

Where Is the Patient in Diabetes Performance Measures?

The case for including patient-centered and self-management measures

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OBJECTIVE — Health policies are important determinants of clinician and patient behavior, and an important policy issue is what items are included in healthcare quality and performance measures. There is consensus that patient-centered care and self-management support are essential evidence-based components of good diabetes care. However, most major diabetes performance measures such as the National Committee for Quality Assurance (NCQA)/American Diabetes Association (ADA) Provider Recognition Program indexes have not included self-management or psychosocial items.

RESEARCH DESIGN AND METHODS AND RESULTS — We review the case for and propose a set of patient-centered, self-management indicators to be included as a standard part of diabetes quality indicators. The proposed indicators include: patient self-management goal(s), measures of health behaviors (e.g., healthy eating, medication taking, physical activity, and smoking status), quality of life, and patient-centered collaborative care. We discuss the evidence and the concerns about patient-report measures and summarize successful incorporation of such patient-centered measures in other countries and by the American Association of Diabetes Educators (AADE).

CONCLUSIONS — The adage that “what gets measured, gets done” applies to diabetes management and many other areas of healthcare. Inclusion of the proposed indicators in national diabetes performance measures would be consistent with Institute of Medicine (IOM), ADA, Centers for Disease Control (CDC), Diabetes Attitudes, Wishes, and Needs (DAWN), AADE, and Society of Behavioral Medicine (SBM) recommendations. Such action would enhance both the priority and delivery of quality, patient-centered care, and diabetes self-management support.

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Performance measures are an important strategy to enhance the quality of health care (1,2), and many health care organizations are required to publicly report such measures. Quality “ratings” may be used by employers or consumers to select health plans or providers and are increasingly part of “pay-for-performance” initiatives.

Since their objectives are to improve the care and health of specified populations, it makes sense to examine performance measures for their consequences

(intended and unintended) and for what they include and do not include. It is important to distinguish clinical recommendations, which are often the product of professional organizations and typically recommend optimal care, from performance measures (2). The latter are measures that are intended to apply to all patients having a given condition and are frequently viewed as the minimum that constitutes responsible, evidence-based care.

Recommended care for diabetes has

shifted over the past decade to an approach that is more patient centered and that places the person with diabetes and joint decision making with health care professionals at the center of care models. Patient-centered care is respectful of and responsive to individual patient preferences, needs, and values and ensures that patient values guide all clinical decisions. This change has come about for multiple reasons, including the greatly enhanced data on the effectiveness of diabetes self-management, the significance of psychosocial factors in diabetes, and the increasing penetration of diabetes empowerment and other evidence-based self-management approaches.

Other key influences behind this shift from treatment that is done to passive recipients by medical experts to treatment that is planned collaboratively with patients have been the adoption of the Chronic Care Model (CCM) (3) and the Institute of Medicine (IOM) report, *Crossing the Quality Chasm* (4). Both the CCM and the IOM report place patient-centered care and self-management support at the heart of their new, evidence-based models of care. The CCM consists of six key components that must be integrated in a patient-centered manner in order to be successful, namely, self-management support, decision support, information systems, organizational support, practice design, and community resources (3,5). The *Crossing the Quality Chasm* report stresses six key issues that must be addressed in order to advance and support quality chronic illness care—care needs to be patient centered, equitable, affordable, timely, safe, and effective (4). In a guide to this IOM report, Berwick (6) emphasizes how at its foundation, patient-centered care and being responsive to patient preferences are “true North” for quality care.

This commentary discusses whether current diabetes performance measures have kept pace with the developments summarized above. It examines several issues related to diabetes performance measures and specifically current National Committee for Quality Assurance

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Abbreviations: AADE, Association of Diabetes Educators; ADA, American Diabetes Association; CCM, Chronic Care Model; DAWN, Diabetes Attitudes, Wishes, and Needs; IDF, International Diabetes Federation; IOM, Institute of Medicine; NCQA, National Committee for Quality Assurance; SBM, Society of Behavioral Medicine.

