mean scores for participants on the study predictor and outcome variable scales. African Americans scored significantly lower on the participation in decision-making scale during medical appointments (MD = -3.0, p = .01) and lower on the understanding of diabetes self-care scale (MD = -2.1, p = .03) than their Caucasian counterparts. No significant MDs were noted between African Americans and Caucasians in their reported diabetes self-management practices (MD = -1.5, p = .06).

Participatory Decision-making during Medical Appointments

Participatory decision-making was significantly associated with patient race in bivariate analyses. African Americans reported fewer opportunities to participate in decision-making compared to Caucasians, and their scores were lower on the PDM scale (mean score = 7.1 versus 9.3, respectively, p = .02). On the dichotomized scale, Caucasians were more likely to report participation in medical decisions compared to African Americans [41.9% versus 21.3%, OR = 2.7, 95% confidence interval (CI) = 0.99–7.3, p = .05). However, this association became statistically insignificant after adjusting for education, patient–physician racial concordance, and patient preference for playing an active or collaborative role in medical decision-making (adjusted OR = 2.7, 95% CI = 0.7–10.9, p = .16). This patient preference for playing an active or collaborative role was found to be an independent predictor of PDM. The odds of reporting participation in medical decisions was about six times higher in patients

Table 1.
Patient and Physician Characteristics by Patient Race

	African American N (%) n = 49	Caucasian N (%) n = 32	p value[a]
Patient			
Current age			
Mean in years (standard deviation)	53.7 (10)	56.5 (12.6)	0.28
≥50 years	31 (63.3)	23 (71.9)	0.42
Gender			
Male	22 (44.9)	17 (53.1)	0.46
Time since diagnosis			
More than 5 years	30 (61.2)	23 (71.8)	0.32
Receiving insulin			
Yes	28 (57.1)	15 (48.4)	0.44
Have at least one complication			
Yes	21 (42.8)	12 (37.5)	0.63
Employed or student			
Yes	20 (40.8)	17 (53.1)	0.27
Married or live with partner			
Yes	18 (36.7)	21 (65.6)	0.01
More than high school education			
Yes	17 (34.7)	19 (59.4)	0.03
Have health insurance			
Yes	45 (91.8)	32 (100)	0.09
Medicaid			
Yes	10 (21.2)	0 (0)	0.005[a]
Physician			
Gender			
Male	22 (44.9)	22 (68.8)	0.035
Race			
African American	11 (22.9)	2 (6.5)	0.057
Caucasian	27 (56.3)	26 (83.9)	
Patient–physician race concordance			
Yes	11 (22.9)	26 (83.8)	<0.0001

[a] p values for continuous variables calculated by Student's t test with pooled (equal) variances unless otherwise indicated, and p values for categorical variables calculated by Chi-square test, unless indicated as Fisher's exact test.

Table 2.
Mean Scores for Study Variables

Variable	Overall median (interquartile range)	African American median (interquartile range)	Caucasian median (interquartile range)	p value[a]
Participatory decision-making	9.0 (7.0)	8.0 (6.0)	11.0 (3.0)	0.01
Understanding of diabetes self-care	23.0 (6.0)	23.0 (6.0)	25.0 (4.0)	0.03
Diabetes self-management practices	10.0 (3.0)	11.0 (2.0)	9.5 (4.0)	0.06

[a] p values for continuous variables calculated by Wilcoxon rank sum test.

who preferred to play an active or collaborative role with their physicians as compared to those who preferred a passive role (adjusted OR = 6.3, 95% CI = 1.5–26.0, p = .01) after adjusting for patient race, education, and patient–physician racial concordance.

Diabetes Self-management Practices

African Americans reported slightly better overall self-management practice compared to Caucasians, but the difference was not statistically significant (MD = 0.92 ± 0.55, p = .10). Excellent PDM was not significantly associated with excellent diabetes self-management practices, as defined in the statistical analysis section. The logistic regression model with patient race, excellent PDM, and education showed that none of these variables were independent predictors of excellent self- management practices (**Table 3**).

We also modeled each of the five self-management domains separately (data not shown) and did not find any significant adjusted associations between race, education, and excellent PDM with each domain of self-management.

