

Patient-Centered Outcomes of Diabetes Self-Care

Associations with Satisfaction and General Health in a Community Clinic Setting

Roger T. Anderson, PhD; Rajesh Balkrishnan, PhD; Fabian Camacho, MS; Ronny Bell, PhD; Vanessa Duren-Winfield, MA; David Goff, MD, PhD

Abstract

Background: Despite the recognition of strategies for diabetes care management, information systems that screen patient diabetes self-care problems are not commonplace, especially among low-income patients. This study examined correlates of three patient-centered outcomes of diabetes self-care (awareness of self-care components, difficulties in diabetes self-care, and adherence to self-care) among low-income diabetic patients.

Methods: Clinical and patient survey data were obtained on 249 participants from 11 primary care community health clinics serving low-income populations in North Carolina in Project IDEAL (Improving Diabetes Education, Access to Care and Living). Measures of patient-centered outcomes of self-care were obtained from the Diabetes Quality Improvement Project (DQIP) Patient-Reported Measures set.

Results: A substantial proportion of patients reported difficulty achieving standard self-care treatment goals. The study identified distinct patient characteristics associated with poor self-care outcomes. Increased understanding of self-care components and adherence to them were associated with increased perception of quality of care and, in turn, better general health perceptions in these patients ($p < 0.01$).

Conclusions: This study identified an unmet need for diabetes self-care knowledge and skills associated with patient outcomes in low-income patients. Routine monitoring of patient-centered self-care outcomes could help improve long-term outcomes of diabetes care in this population.

Key words: DQIP, diabetes care, treatment satisfaction, patient outcomes

DIABETES IS A HIGHLY PREVALENT, chronic illness in the adult population that requires continuing medical care and education to prevent acute and longer-term complications.¹ As a leading cause of morbidity and mortality, diabetes consumes enormous health care resources and is the seventh leading reason for office visits. In the US, it has been estimated that approximately 10% of all primary care visits made for diabetes are directly related to poor glucose control and symptoms from complications of diabetes (e.g., vision and foot complaints).² The high financial costs associated with diabetes, estimated to exceed \$100 billion annually,³ reflect poor control of this disease in terms of hospitalizations, critical care, general medical services delivered

for complications and resulting disabilities (such as blindness or limb amputation), and deficits in physical function.⁴

From a public health perspective, there are efficacious treatment regimens for diabetes,^{5,6} but the disease remains a significant health burden because of suboptimal health care practices in diabetic populations. Although data on access to optimal care and adherence to diabetes regimens are difficult to collect and synthesize, it is known that approximately less than 50% of persons with diabetes have HbA1c levels below 7%, while some 10% of community-living patients have HbA1c levels above 11%.¹ Patient adherence to diabetes medication can be low, perhaps below 40-50%;⁷⁻⁹ inclusion of adherence to diet and exercise prescriptions

All the authors are in the Department of Public Health Sciences at Wake Forest University School of Medicine. Drs. Anderson and Balkrishnan, Mr. Camacho, and Ms. Duren-Winfield are in the Section on Social Sciences; Drs. Goff and Bell are in the Section on Epidemiology. Address correspondence to Dr. Balkrishnan at rbalkris@wfubmc.edu; telephone: 336/716-9213.

would bring this estimate even lower. This suggests that information systems are needed not only to identify untreated or under-treated cases, but to detect problems in diabetes self-care and the need to tailor treatment among those already receiving care for the disease.

Given that the patient is the center of effective diabetes care, any effective diabetes outcomes assessment should include monitoring the patient's perspective of the quality of diabetes care. This relatively new measurement emphasis, as provided in the Diabetes Quality Improvement Project (DQIP),^{10,11} covers four facets that can be classified as patient-centered outcomes of self-care: (1) The patient's experiences with a particular diabetes regimen, in terms of convenience, symptom avoidance, adherence, daily organization, and well-being; (2) perceived barriers to meeting disease management objectives; (3) level of understanding of diabetes self-care, and (4) the patient's rating of quality of diabetes care.

