

Philadelphia College of Osteopathic Medicine
DigitalCommons@PCOM

PCOM Psychology Dissertations

Student Dissertations, Theses and Papers

2006

Development of an Internet-based Disease Management Program for People with Diabetes

Robert L. Mailliard

Philadelphia College of Osteopathic Medicine, rlmrugby@juno.com

Follow this and additional works at: http://digitalcommons.pcom.edu/psychology_dissertations

 Part of the [Clinical Psychology Commons](#)

Recommended Citation

Mailliard, Robert L., "Development of an Internet-based Disease Management Program for People with Diabetes " (2006). *PCOM Psychology Dissertations*. Paper 91.

This Dissertation is brought to you for free and open access by the Student Dissertations, Theses and Papers at DigitalCommons@PCOM. It has been accepted for inclusion in PCOM Psychology Dissertations by an authorized administrator of DigitalCommons@PCOM. For more information, please contact library@pcom.edu.

Philadelphia College of Osteopathic Medicine

Department of Psychology

DEVELOPMENT OF AN INTERNET-BASED DISEASE MANAGEMENT
PROGRAM FOR PEOPLE WITH DIABETES

Robert L. Mailliard

Unpublished Work

Copyright (2006)

All Rights Reserved

Submitted in Partial Fulfillment of the Requirements of the Degree of Doctor of

Psychology

July 2006

**PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE
DEPARTMENT OF PSYCHOLOGY**

Dissertation Approval

This is to certify that the thesis presented to us by Robert L. Mailliard on the 24th day of March, 2006, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

Committee Members' Signatures:

Steven Godin, Ph.D., M.P.H., Chairperson

Stuart Badner, Psy.D.

Janet B. Snyder, Ph.D.

Robert A. DiTomasso, Ph.D., ABPP, Chair, Department of Psychology

Acknowledgements

This program development dissertation is dedicated to all people struggling with diabetes. The goal of this project is to show how the Internet and psychology can be used to create interactive disease management programs to boost patient education and self-confidence to fight chronic disease in order to improve quality of life. As Internet usage continues to grow, it will important to capitalize on this tool as a means of developing cost effective interventions for people suffering from chronic disease.

I would like to thank my chairperson, Dr. Steven Godin and my committee members Dr. Stuart Badner and Dr. Janet Snyder for their guidance and support of this project. I would like to thank all staff members and administrators at St. Clare's Healthcare System – Regional Diabetes Center for their help and support. I would like to thank my wife, Allison, and son, Robbie, for their support, strength, and patience. Without their support none of this would have been possible. Finally, I would like to thank the faculty and staff of the Psychology Department of the Philadelphia College of Osteopathic Medicine for providing me with quality doctoral training and supervision.

Abstract

Diabetes is a chronic illness that currently has no cure. Quality of life can be improved by the person's own adherence to treatment and motivation to manage their diabetes. Both of these factors are difficult to maintain and access to patient education materials is limited. This study developed an Internet-based disease management program for people with diabetes. This diabetes disease management program followed the PRECEDE health program planning model. Focus groups and key informant interviews with people with diabetes were run in order to obtain feedback for this program. Cognitive-behavioral and health behavior change theory were integrated into the program to increase self-efficacy and treatment adherence.

Table of Contents

Acknowledgments.....	i
Table of Contents.....	iii, iv
1. Chapter 1 Introduction.....	1
1.1 Scope of Diabetes and Practice Guidelines.....	3
a. Traditional Disease Management.....	3
1.2 Diabetes Defined.....	4
1.3 Cost Associated with Diabetes.....	5
1.4 Medical Complications Associated with Diabetes.....	6
1.5 Scope of Co-morbid Health Complications in Patients with Diabetes.....	7
1.6 Diabetes Disease Management.....	9
1.7 Application of Cognitive-behavioral and Other Behavior Theories to Diabetes Disease Management.....	13
1.8 Cognitive-behavioral and Behavior Change Theories.....	15
a. Social Cognitive Theory.....	15
b. Health Belief Model.....	19
c. The Transtheoretical Model.....	20
d. Theory of Reasoned Action.....	21
e. The Theory of Planned Behavior.....	22
f. Self-Determination Theory.....	25
g. Role of Health Psychologists in Disease Management.....	26
1.9 Empirically Validated Interventions in Internet-Based Disease Management.....	28
1.10 Examples of Internet-based Disease Management Programs.....	32
1.11 PRECEDE Planning Model.....	34
a. Phase 1 Social Diagnosis.....	35
b. Phase 2 Epidemiological Diagnosis.....	36
c. Phase 3 Behavioral & Environmental Diagnosis.....	37
d. Phase 4 Educational Diagnosis.....	38
e. Phase 5 Administrative & Policy Diagnosis.....	40
f. Focus Groups.....	40
1.12 Application of the PRECEDE Model.....	41
1.13 Learning Modules.....	43
1.14 Purpose.....	45
1.15 Rationale.....	48
2. Chapter 2 Methods.....	50
2.1 Participants.....	50
2.2 Procedure.....	51
a. Social Diagnosis.....	51
b. Epidemiological Diagnosis.....	51
c. Behavioral and Environmental Diagnosis.....	52
d. Administrative and Policy Diagnosis.....	52
e. Internet-based Disease Management.....	53

3. Chapter 3 Results.....	55
3.1 Focus Group Data.....	55
a. Qualitative Results from Focus Group 1.....	56
b. Qualitative Results from Focus Group 2.....	60
c. Qualitative Results from Key Informant Interview 1.....	63
d. Qualitative Results from Key Informant Interview 2.....	65
e. Qualitative Results from Key Informant Interview 3.....	67
f. Qualitative Results from Focus Group 3.....	70
3.2 Summary of Focus Group and Key Informant Qualitative Data.....	80
a. Themes of Focus Group and Key Informant Qualitative Data.....	81
3.3 Results from the MDRTC Diabetes Knowledge Test and Diabetes Self-Management Profile.....	86
3.4 Integrating Psychological Theory to Diabetes Disease Management.....	92
3.5 Learning Modules.....	97
a. Foot Care.....	98
b. Weight Management.....	103
c. Glucose Monitoring and Insulin Therapy (Oral Medication).....	111
d. Routine Physician Appointments-Patient as Member of Treatment Team.....	119
3.6 Proposed Program Evaluation Design.....	129
4. Chapter 4 Discussion.....	130
5. References.....	146
6. Appendixes.....	159
7. Abstract.....	ii

CHAPTER 1

Introduction

The field of behavioral medicine presents many opportunities for psychologists to help patients and their physicians manage chronic, potentially life-threatening, diseases like diabetes. In addition, relatively new technologies, such as the Internet, make it possible for health care providers to reach and engage individuals who otherwise might not make themselves available for such help.

This doctoral dissertation uses a methodology prescribed within a health care planning model in the development of an Internet-based diabetes disease management program linked to a hospital website. This program development project used the Saint Clare's Health System - Dover Regional Diabetes Center as a setting to develop an Internet-based disease management program for patients with diabetes, following the PRECEDE planning model.

PRECEDE is an acronym for Predisposing, Reinforcing, and Enabling Causes in Educational Diagnosis and Evaluation (Green, Kreuter, Deeds, & Partridge, 1980). This planning model helps to condense a large amount of information and organize findings on the cause and effect of health behaviors. The PRECEDE planning model is broken down into five phases: Phase 1 Social Diagnosis, Phase 2 Epidemiological Diagnosis, Phase 3 Behavioral & Environmental Diagnosis, Phase 4 Educational Diagnosis, Phase 5 Administrative & Policy Diagnosis (Green and Kreuter, 1991 & Green, Kreuter, Deeds, & Partridge, 1980).

