Diabetes Self-Management Education

Barrier Study

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Maine Center for Disease Control and Prevention
Division of Chronic Disease
Diabetes Prevention and Control Program

Executive Summary

Diabetes is a chronic disease that can cause severe complications resulting in kidney failure, blindness, amputation, loss of sensation, and cardiovascular disease when not controlled. Two landmark studies published in the mid-nineties demonstrated that many of the debilitating effects of diabetes are avoidable through consistent glucose control, regular medical care, and self-management practices. Several research studies have shown that people with diabetes that attend diabetes self-management education (DSME) have better clinical outcomes compared to those that haven't participated. We have seen similar results here in Maine from statewide data reported on DSME participants over the years. Results consistently show lower complication rates, fewer ER and hospitalization experiences, and improved health measures. Yet with all the evidence that DSME improves clinical outcomes and quality of life only one in four people newly diagnosed attend and less than 3% of the estimated 74,000 people with diabetes participate in a year. For these reasons we conducted research that pivoted around the question, "*why aren't more people referred and attending this resource?*"

After conducting a statewide survey of providers, diabetes educators, and people with diabetes we found five prominent reasons why people in Maine with diabetes don't attend DSME:

- People have an aversion to group classes.
- Many people with diabetes don't feel they need the information offered by these programs.
- Programs are not offered at times/dates that are attractive or convenient.
- Transportation difficulties.
- People with diabetes don't know enough about the program.

Three of the five reasons listed above are perception issues. We recognize that perceptions are not necessarily easy to change but we know they can be changed. To develop a successful plan to change perceptions about diabetes education will require developing a communication and marketing plan with the healthcare community. The survey results point to a need to raise awareness by people with diabetes about the benefits of DSME. Results also point to a need to address structural barriers to referring and participating in this resource. We recommend forming a sub-group to discuss options and recommendations of streamlining the referral process and to address concerns brought-up by providers answering the survey Finally we need

to look at all options to providing awareness, knowledge, and behavior change, especially with populations that are unlikely to participate in traditional DSME as it is currently offered.

Introduction

The Burden of Diabetes

Maine is facing a serious health challenge related to diabetes mellitus. In 1982, the estimated prevalence of diabetes was 2.4%; at that time about 20,000 adults in Maine were diagnosed with diabetes. In only twenty years the estimated diabetes prevalence has more than tripled and as many as one in ten Maine adults have diabetes.

Diabetes is a costly disease that can result in serious complications if left uncontrolled. It is the leading cause of end-stage renal disease and non-traumatic lower extremity amputations, as well as a primary cause of preventable blindness. People with diabetes have a two to four times greater risk of developing cardiovascular disease than people without the disease. Despite these frightening statistics, there is good news. Many of the complications from diabetes can be avoided through self-management and regularly scheduled diabetes medical care.

Description of Diabetes Self-Management

Diabetes mellitus is primarily a self-managed condition. The Institute of Medicine defines self-management as *the task that individuals must undertake to live with one or more chronic conditions*.[1] These tasks include having the confidence to deal with medical, behavioral, and emotional management of their conditions. Self-management is the foundation for achieving optimum glucose control necessary to avoid the complications of diabetes through increasing knowledge and awareness and learning effective behavioral techniques to manage diabetes.

Difficulty in Achieving Self-Management

These behaviors are often difficult for individuals with diabetes to maintain over time. A large study (The Diabetes Attitudes, Wishes, and Needs (DAWN) Study) of more than 5,000 patients with type 1 and type 2 diabetes and almost 4,000 providers from 13 countries were surveyed. about diabetes self-management and related psychosocial issues.[2] The results of the DAWN Study reported that only 46% of patients with type 1 and 39% of patients with type 2 reported achieving success in two-thirds of their self-management behaviors. Self-management is often complex and demanding in nature, however, diabetes self-management education (DSME) is key to quality diabetes care.

Diabetes Self-Management Education (DSME) as the Foundation of Diabetes Care

An integral component of diabetes care is self-management education delivered by an interdisciplinary team. Self-management training helps people with diabetes adjust their daily regimen to improve glycemic control. Diabetes self-management education (DSME) teaches individuals with diabetes to assess the interplay among medical nutrition therapy, physical activity, emotional/physical stress, and medications, and then to respond appropriately and continually to those factors to achieve and maintain optimal glucose control. DSME is understood to be a critical part of diabetes care. Medical treatment of diabetes without systematic self-management education is regarded as inadequate.[3]

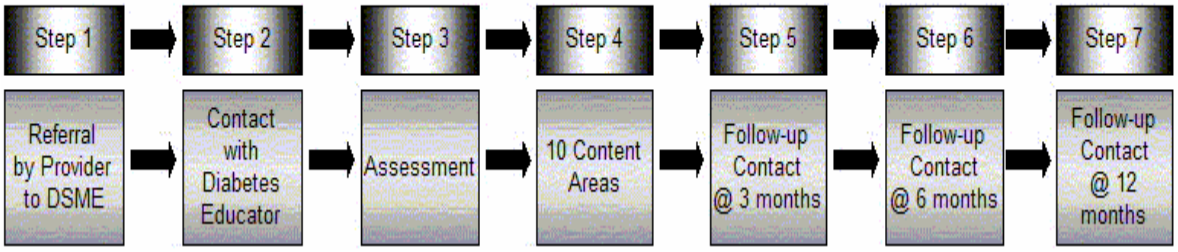
Benefits of DSME

The benefits of self-management are well documented. Several studies show a significant improvement in the health of people that have participated in DSME, measured through decreased rates of diabetes related complications, reductions in hospitalizations, and improved blood-glucose control.[4] [5] Participation of individuals with diabetes in DSME Programs leads to improved clinical outcomes, reduced diabetes-related complications, increased quality of life and reduced health care costs.[6]

Diabetes Self-Management Education (DSME) – the Ambulatory Diabetes Education & Follow-Up (ADEF) Program in Maine

Maine has established a certification process for programs that provide DSME through the Diabetes Prevention and Control Program located within the Maine Centers for Disease Control and Prevention. The state certified programs in Maine utilize a curriculum developed by a committee of diabetes educators termed " the Ambulatory Diabetes Education and Follow-up Program" (ADEF Program). ADEF programs are based on national standards that cover 10 content areas of diabetes management and include follow-up contacts. The program features both one-to- one visits with the nurse and dietitian as well as group classes.

