

Empowerment for Diabetes Management: Integrating True Self-Management into the Medical Treatment and Management of Diabetes Mellitus

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Approximately 16 million people in the United States have diabetes mellitus, and the number of diagnoses is increasing at an alarming rate. A very costly disease in both human and economic terms, diabetes (currently the seventh leading cause of death) is common in both the old and young, crossing all racial, ethnic, and economic barriers. Diabetes significantly increases the risk of cardiovascular, cerebrovascular, and peripheral vascular disease, retinopathy, neuropathy, and nephropathy. The team approach to treating and managing diabetes provides a foundation of support and education for the patient, while allowing the individual control of his or her health care decisions. A self-management education program is essential for diabetes patients and their support systems to learn optimal strategies for dealing with chronic illness and the associated physical and psychological obstacles. Diabetes education must motivate and empower patients with instruction in self-monitoring techniques, proper nutrition and exercise, pharmacologic options, and psychosocial adjustments to depression and stress brought on by chronic disease, as well as provide resources for continuing education. Ochsner is developing a system-wide diabetes self-management education program as a resource for all of Louisiana and parts of Mississippi to improve the outcomes of diabetic patients. The program has demonstrated significant results since 1998 by providing a comprehensive foundation to patients and their support systems and providing a foundation for the lifelong quest to master the chronic disease process.

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Diabetes mellitus was recognized as early as 1500 BC and was considered rare until approximately 100 years ago. A recent *Time* magazine cover story (1) cited current Centers for Disease Control and Prevention (CDC) reports that the incidence of type 2 diabetes increased 33% from 1990 to 1998, and the incidence of type 2 diabetes increased an additional 6% in 1999 alone (2). With the number of diabetes cases increasing at alarming rates, solutions both practical and manageable are needed. It is our responsibility as clinicians to assist our diabetic patients in achieving the best possible outcomes.

Scope of the Problem

Diabetes is a very costly disease, in both human and economic terms. As one of the leading causes of death and disability, diabetes directly affects approximately 16 million people in this country with nearly 800,000 patients newly diagnosed annually (2). According to the CDC, as many as one-third to one-half of these people are unaware of the disease. Diabetes is common in both the old and young crossing all racial, ethnic, and economic barriers and is currently the seventh leading cause of death (>193,000 each year). The combined direct and indirect annual economic cost is estimated at \$98 billion, though financial burdens are just one concern associated with this chronic disease.

The personal losses are staggering. Diabetes contributes to a total of 14 million days lost workdays each year. It is the leading cause of blindness among people aged 20 to 74. People with diabetes are 3 to 4 times more likely to have heart disease and strokes. Nearly 70% of all diabetic patients have nerve damage or neuropathy that may impair sensation in the feet or hands, slow digestion, or cause other forms of autonomic dysfunction. Between 1993 and 1995, 67,000 amputations were performed annually on patients with diabetes.

People with diabetes are also 10%-21% more likely to have kidney disease, and, according to the American Diabetes Association (ADA), diabetes has become the most common single cause of end-stage renal disease (ESRD) in the US and Europe (3). Reasons cited include the increased prevalence and life expectancy of people with type 2 diabetes and the availability of treatment options for those with ESRD and type 2 diabetes who were previously excluded and denied therapy. For nearly one-third of ESRD patients, their disease is the result of diabetic nephropathy. Furthermore, many experts predict that diabetes may soon account for nearly one-half of all ESRD. ADA recommendations include:

- Annual screening for microalbuminuria for early detection of nephropathy (incipient nephropathy)
- Improving glycemic control
- Aggressive antihypertensive treatment
- The use of ACE inhibitors

Additional recommended therapies may include protein restriction and phosphate lowering as required (3).