Despite the recognition of care management processes in diabetes care, information systems that screen patient diabetes self-care problems are not commonplace, especially among low-income patients.¹² Provision of high-quality, individualized care may lead to better disease self-management and, in turn, better outcomes in this particularly vulnerable patient population. However, the extent to which low-income patients have unmet needs for diabetes care, and the relationship of such care to patient-centered (as opposed to clinical) outcomes (such as Health-Related Quality of Life, HRQL), are not fully understood.

To identify diabetes care improvement strategies in this population, we collected data on care experiences of patients diagnosed with diabetes who had sought services from one of 11 public and private not-for-profit primary care community health clinics in North Carolina. The primary goal of this study was to describe patient-centered self-care related outcomes in diabetes and the various patient characteristics associated with them. The study also explored the relationship between patient-centered self-care outcomes, perceived quality of care, and self-reported well-being in low-income diabetic patients.

Research Design and Methods

Data are derived from Project IDEAL (Improving Diabetes Education, Access to Care and Living), a quality of care improvement study in North Carolina funded by the Kate B. Reynolds Charitable Trust.¹² The purpose of IDEAL was to help develop and assist programs capable of improving the quality of care and quality of life of low-income and under-served patients with diabetes mellitus. A major component of the IDEAL evaluation was a baseline assessment of service utilization for diabetes care, clinical measures, and patient-reported aspects of treatment satisfaction.

Eleven of the 14 participating IDEAL community and clinical centers provided a list of names of existing patients

identified as eligible. Eligibility criteria included a diagnosis of diabetes (ICD9-CM code 250) in 1998, with two outpatient visits or one inpatient visit during this same year, and age at least 18 years. A sample of 60 eligible patients was sought for each of the 11 sites. At the seven sites with fewer than 60 eligible patients, the complete list of eligible patients was used. For the remaining four sites, a random sample of 60 was obtained. Baseline clinical care data were collected for 429 patients using an on-site medical chart abstraction of entries for demographics, medical history, physical exams, laboratory testing, and treatment information, as described in Bell et al (2001).¹³ This sample formed the basis for a linked telephone survey procedure that obtained verbal consent and completion of a telephone survey on characteristics of self-care management and health-related quality of life. Using multiple callbacks including daytime and evening calls, 249 (58%) interviews were completed among subjects for whom complete chart review data were available. The study protocols for Project IDEAL have been reviewed and approved by the Human Subjects Committee of the Wake Forest University Institutional Review Board.

Measures

The patients' demographic and diabetes history information was abstracted from the medical chart review. These variables included age, race, gender, whether patients were currently on insulin, whether they were current smokers, whether they had type 1 or type 2 diabetes, and self-reported duration of the disease since diagnosis. Patients were assessed for the following medical complications of diabetes: history of coronary artery disease, hypertension, peripheral vascular disease, neuropathy, nephropathy, and non-traumatic amputation. Glycemic level was recorded from the most recent measures in 1998, and was defined as being in control if the hemoglobin A1c (HbA1c) percentage was lower than 9.5%. The absence of documentation for HbA1c levels in a patient's medical records was assumed to indicate poor management of glucose levels and consequently poor control consistent with DQIP¹⁰.

A brief, multidimensional survey was designed to be completed in less than 20 minutes by telephone interview. The areas assessed in this telephone assessment battery included general well-being, specific health factors of known importance with diabetes, diabetes-related comorbidity, and issues relating to self-care, health education, and patient satisfaction. To assess aspects of the patient's experience with diabetes, we used components of the Patient Reported Measures of the DQIP to assess multidimensional aspects of care quality. These questions assessed the following: perceived quality of care received; patient knowledge of diabetes care topics (10 items related to topics such as blood sugar control and foot care); number of problems with diabetes self-management (seven items including difficulties keeping to a schedule or remembering to take diabetes pills);

Table 1. Descriptive characteristics of the study population (N = 249)