The development of this diabetes disease management program followed each phase of the PRECEDE model. Information for the Social Diagnosis was obtained

through focus groups with people who have diabetes. Epidemiological Diagnosis data was accessed directly from the counties served by St. Clare's Health System and archival data previously collected by the St. Clare's Regional Diabetes Center Educational Program. Behavioral and Environmental Diagnosis and Educational Diagnosis data was obtained through the use of focus groups and surveys. Finally, the Administrative and Policy Diagnosis was obtained through discussions with the St. Clare's Health System Regional Diabetes Center staff and other hospital administrators.

The primary goal of this diabetes disease management program was to teach patients to better manage their diabetes through an interactive and individually tailored intervention within the Regional Diabetes Center website linked to the Saint Clare's Health System. Saint Clare's Health System is located in Dover, New Jersey, and has other sites in Boonton, Denville, and Sussex, New Jersey. Saint Clare's Health System – Dover is a 40-bed (30 Medical-Surgical, 6-Pulmonary Care, and 4-Intensive Care) "Level Three" trauma center. Saint Clare's Health System - Dover offers several services to the community including: breast cancer screenings, pediatrics, outpatient clinics, behavioral health and psychology services, emergency room services, rehabilitation, pulmonary services, and laboratory and dialysis services; and similar to other medical centers, St. Clare's provides educational materials for their patients. The Saint Clare's Health System provides several links to educational materials in the areas of cardiac care, cancer care, women's health issues, prenatal care, behavioral health services, child neurology and epilepsy, support groups, and weight management programs. Saint Clare's Health System – Dover also offers specialized services through their Regional Diabetes Center, Sleep Center, and Pain Management Center.

Scope of Diabetes and Practice Guidelines

According to the Centers for Disease Control and Prevention (2003), the number of diagnosed diabetes cases will increase by 165% between the year 2000 and 2050. The national cost to treat diabetes in the year 2050 is an estimated \$102 billion. In addition, there are approximately 100 million Americans that suffer from some type of chronic disease and more than \$650 billion is spent each year managing these diseases (Centers for Disease Control and Prevention, 2003). Because of the nature of chronic diseases, disease management varies over time, with treatments being adjusted to meet the needs of the patient's ever changing symptoms (Warsi, Wang, LaValley, Avorn, & Solomon, 2004). Therefore, there is a need for health care providers to develop a cost effective disease management programs to help reduce health care costs. According to Warsi, et al., (2004) strategies to reduce health care costs include: decreasing the number of physician appointments, reducing the number of emergency room visits and hospital stays, increase patient productivity (i.e. taking less sick time off from work), increasing the patient's health literacy, increasing treatment adherence, and increasing the patient's motivation toward treatment.

Traditional Disease Management. Traditional disease management strategies have included patient education, health care provider-patient communication, treatment planning, and follow-up evaluations. Traditional patient education is mainly conveyed through printed materials, brochures, booklets, and educational classes or seminars. According to the Saint Clare's Health System staff, newly diagnosed patients with diabetes attend a 12-week patient education program taught by certified diabetes educators and nurses in their Regional Diabetes Center. This existing, lecture style

program, covers several important subject areas including diet, exercise, glucose monitoring, medication and insulin administration, social support (i.e. spouse, significant other, family), treatment plan adherence, and physician-patient communication.

Traditional disease management programs include health care provider-patient interactions typically limited to office visits and telephone consultation. Treatment planning was done by the health care provider and patient that outlines the course of treatment as well as the health care provider's and patient's responsibilities. Follow up would then occur as a means of monitoring the patient's progress and adherence to treatment recommendations as well as to modify any areas of the treatment plan as needed. Traditional disease management programs are more health care provider driven leaving little room for patient collaboration.

Diabetes Defined

Diabetes Mellitus is a chronic illness characterized by the body's inability to produce or properly use insulin. There are three main types of diabetes mellitus; gestational, Type I, and Type II. Gestational diabetes occurs only during pregnancy whereas Type I (juvenile onset or insulin dependent) and Type II (adult onset or non-insulin dependent) are chronic. Type I diabetes accounts for 10% of cases while Type II diabetes accounts for 90% of cases (American Diabetes Association, 1997). Symptoms of Type I diabetes include frequent urination, increased appetite, weight loss, fatigue, decreased energy levels and lethargy, muscle cramps, irritability and emotional lability, vision changes, altered work or school performance, headaches, anxiety attacks, chest pain, breathing difficulty, stomach pain, nausea, and diarrhea or constipation, whereas symptoms of Type II diabetes include frequent urination, increased appetite, fatigue,

weight loss, weakness, and frequent infections (American Diabetes Association, 1997). As of 2002, approximately 6% of the population of the United States has diabetes and it is the seventh leading cause of death (American Journal of Preventative Medicine, 2002; Ciechanowski, Katon, Russo, and Walker, 2001 and Feifer and Tansman, 1999). There are approximately 21 million Americans with diabetes and 41 million Americans are at risk of becoming diabetic. Diabetes affects 6.2% of the US population and this percentage is rising quickly. Type II diabetes is the most common type of diabetes affecting Americans, representing 90-95% of those affected (Quinn, 2004). There are 150 million reported cases of diabetes worldwide and it is expected to jump to 300 million by 2025. The prevalence of diabetes increases with age as evidenced by approximately 20% of Americans over age 65 being affected (Quinn, 2004). There is an estimated 151,000 people below age 20 that are diagnosed with diabetes and one out of every 400 children is diagnosed with Type I or juvenile diabetes (Quinn, 2004). In the United States, the crude mortality incidence due to diabetes is over 140,000 (Nilasena and Lincoln, 1995). Due to the aging population, the Centers for Disease Control and Prevention (2003) estimated that the number of diagnosed diabetes cases will increase by 165% during the 2000-2050 time periods.

Cost Associated with Diabetes

The cost to treat diabetes and the loss of productivity due to diabetes is estimated at \$102 billion per year and on average, people with diabetes, missed 8.3 days of work per year (Ciechanowski, Katon, Russo, and Walker, 2001 and Feifer and Tansman, 1999). In 1997, the average cost of medical care for a person with diabetes was \$10,071 and 8% of the national health care expenditure was for diabetes care alone (CDC, 2003).

There are also several complications from diabetes such as blindness, kidney disease, heart disease, nerve disease, stroke, amputation (lower limbs and feet), and impotence (American Diabetes Association, 1997). In addition, approximately 74% of patients with diabetes have uncontrolled blood pressure, 71% have high cholesterol, and 54% have hemoglobin A1c levels over seven (Bodenheimer, 2003). Hemoglobin A1c is a blood test that shows the average level of sugar (glucose) in your blood over the last six to eight weeks. The chronic complications of diabetes result in multiple hospitalizations for critical care. Patients with diabetes are more prone to infections and take longer to heal. Therefore, patients with diabetes are in the hospital longer and require more time to recover from acute complications and illness compared to patients without diabetes (Funnell, 2004). These complications contribute to several other causes of death most notably heart disease and cerebrovascular disease. Diabetes also leads to other physical disabilities and premature death (Nilasena and Lincoln, 1995). The medical treatment for diabetes and its complications are extremely costly. Treating late diabetic complications costs over \$5 billion in hospital charges per year. These costs are predicted to rise as the baby boomer generation (people born between 1948 to 1963) ages, becomes obese, and are more likely to be diagnosed with diabetes. Diabetes in the baby boomer generation and the elderly is emerging as one of the most significant health care problems of the 21st century (Kesaveadev, Short, and Nair, 2003).

