Insights From the National Diabetes Education Program National Diabetes Survey: Opportunities for Diabetes Self-Management Education and Support

Linda J. Piccinino,1 Roshni Devchand,2 Joanne Gallivan,1 Diane Tuncer,1 Christina Nicols,2 and Linda M. Siminerio4

Diabetes is a complex, self-managed disease, for which 98% of needed care is provided by the patient (1). Self-efficacy, defined as an individual’s perception of his or her competence to successfully perform a behavior (2), and reduced distress are factors associated with effective self-management and are important predictors of positive diabetes outcomes (3). In particular, higher self-efficacy has been associated with improved glycemic control, medication adherence, self-care behavior, and mental health–related quality of life (4). Diabetes self-management education and support (DSMES) provides the knowledge and support required for diabetes self-care on an ongoing basis (5) and is centered on the psychosocial and emotional care needed to address matters associated with self-efficacy such as confidence, depression, and distress (6). Associations between self-efficacy and self-management behaviors have been demonstrated in a large study of health care organization members with type 2 diabetes, in which investigators called for programs to focus on enhancement of self-efficacy and social support to improve diabetes self-management (7).

DSMES is crucially important in providing people with diabetes (PWD) the information, skills, and assistance necessary to manage and cope. DSMES has been shown to improve A1C, reduce the onset and advancement of diabetes complications, improve quality of life for PWD, improve important lifestyle behaviors such as eating a more healthful diet and engaging in regular physical activity, enhance self-efficacy, increase healthy coping, and decrease diabetes-related distress and depression (5). In addition, DSMES is reported to be cost-effective by reducing hospital admissions and readmissions, as well as estimated lifetime health care costs related to a lower risk for complications (5,8). These improvements clearly reaffirm the importance and value-added benefit of DSMES.

DSMES has been shown repeatedly to be effective and is recognized

---

1Social & Scientific Systems, Inc., Silver Spring, MD
2Hager Sharp, Washington, DC
3National Diabetes Education Program, National Institutes of Health, Bethesda, MD
4University of Pittsburgh, Pittsburgh, PA

https://doi.org/10.2337/ds16-0056

©2017 by the American Diabetes Association. Readers may use this article as long as the work is properly cited, the use is educational and not for profit, and the work is not altered. See http://creativecommons.org/licenses/by-nc-nd/3.0 for details.
as a crucial component of diabetes prevention and care; however, the number of people who receive this service is relatively small (9). Research suggests that challenges include poor referral practices, the way in which DSMES service is delivered (10), and health care coverage (5). For example, the responsibility for diabetes education has historically been assumed by physicians. Data from the National Ambulatory Medical Care Survey disclosed that physicians have limited time for patient visits, let alone DSMES (11). Other health care providers, such as diabetes educators, can increase practice efficiency by taking on some of the duties (e.g., patient training, counseling, and follow-up) that require significant time investments (5). Although diabetes educators, such as nurses, dietitians, pharmacists, and community-based supporters, have been shown to facilitate patient improvements in A1C and self-care and a reduction in diabetes distress (12), rates of participation with their services have been limited.

Diabetes care coverage and reimbursement may influence participation in DSMES. Many health insurance plans, including Medicare and Medicaid, currently reimburse for DSMES; however, some insurance plans do not offer these benefits or require high deductibles and copayments. PWD who lack this type of coverage or do not have insurance may forgo needed care and education. It has been reported that only about 4% of uninsured adults receive DSMES that meets standards for quality (13). Concerns have been expressed regarding awareness of PWD regarding their health insurance status, the kinds of coverage their insurance provides, and whether improved understanding of their coverage will increase their use of health care services for diabetes management (14). With an estimated one in three people likely to develop type 2 diabetes by 2050, the U.S. health care system needs to explore opportunities to abate the humanistic and economic burden of the diabetes epidemic.

Understanding and improving self-management behaviors and DSMES practice is essential for improving diabetes outcomes. This article provides findings regarding self-management behaviors and DSMES practices obtained through the most recent (2014) National Diabetes Education Program (NDEP) National Diabetes Survey (NNDS). Insights and gaps in self-management behaviors among PWD (who have type 2 diabetes) and DSMES delivery are examined to identify challenges and offer opportunities for improvement.

The NNDS

The NDEP, founded in 1997, is a federally sponsored initiative of the National Institutes of Health and the Centers for Disease Control and Prevention that involves public and private partners working together to improve diabetes management and outcomes, promote early diagnoses, and prevent or delay the onset of diabetes in the United States and its territories. The NDEP’s overarching goal is to reduce the burden of diabetes and prediabetes by facilitating the adoption of proven approaches to prevent or delay the onset of diabetes and its complications. The NDEP conducts the NNDS, a periodic population-based probability survey of U.S. adults, to assess the attitudes, perceptions, and beliefs of the public to guide and assist the NDEP and diabetes stakeholders in better understanding and addressing target audience behaviors related to diabetes awareness, diabetes care, and education.

