

National Standards for Diabetes Self-Management Education and Support

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 REVISION TASK FORCE

By the most recent estimates, 18.8 million people in the U.S. have been diagnosed with diabetes and an additional 7 million are believed to be living with undiagnosed diabetes. At the same time, 79 million people are estimated to have blood glucose levels in the range of prediabetes or categories of increased risk for diabetes. Thus, more than 100 million Americans are at risk for developing the devastating complications of diabetes (1).

Diabetes self-management education (DSME) is a critical element of care for all people with diabetes and those at risk for developing the disease. It is necessary in order to prevent or delay the complications of diabetes (2–6) and has elements related to lifestyle changes that are also essential for individuals with prediabetes as

part of efforts to prevent the disease (7,8). The National Standards for Diabetes Self-Management Education are designed to define quality DSME and support and to assist diabetes educators in providing evidence-based education and self-management support. The Standards are applicable to educators in solo practice as well as those in large multicenter programs—and everyone in between. There are many good models for the provision of diabetes education and support. The Standards do not endorse any one approach, but rather seek to delineate the commonalities among effective and excellent self-management education strategies. These are the standards used in the field for recognition and accreditation. They also serve as a guide for

nonaccredited and nonrecognized providers and programs.

Because of the dynamic nature of health care and diabetes-related research, the Standards are reviewed and revised approximately every 5 years by key stakeholders and experts within the diabetes education community. In the fall of 2011, a Task Force was jointly convened by the American Association of Diabetes Educators (AADE) and the American Diabetes Association (ADA). Members of the Task Force included experts from the areas of public health, underserved populations including rural primary care and other rural health services, individual practices, large urban specialty practices, and urban hospitals. They also included individuals with diabetes, diabetes researchers, certified diabetes educators, registered nurses, registered dietitians, physicians, pharmacists, and a psychologist. The Task Force was charged with reviewing the current National Standards for Diabetes Self-Management Education for their appropriateness, relevance, and scientific basis and updating them based on the available evidence and expert consensus.

The Task Force made the decision to change the name of the Standards from the National Standards for Diabetes Self-Management Education to the National Standards for Diabetes Self-Management Education and Support. This name change is intended to codify the significance of ongoing support for people with diabetes and those at risk for developing the disease, particularly to encourage behavior change, the maintenance of healthy diabetes-related behaviors, and to address psychosocial concerns. Given that self-management does not stop when a patient leaves the educator's office, self-management support must be an ongoing process.

Although the term “diabetes” is used predominantly, the Standards should also be understood to apply to the education and support of people with prediabetes. Currently, there are significant barriers to the provision of education and support to those with prediabetes. And yet, the strategies for supporting successful behavior change and the healthy behaviors

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DOI: 10.2337/dc12-1707

The previous version of this article “National Standards for Diabetes Self-Management Education” was published in *Diabetes Care* 2007;30:1630–1637. This version received final approval in July 2012.

This article has been copublished in *The Diabetes Educator*.

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recommended for people with prediabetes are largely identical to those for individuals with diabetes. As barriers to care are overcome, providers of DSME and diabetes self-management support (DSMS), given their training and experience, are particularly well equipped to assist individuals with prediabetes in developing and maintaining behaviors that can prevent or delay the onset of diabetes.

Many people with diabetes have or are at risk for developing comorbidities, including both diabetes-related complications and conditions (e.g., heart disease, lipid abnormalities, nerve damage, hypertension, and depression) and other medical problems that may interfere with self-care (e.g., emphysema, arthritis, and alcoholism). In addition, the diagnosis, progression, and daily work of managing the disease can take a major emotional toll on people with diabetes that makes self-care even more difficult (9). The Standards encourage providers of DSME and DSMS to address the entire panorama of each participant's clinical profile. Regular communication among the members of participant's health care teams is essential to ensure high-quality, effective education and support for people with diabetes and prediabetes.

In the course of its work on the Standards, the Task Force identified areas in which there is currently an insufficient amount of research. In particular, there are three areas in which the Task Force recommends additional research:

1. What is the influence of organizational structure on the effectiveness of the provision of DSME and DSMS?
2. What is the impact of using a structured curriculum in DSME?
3. What training should be required for those community, lay, or peer workers without training in health or diabetes who are to participate in the provision of DSME and to provide DSMS?