<i>Variable</i>	<i>Number</i>	<i>Range</i>
Gender		
female	172 (68%)	
male	77 (32%)	
Mean age (Std)	54.4 (14.4)	(14,87)
Race		
white	112 (45%)	
black	112 (45%)	
other	3 (1%)	
N/A	22 (9%)	
Currently on insulin		
yes	79 (32%)	
no	169 (68%)	
N/A	1 (0%)	
	<i>Mean (Std)</i>	
Glucose levels (Hba1c)	8.3 (2.0)	(4.7,16.0)
Years with diabetes	7.8 (9.0)	(0,60)
Absence of leg complaints*	21.6 (3.8)	(8,25)
Absence of difficulties*	29.0 (6.0)	(7,35)
Self-care adherence*	20.4 (2.8)	(10,25)
Understanding of self-care*	23.3 (4.9)	(7,28)
Quality of care		
(1 = poor, 5 = excellent)	3.95 (1.0)	(1,5)
Perceived general health		
(1 = poor, 5 = excellent)	3.4 (1.1)	(1,5)
*higher scores = greater success (more understanding, fewer complaints or difficulties)		

number of patient complaints and symptoms relating to the legs and feet (five items including leg cramps, numbness in the feet, burning sensations, decreased ability to feel temperature, sores or wounds that do not heal). To assess general health and mental and physical well-being, we used the SF-36¹⁴ which has published norms that enable comparison to other chronic or normal populations.

We next created three self-care outcome scores, an overall care rating measure, and a general well-being score. The self-care outcome scores consist of (1) a sum of item ratings on perceived absence of problems with diabetes self-care, (2) a sum of item ratings on degree of adherence actually performing diabetes self-care activities, and (3) a sum of item ratings of level of understanding of diabetes health education. The overall care rating measure was retrieved by the following question from the DQIP: "Over the past 12 months how would you rate the quality of care received for your diabetes?" The general well-being measure was extracted from an item asking for an assessment of one's state of health,

coded with the same five-point response set: poor, fair, good, very good, and excellent.

In order to conduct bivariate and multivariate analyses, correlates of the patient-centered outcomes were chosen based upon scientific interest with regard to general predictors of need and access to care.⁸ These correlates included age, race/ethnicity, gender, number of years with diabetes, currently prescribed insulin, a summary score for diabetes complications, and clinic site.

Data Analysis

Simple proportions and means were used to describe the components of these patient-centered outcomes of self-care: absence of difficulties in performing self-care, adherence in performing self-care, and perceiving oneself as having adequate knowledge of self-care processes and skills. Then the bivariate relationships between these three patient-centered self-care outcomes and several correlates of interest were explored by calculating correlation coefficients when predictor variables were also continuous, t-tests when predictor variables were binary, and finally by examining outcome means by groups. Next, Generalized Estimating Equations (GEE) models were estimated in order to examine the multivariate relationship between the previously selected correlates with the three patient-centered self-care outcomes, as well as perceptions of quality of care and general health.

The three patient-centered self-care outcome variables were entered as covariates in the models exploring correlates of quality of care and general health. All dependent variables in the five regressions were continuous. The GEE method was needed to take into account correlated observations due to clinic clustering¹⁵. The SAS procedure GENMOD was used to fit the models.

Results

Table 1 presents basic demographic and descriptive information on the 249 participants with completed interviews. In results not shown, a majority (84%) of patients were diagnosed with type 2 diabetes, and had had a diagnosis of diabetes for a mean of 7.8 years. Approximately 48.7% rated their health as fair or poor, while only 4.8% rated their health as excellent.