The NNDS has been conducted in 2006, 2008, 2011, and 2014 and provides the NDEP with data to track trends that help guide program strategies, reach, and effectiveness (15–17). Population-based surveys are a well-established evaluation method used by national education programs (18). At baseline, they provide timely and representative national data to inform program planning. When conducted in the post-intervention period, they can be used to assess program outcomes. The need to design a survey with questions related to self-management behaviors and DSMES delivery patterns grew out of information obtained in examining trends noted in past surveys (17). Using findings from the literature and in discussions with researchers and health care professionals (HCPs), aspects relevant to self-management and DSMES were identified and used in the development of the most recent NNDS survey questions. This article focuses on key findings of the NNDS survey that was conducted online using the GfK KnowledgePanel®, a probability-based online panel of the U.S. population, in December 2014 (n = 2,535 adults ≥ 25 years of age) to examine diabetes self-management behaviors and DSMES practice as follows:

- Assess self-efficacy, confidence building, and support for diabetes management, including self-management and glycemic monitoring and control
- Determine the use of physicians and other HCPs as sources for diabetes education and support
- Explore awareness regarding health insurance and health care coverage

NNDS and DSMES: Recent National Findings

New questions were developed for the most recent survey that built on the information gleaned from previous surveys, with particular interest pertaining to psychosocial or emotional aspects of self-management, physician and other HCP involvement in DSMES, health care coverage knowledge, and understanding with respect to managing diabetes among PWD. (PWD are defined as people who were told by a doctor or other health professional that they had diabetes or sugar diabetes.)

Diabetes Self-Management Behaviors

Self-Efficacy and Distress
PWD are expected to understand how to manage their disease and to cope with the demands associated with their disease to attain emotional as well as physical well-being.

PWD provided information on their perceived effectiveness in managing their diabetes. Overall, about one-third (33%, \( n = 176 \)) indicated that there was room for improvement, with some (27%, \( n = 148 \)) reporting that they had sometimes been effective, and a smaller group (6%, \( n = 28 \)) reported that they had not been effective. More than two-thirds (\( n = 297 \)) of PWD reported that their way of managing their diabetes had “usually been effective.”

To gain current insights into self-management, the confidence of PWD in knowing what to do should they encounter issues with their blood glucose, such as high (hyperglycemia) or low blood glucose levels (hypoglycemia), was examined. Questions were based on a 5-point scale adapted from the Lorig 8-item Diabetes Self-Efficacy Scale (19). Survey question scales were labeled as “Not at all confident” and “Totally confident.” Results indicated that a large proportion of PWD reported that they were not confident in their ability to manage blood glucose levels. This finding is consistent with past NNDS data that indicated suboptimal understanding of how to prevent and treat low and high blood glucose levels. Most PWD reported not being totally confident in knowing what to do when their blood glucose became higher (70%, \( n = 309 \)) or lower (58%, \( n = 261 \)) than recommended. A smaller percentage of PWD reported not feeling confident at all about managing their blood glucose levels if they were too high or too low (8%, \( n = 38 \) and 6%, \( n = 32 \), respectively).

Figure 1 shows that a major percentage of PWD were not totally confident with key diabetes management activities, especially with exercise and blood glucose-related management. PWD rated their level of distress in the past 4 weeks due to: 1) “The demands of living with diabetes,” 2) “My diabetes routine,” and 3) “Possible serious long-term complications, no matter what I do.” On a 5-point scale with end points labeled as “No distress” and “Serious distress,” the majority of PWD indicated some level of distress in managing their diabetes. Reported levels of distress were similar for potential serious long-term complications associated with diabetes and for the daily diabetes routine and demands (Figure 2).

Diabetes Management Activities

The efforts of PWD to manage their diabetes, as well as their activities to prevent diabetes-related health issues, were examined. Questions about specific diabetes self-management practices were as follows: “In the past 4 weeks, have you been doing any of the following to manage your diabetes? Using insulin? Taking diabetes pills? Using noninsulin injectable medications for diabetes? Following your diabetes meal plan? Exercising regularly?” (Previous surveys did not ask about all of these practices and included the less explicit timeframe “now.”)

Less than one-fourth (22%, \( n = 115 \)) of PWD reported using insulin for diabetes management in the 4 weeks prior to taking the 2014 survey. Self-testing of blood glucose showed a statistically significant decline from 90% of PWD (\( n = 351 \)) in 2008 to 74% (\( n = 364 \)) in 2014. (This decline was not specific to any race/ethnicity.)
or age group and could be an artifact of the change in the timeframe of the question between 2014 and the previous surveys.)