Medical Complications Associated with Diabetes

Obesity is the leading cause of diabetes among adults (American Diabetes Association, 1997). According to the ADA, the complications of diabetes can be divided into seven categories including macro vascular disease (coronary heart disease, peripheral

vascular disease, and stroke) with the majority of the complications coming from heart attacks and stroke. Nephropathy (chronic renal failure) is when the patient's kidneys and renal system are damaged and cease to function due to high levels of protein being lost through the patient's urine. Neuropathy or nerve damage in feet, legs, arms, and hands (peripheral and/or autonomic) is characterized by the patient's progressive loss of feeling in feet and legs, and progressively works up through the rest of the body. Retinopathy (severe vision loss or blindness) occurs in patients with severely uncontrolled glucose levels and in patients that have suffered from diabetes for a great number of years.

Vision loss and blindness is progressive. Foot disease (tissue infections requiring foot amputation) occurs secondary to the loss of feeling in the patient's toes and feet. Patients with diabetes are more susceptible to foot infections and gangrene that can lead to loss of function and amputation. Improper glycemic control (ketoacidosis-DKA and hypoglycemia) occurs when patients are not monitoring their blood glucose levels on a regular basis which can lead to extremely high or low blood glucose levels that cause the patient to lose protein through their urine causing the body's endocrine system to shut down. Hypertension or high blood pressure, and complications of pregnancy (congenital malformations and prenatal death) can also occur in patients whose diabetes may be poorly controlled (Nilasena and Lincoln, 1995).

Scope of Co-morbid Health Complications in Patients with Diabetes

The most common of these complications are end-stage renal disease, retinopathy, foot infections, and neuropathy. Diabetes has become the single most common cause of end-stage renal disease (ESRD) in the United States and Europe. End-stage renal disease is characterized by an abnormal level of protein in the urine referred to as

microalbuminuria. Patients with diabetes that develop nephropathy will likely develop ESRD within ten years of onset. Patients with diabetes and hypertension develop ESRD earlier than diabetics without hypertension (American Diabetes Association, 2003). End-stage renal disease although prevalent in both types occurs more often in Type I diabetes. In the United States, diabetic nephropathy accounts for approximately 40% of new cases of ESRD. The estimated cost of treating diabetics with ESRD is \$15.6 billion (American Diabetes Association, 2003). Screening for microalbuminuria (protein in the urine) is done through testing the patient's urine for the presence of protein (American Diabetes Association, 2003). Once microalbuminuria is diagnosed, patients will need to be tested two to three times a year. Treatments include improving blood glucose control and using oral medications such as Angiotensin Receptor Blockers (ARBs) and Angiotensin Converting Enzyme (ACE) inhibitors, classes of antihypertensive medication to decrease the rate of progression of the nephropathy (American Diabetes Association, 2003).

Diabetic retinopathy is the most common cause of newly reported cases of blindness among adults between 20 to 74 years of age. Retinopathy is common among both Type I and Type II diabetes, and the earlier the onset, the worse the prognosis (Fong, Aiello, Gardner, King, Blankenship, Cavallerano, Ferris, and Klein, 2003). In Type I diabetes, almost all patients develop signs of retinopathy within the first 20 years of onset. In Type II diabetes, about one third of patients have retinopathy at diagnosis, increasing to two-thirds within 20 years (Bate and Jerums, 2003). The current practice guidelines state that patients with diabetes should have annual vision exams and diabetics with retinopathy require more frequent vision exams based on the severity of the retinopathy (Fong, et. al., 2003). Treatments include improved blood glucose and blood

pressure control. Some patients can benefit from laser photocoagulation (laser surgery) to prevent and delay the progression of the retinopathy (Fong et. al., 2003).

Foot ulcers and amputations are a substantial cause of morbidity and disability as well as emotional and physical costs for patients with diabetes (American Diabetes Association, 2003). The risk of foot ulcers and amputations increases in patients who have had diabetes for more than ten years due to the increased rate of peripheral neuropathy and the loss of healing potential. Other risk factors for foot ulcers include being male, poor blood glucose control, cardiovascular disease, and retinal and renal problems (American Diabetes Association, 2003). The risk factors for lower limb amputation include peripheral neuropathy (loss of feeling or sensation), bone fractures, decreased blood flow to lower limbs and feet, previous ulcers, and nail infections (American Diabetes Association, 2003). The prevalence of lower limb complications is about 6.8% (Berardis, Pellegrini, Franciosi, Belfiglio, DiNardo, et. al., 2004). People with diabetes need to be informed of the importance of foot monitoring on a daily basis as well as proper foot care. Treatments include antibiotics to treat ulcers and medications to increase lower limb sensation (Parmet, Glass, and Glass, 2004; American Diabetes Association, 2003).

Diabetes Disease Management

Once a diagnosis of Type I, Type II, or gestational diabetes is established, appropriate dietary changes need to be made. These dietary changes include identifying a daily diet with the appropriate caloric intake based on the patient's body weight. Sugar and carbohydrate intake needs to be closely monitored. This diet should keep the patient's blood glucose levels in the normal range of 60-120mg/dl (Fauci, Braunwald,

Isselbacher, Wilson, Martin, Kasper, Hauser, and Longo, 1998). In order to maintain appropriate levels, the patient will need to check his/her blood glucose levels on a consistent basis, usually before and after meals or snacks. Blood glucose control is an important predictor of many chronic complications. Each 1% reduction in hemoglobin A1C over a 10 year period is associated with a 21% reduction in diabetes related deaths, a 14% reduction for heart attacks, and a 37% reduction in microvascular complications (Norris, Lau, Smith, Schmid, & Engelgau, 2002). The hemoglobin A1c test is used to check a patient's control of their blood glucose levels over a three month period. The recommended hemoglobin A1c level is seven or below which means that blood glucose levels are in good control on a daily basis.

Patients diagnosed with Type I diabetes are treated with insulin injections, diet, and exercise. As seen in Table 1, there are different types of insulin used to treat Type I diabetes such as; rapid-acting (Humalog), short-acting (Regular), Intermediate-acting (NPH), long-acting (Ultralente), and pre-mixed insulins (Humalog 75/25 and Humalog 50/50) (Inzucchi, 2001 and Fauci, et. al., 1998). A patient with diabetes may require rapid-acting insulin in situations where they need to quickly reduce a high blood glucose level. It should be taken 5 to 15 minutes prior or immediately before a meal. If this is not possible, an injection immediately following the meal can reduce blood glucose levels (Hess-Fischl, 2004). Short and intermediate-acting insulin should be taken 30 minutes prior to meals or snacks and long-acting insulin can be used once a day to help regulate blood glucose levels. Pre-mixed insulin contains either regular or rapid-acting insulin. With a 75/25 mix it should be taken 5 to 15 minutes prior to or immediately following a meal since 75% of the insulin is rapid-acting. With a 50/50 mix, it should be

taken 30 minutes prior to a meal since 50% is short-acting or regular insulin (Hess-Fischl, 2004).