Finally, the Standards emphasize that the person with diabetes is at the center of the entire diabetes education and support process. It is the individuals with diabetes who do the hard work of managing their condition, day in and day out. The educator's role, first and foremost, is to make that work easier (10).

DEFINITIONS

DSME: The ongoing process of facilitating the knowledge, skill, and ability necessary for prediabetes and diabetes self-care.

This process incorporates the needs, goals, and life experiences of the person with diabetes or prediabetes and is guided by evidence-based standards. The overall objectives of DSME are to support informed decision making, self-care behaviors, problem solving, and active collaboration with the health care team and to improve clinical outcomes, health status, and quality of life.

DSMS: Activities that assist the person with prediabetes or diabetes in implementing and sustaining the behaviors needed to manage his or her condition on an ongoing basis beyond or outside of formal self-management training. The type of support provided can be behavioral, educational, psychosocial, or clinical (11–15).

STANDARD 1

Internal structure

The provider(s) of DSME will document an organizational structure, mission statement, and goals. For those providers working within a larger organization, that organization will recognize and support quality DSME as an integral component of diabetes care.

Documentation of an organizational structure, mission statement, and goals can lead to efficient and effective provision of DSME and DSMS. In the business literature, case studies and case report investigations of successful management strategies emphasize the importance of clear goals and objectives, defined relationships and roles, and managerial support. Business and health policy experts and organizations emphasize written commitments, policies, support, and the importance of outcomes reporting to maintain ongoing support or commitment (16,17).

Documentation of an organizational structure that delineates channels of communication and represents institutional commitment to the educational entity is critical for success. According to The Joint Commission, this type of documentation is equally important for both small and large health care organizations (18). Health care and business experts overwhelmingly agree that documentation of the process of providing services is a critical factor in clear communication and provides a solid basis from which to deliver quality diabetes education. In 2010, The Joint Commission published the *Disease-Specific Care Certification Manual*, which outlines standards and

performance measurements for chronic care programs and disease management services, including “Supporting Self-Management” (18).

STANDARD 2

External input

The provider(s) of DSME will seek ongoing input from external stakeholders and experts in order to promote program quality.

For both individual and group providers of DSME and DSMS, external input is vital to maintaining an up-to-date, effective program. Broad participation of community stakeholders, including individuals with diabetes, health professionals, and community interest groups, will increase the program's knowledge of the local population and allow the provider to better serve the community. Often, but not always, this external input is best achieved by the establishment of a formal advisory board. The DSME and DSMS provider(s) must have a documented plan for seeking outside input and acting on it.

The goal of external input and discussion in the program planning process is to foster ideas that will enhance the quality of the DSME and/or DSMS being provided, while building bridges to key stakeholders (19). The result is effective, dynamic DSME that is patient centered, more responsive to consumer-identified needs and the needs of the community, more culturally relevant, and more appealing to consumers (17,19,20).

STANDARD 3

Access

The provider(s) of DSME will determine who to serve, how best to deliver diabetes education to that population, and what resources can provide ongoing support for that population.

Currently, the majority of people with diabetes and prediabetes do not receive any structured diabetes education (19,20). While there are many barriers to DSME, one crucial issue is access (21). Providers of DSME can help address this issue by:

- Clarifying the specific population to be served. Understanding the community, service area, or regional demographics is crucial to ensuring that as many people as possible are being reached, including those who do not frequently attend clinical appointments (9,17,22–24).

- Determining that population's self-management education and support needs. Different individuals, their families, and communities need different types of education and support (25). The provider(s) of DSME and DSMS needs to work to ensure that the necessary education alternatives are available (25–27). This means understanding the population's demographic characteristics, such as ethnic/cultural background, sex, and age, as well as levels of formal education, literacy, and numeracy (28–31). It may also entail identifying resources outside of the provider's practice that can assist in the ongoing support of the participant.
- Identifying access issues and working to overcome them. It is essential to determine factors that prevent individuals with diabetes from receiving self-management education and support. The assessment process includes the identification of these barriers to access (32–34). These barriers may include the socioeconomic or cultural factors mentioned above, as well as, for example, health insurance shortfalls and the lack of encouragement from other health providers to seek diabetes education (35,36).

