



## **Addressing the Need for an Instrument to Measure Behavior Change in Diabetes Self-Management Education**

American Association of Diabetes Educators

June 2011

Diabetes educators provide diabetes self-management education and training (DSME/T) and focus on behavioral goal setting and achievement to accomplish behavior change and optimize clinical outcomes. The importance of assessing outcomes of DSME/T has been established and standardized outcome measures are available for assessing individual and aggregate patient outcomes. Currently diabetes educators lack a metric for objectively assessing behavior change, which is the intended and unique aim of DSME/T.

Diabetes educators have expressed a need for tools with which to objectively measure changes in behavior that lead to better self-management. A behavior score instrument (BSI) was developed by a multi-disciplinary working group convened by the American Association of Diabetes Educators (AADE). It was designed to: 1) help diabetes educators engage people with diabetes in goal setting for DSME/T; and 2) fill gaps in our understanding about the effectiveness of DSME/T in achieving behavior change. This paper considers gaps that educators face in measurement of outcomes relating to DSME/T and describes the background, evolution, and approach used to quantify and measure diabetes-related self-management behaviors and behavior change over time. Educators who have piloted the BSI report that the tool assists them in setting behavior goals, provides them with important feedback on behavior change, and helps them deliver effective diabetes education. The BSI will also provide useful information for accredited/recognized DSME/T programs that report outcomes on an annual basis.

### **Introduction**

Diabetes educators play a key role in addressing a serious chronic illness that affects approximately 23.6 million Americans.<sup>1</sup> Diabetes is the seventh leading cause of death in the

United States, imposes considerable direct and indirect costs, negatively affects workplace productivity, and is rising in prevalence.<sup>1,2</sup> With proper DSME/T, people with diabetes can effectively self-manage their illness to slow the progression of the disease, reduce costs and achieve optimal health and quality of life outcomes.<sup>3-6</sup> Doing so often requires lifestyle and behavior changes.<sup>1</sup>

In providing DSME/T, diabetes educators focus on behavioral goal setting and achievement to accomplish behavior change and optimize clinical outcomes.<sup>6-8</sup> The educational intervention builds upon the chronic care model, educational and behavioral theory, and integrates best practices from clinical guidelines.<sup>7-9</sup> AADE advocates for DSME/T to incorporate seven self-care behaviors into care plans for their patients.<sup>10</sup> These seven behaviors, collectively known as the AADE7 Self-Care Behaviors™, are healthy eating, being active, monitoring, taking medication, reducing risk, problem solving and healthy coping.<sup>9,10</sup>

The importance of assessing DSME/T outcomes has been established and standardized pre-post outcome measures are available for assessing individual and aggregate patient outcomes.<sup>11,13</sup> Most diabetes education programs collect data related to these efforts for continuous quality improvement purposes.<sup>14</sup> In addition, HEDIS and pay-for-performance measures are designed to address process of care and utilization.<sup>15,16</sup> These measures do not, however, provide a metric for objectively assessing behavior change, which is the intended and unique aim of DSME/T. This presents a serious gap that impedes the practice of DSME/T and limits outcomes assessment by diabetes educators and DSME/T programs. Additional information would contribute to an understanding of best practices in DSME/T and benefit people with and at risk of diabetes.

AADE has encouraged the development of behavior change metrics with the overall goal of providing important information to advance the *behavior change* portion of the Health Care Outcomes Continuum (Figure 1) that underlies the delivery of effective diabetes education.<sup>12</sup> These metrics are envisioned to help people with diabetes manage their illness; they will also advance the practice of DSME/T and augment outcomes assessment.

This paper considers the need for an objective way to measure behavior change over time. It also presents an approach to quantifying diabetes-related self-management behaviors and applications for use in clinical practice.