Table 2 presents the percentages of participants across categories of the three patient-centered self-care outcomes: self-care understanding, self-care problems, and self-care adherence. The percentage of persons who neither "completely" nor "pretty well" understand aspects of self care ranged from 5% for the item "how to take your medications" to 20% for the item "how to take care of your feet"; approximately 16% reported a less than adequate understanding of "what to do

Table 2. Patient-reported difficulties in understanding or maintaining diabetes self-care components, by percent

	<i>Percent of sample (N = 249)</i>		
Understanding components of diabetes self-care	Understand pretty well	Confused	Do not understand ¹
Foot care	80	5	15
Medications	95	2	3
Low blood sugar	84	4	12
Appropriate food choices	88	5	8
Blood sugar testing procedure	90	2	8
Complications of diabetes	86	5	9
Appropriate exercise	84	3	13
Having difficulties with diabetes self-care in past month	No difficulties	Moderate difficulties	Major difficulties
Avoiding/limiting foods	35	43	22
Scheduling	44	38	18
Making meal plans	53	31	16
Organizing daily routine	52	35	13
Medication adherence	78	19	3
Remembering to test blood sugar	66	29	5
Work or daily activities impeded by self-care	22	56	22
Time spent managing diabetes	61	31	9
Having difficulties adhering to self-care in past year	No difficulties	Moderate difficulties	Major difficulties
Checking feet for wounds or sores	69	29	2
Checking blood sugar	59	38	3
Exercising regularly	17	60	23
Following diet	18	74	8
Medication adherence	51	48	1

¹Note: Doctor may have failed to explain component to patient.

for symptoms of low blood sugar.” Major problems were reported predominantly for symptom interference with daily activities, avoiding foods to promote glucose control, and having to schedule around medications; these were reported by approximately one-fifth (18% to 22%) of the respondents. Among adherence outcomes, lifestyle changes—such as following a planned diet and exercising—were difficult or extremely difficult for most respondents. More directed self-care behaviors, such as checking blood glucose and taking medications as prescribed, were difficult for approximately four-tenths to one-half of respondents (41% to 49%).

Table 3 shows the bivariate associations between predictors of interest and the three patient-centered outcomes of self-care. Absence of difficulties had significant positive associations with greater age, male gender (both $p < 0.01$), greater number of years with diabetes ($p < 0.05$), and absence of leg and feet complaints ($p < 0.001$). Adherence to self-care had significant positive association with absence of

leg and feet complaints ($p < 0.05$). Understanding of self-care was significantly associated with increased age, higher glucose readings, and absence of leg and feet complaints (both $p < 0.05$).

The multivariate analyses (not shown in detail) found distinct correlates of patient-centered self-care outcomes, as well as quality of care and general wellbeing.[§] Having a decreased number of problems with diabetes care was associated with increasing age ($p < 0.001$), male gender ($p < 0.01$) and fewer leg and feet complaints ($p < 0.001$). Increased adherence to self-care was associated with fewer leg and feet complaints ($p < 0.001$). Understanding of self-care was associated with insulin use ($p < 0.001$) and greater number of years with diabetes ($p < 0.05$). Increased understanding of self-care was associated with slightly increased quality of quality

[§]A detailed technical report of these estimations is available with the corresponding author upon request.

of care perception ($p < 0.001$) as well as with slightly poorer general well-being ($p < 0.001$). A higher degree of self-care adherence was associated with improved perception of quality of care ($p < 0.01$), but not of general well-being. The effects of difficulties were not observed in the multivariate analyses.

Discussion

Patient-centered outcomes relevant to diabetes self-care (awareness of self-care components, difficulties in diabetes self-care, and adherence to self-care) have components that include the patient's need for education, assistance with adoption of behavior change such as with dietary restrictions, weight control and exercise. This reflects the challenging treatment goal of integrating into the patient's daily routine often delicate medication regimens that seek to approximate the normal endogenous insulin secretory response to glucose levels. A logical first step may be conducting surveillance of barriers and problems that may serve as indicators of patient burden with the treatment plan.¹⁶ We studied the prevalence of three patient-centered outcomes in a lower income patient population accessing community health clinics. Our results have shown that a substantial proportion of patients have at least some difficulty, and many report considerable difficulty, achieving their self-care treatment goals.

Not surprisingly, diet and exercise are among the most difficult or burdensome self-care topics. However, for a substantial percentage of respondents, more proximal activities such as medication adherence and monitoring blood glucose were also problematic. This information, taken together with other diabetes care information, may be useful in improving diabetes control in the treated population by directing services toward improving patient self-management skills where needed, or adjusting the medication plan with newer, less burdensome therapies.