STANDARD 4

Program coordination

A coordinator will be designated to oversee the DSME program. The coordinator will have oversight responsibility for the planning, implementation, and evaluation of education services.

Coordination is essential to ensure that quality diabetes self-management education and support is delivered through an organized, systematic process (37,38). As the field of DSME continues to evolve, the coordinator plays a pivotal role in ensuring accountability and continuity in the education program (39–41). The coordinator's role may be viewed as that of coordinating the program (or education process) and/or as supporting the coordination of the many aspects of self-management in the continuum of diabetes and related conditions when feasible (42–49). This oversight includes designing an education program or service that helps the participant access needed resources and assists him or her in navigating the health care system (37,50–55).

The individual serving as the coordinator will have knowledge of the

lifelong process of managing a chronic disease and facilitating behavior change, in addition to experience with program and/or clinical management (56–59). In some cases, particularly in solo or other small practices, the coordinator may also provide DSME and/or DSMS.

STANDARD 5

Instructional staff

One or more instructors will provide DSME and, when applicable, DSMS. At least one of the instructors responsible for designing and planning DSME and DSMS will be a registered nurse, registered dietitian, or pharmacist with training and experience pertinent to DSME, or another professional with certification in diabetes care and education, such as a CDE or BC-ADM. Other health workers can contribute to DSME and provide DSMS with appropriate training in diabetes and with supervision and support.

Historically, nurses and dietitians were the main providers of diabetes education (3,4,60–64). In recent years, the role of the diabetes educator has expanded to other disciplines, particularly pharmacists (65–67). Reviews comparing the effectiveness of different disciplines for education have not identified clear differences in the quality of services delivered by different professionals (3–5). However, the literature favors the registered nurse, registered dietitian, and pharmacist serving both as the key primary instructors for diabetes education and as members of the multidisciplinary team responsible for designing the curriculum and assisting in the delivery of DSME (1–7,68). Expert consensus supports the need for specialized diabetes and educational training beyond academic preparation for the primary instructors on the diabetes team (69–72). Professionals serving as instructors must document appropriate continuing education or comparable activities to ensure their continuing competence to serve in their instructional, training, and oversight roles (73).

Reflecting the evolving health care environment, a number of studies have endorsed a multidisciplinary team approach to diabetes care, education, and support. The disciplines that may be involved include, but are not limited to, physicians, psychologists and other mental health specialists, physical activity specialists (including physical therapists,

occupational therapists, and exercise physiologists), optometrists, and podiatrists (68,74,75). More recently, health educators (e.g., Certified Health Education Specialists and Certified Medical Assistants), case managers, lay health and community workers (76–83), and peer counselors or educators (84,85) have been shown to contribute effectively as part of the DSME team and in providing DSMS. While DSME and DSMS are often provided within the framework of a collaborative and integrated team approach, it is crucial that the individual with diabetes is viewed as central to the team and that he or she takes an active role.

Certification as a diabetes educator (CDE) by the National Certification Board for Diabetes Educators (NCBDE) is one way a health professional can demonstrate mastery of a specific body of knowledge, and this certification has become an accepted credential in the diabetes community (86). An additional credential that indicates specialized training beyond basic preparation is board certification in Advanced Diabetes Management (BC-ADM) offered by the AADE, which is available for nurses, dietitians, pharmacists, physicians, and physician assistants (68,74,87).

Individuals who serve as lay health and community workers and peer counselors or educators may contribute to the provision of DSME instruction and provide DSMS if they have received training in diabetes management, the teaching of self-management skills, group facilitation, and emotional support. For these individuals, a system must be in place that ensures supervision of the services they provide by a diabetes educator or other health care professional and professional back-up to address clinical problems or questions beyond their training (88–90).

For services outside the expertise of any provider(s) of DSME and DSMS, a mechanism must be in place to ensure that the individual with diabetes is connected with appropriately trained and credentialed providers.

STANDARD 6

Curriculum

A written curriculum reflecting current evidence and practice guidelines, with criteria for evaluating outcomes, will serve as the framework for the provision of DSME. The needs of the individual participant will

determine which parts of the curriculum will be provided to that individual.

Individuals with prediabetes and diabetes and their families and caregivers have much to learn to become effective self-managers of their condition. DSME can provide this education via an up-to-date, evidence-based, and flexible curriculum (8,91).