### **Need for Behavior Score Metrics and Tools**

The conceptual model for defining, categorizing, and measuring quality and the impact of healthcare provision has been described by Donabedian as having three dimensions – structure, process and outcomes.<sup>17</sup> Although the Donabedian model focuses on assessment of quality, it also provides a framework for thinking about how to assess patient outcomes.<sup>17</sup> Assessment of clinical and utilization outcomes are increasingly being used by practitioners and outside evaluation organizations as part of an effort to improve the health of the U.S. population, assess which interventions are most useful, and enhance overall quality and safety.<sup>18-20</sup> The importance of tracking change and assessing outcomes is integral to DSME/T; the National Standards for Diabetes Self-Management Education stress the importance of measurement and evaluation for diabetes education programs.<sup>14</sup>

In 2003, Mulcahy et al noted that the National Standards for Diabetes Self-Management Education defined the process by which to conduct an evaluation and establish patient-focused behavioral objectives.<sup>13</sup> However, specific metrics for diabetes education were not defined, being left to the discretion and experience of each educator to determine what to measure. This has unfortunately resulted in great variation in defining and reporting specific attributes of effective diabetes education.”<sup>13</sup> Several papers note that outcomes of learning, behavioral, clinical, and health status, need to be measured and evaluated to assess the interrelationship between DSME and behavior change.<sup>10-13,20,21</sup>

As people with diabetes acquire new self-management skills they modify their actions. Dynamic measurement of change is therefore important to educational research because education is meant to foster change over time and as people learn.<sup>14,20-23</sup> DSME/T programs aim to bring about change and their effectiveness is judged on a “process of consistently measuring specific indicators (outcomes measurement), the frequency and interval of measuring these indicators (outcomes monitoring), and how these outcomes are used for educational and clinical decision making (outcomes management).”<sup>7,10,21</sup> Although behavior has been described as the key outcome of diabetes education, guidance is lacking on how to assess behavior change in an objective manner.<sup>25</sup> This gap underscores the importance of measuring behavior change arising from DSME/T.<sup>10,11,22,23</sup>

The need for a usable and valid means of measuring behavior change over time is highlighted by the literature. The science of change measurement has been studied and published papers are available on the topics of patient activation and readiness to change, which informed the assessment of these concepts.<sup>23,24</sup> There is, however, a notable gap in the literature regarding metrics for assessing behavior change associated with healthcare (and diabetes self-management in particular). A recent systematic review conducted for this project identified only seven such reports.<sup>26-33</sup> Understanding of the value of DSME/T to achieve behavior change is limited by this gap. In addition, the ability to develop bench marks that can help programs and practitioners set standards to which they can measure their program against or strive for is needed to assess DSME/T and healthcare quality.

### **Existing Measurement Approaches**

A considerable body of knowledge exists about behavior change and smoking cessation, dieting and taking medication.<sup>34-36</sup> The metrics for these behaviors can be binary and self-reported as in, “yes, I quit smoking” or “no, I did not,” based on generally accepted and observable metrics such as loss/gain of pounds or ounces, or captured by computerized systems that track interactions such as medication refills. Greca’s 1982 Self-Care Inventory (SCI) and the revised SCI is one tool that aimed to measure self-care; it has been tested in practice and its psychometric properties examined.<sup>37</sup> While the SCI may be useful in some situations, it excludes three of the AADE7 behaviors -- healthy coping, reducing risk and problem solving. Moreover, focus group studies of diabetes educators indicate the need for uniform and objective metrics for measuring DSME-related behavior change in practice settings.<sup>37,39</sup> In addition to the SCI, some scoring tools and measurement scales are available for assessing common problems at the patient level (e.g., pain management scale) and for select self-care behaviors (e.g., Diabetes Problem Solving Interview; ES-SMBPA-2D for physical activity).<sup>40,41</sup> Other scales and scoring instruments that are relevant to diabetes self-management utilize self-reports, trading off the ease of data collection with the problems inherent in patient recall of past behaviors.<sup>42</sup> Several additional factors may affect the accuracy of information gathered through patient self-report including frequency of the measure, educator/patient relationships, and clinical factors. Because health care variables are often abstract, theoretical concepts of the data collection instruments and tools require rigorous validation, tests of reliability, and testing in practical situations.<sup>43</sup>