The most recent NNDS also included questions related to diabetes self-management practices. PWD reported on exercise, diet, and the use of noninsulin injectable medications for diabetes in a “past 4 weeks” timeframe. Among PWD, more than half (57%, n = 265) reported getting regular exercise or following a diabetes meal plan (56%, n = 283) in the 4 weeks prior to taking the survey. Seven percent (n = 40) reported using noninsulin injectables.

Regarding longer-term self-management activities, Figure 3 shows PWD who regularly or occasionally engaged in activities to manage their diabetes. Results showed an emphasis on activities to prevent weight gain, lose weight, and follow a dietary plan (top three bars), engagement in some forms of physical activity (middle three bars), and use of medications (bottom bar). Participation in vigorous activities was less commonly reported.

Self-Management Tools and Resources

With the widespread availability and variety of technologies for self-help and wellness, opportunities abound for PWD to use electronic and social media tools and resources for diabetes learning and self-management. The most recent NNDS added questions to determine what tools—traditional and emerging—were being used by PWD to help them manage their disease. The questions were also designed to ascertain the extent to which social media or new technologies played a role in the diabetes learning or management experiences of PWD.

Use of any self-management tools for diabetes in the 4 weeks prior to taking the survey was not widely reported by PWD (Figure 4). Tools and resources referred to in the survey included in-person support groups, online diabetes community support systems and information (e.g., videos), paper calendars/diaries/journals for tracking diabetes-related activities, and text-messaging support programs, among others. Results showed that traditional tools, such as a paper calendar, diary, or journal were still relevant and were used to track diabetes-related activities by about one-third (34%, n = 173) of PWD. Online health websites reportedly were used by some PWD (13%, n = 66), whereas other technology-based resources, support groups, or programs were used by <10% of respondents.

Social media have emerged in the past decade as potential communication channels for dissemination of health messages. To explore the utility of social media in diabetes education and management, respondents were asked about their use of various social media (e.g., Facebook and Twitter) to help learn about or manage diabetes. Social media outlets were found not to be a significant influence. According to the most recent NNDS, 13% of PWD (n = 62) reported using social media “often” or “only once in a while,” whereas the majority had not used social media at all to manage their diabetes. A larger proportion (27%, n = 112) of younger PWD (ages 35–44 years) reported using social media compared to those 45 years of age (12%, n = 50). We expect social media to grow in prominence.
in future self-management of diabetes and plan to ask the question again in the next round of the survey.

**Sources of DSMES**
Questions were designed to focus on the role of the diabetes care team, including physicians, nurses, dietitians, and pharmacists, as providers of DSMES. The majority of PWD (84%, $n = 405$) reported their “doctor” as their “usual health care provider” for their personal health care. Only 7% of PWD reported regularly seeing a diabetes educator in addition to their usual physician. Physicians were the most-cited source of diabetes management advice or counseling among PWD (94%, $n = 312$) in 2014. Family members constituted the next highest group (45%, $n = 125$), followed by diabetes educators (39%, $n = 117$) and nurse practitioners (38%, $n = 110$). Physicians (79%, $n = 90$) were also the most frequently reported sources of encouragement for attending programs for lifestyle changes to manage diabetes among PWD who reported receiving encouragement from anyone. Again, PWD commonly selected physicians (89%, $n = 422$) as a source of “advice about diabetes that you can trust.” As sources, PWD also reported “family” (39%, $n = 183$) and “diabetes educators” (23%, $n = 114$). An additional source of self-management education for PWD was diabetes education classes (74%, $n = 58$) among those who reported attending diabetes-related groups, classes, or programs in the previous 12 months.

**Awareness and Education Around Health Insurance and Health Care Coverage**
To gauge the influence of health care coverage in reference to DSMES participation among PWD, respondents were queried about health insurance or health care coverage associated with specific components of their medical care. Respondents were asked “Do you currently have health insurance or health care coverage that pays for all or part of your medical care?”

The majority of PWD (92%, $n = 435$) reported having health insurance or health care coverage for all or part of their medical care. However, when asked to report on the types of programs covered, “Does your health care coverage include any weight loss, exercise, or health or wellness programs?” about one-third (34%, $n = 149$) of those with coverage did not know whether their coverage included any weight loss, exercise, or other health or wellness programs. The majority of PWD (62%, $n = 285$) who reported having coverage stated that these program types were included in their coverage. However, when asked “Do you need a referral, prescription, or script from your doctor to attend any of these weight loss, exercise, or health or wellness programs?” some (33%, $n = 54$) did not know whether they needed a referral to participate in programs.