Figure 1: Seven Phases of DSME (ADEF Program)



Improved Outcomes reported in ADEF/DSME Program Participants

Maine ADEF/DSMT Program participants have reported significant improvements in diabetes management after completion of the self-management education program. In a five-year analysis (2000 – 2004) the following changes in health outcome were reported by 6,087 program participants at the 12-month follow-up session:

- 78.1% Lowered their HbA1c value
  - 8.09% HbA1c average at preassessment
  - 6.75% HbA1c average at 12-month follow-up
- 31.4% increase in Podiatric Visits
- 10.9% increase in Eye care provider visits
- 46.3% reduction in emergency room visits

DSME as an Underutilized Resource

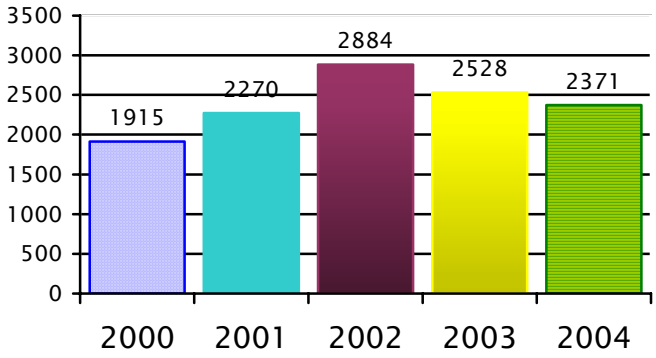
Diabetes Self-Management Education (DSME) is an underutilized resource for people diagnosed with diabetes. Data from the Maine Diabetes Prevention and Control Program show that the average yearly total of persons that attend ADEF/DSME Program (for years 2000 – 2004) is approximately 2,000. We know from an assortment of data that this total grossly under represents the need for diabetes education in the population of Maine. Data from the following surveys and estimates illustrate the gap:

- In 2003, a statewide survey used to track diabetes prevalence estimated that 73, 000 adults in Maine were diagnosed with diabetes.[7]
- The CDC estimates that 6.3/1000 Caucasian adults between 18 -79 are newly diagnosed with diabetes annually.
- Maine has approximately 925,000 adults in this age group, resulting in about 5,828 newly diagnosed cases annually.
- Diabetes prevalence has doubled in the past ten years
- Only 24% or 1 in 4 of newly diagnosed cases are receiving DSME in Maine.

ADEF Program Referral Trends

In Figure 2 we show year to year increases in referrals to ADEF from year 2000 to 2002 with a peak of 2,884. Referrals decline in 2003 and 2004 but remain above baseline (2000).

Figure 2: Referrals



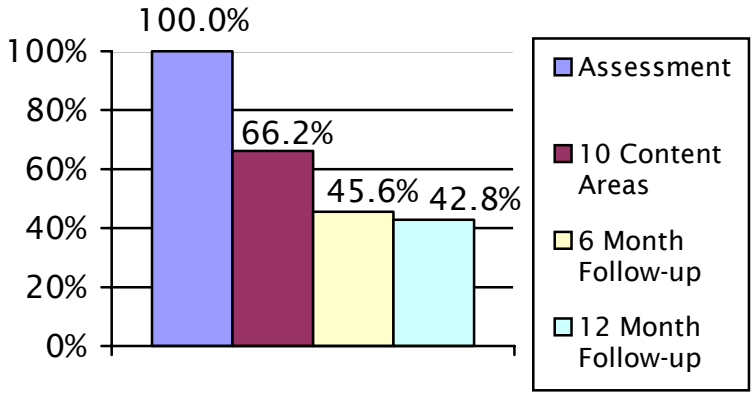
Gaps in DSME Assessments for Newly Diagnosed

Using data from reports sent to the Maine DPCP we identified the number of persons assessed with newly diagnosed diabetes (<= 2 years) per year to be 1,395. This represents 24% or 1 out of 4 of the estimated newly diagnosed (<= 1 year) population being enrolled in a DSME program.

Participation Rates

Figure 3 shows the average participation rate during 2002 to 2004 for participants from assessment through one-year follow-up contact. Only two-thirds (66%) of participants complete the 10 content areas and by twelve months only 42% of participants complete the program.

Figure 3: Participation Rates



Research Question

The Maine CDC – DPCP posed the following question to be researched in this study:

If diabetes self-management education (DSME) is a proven benefit to quality diabetes care, why aren't more individuals taking advantage of the service and what are the barriers?

Summary of other DSME Barrier Studies

Barriers to referral and participation in diabetes self-management education is not a new question. Over the past few years other health organizations have explored these questions. The Maine CDC-DPCP gathered information on studies/ activities (quantitative and qualitative) of a similar nature that were done in Maine over the past five years. The following is a brief summary of findings of the three studies we are aware of.

MaineGeneral Medical Center (MGMC) Diabetes Care Initiative (DCI)

In 2005, as part of the funding received from the Robert Wood Johnson Foundation, the MaineGeneral Medical Center's Diabetes Care Initiative conducted the following surveys/ evaluations:

- Telephone survey to assess barriers and needs of individuals referred to DSME (ADEF Program) but did not attend
- Intercept interview of individuals with diabetes at supermarkets and pharmacies to assess barriers and needs
- Provider telephone surveys

Forty telephone surveys were completed with individuals with diabetes in the Kennebec region who were referred to DSME/ADEF program but did not attend. The top 5 reasons for non-attendance were as follows:

1. timing of classes bad due to illness or illness of family
2. busy work schedule, and times classes are offered are not good
3. no transportation (no car, cannot drive at night)
4. no insurance coverage
5. did not feel needed class

The preferred method for learning listed in rank order by the respondents to the survey were:

1. Reading
2. Hands-on instruction while learning from others
3. Attending a class at a good time
4. Listening to others

5. Internet tutorial/website

Maine Primary Care Association Study

During 2002-2003, the Maine Primary Care Association (MPCA) undertook a comprehensive assessment of diabetes self-management support services This study was funded by a grant from the Maine Health Access Foundation (MEHAF). The study was initiated but not completed. Below we show results of the portion of the study related to services offered at Federally Qualified Health Centers (FQHC's). A staff member of the MPCA conducted focus groups of FQHC staff at 7 health centers. The following barriers to DSME being offered and delivered at the health centers were identified:

- FQHCs not eligible for reimbursement of DSME from CMS (Medicare) as a separate service. Reimbursement is "bundled" into a capped rate paid to FQHCs
- Medicare recipients with diabetes comprise a large percentage of health centers case load
- Uninsured patients also comprise a large number of the health center's case load making delivery of services to them difficult without adequate compensation
- Length (year – long) and structure of DSME program was seen as a barrier for some individuals with diabetes by health center staff
- Core staff to offer DSME (limited time for providers or no qualified staff such as registered dietitian) may be lacking
- Providers may be not been making referrals to DSME programs at other locations because of lack of awareness of resource or view transportation or lack of motivation on patient's part as issues

Diabetes Education Workgroup – February 1, 2005

A workgroup was convened on February 1, 2005 to discuss the barriers and needs related to diabetes education. This diabetes education workgroup was an outgrowth of the Maine DPCP strategic planning process initiated in the Fall of 2004. Representatives from American Diabetes Association, Maine Primary Care Association, Anthem Blue Cross, Northeast Quality Health Care Foundation, University of Maine Cooperative Extension, ME Department of Health and Human Services – Bureau of Elder & Adult services, ADEF/DSME program sites and primary care provider offices comprised the workgroup.