Table 1

Insulin Action

Type of insulin	Onset	Peak	Duration	When to test BG
Short-acting	.5h	2.5-5h	6-8h	4h post inject
Rapid-acting	5-15min	1-1.5h	3-5h	2h post inject
Intermediate-acting	1.5h	4-10h	10-16h	8-10h post inject
Long-acting -UltraLente	2-4h	12h	16-20h	Post inject
-Glargine	2-3h	N/A	22-26h	Pre-meal
Premixed -70/30	.5h	2-12h	20-24h	4 & 8-10h post
-50/50	.5h	2/10h	20-24h	4 & 8-10h post
Pre-mixed rapid -70/30, 75/25	5-15min	2h	22-24h	2 & 8-10h post

A moderate intensity exercise regime four to six days a week for 30 to 60 minutes has proven to decrease the patient's insulin requirements, control blood glucose levels, and control weight. Patients should be careful when starting an exercise program and avoid exercise if blood glucose levels are above 250mg/dl, because exercising will increase this reading. Patients should wait until blood glucose level is around 100mg/dl. Carbohydrate consumption and blood glucose monitoring are keys to maintaining a proper exercise program (American Diabetes Association, 2004).

Patients diagnosed with Type II diabetes can be treated with oral medication (Diabinese or Glucotrol), diet, and exercise. These medications function to increase

insulin secretion from the pancreas (Luna and Feinglas, 2001 and Inzuccho, 2001). If these treatments fail, a patient with Type II diabetes can be treated with insulin injections (Inzucchi, 2001). Exercise is important to controlling Type II diabetes as well. Exercising 30 minutes most days of the week helps to control blood glucose levels, decrease weight, and can delay or prevent the onset of Type II diabetes in at risk patients (American Diabetes Association, 2004). The treatment of diabetes is constantly changing with the advent of oral medication (metformin and sulfonylurea), quicker and more accurate blood glucose monitors, insulin pumps, as well as other equipment and supplies that aid in lowering and stabilizing blood glucose (American Diabetes Association, 2004).

Patients diagnosed with gestational diabetes are typically treated with dietary measures. Patient's carbohydrate and protein intake are carefully monitored and patients test their blood glucose level prior to each meal or snack. If the patient continues to exhibit a higher than normal blood glucose level, even after dietary changes are made, oral medication or insulin therapy may be required in order to stabilize blood glucose levels. Once a patient gives birth, blood glucose levels should return to normal and the patient should no longer require blood glucose testing or insulin therapy. Unfortunately, about 30 percent of women that develop gestational diabetes are diagnosed with either Type I or Type II diabetes within five years following their pregnancy (American Diabetes Association, 2004).

The American Diabetes Association (2003) has proposed practice guidelines for the treatment of diabetes. These practice guidelines are considered to be the standard of care for the treatment of diabetes, and include self-monitoring of blood glucose levels,

frequent hemoglobin A1C testing (determines the patient's average blood glucose levels over the past 2-3 months), medical nutrition therapy (MNT), exercise, foot care, vision care, renal care, neurologic care, and vascular care (Nilasena and Lincoln, 1995). While adherence to these guidelines can reduce the complications of diabetes significantly (Nilasena and Lincoln, 1995), physician adherence to these guidelines has been low as the complexities of these guidelines have made it difficult to incorporate into clinical practice (Nilasena and Lincoln, 1995).

Application of Cognitive-behavioral and Other Behavior Theories to Diabetes Disease Management

This doctoral dissertation integrated Cognitive-behavioral and behavior change theories into the development of a disease management program for people with diabetes. The Cognitive-behavioral and behavior change theories integrated into the disease management program that address nonadherence to treatment regimen and behavior change are: 1) Social Cognitive Theory (self-efficacy), 2) the Health Belief Model, 3) Transtheoretical Model, 4) the Theory of Reasoned Action, 5) Theory of Planned Behavior, and 6) Self-Determination Theory. Research shows that patients with diabetes adhere to dietary recommendations 60% of the time, follow exercise recommendations 34% of the time, and follow foot care recommendations 47% of the time and only one-third of patients with Type II diabetes take their prescribed medication (Cradock, 2004). Buffler, England, and Fleming (2001) found nonadherence to be very costly and discussed diabetes management behaviors that need to increase to improve adherence including patient education, hemoglobin A1c levels, foot care, vision care, and glucose monitoring. By not changing these behaviors the death rate from diabetes and diabetes

related complications will increase (2001). Nonadherence has been widely studied by behavioral scientists to determine and understand its underlying causes (Nichols-English and Poirier, 2000).

Application of behavioral change theory to the development and adherence to new and more adaptive behaviors is influenced by several psychosocial variables including: health beliefs and attitudes regarding benefits from or barriers to desired behaviors, perception of “locus of control” is behavior change going to be more internal or external, emotional status, quality of life, satisfaction with treatment, role of significant others, and patient’s intention to change (Day, Coles, and Walford, 2003). Day, Coles, and Walford (2003) identified six steps for effective behavior change including include the patient, specify the problem, identify successes and failures, negotiate a specific goal, identify ways to achieve the goal, contracting, and tracking. Including the patient means making the patient feel that they are a part of the treatment team with the physicians, nurses, and other health care providers. Specify the problem means having a clear understanding of the problem behavior or health care issue. Identifying successes and failures helps to provide support and praise to the patient but also points out areas for improvement. By negotiating a specific goal, the patient and treatment team are working toward the same outcome. Identifying ways to achieve the goal means that short-term and long-term goals are established and steps are identified to work toward each goal. Contracting is obtaining the patient’s agreement on the goals and course of treatment, and tracking documenting the patient’s progress toward the treatment plan goals (Day, Coles, and Walford, 2003).

Cognitive-behavioral and Behavior Change Theories

Social Cognitive Theory. Bandura's (1986) Social Cognitive Theory postulates that two factors influence the likelihood that the person will take preventative action. First, similar to the health belief model and the theory of reasoned action, the person must believe in the benefits of performing the behavior compared to the consequences. Second, the person must have a sense of self-efficacy to perform a specific preventative behavior (Bandura, 1997 and Rhodes, Fishbein, and Reis, 1997). Self-efficacy is defined as the person's confidence level and ability to perform the behavior in question in the face of obstacles. This confidence and ability allows the patient to take effective action to protect their health and in turn will increase the likelihood that they will take such action (Bandura, 1997 and Freudenberg, et al., 1995). Self-efficacy was developed by Bandura as a by-product of his Social Learning Theory. Self-efficacy contributes to behavioral motivation in several ways including; shaping attitudes and goals, determining how much effort is needed to perform the behavior, and determining the outcomes expected from the patient's efforts (Senecal, Nouwen, and White, 2000). Self-efficacy has been adopted by health educators in order to increase patient adherence to treatment. The staple of Social Cognitive Theory is the concept of observational learning, where the person acquires cognitive and behavioral skills by observing others. Behaviors can be learned through actual observation in real time or through representations of behavior in words or pictures (Rhodes, Fishbein, and Reis, 1997 and Freudenberg, Eng, Flay, Parcel, Rogers, and Wallerstein, 1995).

Norris, Engelgau, and Narayan (2001) found that Social Learning Theory and self-efficacy play an important role in diabetes disease management. When diabetes

education was paired with Social Learning Theory, patients reported greater knowledge of diabetes, improved compliance, improved blood glucose control, and better dietary control as well as weight loss. Patients were instructed to improve their self-management of diabetes through behavior change strategies, didactic education, and positive reinforcement through communication with health care providers (Norris, Engelgau, and Narayan, 2001).