In addition, we examined the associations between excellent understanding and overall/individual excellent self-care, controlling for patient race and education. Excellent understanding of self-care was not a predictor for overall excellent practice of self-care (crude OR = 1.5, 95% CI = 0.6–4.3, p = .41). However, patients with

excellent understanding of self-care had higher odds of following eating plans (adjusted OR = 4.0, 95% CI = 1.2–14.1, p = .03) and possibly higher odds of checking feet for changes (adjusted OR = 4.2, 95% CI = 0.9–19.8, p = .07). African Americans reported better adherence to monitoring blood sugar than Caucasians (adjusted OR = 4.1, 95% CI = 1.2–14.5, p = .03) and higher odds of checking feet for changes (adjusted OR = 3.5, 95% CI = 1.04–11.8, p = .04).

Patient Understanding of Diabetes Self-Care

Overall mean scores for understanding of diabetes self-care were lower for African Americans than Caucasians (mean score 7.1 versus 9.3, p = .07). Caucasians had almost five times higher odds of excellent understanding compared to African Americans (OR = 4.7, 95% CI = 1.6–13.7, p = .005). This association became statistically insignificant after adjusting for both patient education and PDM (adjusted OR = 2.7, 95% CI = 0.68–10.9, p = .11). Education was an independent predictor for excellent understanding after adjusting for patient race and participation in medical decisions. The adjusted odds of having excellent understanding was nearly six times greater among those who had more than high school education compared to those who had less education (adjusted OR = 5.6, 95% CI = 1.6–19.6, p = .007). Excellent participation in medical decisions was associated with excellent under-standing of diabetes self-care, but the association became borderline significant after adjusting for patient race

Table 3.
Adjusted Association between Race, Participatory Decision-making, and Education with Self-Management Practice and Understanding of Self-Management

Outcome	Risk factor	Crude OR and 95% CI	Adjusted OR	95% CI for adjusted OR	p value for adjusted association
Understanding of diabetes self-care score ≥26	Race (African American versus Caucasian)	0.21 (0.07, 0.62)	0.38	0.12, 1.23	0.11
	PDM ≥ 12	3.23 (1.10, 9.46)	3.09	0.91, 10.50	0.07
	More than high school education	6.93 (2.20, 21.87)	5.64	1.63, 19.59	0.007
Diabetes self-management practices ≥12	Race (African American versus Caucasian)	1.87 (0.69, 5.05)	2.33	0.78, 6.92	0.13
	PDM ≥ 12	0.60 (0.20, 1.79)	0.70	0.23, 2.17	0.54
	More than high school education	1.28 (0.50, 3.29)	1.34	0.49, 3.70	0.57
Glycemic control	Race (African American versus Caucasian)	1.21 (0.46, 3.20)	1.51	0.53, 4.34	0.44
	PDM ≥ 12	1.23 (0.42, 3.58)	1.34	0.44, 4.11	0.61
	More than high school education	1.28 (0.48, 3.34)	1.28	0.47, 3.50	0.63

and education. The adjusted odds of having excellent understanding of self-care tripled among those who reported excellent participation in medical decisions compared to those who did not (adjusted OR = 3.1, 95% CI = 0.9–10.5, p = .07). When models were created for each of the understanding domains, excellent PDM was significantly associated with excellent understanding of what to do for symptoms of high blood sugar. The adjusted odds of excellent understanding of what to do for symptoms of high blood sugar was approximately 10 times higher for those who had excellent PDM after adjusting for patient race and education (adjusted OR = 10.6, 95% CI = 1.3–88.7, p = .03). After controlling for patient race and excellent PDM, having more than a high school education was significantly associated with understanding of foot care (adjusted OR = 3.6, 95% CI = 1.0–12.9, p = .045), food choices (adjusted OR = 5.6, 95% CI = 1.1–29.0, p = .04), and HbA1c (adjusted OR = 5.6, 95% CI = 1.9–16.5, p = .002).

Self-Reported Glycemic Control

We used logistic regression models to examine the associations of patient race, education, and excellent PDM with self-reported glycemic control. None of the variables (race, education, or excellent PDM) was a predictor of self-reported glycemic control (see **Table 3**). We also examined the association between excellent understanding of diabetes self-care and self-reported glycemic control for patient race and education. The adjusted odds of self-reported glycemic control is about six times higher among those with excellent understanding of self-care compared to those without (adjusted OR = 5.9, 95% CI = 1.3–26.8, p = .02).

