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Abstract

The clinical care of both type 1 and type 2 diabetes has changed dramatically in recent years. While new therapies and technological advances improve outcomes in diabetes, these can also increase the burden of daily care for people with diabetes and their family members. In order to use these technologies effectively, patients need the information required for advanced decision-making, the skills to incorporate self-management into their lives, and the self-efficacy to assume this level of responsibility. Diabetes self-management education, on-going support, and patient empowerment are strategies that can be used to facilitate patient engagement and active participation, prevent acute complications, and ultimately to improve long-term outcomes and quality of life among people with diabetes.

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Keywords

Self-management · Diabetes self-management education · Diabetes self-management support · Patient empowerment · Self-directed goal setting

Introduction

It is widely recognized that diabetes is a largely self-managed disease, with patients assuming more than 99% of their own day-to-day care. Thus, the implementation of therapeutic recommendations, changes in lifestyle, healthy coping, and ultimately outcomes are largely in the hands of the person with diabetes. This responsibility cannot be negotiated, assigned, or diminished (Anderson et al. 2002). It is therefore fundamental to diabetes that medical treatment and patient behaviors must intersect to guide the course of this illness. (Marrero et al. 2013) Within this context, the role of health professionals is to facilitate self-management, informed decision-making, engagement and empowerment through on-going diabetes expertise, education, and psychosocial support.

Diabetes Self-Management

Diabetes self-management is defined as the tasks patients undertake in order to live well with their illness. (Barlow et al. 2002) It includes the patients' ability, knowledge, skills, and confidence to make daily decisions; select and make behavioral changes; and cope with the emotional aspects of their disease within the context of their lives.

Because of the essential nature of self-management in diabetes, patient education has long been viewed as a cornerstone of diabetes care. Unfortunately, early educational efforts to provide a one-time "inoculation of information" designed to get patients to comply or adhere with their physicians' orders for a lifetime were largely ineffective. The concept of patient empowerment was introduced in 1991 (Funnell et al. 1991) as an alternative approach for people with diabetes and patient education. The resulting efforts to design, implement, and evaluate educational and behavioral interventions has led to significant improvements in both our understanding of and ability to provide effective self-management education and on-going behavioral and psychosocial support for people with diabetes.

Diabetes Self-Management Education (DSME) and Diabetes Self-Management Support (DSMS)

The goal of DSME/S is currently defined as "supporting informed decision-making, self-care behaviors, problem solving, and active collaboration with the health care team, and improving clinical outcomes, health status and quality of life" (Haas et al.

2012). It is also recognized that both DSME and on-going support (DSMS) are essential to “enable people with or at risk for diabetes to make informed decisions and to assume responsibility for the day-to-day management of their disease or risk factors” (NDEP 2015).

The Standards of Care from the American Diabetes Association state that “all people with diabetes should participate in DSME to facilitate the knowledge, skills, and ability necessary to carry out diabetes self-care and receive DSMS to assist with implementing and sustaining skills and behaviors needed for on-going self-management, both a diagnosis and as needed thereafter” (ADA 2017). While the need for self-management is well established and the difficulties patients experience implementing provider recommendations is viewed as a major barrier in clinical care and source of frustration, DSME and DSMS are largely underutilized services. The large multinational second Diabetes Attitudes, Wishes, and Needs Study (DAWN2) found that “most people with diabetes are not actively engaged by their healthcare professionals to take control of their condition; education and psychosocial care are often unavailable” (Nicolucci 2013). In the DAWN2 sample of over 8,000 patients with type 1 and type 2 diabetes from 17 different countries, less than half had received formal diabetes education. Of those who had participated in DSME, however, the majority (81.1%) found it helpful.

A review of claims data in the United States revealed that only 6.8% of privately insured, newly diagnosed adults (ages 18–64) participated in DSME during the first year after diagnosis between 2009 and 2012 (Li et al. 2014). Although the reasons for this are largely unknown and likely complex, the misperception that DSME/S is ineffective, costly, and unnecessary is a limiting factor for health professional recommendations and referrals.