Gaps in knowledge about behavior change measurement were initially addressed by AADE in 2003 when the AADE Position Statement, “Standards for Outcomes Measurement of Diabetes Self-Management Education” and the accompanying “Technical Review,” were published.<sup>7,11</sup> This effort coincided with a multiyear effort to create an electronic system for data capture and research purposes, originally named National Diabetes Education Outcomes System (NDEOS).<sup>12</sup> AADE further evolved these tools into the AADE7™ System, which is designed uniquely for managing DSME/T information.<sup>44</sup> Approximately 1,500 diabetes educators currently use the AADE7 System, meaning that data are captured on more than 40,000 people with diabetes who participate in DSME/T; however, gaps exist in regard to measurement of behavior change and effectiveness of DSME/T.<sup>25</sup>

In 2008, AADE convened experts in the fields of measurement, behavioral science and diabetes education to form a Behavior Score Workgroup (BSW). The BSW aimed to:

- Create a standard metric for assessing behavior of people with diabetes who seek the services of a diabetes educator.
- Develop behavior scores for each of the AADE7 Self-Care Behaviors™ with which to assess changes in patient behavior following DSME.
- Develop a composite behavior score composed of scores for each of the seven behaviors.
- Suggest a mechanism for tracking behavior change over time.<sup>38,39</sup>

The BSW considered the concept of scoring behavior and discussed what was to be measured in light of the self-care behaviors. The group addressed the complex aspects of developing, testing, applying and presenting a metric to measure behavior and its change objectively and in a standardized manner. The BSW was aware of: 1) the need to create a BSI for DSME/T that would provide useful information for the broader healthcare community (e.g., quality measurement groups and payers); and 2) create a measure for each of the self-care behaviors as well as a composite measure. The impact of barriers to general use of the tool in the DSME/T practice, such as literacy, numeracy, time constraints, and cost, were also discussed. Careful consideration was also given to measurement frequency, patient levels of activation, and practice setting applicability.

### **Practicing Diabetes Educators Provided Guidance for the Underlying Concept**

Two focus groups were conducted at the 2008 AADE Annual Meeting to test the concept and potential use of a behavior score in practice.<sup>38</sup> The educators who participated in the focus groups confirmed that, as currently developed, the BSI would be appropriate and useful in practice. Educators also provided guidance for furthering BSI development, suggestions for improving BSI face validity, and Dashboard design. These educators recommended the use of graphics that were similar to stop-and-go lights or gas gauges in the Dashboard. The educators specifically requested that the BSW : 1) design a BSI that would be simple to use; 2) not assume that all individuals have the same goals or education plan; 3) articulate a clear operational definition for each of the seven behaviors; and 4) clarify exactly what would be measured by the BSI.<sup>38</sup>

### **Structure and Design of the Behavior Score Instrument and Dashboard**

Beginning with operational definitions of the AADE7 Self-Care Behaviors, the BSW developed a: 1) scoring methodology; 2) scoring instrument that could be completed jointly by the educator and the patient (or independently by the patient) for each of the seven behaviors; and 3) graphic Dashboard that would be used by the educator to communicate the patients' scores and need for action on one or more behaviors.<sup>45</sup> The Dashboard was specifically designed with literacy and numeracy in mind; to be appropriate to the patient population, the tools need to be at or near the 5<sup>h</sup> grade reading level.<sup>46</sup> HIPAA requirements have also shaped the intended use of the tools and associated data capture and analysis, particularly as the instrument may be integrated into the AADE7 System.<sup>47</sup> For example, the Dashboard shows information for only one patient at a time.

The BSI questionnaire captures patient reported actions for each of the AADE7 Self-Care Behaviors over a specific period of time. Patient behavior is assessed through three questions regarding each of the seven behaviors: "what he/she is currently doing"; "how important he/she thinks the behavior is"; and "how confident he/she is in doing what is needed." It also allows for variation in goals and plans across individuals and diabetes educators. An excerpt from the BSI (Table 1) shows the questions relating to the healthy eating behavior.