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Table 1—Proposed patient-centered measures: definitions and example items

Measurement area	Definition/example references	Sample items
Health behaviors	Self-management actions needed to control diabetes including healthy eating, medication taking, regular physical activity, not smoking, etc. (12).	“How many regular sodas or glasses of sweet tea do you drink each day?” “How many days in the past week did you test your blood sugar?”
Quality of life	Both diabetes-specific and general evaluations of one’s health status. Measures refer to both emotional and physical health (7,10).	“How much of a problem for you is feeling overwhelmed by the demands of living with diabetes?” “Compared to others my age and sex, my health is (good, fair, poor, etc.)”
Self-management goal(s)	Collaboratively set, specific goals or action plans for diabetes management (11,13).	“When I received care for my diabetes, I was . . . helped to set specific goals to improve my eating and exercise; helped to make a treatment plan that I could do in my daily life.”
Patient-centered care	Key aspects include patient engagement in care, shared decision making, and consideration of patient preferences, background, and environment (4,13).	“When I received care for my diabetes, I was asked for my ideas when we made a treatment plan.”

(NCQA)/American Diabetes Association (ADA) Provider Recognition Measures. Our specific objectives are to:

- discuss conceptual and philosophical issues in selecting diabetes performance measures and review the current NCQA/ADA diabetes measures for their congruence with IOM, CCM, ADA, Association of Diabetes Educators (AADE), and related recommendations
- provide examples of how other countries and organizations have used patient-centered diabetes measures
- examine the consequences and public health implications of the current measures and discuss feasibility and methodological issues related to potential behavioral and patient-centered performance measures
- propose the addition of behavioral, quality of life, and patient-centered measures to diabetes performance measurements.

Conceptual and philosophical issues

The key characteristics of good performance measures include applicability to all patients and settings and being evidence based, objective, and feasible to collect. Current NCQA/ADA Provider Recognition Performance Measures (<http://web.ncqa.org/tabid/139/default.aspx>) include indexes related to A1C, blood pressure, and lipids, as well as foot and eye exams.

Absent from current Provider Recognition measures are patient-centered quality of life and health behavior self-management measures. With the exception of smoking status, which is a

dichotomous all-or-none criterion that does not address the quality of behavior change counseling, no self-management behaviors are part of the required measures set, and smoking accounts for only 5 of the 80 possible Recognition Program points. We question whether the absence of patient-reported psychosocial and behavioral endpoints is due to the evidence base or largely to a historical focus on an acute care model that favors biomedical clinical indicators over patient-centered and behavioral measures.

There have been multiple evidence-based reviews of the diabetes self-management literature, almost all of which have concluded that at a minimum, a number of self-management support strategies are effective and are recommended. The Diabetes Prevention Program conclusively demonstrated the powerful effects of well-designed health behavior change interventions on glycaemic and other endpoints. Finally, it is widely recognized that patient quality of life and overall health—and not clinical indicators alone—are the ultimate health care objective (7).

What are missing entirely from the current ADA/NCQA diabetes performance measures are any indicators that assess the patient perspective or the extent to which care is patient centered. As discussed below, it is possible to address historical and logistical objections to inclusion of behavioral, patient-centered, and quality-of-life measures if conceptual perspectives and political will are congruent with the IOM and CCM recommendations and the evidence summarized above.

Table 1 provides a brief definition and

a specific example of items within each of the four patient-centered measurement areas discussed in this commentary.

Methodological and logistical issues

Historically, it has been felt that health behavior, quality of life, and patient-reported psychosocial measures were not sufficiently reliable, related to key outcomes, or feasible to be included as performance criteria. Many of these objections were based on perceptions that validated measures either did not exist, were too time consuming, or were too expensive to be included or based on a view of self-report measures as being less scientific than, for example, blood assays. Such views were arguable a decade ago but are incorrect today. Numerous brief health-behavior and quality-of-life measures are now available and have been demonstrated to be reliable and valid. Self-report measures have been found to be feasible in a wide range of secondary and primary care settings including community health centers. Patient report measures today are widely applied as tools to evaluate therapies, and the U.S. Food and Drug Administration has drafted guidelines requiring quality-of-life measures (www.fda.gov/fdac/features/2006/606_patients.html). In diabetes, key aspects of psychosocial functioning are correlated significantly with clinical endpoints.

Concerns about self-report measures often relate to the length and quality of responses and issues such as social desirability. In each case, there are well-documented methods and tools to address such concerns. With the widespread availability of Web-based surveys,

office-based pen tablets, touch-screen computers, and automated voice-response telephone technologies, features such as automatic error testing, transparent skip patterns, missing data checks, and health literacy concerns can be addressed. Important advances in computer-adaptive testing that can even more dramatically reduce respondent burden have recently been applied.