The Solution: A Team Approach

The team approach to treating diabetes provides a foundation of support and education for the patient, while allowing the individual control of his or her health care decisions (3). The patient is the focal point of all interventions and outcomes and the most significant member of the team, which also includes the patient's support system of family and friends. Team responsibilities include teaching and reinforcing critical diabetes self-management skills designed to prepare the patient to successfully manage his or her chronic disease. Treatment goals focus on long-term behavior changes that facilitate successful management through a series of short-term goals, one step at a time.

"The diabetic person's race is no sprint; it is more than a marathon" (4). Education remains the key to preparing a patient to deal with the lifelong course of chronic illness. The ADA recommends patient and family education for self-management be consistent with the National Standards for Diabetes Self-Management Education Programs to achieve maximum prevention of complications through glycemic control. Diabetes educators and health care practitioners

specializing in diabetes have been plagued by the multitude of questions that arise from attempts to manage this chronic illness. It is important to consider and remember why diabetes education is important, how we teach, what we teach, and what specific outcomes we expect to achieve.

Pathophysiology of Diabetes

Diabetes mellitus is a disease of the metabolism resulting in frequent hyperglycemia, which contributes significantly to the development of micro- and macrovascular complications. Type 1 diabetes is associated with an absolute deficiency of insulin, while type 2 diabetes is related to a relative insulin deficiency as well as insulin resistance. Diabetes therapies are designed to improve or correct the abnormalities related to both type 1 and type 2 diabetes and reduce the risk of complications. Patients often experience signs and symptoms of diabetes without comprehending the association between the symptoms and the disease, or understanding where they are in the disease process. Health care team members must insure that diabetic patients have a functional understanding of the pathophysiology and acute and chronic complications of the disease process. The pathophysiology of diabetes should be presented at the cellular, tissue, and organ levels to teach the functions of glucose and insulin.

Acute Complications

The most frequently encountered acute complication of diabetes is hypoglycemia, defined as blood glucose below 50 mg/dl; however, a level of <70 mg/dl should be treated to provide a margin of safety. It is crucial that the entire diabetes team know whether the patient can sense hypoglycemia. Patients should be taught to recognize the symptoms of hypoglycemia and the precipitating conditions such as skipping meals, exercise, alcohol ingestion, and low carbohydrate meals. The management of acute hypoglycemia using 15 grams of carbohydrate followed by food once symptoms abate should also be taught. Most importantly, patients should be taught methods to avoid hypoglycemia and be instructed to wear diabetes identification.

Chronic Complications

Chronic complications are divided into micro- and macrovascular varieties. Microvascular complications include retinopathy, neuropathy, and nephropathy. Macrovascular complications include cardiovascular, cerebrovascular, and peripheral vascular disease. In addition to instruction about these specific disease processes, significant attention should be given to providing adequate prevention information according to the ADA standards of treatment for the management of blood glucose, weight,

blood pressure, and cholesterol. Preventive foot care is a key element of diabetes education. Severe peripheral neuropathy increases risk of traumatic and non-traumatic foot injuries, which can easily worsen due to the inability to recognize the signs and symptoms. A single daily foot examination can avoid most severe foot complications.

Although the DCCT and UKPDS, as well as several smaller studies (3), demonstrated the significance of good glycemic control in reducing complications of diabetes, in reality, many patients do not achieve or maintain that level of glucose control. Good glycemic control requires a multifaceted approach including meal planning, exercise, education, stress management, counseling, and support elements. Every health care provider can contribute to the continuous educational process required in diabetes. The treatment for diabetes will be most effective if the patient and the patient's support system help to determine the treatment regimen, understand the value of the treatment, and are able to master the necessary skills for following the treatment regimen. A basic diabetes self-management education program is necessary to supply the foundation for the lifelong learning process required for good glycemic control.

Table 1. Seven categories of psychological reactions to chronic illness (6).