The BSI results are displayed using a Dashboard, which calculates and presents scores for each of the seven behaviors as well as a composite/summary score. While the BSI can be completed

on hard copy, ideally, the educator and patient will answer the BSI questions on a computer at the first encounter. In this way, the scores and graphics will be produced immediately by a software program that is embedded in the BSI and linked to the Dashboard. Responses to the questions in the BSI translate into a numeric score that will, in turn, be represented by a graphic on the Dashboard (e.g., red, yellow, or green light). The patient and educator can then objectively see the behavior changes and progress/regression over time. Data captured will be facilitated by the AADE7 System, which will integrate the BSI and Dashboard in 2011.

### **Testing the BSI and Dashboard Cognitive Testing**

In summer 2009, the AADE Professional Practice Committee (PPC) served as the expert panel that reviewed the structure and wording of the questions in the BSI. Face validity was established during a conference call during which the PPC viewed the instrument via a web-based document sharing portal. The PPC members assessed consistency across questions, clarity and readability at lower literacy levels and determined that the questions were well constructed and understandable.

The next step was to test both tools in the practice setting to assess whether the instruments were:

1. Understood and useable within the patient population that are seen by diabetes educators.
2. Able to effectively detect short term (e.g., one year or less) changes in behavior .
3. Perceived as useful in the practice of DSME/T diabetes education from the educators' perspective.
4. Deemed meaningful to patients.
5. Able to effect behavior change and related clinical indicators in a positive way.

### **Field Testing in Practice Settings**

Field testing was undertaken to obtain feedback for how useful the tools are within a variety of DSME/T practices and whether the information is perceived as valuable by the diabetes educators, clinicians and by patients. An initial field test was conducted in Atlanta, GA in 2009 with the goal of determining whether educators and English and Spanish speaking people with diabetes were able to understand the questions being asked and respond with useful answers (Table 1). Three educators and 50 people with diabetes used a hard copy of the BSI (also

translated into Spanish) during the first DSME/T encounter. The following provides a summary of the field test team's experience with the tools.

The BSW posed four questions to the Field Testing Diabetes Education Team to determine whether:

1. Educators and patients were able to understand the BSI.
2. Any parts of the BSI were confusing to patient or educators.
3. Answers were consistent with what the educator otherwise observed.
4. There are any issues with the translation to Spanish.

The results of the field testing indicate that the BSI helped educators obtain information and that there were no problems with the wording of the questions. Patients understood what was meant by "confidence" and "conviction." However, the educator was required to provide explanation as to the words, "how you feel you can do it...." The BSI was not found to be confusing, however, as the behavior scoring concept was new to patients, the educator was required to describe the behavior score concept. The BSI responses were found to be consistent with what is observed with AADE 7 Self-Care Behaviors and the Short Health Form Survey (SF-12) The Spanish version of the BSI is currently in use and working well in the Georgia DSME/T program. The pilot also indicates that the BSI is appropriate for individuals with varying literacy and numeracy levels.<sup>48</sup>

In addition, the Dashboard was tested by the educators and was found to need minor adjustments to the underlying calculations that had been programmed into the spreadsheet. For example, the scoring for the monitoring behavior was calculated so that "poorer" behavior received a higher score. Subsequently, revisions were made to the BSI and Dashboard based on the input received from the field testing team.

### **Pilot Testing in Practice**

A DSME/T program in Texas has systematically integrated the BSI and Dashboard into their DSME/T-related classes, systems and procedures and began a testing program in late 2010. This test will determine if the BSI is sensitive to behavior change that occurs as a result of the DSME/T intervention. Moreover, behavioral outcomes (behavior scores) are being correlated with clinical outcomes (e.g., A1C, blood pressure) in this pilot. Participant and educator

satisfaction with the BSI and Dashboard is being assessed and educators are rating the instruments as to their helpfulness in setting goals and changing behaviors. It is anticipated that the outcomes of this portion of the project will include a simple way to assess and discuss behavior change and its impact on glycosylated hemoglobin and other goals of diabetes care. Psychometric measurements of validity and reliability have not yet been published on the BSI. The BSW not only hopes to validate behavior score tools and metrics, but also gain a preliminary understanding of how these apply to people with diabetes from different cultures, who have various literacy levels and differing first languages. The Texas pilot study participants include adults and children with diabetes (newly diagnosed or existing Type 1 or Type 2) who are referred to DSME/T as well as diabetes educators. At least some of the DSME/T classes will be located in areas with high health disparities and reflect racial and ethnic diversity.