Von Korff, Gruman, Schaefer, Curry, and Wagner (1997) and Anderson (1990) found that teaching patients to co-manage their chronic disease through individualized patient education, positive reinforcement for adaptive health care behavior, increasing social support, goal-setting, and incorporating disease management strategies to the patient's lifestyle supported how Social Cognitive and Learning Theory can improve patient self-management of chronic disease. Wagner, Austin, and Von Korff (1996) and Mullen, Green, and Persinger (1985) found that patient's self-efficacy or confidence to manage their chronic disease increased as a result of integrating social cognitive and social learning concepts to disease management. Patients that received more personalized patient education, reinforcement, and feedback displayed greater levels of self-efficacy compared to patients in the control group that received basic patient education alone.

Bernal, Woolley, Schensul, and Dickinson (2000) and Chang and Lin (1997) found that patients with diabetes reported higher rates of self-efficacy when they attended diabetes education classes and received support from health care professionals (nurses, physicians, diabetes educators). Patients with diabetes reported feeling more confident in

the areas of insulin administration and diet. When these factors were not available to the patient, the rates of patient self-efficacy decreased.

Johnston-Brooks, Lewis, and Garg (2002) and Aljaseem, Peyrot, Wissow, and Rubin (2001) focused on specific diabetes self-care skills including exercise, diet, medication compliance, and blood glucose monitoring. They found that when patients with diabetes perceived barriers to these self-care skills their sense of self-efficacy decreased. They concluded that patients with diabetes with greater levels of self-efficacy were better able to attend to these self-care activities and were able to improve their overall hemoglobin A1C levels.

Kneckt, Syrjala, Laukkanen, and Knuutila (1999) applied the constructs of Social Learning Theory to levels of self-efficacy in patients with diabetes and oral hygiene. They found that patients with diabetes that had good dental self-efficacy also had greater diabetes treatment adherence. Patients with diabetes that visited their dentist on a regular basis showed an increase in diabetes treatment adherence as evidenced by improved hemoglobin A1C levels and positive diabetes self-care behaviors.

Corbett (1999) focused on patient education and judgment. This study found that patients with diabetes that attended diabetes education classes regularly and improved their judgment and decision-making ability reported greater levels of self confidence and self-efficacy in managing their diabetes. This study also found that diabetes education classes that included fewer lectures and more practical, interactive exercise that focus on diabetes self-care skills were more effective than lectures alone.

Po (2000) studied the use of telecommunication strategies as a means of providing patient education to increase patient self-efficacy. Po found that by altering the delivery

of diabetes patient education information, self-efficacy and self-management increased as a function of patients having greater access to information. This increased access to patient education information and greater self-efficacy helped to improve hemoglobin A1C levels.

Senecal, Nouwen, and White (2000) applied the constructs of Social Cognitive Theory and self-efficacy to the dietary needs of patients with diabetes. They found that patients with high self-efficacy adhered better to their dietary needs and that patients reported feelings of success and confidence due to their ability to adhere to their dietary regime. Patients reported improved problem-solving skills and coping skills as well as increased feelings of empowerment and improved quality of life.

Kohler, Fish, and Greene (2002) and Lox and Freehill (1999) applied the Social Cognitive Theory to Chronic Obstructive Pulmonary Disease (COPD) and COPD rehabilitation. Kohler, Fish, and Greene (2002) found that patients with COPD experienced a better quality of life when they exhibited strong self-efficacy, which allowed them to feel more capable in managing their COPD and also decreased physical impairment. In terms of COPD rehabilitation, Lox and Freehill (1999) found that patients with a high degree of self-efficacy exhibited greater adherence to their rehabilitation regimen.

Many of these interventions were effective and shared common characteristics. The interventions were short term (less than 6 months) and integrated Social Cognitive and Social Learning Theory with diabetes education. The effectiveness of these interventions included: improved blood glucose control, weight loss, decreased blood

pressure, decrease in cholesterol, increase in self-management skills, and an increase in patient self-efficacy (Norris, Engelgau, and Narayan, 2001).

Health Belief Model. The Health Belief Model was developed to explain why people engage in preventative behaviors. The model proposes that changes in beliefs about the severity and susceptibility to a health outcome and its consequences are associated with the motivation to take action (Rosenstock, 1974). The cognitive elements include the beliefs about the nature of the threat of illness in terms of its “perceived severity”, beliefs that specific actions have benefits in protecting against the threat of illness, and the beliefs about the barriers or costs associated with taking such an action (Rhodes, Fishbein, and Reis, 1997). Applying the Health Belief Model to an illness has displayed positive results. Where an illness was diagnosed and a treatment regimen was recommended, the patient’s perception of the threat of the illness represented by symptoms becomes the patient’s focus. It is the patient’s perception of threat of the illness and the physician’s recommendations that guide the patient’s decision-making process. The patient evaluates his/her options and takes preventative action that outweighs the perceived costs (Rhodes, Fishbein, and Reis, 1997).

Goldring, Taylor, Kemeny, and Anton (2002) applied the Health Belief Model to the quality of life and physician-patient relationship in patients with inflammatory bowel disease. They found no significant correlation between quality of life and patient’s perception of illness. Although they did find significant correlations between adherence to medication and patient’s motivation and intention to improve their health care behavior. The physician-patient relationship was found to be more productive and

stronger when patients felt there was a shared decision-making relationship with the physician (Goldring, Taylor, Kemeny, and Anton, 2002).

Skinner, Hampson, and Fife-Schaw (2002) applied the Health Belief Model to personality, personal model beliefs, and self-care in adolescents and young adults with Type I diabetes. They studied how young adults and adolescents perceived the seriousness of their diabetes as well as their intention and motivation to better manage their diabetes and to prevent complications. They hypothesized that patients with diabetes that exhibited emotional instability, low self-efficacy, and poor health care behavior would have greater difficulty managing their blood glucose levels, report more symptoms, and have a negative prognosis (Skinner, Hampson, and Fife-Schaw, 2002). They found that patients that exhibited a positive perception of treatment effectiveness had better blood glucose control, reported less symptoms, and were able to prevent complications. Patients that were experiencing emotional distress tended to be less involved in their treatment and had negative beliefs regarding perceived treatment benefit. This finding suggests that more conscientious patients tend to seek out more educational and treatment information that strengthens their beliefs that treatment will be effective compared to patients that respond poorly to the stress of diabetes (Skinner, Hampson, and Fife-Schaw, 2002).

The Transtheoretical Model. The Transtheoretical Model or Stages of Change Model was designed by Prochaska and DiClemente (1984) to provide a framework for understanding health-related behavior change. This model describes the five stages that patient's typically progress through when changing a behavior. The Stages of Change are as follows: precontemplation, contemplation, preparation (readiness), action, and

maintenance (Willey, Redding, Stafford, Garfield, Geletko, Flanigan, Melbourne, Mitty, and Caro, 2000; Rhodes, Fishbein, and Reis, 1997; and Prochaska and DiClemente, 1984). The precontemplation stage is defined as when the person has no intention to change their behavior or does not see a reason to change their behavior, due to denial or lack of awareness. Contemplation is characterized by a person's identification and short or long-term plan to change their behavior, but has not yet begun to change it. Preparation is characterized by the person's strong intention to change their maladaptive behavior. Action is characterized by the person's changing the maladaptive behavior to a positive one and is engaging in the new behavior. Maintenance is when the person continues to engage the new, more adaptive behavior to prevent relapse. (Willey, et. al., 2000; Rhodes, Fishbein, and Reis, 1997; and Prochaska and DiClemente, 1984). The Transtheoretical Model is a model of health behavior change; therefore, patients may progress, regress, or remain static with respect to their initial stage (Armitage, Sheeran, Conner, and Arden, 2004). The Stages of Change Model has been effective in the patients' adoption of positive health care behavior including smoking cessation, diet, exercise, participation in breast cancer screenings, self-management of diabetes, and glucose monitoring. The Stages of Change Model can be tailored to the patient's illness and current readiness to change (Armitage, Sheeran, Conner, and Arden, 2004; Willey et. al., 2000; and Prochaska and DiClemente, 1984).