1. Perceived threat to self-esteem and body intactness that challenges individuals' beliefs that they are masters of their own bodies (impotence, hyperglycemia, gait disturbance)
2. Fear of loss of love and approval that evolves from patients' fears that illness and dependence on others will cause significant others to withdraw (entire family must be supportive of diet, exercise, and other necessary therapies)
3. Fear of loss of control of achieved body functions and/or parts with resulting loss of independence (dialysis, amputation, blindness)
4. Anxiety resulting from separation from loved ones and familiar environment that provided support, gratification, and a sense of intactness (real or imagined, but depression exacerbation)
5. Guilt and fear of retaliation for having incurred the health problem in the first place or for having lost control (diabetes is an expensive disease)
6. Fear of pain (neuropathy, peripheral vascular disease, needle sticks)
7. Fear of strangers providing intimate care (privacy and independence)

Table 2. Five factors necessary for positive adjustment to chronic illness (7).

1. **Knowledge:** an understanding of the disease process as well as medical interventions included in therapy
2. **Coping resources:** any available to assist the patient in overcoming, managing, or resolving problems
3. **Problem-solving attitude:** perceives a problem and provides, reviews, and evaluates several possible means of confronting the problem
4. **Personal mastery:** a desired level of confidence to make decisions and manage disease-related issues
5. **Motivation:** that which continues to cause the patient to be wholly involved in decisions determining, to the greatest extent possible, outcomes related to the disease process

Diabetes is a chronic disease, and a prerequisite for developing an education process for any chronic illness is a basic understanding of the disease process and the myriad effects it has on the patient and support system. Reif (5) identified three general features of chronic illnesses:

1. The disease symptoms interfere with many normal activities and routines
2. The medical regimen is limited in its effectiveness
3. Treatment, although intended to mitigate the symptoms and long-range effects of disease, contributes substantially to the disruption of the usual patterns of living

Understanding these features provides the foundation of a successful education process for patients with diabetes. Table 1 lists seven categories of psychological reactions to chronic illness (6). The central theme is loss of control, a feeling that begins with the onset of disease and continues to be pervasive in all aspects of life throughout the course of the disease. Successful diabetes education programs will facilitate patient control and management of health care decisions.

The nursing term for this loss of control is "powerlessness," which denotes a perception or belief that one has lost the necessary control to effect outcomes. The inability to effect outcomes, both large and small, is a frightening experience. Turk (7) identified the five factors necessary for positive adjustment to chronic illness shown in Table 2. For education to positively impact outcomes in chronic illness, it must impact these five factors.

Most involved in treating and educating patients with diabetes consider the compliance issues of diabetes, such as lifestyle and

behavior modifications, paramount to achieving blood glucose control, limiting complications, and improving quality of life. The diabetes team should routinely suggest and advocate for means of controlling high blood pressure, lowering blood glucose and cholesterol levels, adhering to a meal plan, increasing exercise, and obtaining routine eye and dental examinations. Ultimately, necessary lifestyle changes depend on each individual. After all, the individual must leave our offices and face the day-to-day challenges of diabetes self-management and deal with the changes, limitations, physical and psychological impacts, and costs associated with chronic disease management.

Noncompliance and Powerlessness

The simplistic equation of *good blood glucose control = improved diabetes wellness* has overextended the idea of noncompliance. Clinicians assume that patients are provided with all necessary information (medical direction, diabetes education, and nutrition planning) and expect them to leave the doctor's office fully equipped for good blood glucose control and return with appropriately improved glycosylated hemoglobins. When that is not the outcome, patients are labeled "noncompliant." This requires reevaluation.

Metz and Benson (8) summed up the current approach:

...the *sine qua non* of good diabetes therapy is to persuade, encourage, coach, and equip patients to develop the knowledge, tenacity, courage, and optimism necessary for long-term successful management of their diabetes.

Is noncompliance a failure of the patient, the diabetes team, or both? Does the label "noncompliant" improve results and outcomes? Historically, clinicians have tried to manage diabetic patients with a "do-it-my-way" approach; however, for successful outcomes, patients must be truly empowered to self-manage their disease. The perception of powerlessness (innate in chronic illness) must be treated if patients are to be provided with the appropriate tools to self-manage chronic illness. "It's not that people are unwilling to change, it's that people are unwilling to be changed" (9).