The curriculum is a coordinated set of courses and educational experiences. It also specifies learning outcomes and effective teaching strategies (92,93). The curriculum must be dynamic and reflect current evidence and practice guidelines (93–97). Recent education research endorses the inclusion of practical problem-solving approaches, collaborative care, psychosocial issues, behavior change, and strategies to sustain self-management efforts (12,13,19,74,86,98–101).

The following core topics are commonly part of the curriculum taught in comprehensive programs that have demonstrated successful outcomes (2,3,5,91,102–104):

- Describing the diabetes disease process and treatment options
- Incorporating nutritional management into lifestyle
- Incorporating physical activity into lifestyle
- Using medication(s) safely and for maximum therapeutic effectiveness
- Monitoring blood glucose and other parameters and interpreting and using the results for self-management decision making
- Preventing, detecting, and treating acute complications
- Preventing, detecting, and treating chronic complications
- Developing personal strategies to address psychosocial issues and concerns
- Developing personal strategies to promote health and behavior change

While the content areas listed above provide a solid outline for a diabetes education and support curriculum, it is crucial that the content be tailored to match each individual's needs and be adapted as necessary for age, type of diabetes (including prediabetes and diabetes in pregnancy), cultural factors, health literacy and numeracy, and comorbidities (14,105–108). The content areas will be able to be adapted for all practice settings.

Approaches to education that are interactive and patient centered have been shown to be effective (12,13,109–112).

Also crucial is the development of action-oriented behavioral goals and objectives (12–14,113). Creative, patient-centered, experience-based delivery methods—beyond the mere acquisition of knowledge—are effective for supporting informed decision making and meaningful behavior change and addressing psychosocial concerns (114,115).

STANDARD 7

Individualization

The diabetes self-management, education, and support needs of each participant will be assessed by one or more instructors. The participant and instructor(s) will then together develop an individualized education and support plan focused on behavior change.

Research has demonstrated the importance of individualizing diabetes education to each participant's needs (116). The assessment process is used to identify what those needs are and to facilitate the selection of appropriate educational and behavioral interventions and self-management support strategies, guided by evidence (2,63,116–118). The assessment must garner information about the individual's medical history, age, cultural influences, health beliefs and attitudes, diabetes knowledge, diabetes self-management skills and behaviors, emotional response to diabetes, readiness to learn, literacy level (including health literacy and numeracy), physical limitations, family support, and financial status (11,106,108,117,119–128).

The education and support plan that the participant and instructor(s) develop will be rooted in evidence-based approaches to effective health communication and education while taking into consideration participant barriers, abilities, and expectations. The instructor will use clear health communication principles, avoiding jargon, making information culturally relevant, using language- and literacy-appropriate education materials, and using interpreter services when indicated (107,129–131). Evidence-based communication strategies such as collaborative goal setting, motivational interviewing, cognitive behavior change strategies, problem solving, self-efficacy enhancement, and relapse prevention strategies are also effective (101,132–134). Periodic reassessment can determine whether there is need for additional or different interventions and future reassessment (6,72,134–137). A variety of assessment modalities, including telephone follow-up

and other information technologies (e.g., Web based, text messaging, or automated phone calls), may augment face-to-face assessments (72,87,138–141).

The assessment and education plan, intervention, and outcomes will be documented in the education/health record. Documentation of participant encounters will guide the education process, provide evidence of communication among instructional staff and other members of the participant's health care team, prevent duplication of services, and demonstrate adherence to guidelines (117,135,142,143). Providing information to other members of the participant's health care team through documentation of educational objectives and personal behavioral goals increases the likelihood that all the members will work in collaboration (86,143). Evidence suggests that the development of standardized procedures for documentation, training health professionals to document appropriately, and the use of structured standardized forms based on current practice guidelines can improve documentation and may ultimately improve quality of care (135,143–145).

STANDARD 8

Ongoing support

The participant and instructor(s) will together develop a personalized follow-up plan for ongoing self-management support. The participant's outcomes and goals and the plan for ongoing self-management support will be communicated to other members of the health care team.