Additional efforts are underway to assess the BSI's criterion and content validity. This is being done by comparing the BSI to existing instruments designed to assess similar outcomes, specifically: patient perceived importance of, confidence in ability, and action of the seven behaviors. The BSI is also being evaluated to determine if it serves as a companion to tools that are designed to produce patient self-assessment scores.<sup>49</sup>

### **Summary**

Diabetes educators understand that assessment of the outcomes of DSME/T is important, ongoing and required by the bodies that accredit/recognize DSMT programs.<sup>14</sup> Progress has been made by diabetes educators in data capture and outcomes measurement since the AADE Outcomes Measurement Task Force met in the late 1990s.<sup>21</sup> Data collection is facilitated by electronic medical records and diabetes education-specific data collection tools such as the AADE7 System and ADA's Chronicle Diabetes.

Following the Donabedian model, DSME/T assessment includes structure, process and outcomes.<sup>17</sup> To date, however, much of the data capture and evaluation have focused on process measures, such as whether an eye exam occurred. Interest is increasing among policy makers and payers for interventions to demonstrate value in other ways and diabetes educators have expressed a need for additional metrics and tools that will allow them to demonstrate the behavior change that results from their services, and do so in a systematic way.<sup>38</sup>

Educators and content experts who participated in research Symposia and focus groups have noted that behavior assessment has been impeded by a lack of simple methods, useful tools, available definitions, and validated and reliable measures.<sup>50,51</sup> To fill the gap, an expert workgroup worked to augment self-management behavior measurement by developing methods and metrics for assessing behavior of people who attend DSME/T classes.<sup>52-55</sup> These metrics are incorporated into the behavior score instrument (BSI) and Dashboard.

The BSI questionnaire, which was designed for use by diabetes educators in their practices, captures patient self-reports of actions relating to each of the AADE7 Self-Care Behaviors over a specific period of time and is designed to be administered pre and post DSME/T or more often as appropriate. The BSI and Dashboard give a numeric reading on how well the person with diabetes is achieving his/her goals at any one point in time. Subsequent measurements with the BSI indicate changes over time. The BSI does not assume that all individuals have the same goals or education plan, thereby allowing variation in goals and plans across individuals and diabetes educators

People with diabetes have varying levels of literacy and numeracy, and may not be native English speakers. Their ability to comprehend and use health information is to a large extent dependent upon how the information is presented as well as literacy and numeracy levels. Peters et al reported that “less is more” when presenting information to consumers.<sup>54-56</sup> Hence, the BSI and Dashboard were created to be easily understood and able to communicate information to individuals with differing backgrounds and levels of education.

Initial indications from diabetes educators are that the BSI and Dashboard will fill an existing gap, are easy to use, and are perceived as being feasible for use in practice with different patient populations. Behavior scoring methods and tools are currently being validated with input from measurement experts, researchers, practitioners and people with diabetes.

The validation and testing phase of the project aims to demonstrate that the BSI and Dashboard are effective components of DSME/T. Efforts are underway to compare the BSI with similar instruments to indicate the strength of correlation across the BSI and Dashboard and other accepted and validated behavior assessment tools. In these cross-comparisons, BSI results will be compared to those found in the SF12 or other such “gold standard” instruments and

correlated to clinical outcomes (e.g., A1C).<sup>57</sup> The testing will also reveal whether the BSI can effectively be used by the individual with diabetes on his/her own or is it best used in collaboration with an educator. The breadth of this effort serves as the foundation to determine the appropriateness of the measures for use in DSME/T practice. The BSI will be available for widespread use in the practice of diabetes self-management education and training in the near future.

## **Conclusion**

The increasing prevalence of diabetes indicates a growing need to better control the disease and its co-morbidities. Behavior change is fundamental to successful self-management for people with diabetes and DSME/T has been proven to be effective. Diabetes educators who provide DSME/T bring about positive behavior change by imparting knowledge, skills, and empowering people with diabetes to more effectively self-manage their disease. Standardized and objective metrics for behavior change outcomes have not been integrated into most practices, in large part because of the individualized nature of self-management education. However, without standardized behavior change metrics, it is difficult to achieve optimal self-management for those with diabetes and to demonstrate the value of diabetes education interventions.