Theory of Reasoned Action. The Theory of Reasoned Action states that all behaviors are based on the person's intention to perform the behavior. This means that immediate cause for any behavior is the person's intentions to engage in or refrain from that specific behavior (Ajzen and Fishbein, 1980 and Ajzen and Fishbein, 1975). The

decision to perform the behavior is determined by two factors; the person's attitude toward performing the behavior and the person's perception of the social or normative pressure exerted on the person to perform the behavior (Ajzen and Fishbein, 1980 and Ajzen and Fishbein, 1975). The person's attitude toward performing the behavior is driven by their beliefs about the benefits and consequences for performing the behavior (Rhodes, Fishbein, and Reis, 1997; Ajzen and Fishbein, 1980; and Ajzen and Fishbein, 1975). The person's perception of the social norms is based on set of beliefs concerning whether or not others will approve or disapprove of the behavior and how motivated the person is to comply with these social norms (Morrison, Golder, Keller, and Rogers-Gillmore, 2002; Ajzen and Fishbein, 1980; and Ajzen and Fishbein, 1975).

According to the Theory of Reasoned Action, there are four elements needed to perform a behavior: action, target, context, and time. Action is the actual behavior the patient displays consistent with their beliefs and perceptions. Target is what the behavior is focused on. Context is the situation or environment where the behavior is being performed and time is the frequency of the behavior. For example, testing blood glucose level prior to a meal, the action (testing), target (blood glucose level), context (prior to a meal), and time (always) are all identified by the person. The advantage of this model is that once a behavior is defined by these four elements it can be generalized to other contexts whereby making the behavior effective for several similar situations rather than only one (Rhodes, Fishbein, and Reis, 1997).

The Theory of Planned Behavior. The Theory of Planned Behavior is an extension of the Theory of Reasoned Action. The Theory of Planned Behavior integrates perceived behavioral control as a determinant of intention and behavior in addition to

attitude and social norms. Perceived behavioral control is defined as the person's perception of the ease or difficulty involved in performing a behavior. The Theory of Planned Behavior states that the belief that the person is able to perform the behavior is as important as the actual performance of the behavior (Ajzen, 1991 and Rhodes, Fishbein, and Reis, 1997). Individuals tend to perform a behavior when they evaluate it positively, believe that significant others think they should perform it, and perceive the behavior to be under their control (Ajzen 1991 and Sheeran, Conner, and Norman, 2001).

The Theory of Planned Behavior has been applied to several health behavior studies including; exercise, weight management, healthy eating habits, breast cancer, and coronary heart disease. No research has been conducted using the constructs of the Theory of Planned Behavior as it applies to diabetes management. It has been applied to other chronic health conditions similar to diabetes and this theory discusses how people perceive and modify their behavior to achieve a goal of treatment adherence.

Lowe, Bennett, Walker, Milne, and Bozionelos (2003) and Blanchard, Courneya, and Rodgers (2002) applied the Theory of Planned Behavior to the exercise intention of patients in cardiac rehabilitation. They found that perceived behavioral control played a key role in the patient's intention to adhere to an exercise regimen. Patients that exhibited stronger perceived behavioral control adhered better to the exercise protocol compared to patients with weak perceived behavioral control. The patient's level of perceived behavioral control influenced their intention to exercise. Courneya, Friedenrich, Arthur, and Bobick (1999) and Courneya (1995) also studied exercise motivation in colorectal cancer patients and exercise in the elderly population. Courneya, Friedenrich, Arthur, and Bobick (1999) found that patients with colorectal cancer with

strong perceived behavioral control and intent to exercise were more likely to adhere to an exercise program post-surgery. Courneya's (1995) results were similar to the findings of the colorectal cancer patients. Older adults were more likely to engage in exercise when they exhibited strong intent to exercise and strong perceived behavioral control.

Schifter and Ajzen (1985) applied the Theory of Planned Behavior to weight management. They found that the intention to lose weight was consistent with the person's perceived behavioral control over the weight loss goal. Individuals with strong weight loss intent and perceived behavioral control were more likely to attain their weight loss goals compared to individuals with weak intent and perceived behavioral control. Connor, Norman, and Bell (2002) applied this theory to healthy eating habits. They found that healthy eating intentions, behavior, and social support predicted the initiation and maintenance of healthy eating behavior over time.

Jones, Courneya, Fairey, and Mackey (2005) applied the Theory of Planned Behavior to breast cancer survivors and their ability to follow oncologist's treatment recommendations. They found that patients with strong perceived behavioral control and intentions to follow the oncologist's treatment recommendations were more compliant with these recommendations (i.e. exercise regimen) compared to patients with less motivation to engage in the recommended health care behavior. Johnston, Johnston, Pollard, Kinmonth, and Mant (2004) found that patients diagnosed with coronary heart disease exhibited a decrease risk behavior (i.e. smoking and poor fitness) when the patient's perceived behavioral control and intent were strong. They also found that perceived behavioral control alone and intent alone had no effect on risk behavior.

Self-Determination Theory. The Self-Determination Theory differentiates between autonomous and controlled behavior. Autonomous behavior is described as a true sense of choice based on the personal importance of the behavior. Controlled behavior is characterized by feeling pressured to act by either internal or external forces (Williams, Rodin, Ryan, Grelnick, and Deci, 1998). When the person makes an autonomous choice and receives support from significant others in their life, adherence is increased. This support spurs motivation and increased self-regulation that transfers to improved compliance to a complex treatment regimen (Williams, et. al., 1998). Quinn (2004) and Walker (1999) found adult patients with diabetes that had a strong significant other and/or other social support seemed to be more motivated to change their health care behavior. In addition, these patients participated in more self-directed learning that spurred more autonomous decision-making that improved patient's participation in their diabetes disease management (Quinn, 2004; Walker, 1999). Williams, Freedman, and Deci (1998) found that when patients with diabetes received support for their autonomous health behavior from health care providers that these patients exhibited an increase competence that led to improved adherence to medication regimen and blood glucose control.

Cognitive-behavioral and behavioral interventions integrated with patient education has helped to change patient health care behavior as well as to make the patient a more active member in their diabetes disease management. Cognitive-behavioral interventions have helped patients to develop coping skills, competence, and mastery for managing their diabetes (Grey and Barry, 2004). This improvement has been made possible by retraining patients to develop and replace their maladaptive health care

behavior and attitudes with more appropriate ones. This change in behavior and attitude has helped patients to better self-manage their diabetes (Grey and Barry, 2004).