While DSME is necessary and effective, it does not in itself guarantee a lifetime of effective diabetes self-care (113). Initial improvements in participants' metabolic and other outcomes have been found to diminish after approximately 6 months (3). To sustain the level of self-management needed to effectively manage prediabetes and diabetes over the long term, most participants need ongoing DSMS (15).

The type of support provided can be behavioral, educational, psychosocial, or clinical (11–14). A variety of strategies are available for providing DSMS both within and outside the DSME organization. Some patients benefit from working with a nurse case manager (6,86,146). Case management for DSMS can include reminders about needed follow-up care and tests, medication management, education, behavioral goal setting, psychosocial support, and connection to community resources.

The effectiveness of providing DSMS through disease management programs, trained peers and community health workers, community-based programs, information technology, ongoing education, support groups, and medical nutrition therapy has also been established (7–11,86,88–90,142,147–150).

While the primary responsibility for diabetes education belongs to the provider(s) of DSME, participants benefit by receiving reinforcement of content and behavioral goals from their entire health care team (135). Additionally, many patients receive DSMS through their primary care provider. Thus, communication among the team regarding the patient's educational outcomes, goals, and DSMS plan is essential to ensure that people with diabetes receive support that meets their needs and is reinforced and consistent among the health care team members.

Because self-management takes place in participants' daily lives and not in clinical or educational settings, patients will be assisted to formulate a plan to find community-based resources that may support their ongoing diabetes self-management. Ideally, DSME and DSMS providers will work with participants to identify such services and, when possible, track those that have been effective with patients, while communicating with providers of community-based resources in order to better integrate them into patients' overall care and ongoing support.

STANDARD 9

Patient progress

The provider(s) of DSME and DSMS will monitor whether participants are achieving their personal diabetes self-management goals and other outcome(s) as a way to evaluate the effectiveness of the educational intervention(s), using appropriate measurement techniques.

Effective diabetes self-management can be a significant contributor to long-term, positive health outcomes. The provider(s) of DSME and DSMS will assess each participant's personal self-management goals and his or her progress toward those goals (151,152).

The AADE Outcome Standards for Diabetes Education specify behavior change as the key outcome and provide a useful framework for assessment and documentation. The AADE7 lists seven essential factors: physical activity, healthy

eating, taking medication, monitoring blood glucose, diabetes self-care–related problem solving, reducing risks of acute and chronic complications, and psychosocial aspects of living with diabetes (93,153,154). Differences in behaviors, health beliefs, and culture as well as their emotional response to diabetes can have a significant impact on how participants understand their illness and engage in self-management. DSME providers who account for these differences when collaborating with participants on the design of personalized DSME or DSMS programs can improve participant outcomes (147,148).

Assessments of participant outcomes must occur at appropriate intervals. The interval depends on the nature of the outcome itself and the time frame specified based on the participant's personal goals. For some areas, the indicators, measures, and time frames will be based on guidelines from professional organizations or government agencies.

STANDARD 10

Quality improvement

The provider(s) of DSME will measure the effectiveness of the education and support and look for ways to improve any identified gaps in services or service quality using a systematic review of process and outcome data.

Diabetes education must be responsive to advances in knowledge, treatment strategies, education strategies, and psychosocial interventions, as well as consumer trends and the changing health care environment. By measuring and monitoring both process and outcome data on an ongoing basis, providers of DSME can identify areas of improvement and make adjustments in participant engagement strategies and program offerings accordingly.

The Institute for Healthcare Improvement suggests three fundamental questions that should be answered by an improvement process (149):

- What are we trying to accomplish?
- How will we know a change is an improvement?
- What changes can we make that will result in an improvement?

Once areas for improvement are identified, the DSME provider must designate timelines and important milestones including data collection, analysis, and

presentation of results (150). Measuring both processes and outcomes helps to ensure that change is successful without causing additional problems in the system. Outcome measures indicate the result of a process (i.e., whether changes are actually leading to improvement), while process measures provide information about what caused those results (144,150). Process measures are often targeted to those processes that typically impact the most important outcomes.

Acknowledgments—No potential conflicts of interest relevant to this article were reported.

The Task Force acknowledges Paulina Duker, ADA Staff Facilitator; Leslie Kolb, AADE Staff Facilitator; Karen Fitzner, PhD, meeting facilitator (FH Consultants, Chicago, Illinois); and Sara Sklaroff for technical writing assistance.

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