Effectiveness of DSME/S

Multiple studies, reviews, and meta-analysis have documented that DSME is effective for improving A1C and other metabolic outcomes and quality of life, and is also cost-effective for reducing hospitalizations and readmissions (Brunisholz et al. 2014; Steinsbekk et al. 2012; Duncan et al. 2009; Heinrich et al. 2010; Pillay et al. 2015a, b). In general, DSME has a positive effect on diabetes-related health and psychosocial outcomes; specifically, glycemic control, blood glucose monitoring, dietary and exercise behaviors, foot care, medication-taking, diabetes-related distress, and healthy coping. (Powers et al. 2015).

DSME/S Content

The International Diabetes Federation (IDF 2009) and many countries have developed Standards for Diabetes Education that include content areas and methods as well as program structure, process, evaluation, and outcomes. In the USA, National Standards for Diabetes Self-management Education and Support (DSME/S) were

Table 1 Recommended diabetes self-management content areas

Diabetes pathophysiology and treatment options
Healthy eating
Physical activity
Medication usage
Monitoring and using patient-generated health data
Preventing, detecting, and treating acute and chronic complications
Healthy coping with psychosocial issues and concerns
Problem solving

From Beck et al. 2017

first published in 1982 and are revised every 5 years based on the current evidence (Beck et al. 2017). Content areas identified by these Standards are outlined in Table 1. Evidence for meeting these Standards through either recognition by the American Diabetes Association (ADA) or certification by the American Association of Diabetes Educators (AADE) is required for reimbursement by Medicare, Medicaid, and most private insurers.

DSME/S Frequency

A joint Position Statement was recently published by the ADA, AADE, and the Academy of Nutrition Sciences to better define the provision of DSME and DSMS for adults with type 2 diabetes (Powers et al. 2015). Critical times to assess and refer for DSME, DSMS, and Medical Nutrition Therapy (MNT) are at diagnosis, during the annual visit, when new or complicating factors affect self-management, and when transitions in care occur (see Fig. 1). As examples, adults with type 2 diabetes who begin insulin therapy, experience depression, are struggling with self-management, or move from home to extended care all need to be assessed to determine if DSME/S is needed. Specific content and action steps for each of these critical times are described in Fig. 2.

DSME/S Methods

Although the evidence supports the efficacy of DSME/S, it is not possible to define an optimal DSME/S program (Norris 2002). However, characteristics that enhance effectiveness have been identified in both clinical and nonclinical settings and are summarized in Table 2. As examples, educational programs that provide more contact than the 10 h typically covered by reimbursement in the USA are more effective than programs that provide 10 contact h or less (Pillay et al. 2015b). In addition, programs that integrate psychosocial and behavioral content and are empowerment-based report better outcomes than traditional, lecture-based educational programs (Norris et al. 2002). There is no difference in the effectiveness of group DSME/S compared with individually provided education.