**Potential Strategies to Support DSMES**
The NNDS offers information that can help to set the stage for further opportunities to explore and improve participation in DSMES. Health care teams have an opportunity to work together to overcome challenges associated with access and utilization of DSMES, such as a comprehensive team approach that engages HCPs for diabetes education and support and increased referrals to DSMES programs. Further, DSMES may prove to be the vehicle that can help PWD with:

- Skills-building to improve their self-efficacy in managing their diabetes
- Training and programs to address the emotional and psychosocial needs associated with diabetes
- Understanding the health insurance benefits available to them

**Summary and Conclusion**

**Self-Efficacy and Confidence Building**
Self-efficacy and distress in managing diabetes was still an issue for PWD, as reported in the most recent NNDS. More than half of PWD reported that they were not fully confident in knowing what to do when their blood glucose was too high or too low. More messaging is needed about glycemic monitoring and control and how PWD can avoid or manage hypoglycemia and hyperglycemia. Most PWD reported some level of distress in managing their diabetes. PWD reported moderate levels of effectiveness dealing with diabetes on a daily basis, which underscores the need for continued support to further increase self-efficacy in managing and coping with the demands of diabetes.

We recognize that emotional aspects play into diabetes management and encourage HCPs, educators, and others to talk with PWD about their feelings and ability to cope with their diabetes. Issues surrounding diabetes distress can be addressed through provision of psychosocial/emotional support.

The most recent NNDS findings demonstrate physicians’ prominence as a source for diabetes management information, which may reflect the high value PWD placed on their advice. Physicians, however, have limited time for and experience with DSMES. Therefore, continued heavy reliance on physicians as sources of DSMES indicates a need to bring a more diverse set of HCPs into DSMES efforts. Efforts to increase awareness of and referral to diabetes care team members such as diabetes educators and registered dietitians/nutritionists can help extend the health care team and lighten the burden on physicians.

Resources such as family and friend networks also appeared to figure prominently in the most recent NNDS in providing advice/counseling on diabetes prevention and management. Family and friends may prove effective in offering emotional and other nonmedical support to reduce distress, as well as help empower PWD to maintain proper self-care behaviors.
There is a need to encourage PWD to understand and ask about coverage for diabetes-related services and care to reduce barriers and issues that can affect access and utilization of DSMES programs. To meet these challenges, the NDEP’s Practice Transformation for Physicians and Health Care Teams web resource provides access to models, tools, and resources for HCPs undergoing practice redesign associated with health care reform. This resource provides authoritative information about models and processes of care delivery that can enhance the quality of diabetes care and correspond with national standards and performance initiatives.

**NDEP Activities to Address DSMES**

The recent NNDS findings on DSMES will inform the NDEP’s various activities, such as the “Managing Your Diabetes Is Not Easy, But It’s Worth It” campaign. This campaign was first developed to address self-efficacy messages to communicate the seriousness of diabetes and its complications and to promote the importance of making a plan of action. The 2015 National Diabetes Month campaign “Diabetes Education and Support: Everyone Has a Role. What’s Yours?” highlighted the need for ongoing diabetes education and support among PWD and those who care for them. Finally, the Diabetes HealthSense website connects PWD to vetted resources to help make lifestyle changes and address psychosocial issues associated with DSMES. Leveraging these resources to respond to the NNDS findings can further enhance DSMES for PWD.

Future rounds of the NNDS likely will include more questions about support provided by specific types of HCPs, including health educators, registered dietitians/nutritionists, community health workers, health coaches, and similar professionals. Subsequent administrations of the NNDS may explore issues such as access to diabetes educators and its influence on behaviors among PWD currently receiving DSMES.

**Acknowledgments**

The NNDS was funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) under contract number GS23F0024M/Task Order Number HHSN276201200001U and the NIH Office of Program Evaluation and Performance under contract number 04-207-NIDDK and 07-2006-NIDDK.

**Author Contributions**

Authors J.G. and D.T. are the former director and deputy director, respectively, of the NDEP at the NIH’s NIDDK. Together they managed the funding under which this work was conducted. They also participated in interpretation of the data and in the preparation and review of the manuscript. Social & Scientific Systems, Inc. (author L.P.) and Hager Sharp (authors R.D. and C.N.) received funding from the NDEP and from the NIH for the work discussed in the article. All three authors had major roles in the design and conduct of the study; the collection, analysis, and interpretation of the data; and the preparation and review of the manuscript. Author L.M.S. is chair of the NDEP and executive director of the University of Pittsburgh Diabetes Institute and professor of medicine in the university’s Division of Endocrinology and Metabolism. She provided considerable insight and interpretation of data, as well as preparation and review of the manuscript.

**Duality of Interest**

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

**References**