Clark (10) summarized the education process:

...the health care practitioner is not the person who stands back, assesses, plans, and evaluates, but a facilitator who teaches clients how to self-assess, decide on wellness goals, plan on actions to meet those goals, and self-evaluate success.

Self-Management Education

Diabetes self-management education must meet the goal of providing both knowledge and resources while assisting in the development of the skills required to overcome the feelings of powerlessness associated with chronic illness. "Knowledge is a power resource" (11); the ability to control increases relative to knowledge. Patients with chronic illness must understand the expectations for physical, psychological, and emotional outcomes and should be supplied with information regarding proposed therapies, related outcomes, and medications in order to make informed decisions regarding treatment modalities.

"If health information is to be effective, it must be communicated in such a way as to motivate each person to understand it and then to use it" (12). Motivation starts with communication and education. Assisting the patient in the acquisition of knowledge is, therefore, the first intention of diabetes self-management education. However, many separate areas must be addressed if the patient is to be truly prepared to manage this chronic illness.

Nutrition

Nutrition counseling is a critical aspect of diabetes education because it empowers the patient to manage the disease process on a daily meal-to-meal basis. However, nutrition counseling must be realistic. An individual meal plan, appropriate and realistic for the patient's lifestyle and diabetes management goals, should be prepared by a registered dietitian. Meal plans should also consider other nutrition goals, such as lower lipid levels or weight loss, with a goal of improving overall patient health.

Pharmacologic Therapies

Patients should be given an understanding of pharmacologic interventions that may be encountered in the course of their disease. Health care providers have little time to discuss each medication in detail, yet patients must have a clear understanding of these medications in order to develop appropriate expectations related to outcomes. Patients should receive broad-based instruction in insulin types, uses, and storage, as well as information on the various oral hypoglycemic agents, proper dosage ranges, and times of administration. Included in these discussions should be information relevant to all medication usage, such as the need for proper reporting of medications to all health care providers and individual responsibility to use medications as prescribed.

Exercise

The effects of exercise in people with diabetes were recognized as early as the 1920s. Patients should understand the associated benefits of exercise related to control of blood glucose levels as well

as benefits related to overall health. Exercise lowers blood glucose, lowers blood pressure, relieves stress, improves cholesterol levels, improves cardiac stamina, and improves overall health (3). A majority of type 2 diabetes patients are middle-aged and have practiced a sedentary lifestyle for the majority of their years. Convincing patients of the necessity of changing this behavior requires more than just providing the appropriate theory just as affecting change requires realistic expectations.

Monitoring Blood Glucose Levels

Patients are taught to self-monitor blood glucose levels for many reasons. Being taught to raise or lower their own glucose by balancing insulin, diet, and exercise can empower and help them identify the impact of various elements on blood glucose levels. Learning how various foods, activities, emotional and physical stressors, and medications affect blood glucose levels provides the patient with some control over the disease process. Patients should be encouraged to monitor blood glucose results in a log that can serve as a guide to how various foods, activities, medications, etc. affect glucose levels and can be used by health care providers to help guide treatment decisions. Patients will gain confidence as they observe glucose levels responding to their decisions and correlating with HbA1c levels (the MDs score card for success over the previous 3 months). Maintaining and paying attention to such a log can also alert patients to when they should seek assistance from their health care providers between appointments.

Psychosocial Adjustment: Depression & Stress

Due to the chronic nature of the disease process, psychosocial adjustment is a prerequisite for healthy management. The grieving process should be discussed with patients along with its relevance to the diagnosis of diabetes mellitus in order to foster an understanding of the feelings most patients experience at diagnosis and throughout the disease process. Patients should also be taught to develop and use various techniques to assist in the management of stress. Stress management is significant because stress can significantly elevate glucose levels or deter appropriate behaviors necessary to maintain adequate glucose control.