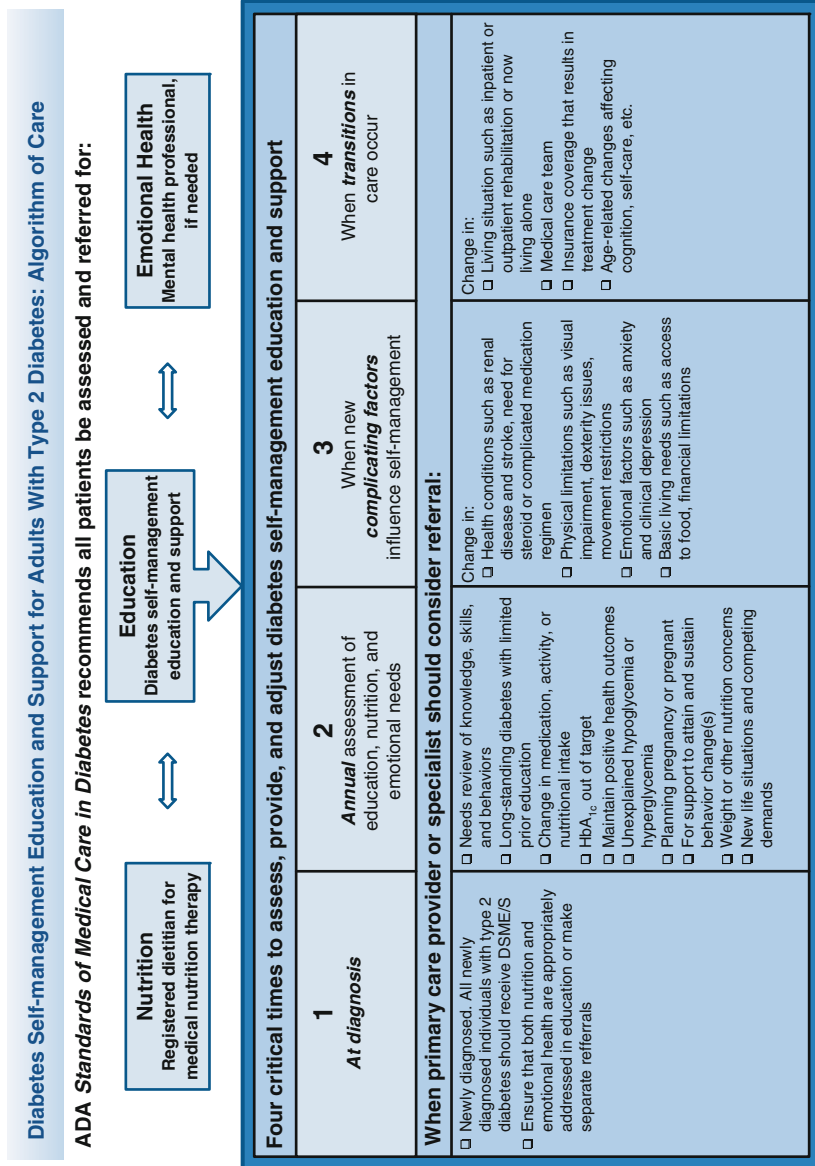


Fig. 1 DSME/S algorithm of care. (Reprinted with permission Powers et al. 2015)