Conclusions

This study affirms the importance of patient participation in medical decision-making for improving understanding of diabetes self-care, behaviors that are associated with self-management, and glycemic control. The roles that patients prefer in making medical decisions (i.e., active, collaborative, or passive roles) appear to be linked to their actual participation in decision-making about their diabetes. Those who prefer active or collaborative roles have about six times higher odds of reporting excellent opportunities for participation with their physicians compared to those who prefer a more passive role with their physicians.

Our study findings indicate that patient understanding of diabetes self-care was significantly associated with reported glycemic control, after adjusting for patient race and education. This is consistent with results from

other studies that utilized self-reported glycemic control or measurements of HbA1c.[26,27] In a meta-analysis of randomized controlled trials, patients assigned to receive diabetes education showed significant improvements in glycemic control following intervention (net reduction in HbA1c = -1.14, 95% CI = -1.5, -0.79).[28] Our data suggest that physician guidance about diabetes self-care significantly predicts glycemic control. This guidance is particularly important for patients with less than high school education who are at risk of poorer understanding of how to monitor HbA1c, food choices, and foot care.

In diabetes self-management, the prevalence of non-adherence varies across the different components of the diabetes regimen, over the course of the disease, and across the patient's lifespan.[29,30] In the study by Heisler and associates,[4] patient understanding of self-care predicted overall self-management and self-management in each of the five domains. Piette and colleagues[10] found diabetes-specific communication to be a predictor of patient frequency of foot care (21% improvement in the probability of daily checks), adherence to hypoglycemic medication (11% absolute improvement), following dietary plans (nine-fold increase), and probability of daily exercise (17% absolute increase). Despite a small sample size, our study confirmed a disparity regarding patient understanding of diabetes self-care. Caucasian patients were almost five times as likely as African Americans to demonstrate an excellent understanding of their required self-care. However, this disparity became statistically insignificant after adjusting for education level and participation in medical decision-making. Overall, patients with higher education levels reported more opportunities to participate in medical appointments and better understanding of self-care activities.

Our findings were similar to those of other studies in which racial minority patients rated their visits with physicians as less participatory.[31,32] This disparity for African Americans and Caucasians was no longer evident after adjusting for education, patient–physician race concordance, and patient preference for playing an active or collaborative role in medical decision-making. The 1994 Commonwealth Fund Minority Health Survey found patients choose racially similar physicians when given the opportunity. Survey findings also identified that patient–physician race concordance results in patient satisfaction in all race subgroups.[24,25] Our findings support these and imply that racial and ethnic similarity among physicians and patients may have a positive impact on the quality of patient–physician communication from the perspectives of both patients and physicians.

There were some limitations in the design of this study. It is a cross-sectional study for which causal relationships of the independent variables and study outcomes of understanding of self-care and self-management practices could not be determined. Study participants were patients treated in a comprehensive diabetes management center, so they are not representative of the general diabetes population. We tried to minimize the effect of being treated in this center by excluding patients who had participated in the self-management educational programs. While our study measures relied on self-report, we used a valid tool that was used in previous studies and was pilot tested in our study population. Patient understanding of self-care depended on patient reports of their knowledge on questionnaires and not direct observation of patient skills. Patient reporting of glycemic control without medical chart confirmation could have introduced a misclassification bias of patient status. To minimize this bias, patients were not asked for numerical values of their HbA1c levels but were asked the following question: "In your last visit to your regular doctor, did he/she tell you that your blood sugar level was controlled?" Response categories included yes, no, or not sure/don't know.

In conclusion, patient understanding of diabetes self-care was determined to be necessary for promoting evidence-based self-care practices in this study, including glycemic control. Patient participation in medical appointments and decision-making was associated with better understanding of self-care. In this study, patient–physician communication was shown to significantly affect patient decisions about their health practices and the behaviors that are associated with diabetes outcomes. Information from this study is useful in the development of appropriate individualized messaging for telehealth and mobile technology diabetes care.[33,34]

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