Problem-Solving Techniques

Problem-solving skills are developed using case scenarios. Patients should be provided with multiple tools for self-management and many opportunities to become proficient with those tools. Through the use of real-life scenarios, patients are afforded opportunities to put newly acquired knowledge into practical use, thus developing the problem-solving skills which will be invaluable in self-managing their chronic disease.

Resources

Successful self-management of diabetes depends upon the support of the diabetes team. Patients must understand who the various team members are relative to their care and should be taught the best way to use their health care delivery system and other appropriate resources. Patients need to understand why it is important to see a dentist, podiatrist, and ophthalmologist routinely, as well as the functions and requirements of the many other specialists who are required periodically to facilitate optimum care.

Diabetes self-management instruction is merely the beginning of what must become an ongoing educational process. Table 3 provides several resources available to diabetes patients and their families. Many journals are available (by subscription, from a local library, or on the Internet) that provide updates on research and medication, stories on self-management written by others experiencing the disease process, and nutrition updates and interesting recipes. The use of diabetes-specific recipe books and magazines should be encouraged to facilitate adherence to an appropriate diet. Seminars and health fairs are often provided by various local health care institutions and are frequently free of charge. In addition, "800" numbers and websites for various diabetes associations provide free information and opportunities to update knowledge.

The establishment of goals should be emphasized throughout the education process. For many patients, the concept of setting goals may be unfamiliar as a conscious thought process. It is helpful to demonstrate that goal setting has been evident throughout their

Table 3. Diabetes continuing education resources.

- American Association of Clinical Endocrinologists (AACE): www.aace.com
- American Association of Diabetes Educators (AADE): www.aadenet.org
- American Diabetes Association (ADA): www.diabetes.org 1-800-DIABETES
- Centers for Disease Control and Prevention (CDC): www.cdc.gov 1-800-311-3435
- Diabetes Control and Complications Trial (DCCT): www.niddk.nih.gov/health/diabetes/pubs/dcct1/dcct.htm
- Juvenile Diabetes Foundation International (JDF): www.jdfcure.org 1-800-533-CURE
- National Institute of Diabetes and Digestive and Kidney Disease (NIDDK): www.niddk.nih.gov
- National Institutes of Health (NIH): www.nih.gov
United Kingdom Prospective Diabetes Study (UKPDS): www.dtu.ox.ac.uk/index.html?maindoc=/ukpds/

lives, even if it has been a relatively unconscious process, and that goal setting has played a significant role in each patient's individual life successes. Once the patient accepts this concept, they become more willing to establish goals to facilitate the management of their diabetes. Again, the use of real world scenarios and class discussions promotes this process.

Ochsner Diabetes Self-Management Education Program

Ultimately, the goal of the educational process is to assist patients in developing the skills necessary to self-manage their disease. For example, we teach the following processes for the prevention of kidney disease and slowing progression of kidney disease:

- Maintaining blood glucose levels as close to normal as possible
- Maintaining blood pressure at less than 130/80 to prevent kidney damage
- Following an appropriate meal plan as designed by a registered dietitian for individual needs
- Evaluating kidney function annually by a microalbumin creatinine ratio

At Ochsner, we are developing a system-wide management program to improve the outcomes of our diabetic patients. A registry of Ochsner's approximately 19,000 diabetic patients has been developed to classify potential risk of complications by identifying patients, regulatory requirements, and outcomes data reporting. Several initiatives are being developed within the institutions to identify best practice methods and develop clinical practice

guidelines. For example, a team approach will be applied to annual screenings of diabetes patients through the Department of Internal Medicine, which will contribute to our education programs, and Ochsner Health Plan (OHP) is undertaking a number of initiatives featuring diabetes education programs. Tiered services will be offered to various defined risk populations, a process that already occurs with referrals to specialists for higher risk patients. This area will grow in the future, however, as we improve care and cost effectiveness.