The workgroup offered their perceptions of barriers to DSME. The perceived barriers were categorized by six themes and are as follows:

Access issues

- Transportation issues
- Workforce issues
- Timing of program/classes

- Reimbursement issues
- Systems issues
- Physical/mental challenges

Consumer Perceptions
- Consumer thinking they are doing OK with their diabetes
- Negative perception of DSME as "school"
- Misinformation about good diabetes management

Psychosocial/Behavioral issues
- Consumer attitudes (ie. overwhelmed, fear, denial)
- Stressful lives – diabetes not a top priority
- Failure of health care professional to individualize recommendations

Education program – Content & Structure
- Program may not be conducive to those requiring low literacy or specific cultural focus
- Language used in program may be difficult to understand
- Too much information – need to know vs nice to know
- Lack of individual (empowerment) approach
- Length of classes/program
- More flexible ADEF/DSME program
- Alternative to classroom learning such as: internet tutorials, peer to peer learning

Referring Provider Issues
- Uninformed medical provider
- PCP may not understand what DSME entails and its benefits, therefore not making referrals or encouraging consumer to attend
- PCP may not have the latest medical information for managing diabetes
- Referral form and paperwork may be daunting to PCP
- No time for PCP to address diabetes in own setting

Perception about diabetes in general
- Diabetes not given the visibility nationally as a major contributor to morbidity and mortality such as CVD and breast cancer
- Diabetes seen as old person's disease

Methods

Background / History

In the fall of 2003 the Maine Center for Public Health (MCPH) conducted a rigorous *systems-based assessment of the Statewide Diabetes Health System (SDHS) based on a modified version of the National Public Health Performance Standards (NPHPS) assessment tool based on the Essential Public Health Services (EPHS).*[8] The purpose of this assessment was to identify strengths, limitations, gaps, and needs within the SDHS. The intent was to utilize the results of the assessment as the impetus for the development of a performance improvement plan.

Based in the findings of the Assessment, the Maine CDC-DPCP embarked on a strategic planning process in the Fall of 2004. Many of the partner organizations involved in the Assessment continued to be actively involved in the strategic planning initiative. One of the major recommendations resulting from the planning and outlined in the *Maine Diabetes Health System Strategic Plan* [9] was to conduct a survey to identify barriers to referral and participation in DSME.

Development, Implementation, and Analysis of Surveys

A diabetes education workgroup (referenced above) convened by the Maine CDC-DPCP met on several occasions in the Spring of 2005. The workgroup determined that the DSME barrier survey would be directed toward the three primary groups involved in the DSME process. Separate survey questionnaires were designed by the workgroup for the following groups:

- primary care providers
- team members at ADEF/DSME Program sites
- individuals with diabetes.

(See sample of surveys in Appendix). The Maine CDC-DPCP assumed leadership in administering the provider and DSME Program site surveys Anthem (a commercial insurer) and Maine DHHS – Maine Care Program (a public insurance program) took responsibility for administering surveys to their members diagnosed with diabetes. The provider and ADEF/DSME Program site surveys were administered in the Summer of 2005. The individual with diabetes surveys were administered by the Maine Care Program in the Fall of 2005 and the Anthem survey during the winter of 2006. Maine CDC-DPCP performed the statistical analysis of the provider, ADEF/DSME program site, and Anthem surveys, while DHHS – Maine Care Program with the assistance of USM – Muskie School of Public Service, Institute for Health Policy analyzed the results of the survey of Maine Care Program participants

Provider Survey Results

Purpose

The primary objective of this survey was to identify provider perceptions of DSME programs and barriers to referrals that could be used to make improvements to increase referral and participation rates.

Methodology

The survey was constructed by a workgroup that consisted of diabetes educators, healthcare quality improvement specialists, and public health professionals from the state diabetes prevention and control program. This was a collaborative process that involved several conference calls between members of the workgroup. The final product, a six-question survey (See Appendix) was sent to physicians (MD's and DO's), physician assistants (PA's), and nurse practitioners (NP's and FNP's) throughout the state of Maine. Mailing lists maintained by the Maine Diabetes Prevention and Control Program were used to identify practitioners. An introductory letter was sent to practitioners to encourage their participation in completing the survey. The letter was co-signed by both a prominent Maine endocrinologist and the Director of the Maine Diabetes Prevention and Control Program.

The providers' questionnaire focused on practitioner's referral frequency, perception of existing diabetes self-management education (DSME) programs in Maine, and barriers to patient attendance. At the recommendation of the workgroup the survey was kept short and unfamiliar terms were defined for providers. "DSME" was defined in the first question to increase reliability of responses to survey questions. Practitioners were asked if they refer patients to DSME programs. Based upon their answer, a sub-question branched either to frequency of referral for yes answers or to a set of seven reasons for no answers. A choice of "Other", allowing descriptive text, was included for those responses not captured in the fixed choices. Respondents were instructed to check all reasons that apply, making the "No" subset a multiple response question. The survey asked respondents to estimate the percentage of persons that follow-through and attend DSME after referral. This question was asked to gauge the impact of follow-through by referral patterns. Cross tabulations of referral frequency to provider perception of follow-through were made.

Results

Response Rate

2,267 surveys were mailed to three groups of providers that refer to DSME. Five hundred and fifty-six (556) completed surveys were returned for an overall response rate of 25%. Response rates by group are shown .

Table 1: Refer Patients to DSME

Profession	Mailed	Return	Rate (Percent)
Physicians	1,342	357	27.0
Physician Assistants	434	69	17.0
Nurse Practitioners	491	120	24.0
Unidentified	0	10	1.8
Total	2,267	556	24.5

Physicians had the highest response rate of completed surveys with 27%, followed by nurse practitioners at 24%, and physician assistants with 17%.

Provider Referral Frequency

We asked providers if they refer patients to DSME programs and provided the following definition:

"Diabetes Self-Management Education is defined as 1:1 and group education provided by a team of diabetes educators such as nurses and dietitians in the ADEF Program"

The following table shows the frequency of referral to DSME by providers responding to the survey. For this sample, 84% refer and 16% do not.