Diabetes Self-management Education and Support Algorithm: Action Steps			
Four critical times to assess, provide, and adjust diabetes self-management education and support			
At diagnosis	Annual assessment of education, nutrition, and emotional needs	When new <i>complicating factors</i> influence self-management	When <i>transitions</i> in care occur
<p>Primary care provider/endocrinologist/clinical care team: areas of focus and action steps</p> <ul style="list-style-type: none"> <input type="checkbox"/> Answer questions and provide emotional support regarding diagnosis <input type="checkbox"/> Provide overview of treatment and treatment goals <input type="checkbox"/> Teach survival skills to address immediate requirements (safe use of medication, hypoglycemia treatment if needed, introduction of eating guidelines) <input type="checkbox"/> Identify and discuss resources for education and ongoing support <input type="checkbox"/> Make referral for DSME/S and MNT 	<p>Annual assessment of education, nutrition, and emotional needs</p> <ul style="list-style-type: none"> <input type="checkbox"/> Assess all areas of self-management <input type="checkbox"/> Review problem-solving skills <input type="checkbox"/> Identify strengths and challenges of living with diabetes 	<p>When new <i>complicating factors</i> influence self-management</p> <ul style="list-style-type: none"> <input type="checkbox"/> Identify presence of factors that affect diabetes self-management and attain treatment and behavioral goals <input type="checkbox"/> Discuss effect of complications and successes with treatment and self-management 	<p>When <i>transitions</i> in care occur</p> <ul style="list-style-type: none"> <input type="checkbox"/> Develop diabetes transition plan <input type="checkbox"/> Communicate transition plan to new health care team members <input type="checkbox"/> Establish DSME/S regular follow-up care
<p>Diabetes education: areas of focus and action steps</p> <p>Assess cultural influences, health beliefs, current knowledge, physical limitations, family support, financial status, medical history, literacy, numeracy to determine content to provide and how.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Medications—choices, action, titration, side effects <input type="checkbox"/> Monitoring blood glucose—when to test, interpreting and using glucose pattern management for feedback <input type="checkbox"/> Physical activity—safety, short-term vs. long-term goals/recommendations <input type="checkbox"/> Preventing, detecting, and treating acute and chronic complications <input type="checkbox"/> Nutrition—food plan, planning meals, purchasing food, preparing meals, portioning food <input type="checkbox"/> Risk reduction—smoking cessation, foot care <input type="checkbox"/> Developing personal strategies to address psychosocial issues and concerns <input type="checkbox"/> Developing personal strategies to promote health and behavior change 	<p>Diabetes education: areas of focus and action steps</p> <ul style="list-style-type: none"> <input type="checkbox"/> Review and reinforce treatment goals and self-management needs <input type="checkbox"/> Emphasize preventing complications and promoting quality of life <input type="checkbox"/> Discuss how to adapt diabetes treatment and self-management to new life situations and competing demands <input type="checkbox"/> Support efforts to sustain initial behavior changes and cope with the ongoing burden of diabetes 	<p>When new <i>complicating factors</i> influence self-management</p> <ul style="list-style-type: none"> <input type="checkbox"/> Provide support for the provision of self-care skills in an effort to delay progression of the disease and prevent new complications <input type="checkbox"/> Provide/refer for emotional support for diabetes-related distress and depression <input type="checkbox"/> Develop and support personal strategies for behavior change and healthy coping <input type="checkbox"/> Develop personal strategies to accommodate sensory or physical limitation(s), adapting to new self-management demands, and promote health and behavior change 	<p>When <i>transitions</i> in care occur</p> <ul style="list-style-type: none"> <input type="checkbox"/> Identify needed adaptations in diabetes self-management <input type="checkbox"/> Provide support for independent self-management skills and self-efficacy <input type="checkbox"/> Identify level of significant other involvement and facilitate education and support <input type="checkbox"/> Assist with facing challenges affecting usual level of activity, ability to function, health beliefs, and feelings of well-being <input type="checkbox"/> Maximize quality of life and emotional support for the patient (and family members) <input type="checkbox"/> Provide education for others now involved in care <input type="checkbox"/> Establish communication and follow-up plans with the provider, family, and others

Fig. 2 DSME/S algorithm of care: action steps. (Reprinted with permission Powers et al. 2015)

Table 2 Effectiveness of DSME and DSMS

Characteristics of effective interventions
Regular reinforcement is more effective than one-time or short-term education.
Patient participation and collaboration appear to produce more favorable results than didactic interventions.
Group education is more effective than one-on-one education for lifestyle interventions and appears to be equally effective for improving knowledge and accuracy of self-monitoring of blood glucose (SMBG).
Studies with short-term follow up are more likely to demonstrate positive effects on glycemic control and behavioral outcomes than studies with long-term follow-up.
Programs with less than 10 contact hours and without added support provide limited long-term benefit.
Effectiveness in clinical settings
In the short term (<6 months), DSME improves knowledge levels, SMBG skills, and dietary habits (per self-report).
In the short term (<6 months), glycemic control improves.
Improved glycemic control does not appear to correspond to measured changes in knowledge or SMBG skills.
Weight loss can be achieved with repetitive interventions or with short-term follow-up (<6 months).
Physical activity levels are variably affected by interventions.
Effects on lipids and blood pressure are variable but are more likely to be positive with interactive or individualized repetitive interventions.
Effectiveness in nonclinical settings
Some evidence indicates that DSME is effective when given in community gathering places (e.g., churches and community centers) for adults with type 2 diabetes.
The literature is insufficient to assess the effectiveness of DSME in the home for adults with diabetes.
The literature is insufficient to assess the effectiveness of DSME in the workplace.