Krichbaum, Aarestad, and Buethe (2003) found that by combining cognitive-behavioral and behavioral interventions with diabetes patient education that patients became more motivated to care for themselves, actively sought out additional information about diabetes, and adjusted their behavior to improve their lifestyle. These improvements increased patient self-efficacy and self-management. Finally, Steed, Cooke, and Newman (2003) found that patients with diabetes had co-morbid psychological problems including depression, anxiety, adjustment issues, and quality of life issues. Patients that participated in cognitive-behavioral and self-management patient education programs decreased their symptoms of depression and anxiety. Patients also experienced a decrease in adjustment issues and improved quality of life (Steed, Cooke, and Newman, 2003).

Role of Health Psychologists in Disease Management. Psychologists can have an active role in developing and implementing disease management programs by assessing the cognitive and behavioral changes made by the patient. Psychologists can also provide helpful advice and feedback and provide counseling and therapy to address the patient's mental health or emotional issues related to their disease state. The field of psychology is growing and changing as it enters the 21st century. Psychological interventions have become more readily available in health care settings and psychologists have an opportunity to stress the importance of their roles and functions in health care. Psychologists can not only contribute to mental health but also physical health through enhancing treatment outcomes, preventing stress-related disorders, reducing the

overutilization of limited medical interventions, and offering effective alternatives to traditional medical treatments (Groth-Marnat and Edkins, 1996). New Current Procedural Terminology (CPT) codes, psychologist prescription privileges, and mental health parity legislation have broadened the scope of psychological practice in primary care. Psychological interventions are being proven effective in treating common medical conditions and comorbidities with psychological disorders. Psychological interventions have been proven effective in treating patients with anxiety, chronic pain, cardiovascular disorders, smoking cessation, and increased adherence to medical regimens (Groth-Marant and Edkins, 1996).

Cox and Gonder-Fredrick (1992) found that psychologists can have an effective role in treating patients with diabetes. They found that patients with diabetes suffer from psychological stress secondary to poor adjustment to diagnosis of diabetes. Psychologists can positively impact patients by focusing on the psychosocial stressors and barriers to behavior change (Cox and Gonder-Fredrick, 1992). Psychologists can aid patients in self-treatment behaviors including weight management and blood glucose monitoring. Psychological assessment and interventions have been helpful in improving the patient's quality of life and physical well-being (Cox and Gonder-Fredrick, 1992).

Feifer and Tansman (1999) found that psychological interventions have been helpful in treating patients with diabetes by integrating assessment and therapy. They found that blood glucose control could be improved by increasing the patient's acceptance of their disease state, enabling behavior change for self-care, and removing barriers to disease control (Feifer and Tansman, 1999). The psychological interventions provided were geared toward acceptance of disease state, adjusting treatment to patient's

readiness, coping with medical regimen, and enhancing patient-doctor communication. These factors helped to improve blood glucose control and other self-management behaviors (Feifer and Tansman, 1999).

Gonder-Fredrick, Cox, and Ritterband (2002) discussed the need for psychology and primary care integration when working with patients with diabetes. Their study found that psychological and behavioral interventions helped to improve blood glucose control, quality of life, and adjustment to diagnosis of diabetes. The collaboration between psychologists and primary care providers needs to become an essential aspect of the patient's treatment. The patient will receive information about their disease state and then learn to better cope with their new lifestyle through psychological and behavioral interventions (Gonder-Fredrick, Cox, and Ritterband, 2002).

The provision of psychological services also offers a cost savings to the patient, physicians, and the health care system. Through open collaboration and consultation with physicians, psychologists can have a more active role in patient care and disease management.

Empirically Validated Interventions in Internet-Based Disease Management

New technology is beginning to be applied to disease management. Recently, hospitals and physician offices have begun to use computer and electronic mail (e-mail) technology to assist in making their record keeping and their offices running smoothly (Centers for Disease Control and Prevention, 2001). Most hospitals and physician's offices have converted to some form of electronic record keeping or electronic medical record. This not only saves time, but also space. Hospitals and physician's offices have also begun to notify patients via e-mail for appointment reminders, prescription

reminders, and to allow patients to consult with nurses and physicians (Centers for Disease Control and Prevention, 2001). These emails have started to replace traditional telephone notifications and reminders. The Internet is emerging as an important tool for people to access information at any time. The US Department of Commerce (2001) reported that in 1998 26% of the US population had Internet access either at home or at work. This percentage climbed to 60% in 2001. In 2000, the worldwide Internet usage was estimated to be approximately 400 million and rising rapidly (NUA, 2000). NUA, a national organization that studies Internet usage, reported that the Internet is used for a variety of reasons including e-mail (89%), chat rooms (21%), and to gather information (95%) (2000). When the Internet is accessed to gather information, users are primarily visiting health-related and preventive care websites. In 2000, 86% of adults used the Internet to access health information (Harris Interactive, 2000 and Pew Internet & American Life Project, 2000). The Robert Wood Johnson Foundation reported that in 2001 there were approximately 19,000 health-related websites indexed in a Yahoo search. The actual number of health-related websites is unknown (2001). The most commonly searched medical and mental health topics include allergies/sinus conditions, cancer, arthritis/rheumatism, hypertension, migraines, CVD/heart disease, bipolar disorder, depression, anxiety, and sleep disorders (Godin, Truschel, and Singh, 2005). By applying Internet technology to disease management it enables patients to have constant access to educational information and medical records. The Internet and email also improves health care provider-patient communication. This communication allows patients to have better access to health care providers on a more consistent basis. These

advances in technology can greatly improve the delivery and effectiveness of disease management programs throughout the health care field.

During the past five years physicians, hospitals, insurance companies, HMOs, and other health care organizations have been attempting to integrate Internet and e-mail technology to disease management. Internet-based disease management may not be effective for every patient or every disease state, but may be a valuable tool in patient education and for suitable patients and diseases; Internet-based disease management can be an extremely beneficial (Managed Care Week, 2000). As of June 2000, approximately one-half of the 160 traditional disease management organizations are developing Internet-based programs. There are also about ten new start-up companies focusing only on Internet-based disease management (Managed Care Week, 2000).

Traditional disease management companies spend approximately \$300-\$1000 per patient per year, while an Internet-based program may cost only around \$50 (Managed Care Week, 2000). Expected benefits of Internet-based disease management programs include the customization of clinical information, receipt of information, advice, and instructions tailored to a patient's disease state, improved physician-patient communication, patient empowerment, patient education, and increased patient monitoring (Joch, 2000 and Managed Care Week, 2000). Internet-based disease management programs can also be personalized to a patient's specific needs. By providing customized clinical information, patients are better able to access pertinent information for themselves rather than navigating through vast quantities of clinical information.

Several different healthcare organizations have set-up disease management programs online for a variety of diseases. For example, CorSolutions Medical, Inc. in Illinois has designed a program to manage heart disease (Joch, 2000). Lifemetrix, Inc. has developed a disease management program for cancer and Accordant of Greensboro, North Carolina is developing programs for cystic fibrosis, multiple sclerosis, and Parkinson's disease (Managed Care Week, 2000). Some insurance companies and HMOs are also working on disease management programs. Anthem Blue Cross Blue Shield of New Hampshire, PacifiCare Health Systems, Health Hero Network, Inc of California, Highmark Blue Cross Blue Shield of Illinois, and CIGNA Healthcare of Tennessee are working on developing disease management programs for diabetes and cardiac illness (Tufts Managed Care Institute, 2001). Other examples of disease management websites and patient education websites include www.lifemasters.com, www.aleve.com, www.cognimed.com, www.confer.com, www.doctorquality.com, www.healthhero.com, and www.renaldiseasemanagement.com (Joch, 2000 and O'Reilly, 1999). The First Consulting Group suggests four models of Internet-based disease management programs. These models are a self-directed program where the patient has no link to others involved in their care, a linked model where the patient is linked with others involved in their care, a model with physician and patient linkage and support, and a physician-focused and patient-focused model which provides decision support to disease management from the physician's practice site (Soltis, 2002).