Table 2: Refer Patients to DSME

	Frequency	Rate (Percent)
No	91	16.4
Yes	465	83.6
Total	556	100.0

The data file was sorted by whether respondents indicated they referred to DSME. Those that responded "No" were not included in the next analysis. For respondents that indicated "Yes' they refer, we asked about frequency, ranging from "rarely to "all the time". Table 3shows that almost 75% of respondents indicate they refer either most of or all of the time.

Table 3: Referral Frequency

	Frequency	Rate (Percent)
Rarely	18	3.9
Occasionally	97	20.9
Most of the time	234	50.3
All of the time	112	24.1
29	1	.2
Total	462	99.4
Missing	3	.6
	465	100.0

Reasons for not referring to DSME

Providers that indicated they did not refer were asked why not. A multi-answer response was allowed, as well as textual responses under "other".

Of the providers who do not refer to DSME, the following lists the top three reasons for non-referral to DSME:

1. patient refuses or declines
2. provider does not see patients with diabetes
3. provider does not have enough information on DSME

Providers' perceptions of attendance of patients at DSME

Providers were asked what percent of patients attend DSME. The following is an estimate of providers' perception of what percent of patients attend DSME after referral.

Table 4: Providers Perception of DSME Attendance

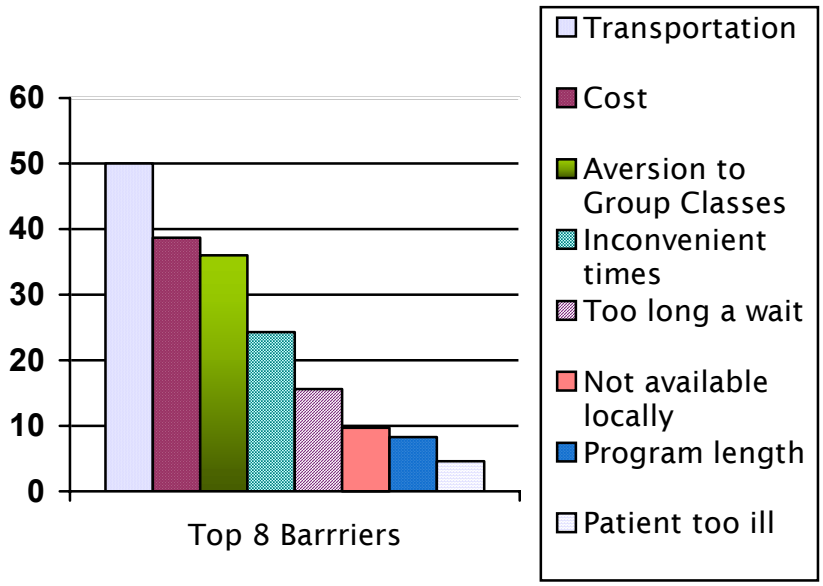
Range of Percent of Attendance	Number of Providers	Percent of Providers
0-24%	50	10.6
25-49%	99	21.0
50-74%	198	42.0
75-100%	124	26.4
Total	471	100.0

Of the providers that refer patients to DSME, more than half of the providers (68.4%) feel that the patients do attend 50 – 100% of the time.

Providers perceived reasons for non-attendance at DSME

The chart below shows provider responses to the survey question listing eight barriers to DSME. For this summary both referring and non-referring provider responses were tallied. The denominator consisted of the total responses (n = 556) for the survey.

Figure4: Perceived Barriers to DSME



Rank order for providers' perceptions of reasons for non-attendance at DSME

From Figure 4 the rank order for providers' perceptions of reasons for non-attendance at DSME is as follows:

1. Transportation
2. Cost
3. Aversion to group classes
4. Program at inconvenient times
5. Too long a wait to begin program
6. Not available locally
7. Program length
8. Patient too ill

Providers' Perceptions of Helpfulness of DSME Program

A total of 84.9% (472 out of the 556 surveys returned) of the providers rated how helpful a DSME Program was to their patients. The results are as follows:

Table 5 Providers' Perception of Helpfulness of DSME

Was DSME Helpful	Response	Percent
Very helpful	229	48.5
Helpful	180	38.1
Somewhat helpful	58	12.3
Not at all helpful	2	< 1.0
Definitely not helpful	3	<1.0
Total	472	100.0

A total of 86.6% of providers returning the survey rated DSME programs as helpful or very helpful.

ADEF/DSME Program Site Survey Results

Surveys were mailed by the Maine Diabetes Prevention & Control Program (DPCP) to diabetes educator instructional teams at 35 ADEF/DSME Program sites. Seventeen surveys were returned for a response rate of 48.6%

Purpose
The purpose of the survey was to gather information from teams of diabetes educators at diabetes education program sites on barriers and needs related to diabetes self-management education.

Methodology
A one-page survey consisting of five questions was sent to the coordinator of each of the 35 ADEF Program sites. (See Appendix for copy of survey). The coordinator was asked to gather the diabetes instructional team (nurses and dietitians) at their site and provide responses to the questions from the team as a whole. The completed survey was faxed back to the DPCP. The majority of the questions were qualitative in nature. Teams were asked to respond to opened-ended questions and were **not** given a checklist of choices to select. Therefore multiple responses were given for each open-ended question. Responses were complied by the DPCP into categories of like responses or themes. The number of responses for each theme was counted and were rank - ordered by themes with highest to lowest number of like responses. Consideration was not given to the way teams may have listed the order of their responses to the questions.

Results:

Referrals specifically for Diabetes Self-Management Education

The first question on the survey asked, *"Of the individuals that you see for diabetes education, what percent do you estimate are specifically referred for diabetes self-management education (ADEF Program)?* ".

Diabetes education program site teams offer a number of services in addition to DSME such as: insulin starts, instruction in insulin pump therapy, and individual education for gestational diabetes and medical nutrition therapy. The question stated above was designed to help differentiate the percentage of referrals for DSME from other diabetes education services. The majority of sites indicated that large portions of referrals are for DSME.

Of the 17-team responses, 65% indicated that 3/4ths or more of their referrals were for DSME. Only 1 of 17 responses indicated less than 50% of referrals being for DSME.

Table 6: Percentage of Referral to DSME

Range of Referrals	Responses	Percent of Total
0-24%	0	0
25 – 49%	1	5.9
50 – 74%	5	29.4
75 – 100%	11	64.7

Estimate of percent attending DSME

The second question on the survey asked, *"Of the individuals referred to the ADEF Program, what percent do you estimate actually attend?* **".**

This question was asked to gauge barriers that can occur after referral. Although site teams reported a large portion of individuals with diabetes are referred to DSME, they also indicated that only half of individuals referred, actually attend the DSME program.