Ochsner's diabetes self-management education program is composed of a 10-hour outpatient course divided into three modules taught by certified diabetes educators. This basic course should be attended by all diabetes patients at least once to enhance understanding of diabetes management and improve outcomes. Four modular courses are available per month at Ochsner's main campus in New Orleans and one course per month at the Ochsner clinic in Slidell, LA. The program is recognized by the ADA as are our endocrinologists. Survival skill classes for diabetes patients are also taught at Ochsner Foundation Hospital. Figure 1 illustrates the baseline results compared with post-education results and may suggest that a short refresher course is needed at 9 months to 1 year. These data should be interpreted with some caution since they are based on the patients who return for follow-up evaluation.

Figure 2 demonstrates the HbA1c results for the years 1998-2000. There appears to be a general trend for all 3 years that the greatest improvement in HbA1c levels occurred in the first 3 months with either a slight improvement or maintenance at 6 months. Although the HbA1c was not normalized, the reduction by 1%, if continued, would reduce microvascular complications by 35% (3). Our goals are to obtain HbA1c levels below 7.0% at the 3-month

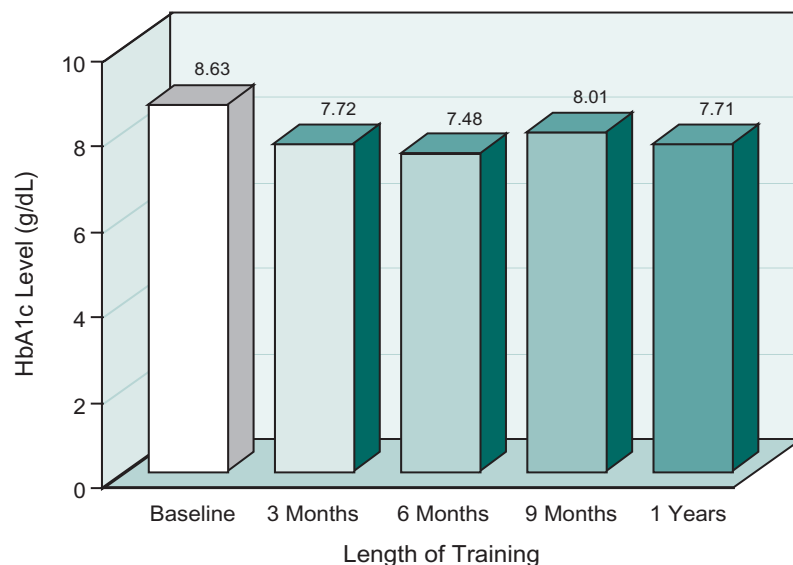


Figure 1. HbA1c baseline results compared with post-education results of patients who return for follow-up evaluation after completing the Ochsner Diabetes Education Program.

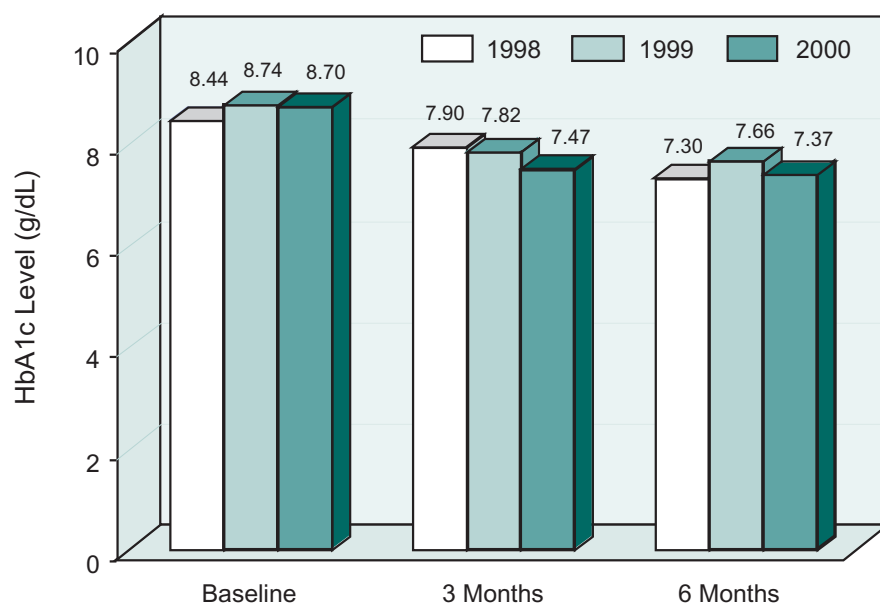


Figure 2. 1998 – 2000 HbA1c results of patients in the Ochsner Diabetes Education Program.