Realistic alternatives and successful demonstrations

Below, we present three examples that demonstrate the clinical significance, importance, and feasibility of collecting patient-centered and behavioral measures such as those proposed above.

The international Diabetes Attitudes, Wishes, and Needs project: psychosocial dimensions of care

There is a sufficient clinical rationale, evidence of efficacy, and “proof-of-concept” to include psychosocial aspects in the quality model for diabetes care. This was the conclusion of the international Diabetes Attitudes, Wishes, and Needs (DAWN) Program, a global partnership initiative led by the International Diabetes Federation (IDF) and Novo Nordisk A/S, together with an international advisory board network of experts. Through international psychosocial surveys, literature reviews, and scientific congresses, widespread consensus has been reached that a critical gap exists between the psychosocial and self-management support needs of diabetic patients and the current access to support on these dimensions (8).

Psychosocial issues have been recognized as playing a central role in effective diabetes self-management for decades, yet the international DAWN Study revealed that people with diabetes across 13 countries have major psychosocial issues that are not adequately addressed in the existing healthcare systems. The DAWN Study reported that diabetes-related distress is very common and associated with poor self-management. The vast majority of diabetes professionals recognized that psychosocial issues play a key role for the poor self-management of their patients but did not feel able to assess or address psychosocial needs of their patients. A strong majority expressed interest in obtaining simple measures to help them evaluate psychosocial aspects as part of ongoing care.

In 2004, the DAWN Call to Action

was developed by leading experts from more than 30 countries and published world-wide by the IDF. It specified five goals for improved diabetes care; these were that quality improvement initiatives must seek to improve patient-provider communication, promote team-based care and the role of the nurse, promote active self-management, overcome psychosocial barriers to effective therapy, and improve access to psychosocial support. The DAWN program facilitates implementation of these goals in alignment with the global IDF guidelines on psychological aspects of diabetes and the global charter on patient-centered diabetes care (9).

Both the IDF global treatment guidelines as well as a growing number of national evidence-based treatment guidelines include sections on psychosocial assessments as part of regular diabetes care. Countries that have guidelines with a separate section dedicated to psychosocial aspects of diabetes care include Germany, the Netherlands, Australia, the U.K., and Romania.

The recent IDF global type 2 diabetes treatment guidelines (9) require that in “standard care” for psychological aspects of diabetes care one “assess well-being and psychological status (including cognitive dysfunction), periodically, by questioning or validated measures” and “discuss the outcomes and clinical implications with the person with diabetes, and communicate findings to other team members where appropriate.”

The Problem Areas in Diabetes (10) is an example of a validated assessment tool that has important clinical qualities and provides a useful quantitative assessment. It has been evaluated for use as part of annual assessments of diabetic patients, and patients who were given individual assessment and feedback exhibited improved quality-of-life scores compared with control subjects.

A network of international diabetes centers began the DAWN MIND (Monitoring Individual Needs of People with Diabetes) initiative in 2006. Diabetes centers from all continents have joined the program with the aim of improving clinical care by implementing a standardized psychosocial evaluation procedure for annual visits and training health professionals in psychosocially oriented diabetes care. The MIND initiative includes systematic collection of psychosocial data from all people with diabetes and patient-

reported psychosocial endpoints for benchmarking care improvements.

Defining and collecting patient-centered outcome measures

The AADE has supported a multi-year project to develop a framework for patient self-care measures, standards for diabetes education outcomes, practical data collection tools, and a web-based information system for data collection and reporting. The comprehensive system demonstrates that it is feasible for patients to input self-report data, for clinicians to review data and document interventions at the point of service, and for patient- and program-level reports to be generated.

In 2003, the Standards for Outcome Measurement of Diabetes Self-Management Education (DSME) were published, and these standards have been incorporated into the 2007 National Standards for Diabetes Self-Management Education. The Outcome Standards directed diabetes programs to collect pre-intervention and post-intervention data on patient self-care and behavior change. These data are used for informing the patient of interventions and for guiding quality improvement activities and population management. In addition to immediate and intermediate outcomes of learning and behavior change, the outcomes of health status and quality of life must be captured to provide a comprehensive picture of the patient's overall response to clinical care, self-management education, on-going support, and follow-up.