Adapted from Norris et al. 2002

DSME/S is designed to match the health literacy of participants and that is culturally relevant to the target population is more effective (AHRQ 2015). Functional health literacy is defined as a measure of a patient's ability to perform basic reading and numerical tasks required to function in the health care environment and is distinct from education level and language ability (AlSayah et al. 2013; Bailey et al. 2014). Patients with low functional health literacy often:

- Have greater difficulty understanding their condition
- Are less likely to engage in self-management
- May have worse glycemic control
- Have poorer communication with providers
- Are less confident managing their diabetes

It is recommended that “universal precautions” (AHRQ 2015) be applied during all patient interactions, which include:

- Use of plain language in speaking and written and spoken materials (no jargon; words less than three syllables)
- Explain medical terms
- Avoid phrases with two interpretations (e.g., positive test results; stable test results)
- Open-ended questions (“What questions do you have?” not “Do you have questions?”)
- Highlight key recommendations

The DAWN2 US Study evaluated ethnic differences in psychological outcomes among adult non-Hispanic whites, Mexican Americans, African Americans, and Chinese Americans with diabetes and their adult family members (Peyrot et al. 2014). While there were differences among and between groups and a substantial amount of diabetes distress was found for both people with diabetes and their family members, those in minority groups experienced more diabetes distress than non-Hispanic whites. However, a large social support network was found to positively influence better psychosocial outcomes and health behaviors. Asking patients about cultural or religious influences on their diabetes self-management, use of traditional medicines, inviting family members to participate in care and educational visits, and tailoring education to match ethnic and religious dietary and other preferences are effective strategies for DSME/S. (Funnell et al. 2015).

With the advent of and greater access to various forms of technology, its use has been proposed as an efficient and effective method for providing DSME/S. Although there is a great deal of information available to patients, unfortunately much of it is provided by those who are uninformed, misinformed, or promoting products. The current evidence indicates that the data are mixed in terms of technology-based DSME with some studies reporting modest improvements in glycemic outcomes (Pal et al. 2014). However, technology has been effective for delivering diabetes prevention programs DSMS, including on-going psychosocial support, behavioral and educational reinforcement, tracking behaviors, and patient-provider communication. It is also clear that the use of technology will increase as it becomes more widely available and desired.

Incorporating DSME and DSMS into Clinical Care

DSME and DSMS also need to occur during clinical visits. However, studies have shown that patients typically remember less than 50% of what was said by the provider, and patients with low functional health literacy may remember even less (Schillinger et al. 2002). Use of effective strategies such as the “ask, tell, ask” interactive communication loop can improve the effectiveness of DSME/S during a clinical visit (Schillinger et al. 2003). The visit begins with the provider asking the patient the issue that is most important to address or what is most difficult about their diabetes or current treatment. Information, support, or referrals are then provided based on the patient’s issue, specific questions are addressed, and the patient is

Table 3 Key messages

Diabetes is self-managed which means you have an active role to play.
In order to self-manage effectively, you need both education and ongoing support.
Negative emotions (anger, fear, frustration, and guilt) are common.
Learning how to make changes in behavior is essential.
Your treatment will change over time, which does not mean that you have failed but simply that your body needs more help.
Complications are not inevitable.
Diabetes self-management is not easy, but it is worth it.

then asked to repeat or “teach back” the information. This patient-centered communication strategy not only checks for recall but can also provide the opportunity to take advantage of “teachable moments” related to a patient-identified issue, reinforce and tailor DSME/S education, uncover inaccurate beliefs and misunderstandings, and actively engage patients to participate in their treatment and self-care. Table 3 outlines key educational messages to provide during a clinical visit.

On-going care visits also provide an excellent opportunity to provide DSMS in order to sustain improvements and maintain motivation for diabetes self-management. The use of care managers, care navigators, peers, community health workers, and referral to virtual or in person support groups are effective strategies for DSMS.