Table 7: Estimated Percent of Attendance DSME

Range Attendance	Responses	Percent of Total
0-24%	2	11.8
25-49%	7	41.2
50-74%	3	17.6
75-100%	5	29.4

Reasons why individuals who are referred do not attend DSME Programs

Teams were also asked to list reasons why they thought individuals referred do not attend. Seventeen teams provided 59 responses. These qualitative data were sorted and compiled by theme or reason. We list the top reasons below. When there was the same number of reasons for a category, we list both reason under the same ranking.

1. participants feel they do not need it – not interested
2.
   - financial issues
   - conflicts with schedule/scheduling issues
3. transportation
4. time / too busy
5.
   - readiness
   - aversion to group classes

Estimate of percent completing DSME

As with the other two surveys, we asked a question to gauge completion or participation rates., "*Of those who attend the ADEF program, what percent do you estimate actually complete the program*?**"** Twelve of 17 site teams indicated that greater than 50% of participants complete the DSME program, while 5 of 17 sites reporting indicated that less than 50% complete the DSME program

Table 8: Estimate of percent of completion DSME

Range of completion	Responses	Percent of total
0 – 24%	2	11.8
25 – 49%	3	17.6
50 – 74%	1	5.9
75 – 100%	11	64.7

Reasons why participants do not complete the DSME program

In addition, teams were asked to list reasons why they thought individuals that attend DSME do not complete the program. Seventeen teams provided 48 responses. These qualitative data were sorted and compiled by theme or reason. We list the top reasons below. When there was the same number of reasons for a category, we list both reason under the same ranking.

1.
    - not wanting to commit/ take responsibility
    - transportation issues
2.
    - scheduling problems
    - feel they are doing OK/ do not need information
3.
    - health insurance issues
    - not a priority for participant

Suggestions for meeting the needs of individuals related to diabetes education

Site teams were asked for their suggestions on meeting the needs of individuals to increase participation and completion rates of diabetes education. Responses were categorized by themes. A listing of team responses are shown below:

Structural Issues related to DSME:

- Less wait time for patients to be seen.
- Altering class schedule to different days of the week or different times, as well as divided sessions vs. 1-day programs
- Increase frequency of class offerings
- Increasing class time component
- Limiting class time component
- Allow flexibility for appointments
- More follow up to those who do not attend program or scheduled appointments
- Do reminder phone calls, send out reminder letters, office phone triage
- Conduct participant evaluations to determine what works
- Yearly follow up after completion of program

- Streamline paperwork
- Conduct CQI related to structural issues

Other education delivery modes:

- Possible reimbursable telephonic education in future for follow-ups
- WEB based program/resources where individual can ask general questions etc
- Educate at every opportunity
- Provide handouts or a "canned presentation – PowerPoint
- Provide resources

Community outreach/ partnering

- Collaborate with local providers, home care, community education resources and Healthy Maine Partnerships.
- Provide diabetes information via local access TV
- Refer to physical activity resources
- Offer additional support programs, cooking programs
- Offer diabetes support group
- Conduct community health fairs/ Diabetes Expos
- Incorporate self management training into non classroom activities, exercise class, supermarket tour etc

Promoting DSME/ marketing services

- More education to physicians – acute care nurses – support groups
- Make more effort to show people what other resources already exist
- Speak yearly (if not quarterly) with physicians educating the other clinical staff re: importance of DSME

Address issues for those without insurance and have health insurance financial concerns

- Need to change insurance companies view education and cost
- Convince more insurance companies to cover the cost

Individual with Diabetes Survey Results

Surveys were administered to individuals with diabetes in two health-insurance programs. The two programs represent commercial and public insurances in Maine. Maine Department of Health & Human Services MaineCare Program is publicly funded Medicaid program. They are estimated to cover a quarter of the population within the state. Anthem – Blue Cross/Blue Shield is a commercial health insurance program. It is the largest commercial payor in the state and represents almost seventy percent of the commercial market. We attempted to capture the experience of those receiving the Medicare benefit by having surveys distributed by federally qualified health centers to Medicare recipients with diabetes. A very limited response to the survey, occurred therefore no analysis was able to be conducted.

The purpose of the surveys was to gather information from varying populations of individuals with diabetes on barriers and needs related to DSME.

Methodology

In May 2003, the Maine Care Program established a MaineCare Diabetes Registry to provide targeted information, resource referral, and self-care reminders to MaineCare Program members with diabetes. In September of 2005, the Maine Care Program took leadership in sending members of the MaineCare Diabetes Registry a survey to measure their experience with the program, including their understanding of materials, interaction with providers, participation in DSME, and their extent of their self-management practices and to identify additional educational needs. This survey included questions about barriers and needs to DSME similar to the ones asked of providers and diabetes education site teams on their respective surveys. As part of the MaineCare Policy Cooperative Agreement, the Muskie School of Public Service conducted the analysis of the findings of the survey.

Anthem – Blue Cross/ Blue Shield of Maine also has a registry of members diagnosed with diabetes. In February of 2006, Anthem assumed responsibility in sending a one-page survey asking about barriers and needs related to DSME that incorporated questions similar to the ones asked of providers and diabetes education site teams. (see Appendix for copy of the survey). The Maine CDC – DPCP performed the analysis of the Anthem survey.

Results – Maine Care Program Survey

Surveys were mailed to 4532 members of the MaineCare Diabetes Registry and 2147 were returned for a response rate of 47.4%

Referral to DSME/Provider interaction

Most respondents (93.5%) to the MaineCare Diabetes Registry survey reported that they have a doctor who takes care of their diabetes. To evaluate providers' interaction with members, the survey asked members several questions about how often their providers talked with them about behavior concerning management of their diabetes

Doctor Always or Usually Talks to You About…?
(N = 2,080)

Table 9: Doctor Always or Usually Talks to You About…?

How often does your doctor talk to you about…?	**Always/Usually (Percent)**
Checking your blood sugar	89.7
Your blood pressure	81.8
Healthy eating	81.8
Checking your feet	75.8
Getting exercise	75.1
Your cholesterol level	73.4
Getting an eye exam	70.3
Going to a Nutritionist/Dietitian	36.3
Going to classes about diabetes	28.2

- According to respondents, providers were most likely to always or usually talk with them about checking their blood sugar, about their blood pressure and about eating a healthy diet. Over 80% of respondents reported discussing these behaviors with their doctor
- Between 70% and 80% of respondents recalled their providers always or usually talked to them about checking their feet for sores, getting exercise, their cholesterol levels, and getting eye exams

- Only 28% of respondents reported that their providers talked to them about going to diabetes management education classes and 36% said that their providers talked to them abut going to a nutritionist.