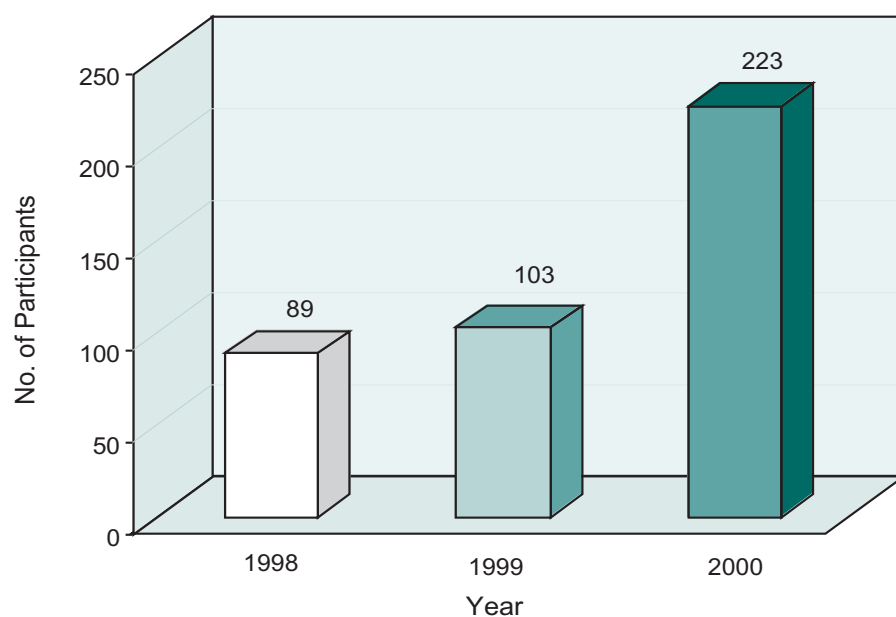


Figure 3. Participation in Ochsner Diabetes Education Classes 1998 – 2000.

post-education visit and to offer our education program to more patients. The basic education classes currently average 55 persons per month, and we expect to educate a minimum of 660 patients this year. However, only 44% completed the entire course (including follow-up visit) in the period from August 2000 to January 2001. These data are being studied and the classes evaluated in order to improve attendance and outcomes. Determinants may include the scheduling of classes around work times, and the restructuring of follow-up visits by either phone or email. This past year has shown improved program effectiveness (based upon pre- and post-test scores) from 80.7% to 90.8%.

The number of patients who have participated in our programs has increased over the past 3 years, and yet the expectation is to educate far more of our diabetic population in the near future. We consider our program a resource for all of Louisiana and parts of Mississippi. Figure 3 depicts the numbers of patients who have completed the courses through follow-up from 1998 to 2000. Figure 4 demonstrates the changes in attendance from August 2000 to February 2001, which showed an increase in the average from 18 to 28 per month.