Patient Empowerment

Self-management requires considerable effort that must be sustained over a lifetime of diabetes. Adults with diabetes are often expected to make significant changes in their lifestyle without taking into account their competing priorities, work and other life goals, family responsibilities, and other demands on their time and energy. In addition, patients are also dealing with the emotional consequences of a serious chronic illness and the potential for complications. It is therefore unsurprising that adults with both type 1 and type 2 diabetes and their family members perceive diabetes to be a significant burden and experience diabetes-related distress (Nicolucci et al. 2013). Empowerment is a patient-centered approach based on the understanding that motivation is most effective when it is internally determined and directed towards behaviors that are personally relevant and meaningful (Funnell et al. 1991; Funnell and Piatt 2017). Patient empowerment involves creating a collaborative (rather than a directive) relationship with patients and actively engaging them in shared-decision-making, incorporating their abilities, goals, needs, barriers, and values.

Effective communication skills are critical to the success of using the empowerment approach. The ALE approach (Ask, Listen, Empathize) is a nondirective communication style using questions to elicit the patient’s concerns and active listening and empathy to encourage further discussion, in order to identify personally

Table 4 Five-step goal setting model

Identify the problem
<i>What is the most difficult or frustrating part of caring for your diabetes at this time?</i>
Determine feelings and their influence on behavior
<i>How do you feel about this issue? How are your feelings influencing your behavior?</i>
<i>On a scale of 1–10, how important is it for you to address this problem? On a scale of 1–10, how confident do you feel that you can resolve this issue?</i>
Set a long-term goal
<i>What do you want? What do you need to do? What problems do you expect to encounter? What support do you have to overcome these problems? Are you willing/able to take action to address this problem?</i>
Create an I-SMART plan
<i>What will you do this week to get started working toward your goal?</i>
<i>I-important</i>
<i>S-specific action step</i>
<i>M-measurable</i>
<i>A-attainable</i>
<i>R-relevant to long-term goals</i>
<i>T-time specific</i>
Assess how the experiment worked
<i>How did it work? What did you learn? What might you do differently next time?</i>

Adapted from Funnell and Anderson 2004

meaningful and relevant solutions and set behavioral goals (Anderson et al. 2002). An example of empowerment-based communication when choosing treatments is shared-decision-making which has been shown to improve medication-taking behaviors. (Veroff et al. 2013).

These same communications skills are used when setting behavioral goals and providing empowerment-based DSME and DSMS. Self-directed behavioral goal-setting is an effective intervention to facilitate self-management and behavioral change (ADA 2017; Glasgow et al. 2003). Goal-setting is a process beginning with the patient identifying a problem that is personally meaningful and results in an action plan developed by the patient. Table 4 outlines the empowerment-based five-step process for goal-setting that supports a collaborative approach, addresses both behavioral and psychosocial issues, and includes the development of an I-SMART plan. This action plan is designed as an experiment with the goal of learning about what will and will not work to facilitate goal attainment and improve outcomes. (Funnell and Piatt 2017).

Empowerment-based DSME and DSMS interventions are patient-guided rather than content-driven and designed to provide participants with the knowledge and skills needed to engage with their provider, make informed decisions, solve problems, choose and achieve goals and cope with the demands of diabetes. This approach to DSME and DSMS, which is designed to meet the needs identified by patients, is effective for improving clinical, psychosocial, and behavioral outcomes (Funnell et al. 2014).

Summary

Diabetes self-management education and on-going support strategies improve outcomes and quality of life among people with diabetes. Although access and reimbursement has increased over the last decade, many people with diabetes and their families do not receive referral to or take advantage of these important services. In addition, making the shift to more collaborative, patient-centered models of care has been slow among providers, although the advent of Medical Homes and Accountable Care Organizations has led to renewed interest in empowerment-based approaches to care and education.

Outcomes in diabetes, including long-term morbidity and mortality, are dependent on the ability of people with diabetes to effectively make decisions and care for themselves for a lifetime with this burdensome disease. They therefore have a right to receive effective diabetes self-management education and on-going support, and health care professionals have a responsibility to ensure that they are aware and take advantage of these essential aspects of their treatment.

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