Attendance at DSME

MaineCare Program survey respondents were asked if they have ever gone to classes to learn how to care for their diabetes[10]approximately 60% of survey respondents attended a diabetes class. This compares to:

- An estimated 57% of Maine people with diabetes, according to prevalence estimates from a BRFSS survey conducted in 2002, 2003, and 2004
- 73% of Anthem respondents who said they attended a program that has classes and individual visits with a nurse and dietitian

Survey results form the MaineCare Diabetes Registry survey show that members in younger age categories were more likely to attend classes than those who are older. Also, more females than males attend classes. These differences by age and gender are statistically significant.

Reasons for not attending DSME

Maine Care members who reported that they did not attend classes provided the following reasons for not attending

Reasons for Not Attending Diabetes Classes
(N = 797)

Table 10: Reasons for Not Attending Diabetes Classes (n=797)

Why Didn't You Attend Diabetes Classes	**Percent**
Don't like group classes	23.7
Not interested	20.5
Do not need the information	18.3
Didn't know about it	17.2
Didn't have transportation	15.9
Not available at convenient time	10.7
Too busy	10.4
Too hard to understand	10.4
Not available in my area	9.7
Too long	8.8
Too long of a wait	5.5

* Note percentages do not add up to 100% because respondents could choose more than one reason

- they do not like group classes (23.7% of those who did not attend class)
- they are not interested (20.5% of those who did not attend class0
- they do not need information (18.3% of those who did not attend)

Best option for receiving information

MaineCare Program members were asked for the best option for receiving information on diabetes.

Best Option for Receiving Information
(N = 2,080)

Table 11: Best Option for Receiving Information (n=2,080)

Best Option for More Information	Frequency	Percent of Respondents
Get information from my doctor or primary care provider	1036	49.8
Get information from computer websites and internet	453	21.8
Get information from books, CD, or video from library	436	21.0
Attend diabetes program with group classes & individual time with nurse & dietitian	407	19.6
Attend cooking class	288	13.8
Attend a diabetes support group meeting	269	12.9
Attend community program on healthy eating and increasing physical activity	252	12.1
Get information from health care provider by telephone	219	10.5
Get information from a member of my community who has diabetes	215	10.3
Attend group visits at my doctor's or provider office	162	7.8
Participate in supermarket tours	147	7.1

Note: *Percentages add to more than 100% because respondents could select more than one option*

Half of the members with diabetes surveyed indicated that they wanted to receive information about diabetes from their doctor or primary care provider

Diabetes education topics desired

Maine Care Program members with diabetes were also asked what type of information they wanted.

Type of Information Wanted
(N = 2,080)

Table 12: Type of Information Wanted (n=2,080)

Type of Information Wanted	Frequency	Percentage of Respondents
Diet/Food planning	1144	55.0
Relaxing or reducing stress	1037	49.9
Weight loss	961	46.2
General information	825	39.7
Eye problems	781	37.5
Understanding blood sugar	746	35.9
Medications	745	35.8
Understanding cholesterol	727	35.0
Mental health information	520	25.0
Quitting smoking	366	17.5
No information needed	281	13.5

Note: *Percentages add to greater than 100% because respondents could select more than one option*

Fifty – five percent desired information on diet/food planning, while close to 50% wanted information on relaxing or reducing stress and weight loss

Results – Anthem Survey

Two thousand surveys were mailed to Anthem members with diabetes and 573 were returned for a response rate of 28.6%

Referral to DSME

According to Anthem survey respondents, approximately 80% indicated that their health care provider referred them the diabetes self-management education

Table 13: Referred

Valid	Frequency	Percent
Yes	454	79.2
No	114	19.9
Missing	5	< 1.0
Total	573	100.0

Attendance at DSME

Of the 454 respondents that indicated they were referred to diabetes education 73% attended.

Table14: Attend

Valid	Frequency	Percent
Yes	420	73.3
No	44	7.7
Missing	109	19.0
Total	573	100.0

The referral and attendance rates to DSME were larger in the Anthem population as opposed to the MaineCare Program population.

Anthem members perception of Helpfulness of Program

Individuals with diabetes in the Anthem population that attended a DSME program were asked how helpful they felt the program was. The table below shows the results:

Table 15: Anthem members perception of helpfulness of DSME

Was DSME Helpful?	Responses	Percent
Very Helpful	213	37.2
Helpful	132	23.0
Somewhat Helpful	61	10.6
Not at All Helpful	7	1.2
Definitely Not Helpful	3	< 1.0
No Response	157	27.4

Sixty percent (60%) of Anthem members reported that attending a DSME program was very helpful or helpful.

Reasons for not attending DSME

Anthem members who did not attend DSME programs offered the following reasons:

Table 16: Reasons for not attending DSME

Reason	Frequency	Percent of respondents
Can manage on own	41	24.1
Not convenient time & date	17	10.0
Don't need information	16	9.4
No time	16	9.4
Don't like groups	14	8.2
No insurance/cost too high	11	5.9
Not enough information about DSME	9	5.3
Not interested	6	3.2
Not available locally	5	2.9
Information doesn't meet needs	4	2.7
Transportation issues	2	2.4
Wait too long	1	< 1.0
Other	28	16.5

The major reasons offered by Anthem members for not attending DSME were as follows: can manage on own, program not offered at convenient time & date, do not need the information, and no time to attend.

Best option for receiving information

Anthem members responses to the best way to receive information about diabetes is listed in the table below

Table 17: Best option for receiving information

Best option for information	Frequency	Percent of Respondents
Get information from health care provider	317	19.9
Attend diabetes program with group classes with individual time with nurse & dietitian	237	14.8
Get information from computer websites & internet	228	14.3
Get information from books, CD pr video from library	153	9.6
Attend a diabetes support group meeting	119	7.5
Attend community program on healthy eating or increasing physical activity	119	7.5
Attend cooking class	116	7.3
Get information from health care provider by telephone	73	4.6
Participate in supermarket tour	70	4.4
Attend group visits at my doctor's provider's office	65	4.1
Get information from a member of my community who has diabetes	50	3.1
Other	49	3.1

Discussion

(comparison of themes/results across all surveys)

The main objective of surveying the four groups: referring health care providers; diabetes educators at DSME/ADEF Program sites; MaineCare program members with diabetes and Anthem members with diabetes was to determine barriers to referral and participation at DSME Programs in Maine.