The AADE focused on defining a core measurement set for self-management behaviors. Seven self-care behaviors were identified through literature review, expert consensus, and clinicians in practice: healthy eating, being active, monitoring, medication taking, problem solving, reducing risks, and healthy coping. Many research instruments have historically focused on one to three behaviors with many multi-item questions. Educators and clinicians needed a practical, comprehensive approach that could be implemented at the point of service. These seven self-care behaviors have evolved to the “AADE 7” framework, which has been used as the organizing structure for data collection tools, diabetes self-management education program materials, and other activities for self-management support (11). Data collection tools to support the assessment and documentation of behaviorally focused assessment and inter-

ventions have been developed through partnership with clinicians, researchers, industry allies, and patients. The AADE 7 patient self-care data and educator assessments can be collected reliably at point of service to guide behavioral interventions and support diabetes education program reporting and quality improvement (12).

As educators began to use the AADE 7 framework in their practice, they provided feedback that it was also a useful approach for patients with hypertension, hyperlipidemia, and other chronic conditions. Also, as they focused on diabetes prevention, many described the seven behaviors as a useful approach to talking about health and prevention in general.

The AADE 7 self-care behaviors can serve as a generalizable framework for patient-centered chronic disease prevention and self-management. For example, using the National Standards for Diabetes Self-Management Education content areas, the National Cholesterol Guidelines, and the National Blood Pressure Guidelines as the source for patient-centered recommendations or issues, the seven self-care behaviors map directly to all three disease areas. Instead of addressing each disease as a separate entity, a patient-centered approach applies the behavior framework as a way of addressing all three conditions from the patient's self-management perspective. Many clinicians take such an integrated approach, but our measurement strategies do not.

The AADE 7 self-care behaviors can be viewed as a "behavioral" review of systems, just as the "head-to-toe" review of systems is standard for performing physical exams. This standardized nomenclature can provide a foundation for shared communication among patients, clinicians, payers, and health systems, especially as health information technology becomes more integral to care delivery. Using this structured framework, measures for patient self-care can be integrated along with biochemical and process measures at the point of service.

Proposed policy changes

The Society of Behavioral Medicine (SBM) recently approved a policy brief recommending the inclusion of measures of health behaviors, patient quality of life, self-management goals, and patient-centered care as a standard part of diabetes quality measures (www.sbm.org/policy/diabetes.asp). The SBM document summarizes the rationale for these measures, key research studies supporting

these recommendations, and publicly available measures within each domain.

We support the recommendations in the SBM policy brief and urge health plans, employers, consumers, professional associations, the NCQA, and ADA to join in promoting and supporting care that is patient centered. It is time to "put our diabetes care measures where our values and evidence are." It is time for the U.S. to join international diabetes organizations in adopting the DAWN vision of patient-centered and psychosocially oriented diabetes care and the AADE 7 key health behaviors to help make diabetes care truly a collaborative, shared decision-making, and patient-centered endeavor.

As a concrete next step, we call for an alliance of diabetes and quality-of-care organizations to identify specific items to be used as performance measures within each of the four areas discussed above and summarized in Table 1. There are several validated measures within each area, but consensus is needed to focus on a practical set of items within each area.

CONCLUSIONS— In summary, there are now compelling research evidence and philosophical, conceptual, pragmatic, and ethical grounds for including health behaviors, patient-centered care, and quality of life as part of standard performance measures for diabetes. We recommend a realignment of diabetes quality and performance measures to reflect the new evidence warranting a focus on patient well-being and self-management as part of quality care.

The adage in quality improvement that "what gets measured, gets done" is true in diabetes as well as its corollary—what is not measured does not get done. It is now time to expand the content of diabetes performance measures to include patient-reported psychosocial and behavioral measures. Inclusion of such measures would make several important contributions in addition to aligning measurement with current evidence and values. Adoption of these measures would help address the "one-size-fits-all" criticism leveled against current diabetes performance measures and serve as a way to individualize evidence-based treatment based upon patient preferences and situations. Such measures, because they are applicable across illnesses, would aid clinicians and patients in coping with the complexities of multiple chronic conditions and help to integrate care (6). Fi-

nally, measurement of psychosocial and emotional aspects of diabetes is a necessary first step to addressing the well-documented unmet need for psychosocial support.

We think that the time is right to add well-validated and feasible behavioral and psychosocial measures to the Provider Recognition Program and other diabetes measurement sets. We recognize that securing broad agreement on new standard measures poses a challenge to the diabetes community and that several steps are required for full-scale implementation. However, valid measures with broad-based support are now available, and specific performance criteria should be identified for health behaviors, quality of life, self-management goals, and patient-centered care.

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Diabetes performance measures

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