New behavior score concept and tools (Behavior Score Instrument and Dashboard) have been designed to objectively measure seven self-care behaviors and their change over time. The tools can be thought of as the behavioral equivalent of well understood and accepted measures of the health status of people with diabetes, such as A1C. Initial indications are that the behavior score tools can be used in the practice of DSME/T for a variety of populations. By contributing to the achievement of optimal outcomes for people with diabetes, the behavior score tools will have relevance for diabetes educators and the broader health care community.

**Table 1. Behavior Score Instrument Excerpt**

**Healthy Eating**

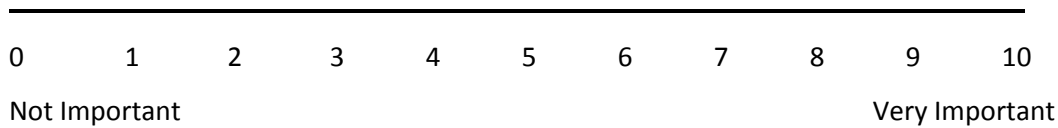
Following an eating plan that is good for you includes: not eating too much, counting the amount of carbohydrates you eat, not eating too much fat; keeping an eye on and/or drinking less alcohol. It also means eating fruits, vegetables, whole grains, beans, and other foods with high fiber.

Following an eating plan that is good for you may also include reaching goals for losing weight, and limiting the amount of protein and salt you eat.

During the past two weeks, how many days were you able to follow an eating plan that is good for you?

1. I do not currently follow an eating plan that is good for me
2. 3 days or fewer
3. 4 to 7 days
4. 8 to 11 days
5. 12 or more days

How important is it to you to follow an eating plan that is good for you, where 0 is not important at all and 10 is very important?

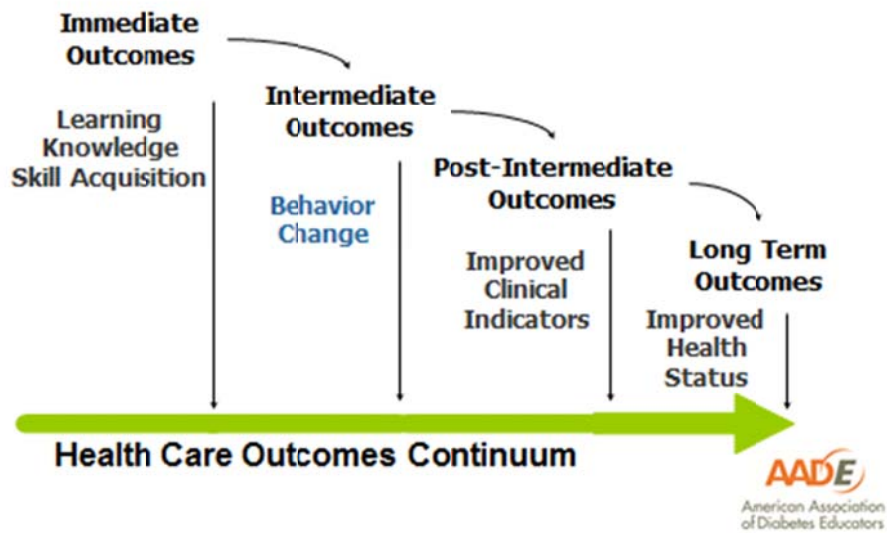


How sure are you that you are able to follow an eating plan that is good for you, where 0 is not sure at all and 10 is very sure?



Figure 1.

# DSME Outcomes Measures



**Acknowledgements:** Daniel Touchette; Russell E. Glasgow, Ph.D.; Karen Fitzner, PhD; Sue Boren, PhD, MHA; Martha J. Price, DNSc., ARNP, CDE; Susan Grinslade, PhD, RN, APRN, BC; Chih-Hung Chang, PhD; Marian Chima, MSN, RN, CDE; Dawn Sherr, RD, CDE

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