The results of this study provide additional information on patients' burden with diabetes self-care; this information is consistent with reports in the literature that show a considerable range of adherence with blood glucose testing, medication, and lifestyle factors, with average adherence rates near 50%. Litwak et al¹⁷ studied purchase of blood testing supplies for patient diabetes monitoring and found that patients obtained supplies sufficient to test blood only 70% of days in the first four years post-diagnosis, and only 50% of days following this period. Evans¹⁸ and Beckles et al¹⁸ found that approximately 20 to 22% of patients did not monitor their blood glucose levels at all. Adherence rates in the patient population to tablet medications has generally ranged from 20-60%,⁸ with estimates of adherence to insulin injections ranged from 20-90%. A recent analysis of 762 continuously enrolled Medicare managed care patients with diabetes in the US Southeast showed a medication possession rate of 57% for oral hypoglycemics and 40% for insulin therapies.²⁰ Elsewhere, adherence with aspects of diabetes have been reported from 19%²¹ to 30%²¹ when issues of dietary

restrictions and weight loss behaviors are included.

Screening for problems with diabetes self-management may be clinically useful if effective actions can be taken to address patient needs. A considerable research literature exists demonstrating the role of self-efficacy interventions with diabetes self-care and monitoring behaviors²³⁻²⁶ and HbA1c levels mediated through adherence.²⁶ This theory-grounded approach, coupled with the successes of existing diabetes patient education programs, provides a means for going forward from screening to action.

Examination of a set of hypothesized predictors revealed that only the leg complaints score was consistently associated with at least two of the study's three patient-centered outcomes. Most notable was that HbA1c level was not significantly ($p < .05$) correlated with our outcomes. However, we did not have information on the array of mediating or mitigating factors that can effect glycosolated hemoglobin, such as weight, medication regimen, and time since treatment was initiated. The IDEAL sample contained some new or recently treated patients. Also, HbA1c values reflect the last value recorded, which varied across subjects; thus recent changes in HbA1c levels are not possible to examine.

Individual factors such as weight and medication dosing were also unavailable. Since medication adherence, patient education, and ability to perform basic diabetes self-care activities are recognized diabetes treatment goals, patients reporting problems should be of clinical interest. In a cross-cultural validation study of the Problem Areas in Diabetes scale (PAID), a more extensively tested instrument covering more depth of content than the DQIP set, Snoek and colleagues²⁷ found statistically significant correlations of $r = .11$ to $.15$ with self-reported HbA1c values and self-monitored blood glucose readings for content areas reflecting emotional problems and treatment problems with regard to diabetes care, while diet and social support were not related to either test result. It is possible, therefore, that the DQIP¹⁰ lacked sensitivity to some problem areas more directly influential of HbA1c control.

Information on patient's lifestyle adjustments and treatment adherence is a key concern in diabetes care clinics; routine and systematic data collection processes may more accurately determine the prevalence of diabetes self-care problems in a patient population, allowing for more efficiently targeted resources. This information can be collected from patients using surveys that do not require a clinic visit. Before a set of measures can be recommended for this purpose, however, further study is needed to determine whether self-reported information using the DQIP¹⁰ scale has sufficient sensitivity and specificity to minimally important levels of difficulty self-managing diabetes care—those that effect long term diabetes control and patient distress.