Overall a large percentage (84%) of the providers that responded to the survey indicated they refer to DSME/ADEF programs and most (86%) also indicated that the DSME program they refer to was "very helpful" or "helpful" for individuals with diabetes. Although the responses we received were likely to be from a self-selected group of providers familiar with DSME programs. We have no evidence to suggest a negative view of the program. There were structural concerns raised by some providers about the process of referring to the program. Given the pressure on all providers to be as efficient as possible, this issue should be thoroughly explored with an advisory group of diabetes educators and healthcare professionals.

A major issue identified through these surveys was that individuals with diabetes may not be attending DSME once they are referred. Both providers and diabetes educators at DSME/ADEF program sites that were surveyed perceived that only a little more than a quarter of those individuals referred actually attend 75- 100% of the time. Responses from members we surveyed show that many people with diabetes attend some amount of diabetes education. Seventy-three percent (73%) of Anthem members and 60% of MaineCare program members indicated that they attended diabetes education. Data from Maine ADEF programs show that only 43% of participants that start the ADEF program actually complete it. These two data results suggest that more attention needs to be focused on both attracting and retaining participation in these programs.

Although referrals to DSME programs have increased over the past five years there continues to be a large gap between the current rate of newly diagnosed receiving diabetes education (one out of four) and the recommended goal (100%). More needs to be done to increase referrals and continued participation in this resource. Survey results suggest there may be structural barriers in the process of making referrals by providers and a variety of perception and structural barriers exist for patients too. A list of barriers follows.

Rank order of barriers

From the data gathered though the surveys certain barriers and themes were identified. The following chart offers a comparison of the barriers across the four populations:

Table 18: Rank order of barriers by population surveyed

Rank order	Referring Providers' barriers	Diabetes educators at DSME/ADEF Program sites' barriers	MaineCare Program members with diabetes barriers	Anthem Members with diabetes barriers
1	Transportation issues	Participants feel they do not need it	Aversion to groups	Can manage on own
2	Cost issues	Cost issues	Not interested	Program at inconvenient times/dates
3	Aversion to groups	Conflicts with scheduling	Participants feel do not need it	Participants feel do not need it
4	Program at inconvenient times/dates	Transportation issues	Don't know about DSME program	Time issues/too busy
5	Too long of wait to begin the program	Time/ too busy	Transportation issues	Aversion to groups

Top five barriers across populations surveyed

From the chart it is noted that there was no one single reason that stood as a barrier to attendance at DSME programs. Of the top three barriers, the theme of lack of need/interest was evidenced by the ranking of barriers such as: participants feeling they do not need it, can manage on their own, or not interested. Cost was perceived to be the second highest rated barrier by the referring providers and diabetes educators, but was **not** perceived as one of the top five barriers for the individuals with diabetes. Transportation ranked number one for the referring health care providers as a barrier and ranked as the fourth barrier by diabetes educators. Interestingly Maine Care program respondents ranked transportation as the number five barrier, even though the Maine Care Program pays for transportation to medical visits. This would indicate a lack of awareness on the part of Maine Care members and perhaps health care providers of assistance with transportation. Scheduling issues such as: program offered at inconvenient times and dates; conflicts with scheduling and too long of a wait to get into the program, were also indicated as one of the top five barriers across the populations. Aversion to groups was also listed as one of the top five barriers of all the populations surveyed except for the diabetes education site teams..

Barrier Themes

From the data obtained from the surveys, several major themes emerged.. The themes include:

- consumer perceptions
- referring provider issues
- access issues

Consumer Perceptions

From the survey, many consumers (individuals with diabetes) perceive that that are doing "OK" with their diabetes management, when it reality many do not realize that they could benefit from DSME. A large proportion indicated that they felt they did not need the information. However, they may not be informed about good diabetes management and how it could benefit them. No time, was also reported as a reason for non-attendance at DSME. In these days of stressful lives, DSME may not be seen as a priority. If health care providers do not emphasize the importance and benefits of DSME, it could be easy for it not to be taken seriously by individuals with diabetes. The attitude of "it might be nice if you went but it's up to you" does not convey the message that DSME is essential and the foundation for diabetes care. Psychosocial issues may also pay a role. Feelings such as fear, denial, or being overwhelmed may also be barriers to attendance at DSME. These emotions also make it difficult to take the next step in facing one's diabetes by attending a DSME Program. In addition, aversion to group classes was also indicated as a major barrier, especially by MaineCare Program participants who listed this as the number one barrier.

Referring Provider Issues

A majority of providers who responded to the survey indicated that they did refer to DSME. For those who do not refer, a number of reasons were given. From the survey some providers indicated that they provide diabetes education in their office. Others were not aware of a DSME Program in their area. Even if they are aware of the Program they may not understand the scope of the program and all that it entails. As mentioned previously, they may not realize that the program is an opportunity for comprehensive education about diabetes for the patient. It is also an opportunity for them as providers to work closely with the nurse, dietitian and patient in carrying out the plan of care and work on self-management goals. Encouragement for all patients to attend DSME might not occur, but rather be reserved for a select few. Individuals with diabetes indicated that they wished more information from their provider. A stronger message about the importance of DSME from the health care provider to all individuals with diabetes may help the individual get from referral to actual attendance. Another issue indicated by some providers is confusion about the referral process. In some cases, the providers

indicated that they were unclear about how to refer or found the process too difficult. Wait time to enter the program or limited options for the time of the program were also indicated as issues.

Access Issues

Transportation was perceived to be a larger barrier to attending DSME by referring providers and diabetes education site teams than by individuals with diabetes. Cost or financial issues were also indicated as top barriers by the referring providers and diabetes education site teams, but was not ranked in the top five barriers by individuals with diabetes. Scheduling of the program was ranked as one of the five top barriers by the majority of the populations surveyed. DSME sites that only offered day classes or just evening classes may make it difficult for participants to attend. Also, workforce issues, such as limited number of hours for the instructors to be able to offer the classes more frequently or at different times may be factors.