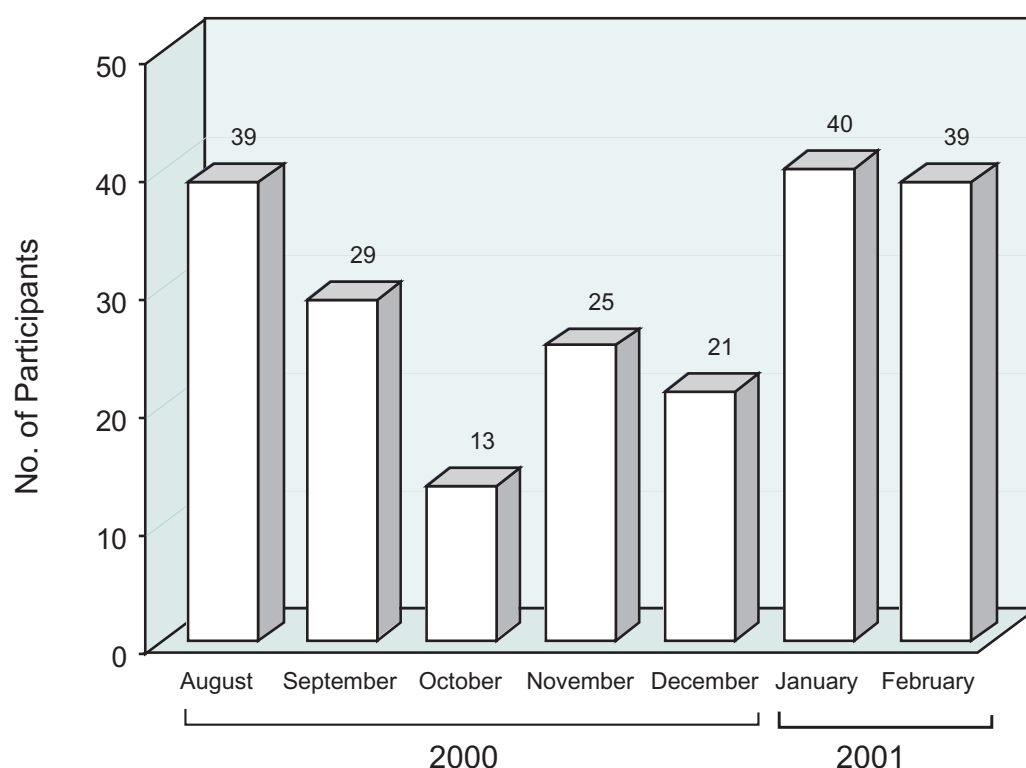


Figure 4. Participation in Ochsner Diabetes Education Classes August 2000 – February 2001.

Ochsner's Section on Endocrinology has beta-tested glucose monitoring on the Internet with the company eDiabeticLife (New Orleans, LA). Our current education classes provide comprehensive education and management techniques; however, these classes do not provide specific guidelines for medication adjustment. The vast majority of our patients do not feel competent to adjust their own insulin. Theoretically, by posting their glucose results and medications, the diabetes team may have the opportunity to more frequently adjust medications instead of waiting for the next outpatient visit. This system also provides documentation, more efficient communication, and may potentially be a convenient source of data collection for regulatory requirements of reporting outcomes data. We hope to utilize the current program to enhance our existing programs and develop new, more advanced services. Potential benefits include the development of advanced classes for carbohydrate counting and insulin pattern and insulin pump therapy management.

Internists and family practitioners manage the vast majority of diabetes patients. Thus, communication and planning between the various groups involved in the care of diabetic patients is required. We plan to further educate primary care physicians with an interest in becoming diabetologists. We also recognize the need for both a

behaviorist and a diabetes support group to further enhance our program. All of these endeavors will facilitate the integration of diabetes self-management into the medical management plan and promote patient empowerment.

Summary

Diabetes education is critical to self-management of the disease and achieving the optimum level of glycemic control. All of the members of the health care team serve as teachers and each has unique skills and perspectives to offer. Each patient visit is an opportunity to offer support and counsel the patient on aspects of the treatment regimen. However, information must be consistent, requiring coordination between team members to provide patients with educational materials, research information, and research-based advice on disease management. Team members can reinforce the significance of frequent monitoring of blood glucose levels, stress adherence to a consistent meal plan and regular exercise regimen, and act as the patients' advocates. Each member of the health care team is an educator; each contribution is an important help in the lifelong quest to master the chronic disease process.

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