There is some question whether, or to what extent, patient-centered outcomes such as barriers to self-management are legitimate indicators of quality of diabetes care in primary care. This study found that understanding of diabetes self-care components was associated with perceptions of

Table 3. Significant bivariate associations between patient-centered self-care outcomes and patient attributes (higher scores indicate better success)

Outcomes	Attributes	Group means
Absence of difficulties	<i>Demographics</i>	
	Age **1	<45 yrs 27.9
		45-64 yrs 28.4
		≥65 yrs 30.8
	Gender**2	male 30.7
		female 28.2
	No. years with diabetes* 1	0-5 yrs 28.8
		6-10 yrs 28.4
		11-15 yrs 29.4
		≥16 yrs 30.0
	Race	non-black 28.9
		black 29.0
	<i>Clinical measures</i>	
	Currently on insulin	yes 28.9
		no 29.0
	HbA1c	<9.5 29.5
		≥9.5 28.8
	<i>Symptoms/complaints</i>	
	Absence of leg/feet complaints***1	high median 29.8
		low median 27.9
Self-care adherence	<i>Demographics</i>	
	Age	<45 yrs 20.1
		45-64 yrs 20.4
		≥65 yrs 20.5
	Gender	male 20.6
		female 20.3
	No. years with diabetes	0-5 yrs 20.3
		6-10 yrs 20.6
		11-15 yrs 19.9
		≥16 yrs 20.5
	Race	non-black 20.5
		black 20.3
	<i>Clinical measures</i>	
	Currently on Insulin	yes 20.5
		no 20.3
	HbA1c	<9.5 20.6
		≥9.5 20.7
	<i>Symptoms/complaints</i>	
	Absence of leg/feet complaints*1	high median 20.7
		low median 19.9

[continued on next page]

higher quality of care and well-being. Self-care adherence was associated with improved perception of quality of care, which in turn, was independently associated with improved perception of general health. The ADA position that a successful diabetes treatment regimen is an “individualized therapeutic alliance” of doctor, patient and family lends credence

to the idea that the collaboration within this alliance raises the bar for defining quality by considering outcomes previously attributed to patients. Indeed, Donabedian²⁸ explains that there can be a variety of “standards” of care varying from “maximum conceivable benefit” to “desired” or “achievable benefit.”

Table 3 (continued). Significant bivariate associations between patient-centered self-care outcomes and patient attributes

Outcomes	Attributes		Group means
Understanding of self-care	<i>Demographics</i>		
	Age*	<45 yrs	23.8
		45-64 yrs	23.6
		≥65 yrs	22.5
	Gender	male	23.0
		female	23.5
	No. years with diabetes	0-5 yrs	23.2
		6-10 yrs	23.7
		11-15 yrs	23.4
		≥16 yrs	23.2
	Race	non-black	23.2
		black	23.5
	<i>Clinical measures</i>		
	Currently on insulin	yes	24.2
		no	23.0
	HbA1c* ¹	<9.5	22.8
		≥9.5	25.1
	<i>Symptoms/complaints</i>		
	Absence of leg/feet complaints*	high median	23.9
		low median	22.9

*P-value < .05; **P-value < .01; ***P-value < .001

¹ Tests conducted for zero correlation of underlying continuous variables.

² T-Tests conducted for binary variables.

As stated above, the set of patient-centered outcomes was predictive of patient perceptions of both individual well-being and quality of care, suggesting that providers' focus on patient self-management skills is one criterion that patients use to define quality of care. However, it is also evident that the use of care satisfaction ratings would not be a sufficient indicator of unmet patient needs; diabetes care centers that receive high patient ratings also have appreciable percentages of patients whose diabetes control could be improved by targeting supportive services to assist regimen adherence. In conclusion, routine surveillance of behavioral processes important to self-management of diabetes may help healthcare providers identify effective supportive services such as education regarding nutrition; medication adherence; and individualized, less-burdensome treatment regimens for low-income patients. This study found that a substantial percentage of low-income patients experienced problems and difficulties with key aspects of a traditional diabetes self-care regimen. These difficulties with self-care were very predictive of well-being as well as treatment quality perceptions in these patients. Routine monitoring of patient-centered outcomes could help strengthen the therapeutic alliance, thereby improving long-term outcomes of diabetes care.

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ERRATUM

On page 291 of the November/December 2002 issue of the *Journal* (Molloy et al. The epidemic of childhood overweight and obesity. *NC Med J* 2002;63), there is an error in Table 1. "Physical activity" should read "physical inactivity." The *Journal* regrets the error.