Ranking of preferred education methods

In both the Maine Care and Anthem surveys, individuals with diabetes were asked how they preferred to receive diabetes education. The following chart provides a comparison:

Ways to Learn / Get Information

Table 19: Best Option For Receiving Information Comparison

Anthem		Maine Care	
Ranking	**Ways to learn**	**Ranking**	**Ways to learn**
1	Get info from provider	1	Get info from provider
2	Classes with RN & RD	2	Computer/internet
3	Computer/ internet	3	Info from books, CD/videos/ library
4	Info from books, CD/videos/libraries	4	Classes with RN & RD
5 – tie	Diabetes support groups/ attend community programs	5	Attend cooking classes
6	Attend cooking classes	6	Diabetes support groups
7	Telephone	7	Attend community programs on healthy eating and exercise
8	Supermarket tours	8	Info from community members
9	Group medical visits	9	Telephone
10	Info from community members	10	Group medical visit

Of the top ten reasons for receiving information, interestingly the top four reasons identified by both the Maine Care and Anthem populations were the same. Only the ranking differed. Both populations reported receiving information from their provider as the preferred method of education. Three other methods: classes with RN & RD; computer/

internet information; and books and CD/videos from library varied among the MaineCare and Anthem members as to the second, third and fourth rankings.

As evidenced in the literature, it is known that individuals that engage in DSME programs have exhibited significant improvements in diabetes management and reduced complications. Given this fact, the Maine DPCP views DSME as the foundation of diabetes care that all individuals. DSME in Maine delivered via the ADEF Program (group classes, one-to-one with RN & RD, and follow-up) is viewed as essential for every individual with diabetes. Other methods of education such as: computer/internet; and books, video/CDs from the library as well as other methods of education in the community are important supports. One method of education does not work for all. The results of the surveys indicate that individuals with diabetes wish information from their provider. If the provider is unable to directly offer DSME out of his/her office, the provider in turn can refer patients to DSME for the comprehensive foundation. Providers can also recommend other education modalities such as: internet, reference books, community resources such as support groups, community lifestyle programs, telephonic programs to provide additional on-going support.

Conclusions/Recommendations

By surveying referring providers, diabetes educators, and individuals with diabetes, the DPCP was able to gather important information about barriers to referral and participation in diabetes self-management education in Maine. Now that we have gathered this information and analyzed the results we present our recommendations on "next steps" to take.

Although many referring providers and Anthem members with diabetes that responded to our surveys indicated that DSME programs are "very helpful" or "helpful". There were also multiple barriers, both structural and perceived, that may be getting in the way of people with diabetes using this resource. Many of the needs that have been identified could be positively impacted through a marketing and communication plan. We offer the following recommendations to address these barriers and needs

1. Advisory group
    a. Form an advisory group made-up of diabetes educators, health care professionals, and members of the healthcare system
    b. Review, modify, and finalize plans to:
        i. Develop a streamlined referral process to DSME for consideration by providers
        ii. Develop a statewide communication plan that encourages more referrals to DSME by providers
        iii. ME AADE to review barriers to attending and continued participation in DSME
        iv. Participate in planning sessions and review of efforts to increase access to DSME
        v. Assist the DPCP in identifying populations, i.e. persons with severe and persistent mental illness and diabetes, that are not currently served by the DSME program format and make recommendations on how to best serve persons in these groups.

2. Coordinated Marketing Plan
    a. Education of referring providers (physicians, physician assistants, nurse practitioners, care managers) about DSME/ADEF programs including description, benefits, availability
    b. Education of individuals with diabetes & support persons about DSME/ADEF programs including description, benefits, availability
    c. Promotion of message that DSME is the foundation of diabetes care and other methods of education such as internet, library, care management, community programs

such as support groups, lifestyle programs are important adjuncts to diabetes care. All resources should be identified and promoted to individuals with diabetes to assist them in their self-care

3. Increased access
    a. Review and revision of systems to aid in referral to actual attendance at DSME program
    b. Increase options for times DSME programs offered (evenings & days & possible weekends)
    c. Hire more DSME staff to decrease waiting time and facilitate offering of more DSME programs at various times
    d. Identify resources to assist individuals without health insurance to access DSME programs
    e. Identify resources to assist those without transportation to access program & increase awareness of MaineCare program members about availability of transportation
    f. Identify resources for DSME for special population groups who are unlikely to participate in DSME as it is currently offered

The DPCP has plans underway to convene the DSME Barrier Study Advisory group to review this report, make recommendations, and develop an action plan to address barriers and needs related to DSME in Maine. Once the action plan is implemented with the help of all partners, it is hoped that reduced complications and increased quality of life will occur for all individuals diagnosed with diabetes.

Appendix

Diabetes Self-Management Education (DSME) Programs Provider Survey

Survey – ADEF Program Site Teams – June 2005

Diabetes Self-Management Education (DSME) Program Individuals with Diabetes Survey

References

[1]Institute of Medicine, 2004 referenced in a presentation by Kate Lorig, June 15, 2006, Auburn, Maine

[2] Peyrot, M, Rubin, RR, Lauritzen, T, Snoek, FJ, Matthews, DR, Skovlund, SE, Psychosocial problems and barriers to improved diabetes management: Results of the Cross-National Diabetes Attitudes, Wishes, and Needs (DAWN) Study. DiabetMed 22:1379-1385, 2005

[3] American Diabetes Association. Clinical Practice Recommendations 2006, Third-party reimbursement for diabetes care, self-management education, and supplies, *Diabetes Care*, Volume 29, Supplement 1, January 2006, S68

[4] Norris, SL, Engelgau, MM, Narayan, KM, Effectiveness of self-management training in type 2 diabetes: a systemic review of randomized controlled trials. *Diabetes Care* 2001: 24:561-587

[5] Norris, SL, lau, J, Smith, SJ, Schmid, CH, Engelgau, MM. Self-management education for adults with type 2 diabetes: a meta-analysis of the effect on glycemic control . Diabetes Care 2002:25: 1159-1171

[6] American Diabetes Association. Clinical Practice Recommendations 2006, Third-party reimbursement for diabetes care, self-management education, and supplies, *Diabetes Care*, Volume 29, Supplement 1, January 2006, S68

[7] Maine BRFSS (2000-2004) Maine Center for Disease Control & Prevention/DHHS

[8] Joly,B, O'Rourke,K. *Diabetes Assessment: A Systems Approach, Maine Diabetes Health System Final Assessment Report,* Maine Center for Public Health, March 2004

[9] Maine Department of Health & Human Services, Maine Center for Disease Control & Prevention, Diabetes Prevention & Control Program, *Maine Diabetes Health System Strategic Plan*, May 2005

[10] American Diabetes Association website: http:// www.diabetes.org/diabetes-statistics/complications.jsp

[11] Strine TW, Okoro CA, Chapman DP, Beckles, GL, balluz L, Mokdad AH. The impact of formal diabetes education on the prevention health practices and behaviors of persons with type 2 diabetes. PrevMed. 2005 Jul:41 (1): 79-84, Epub 2004 Nov 19

[12] It is important to note that the survey did not distinguish the type of class attended (comprehensive DSME Program versus a one hour class)