Through the Internet, patients will be able to co-manage their own disease online with health care professionals through frequent communication, automated treatment reminders, and information sharing (Wilkins, 1999). Internet-based disease management

programs also help to increase the confidence and effectiveness of patients as they begin to feel more empowered as an active member of their treatment team. Funnell (2004) defines patient empowerment as helping people to discover and use their innate ability to gain mastery over their diabetes. Strategies that increase patient empowerment include: education on informed decision-making, assisting patients to weigh the costs and benefits of different treatment options, selecting behavioral goals, and providing information on the importance of the patient's role in their diabetes disease management (Funnell, 2004).

Examples of Internet-based Disease Management Programs

Ralston, Revere, Robins, and Goldberg (2004) designed a web-based diabetes support program following a chronic care model. The program consisted of patients having access from home to electronic medical records, secure communication between patients and health care providers, and interactive disease management tools. The program focused on four areas including self-management support, delivery system design, clinical information systems, and decision support (Ralston, et. al., 2004). This study found that patients felt a greater sense of security about their health and health care that promotes an improvement in health care behavior and a better quality of life for patients with diabetes (Ralston, et. al., 2004).

Kim and Ladenson (2002) conducted a literature review using a popular Internet search engine focusing on diabetes and found several web sites with direct links to basic information about diabetes. The American Diabetes Association's web site includes patient education information, information on diagnosis and treatment, and provides links to community resources for each state in the United States. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) web site provides information on

diagnosis, treatment, monitoring, complications, experimental treatments, and alternative therapies (Kim and Ladenson, 2002).

The Joslin Diabetes Center's web site offers information tailored to patients newly diagnosed with diabetes. The Diabetes Monitor web site provides general information about diabetes, types of diabetes, complications, coping strategies, medication, monitoring, and research. This web site also provides links to publications and lists personal web sites for additional patient education. The Diabetes Monitor includes a "Diabetes 123" section that has answered 8000 specific questions about diabetes that have been screened by their team of specialists (Kim and Ladenson, 2002).

Diabetes Portal: Diabetes Living web site offers basic information about diabetes, diabetes management, parenting and children, complications, coping, and new research information. The New York Online Access to Health Project's web site contains information on care and treatment of diabetes, complications and related concerns, and information resources (Kim and Ladenson, 2002).

The Diabetic Gourmet Magazine's web site provides information on food selection and preparation. The Canadian Diabetes Association's web site offers a full color booklet and Internet version that clearly illustrates how to draw, mix, and inject insulin. The Children with Diabetes web site focuses on insulin pump therapy and provides information for and against insulin infusion therapy. The National Eye Institute's web site provides specific information regarding diabetic retinopathy. The site provides patient education information, diagnosis, and treatment strategies (Kim and Ladenson, 2002).

The Diabetes Resource Center's web site includes specific patient education information regarding foot ulcers and lower limb amputation. This site focused on basic foot care and other prevention strategies as well as treatment. The Diabetes News web site focuses on maintaining an updated list of full-text patient education articles focusing on the treatment of diabetes and its complications (Kim and Ladenson, 2002). However, the current status of these diabetes disease management programs lacks an individually tailored approach to diabetes disease management. These programs are not theory-driven and are limited in their ability to enact and sustain true health behavior change on the part of the patient. By integrating psychological theory the proposed intervention will aid in increasing treatment adherence by increasing the patient's motivation to change their health care behavior.

PRECEDE Planning Model

The Internet and the World-Wide-Web are turning personal computers into virtual medical libraries. Patients as well as the general public now have access to a multitude of medical and health care information. The Internet is beginning to be used as a tool for patient education and disease management for a variety of diseases. The future of health care lies within the Internet. Soon patients will only need to turn on their televisions to have access to the Internet and eventually use the Internet to participate in physician appointments, submit blood work, and interact with their physician in real time through an Internet connection. Therefore, it is important to harness Internet technology and apply it to disease management. The purpose of this study is to develop a disease management program for patients with diabetes to determine if the Internet can be a viable medium for patient care.

The planning of this program development study followed the PRECEDE planning model. PRECEDE is an acronym for Predisposing, Reinforcing, and Enabling Causes in Educational Diagnosis and Evaluation (Green, Kreuter, Deeds, & Partridge, 1980). This planning model helps to condense a large amount of information and organize findings on the cause and effect of health behaviors. The PRECEDE planning model is broken down into five phases: Phase 1 Social Diagnosis, Phase 2 Epidemiological Diagnosis, Phase 3 Behavioral & Environmental Diagnosis, Phase 4 Educational Diagnosis, and Phase 5 Administrative & Policy Diagnosis (Green and Kreuter, 1991 & Green, Kreuter, Deeds, & Partridge, 1980).

Phase 1 Social Diagnosis

The focus of this phase is to identify and evaluate the social problems which impact the quality of life of a target population. This requires program planners to gain an understanding of the social problems which affects the quality of life of the patient or consumer as they perceive those problems. The next step is to establish a link between these problems and specific health issues which may become the focus of planned intervention. The link is essential in life and, in turn, how the quality of life affects social problems.

Methods used for social diagnosis may be one or more of the following: community forums, nominal groups, focus groups, surveys, and interviews. Community forums are a way to obtain public opinion regarding a topic by allowing anyone from the community to attend and participate. Typically the researcher presents the topic to the audience and the audience is then able to respond with questions or feedback. Community forums are similar to “Town Hall” meetings (Green, 1980). Nominal and

focus groups can also be used to obtain feedback and information from the target population. Nominal and focus groups are used to gain insight in to the perceptions, beliefs, and opinions of the target population (Goldman and Schmalz, 2001). Nominal and focus groups are designed to create a non-threatening environment for participants to speak freely and openly about the topic. Nominal and focus groups encourage the participants to express and defend their opinions (Goldman and Schmalz, 2001). Surveys and interviews function similar to forums and groups as a means of gathering information. Surveys are written materials given to participants that usually contain questions regarding the topic. Participants respond to these questions and return the surveys to the researcher. Interviews are face-to-face, one-to-one interactions between the participants and the researchers. In interviews the researcher will ask the participant specific questions regarding the topic and will take notes on the participant's responses and other feedback.

Phase 2 Epidemiological Diagnosis

The Epidemiological Diagnosis helps determine health issues associated with the quality of life. It helps identify behavioral and environmental factors related to the quality of life issues. The focus of this phase is to identify specific health problems and non-health factors which are associated with a poor quality of life. Describing these health problems can: 1) help establish relationships between health problems, other health conditions, and the quality of life; 2) lead to the setting of priorities which will guide the focus of program development and resources utilization; and 3) make possible the delineation of responsibilities between involved professionals and organizations and agencies. These priorities are defined as program objectives which define the target

population (WHO), the desired outcome (WHAT), and HOW MUCH benefit the target population should benefit, and by WHEN that benefit should occur. Examples of Epidemiological data include vital statistics, years of potential life loss, disability, prevalence, morbidity, incidence, and mortality. This data will be obtained by through accessing vital statistical information from www.census.gov, the New Jersey State Department of Health, and archival data from the St. Clare's Health System Regional Diabetes Center program.

Phase 3 Behavioral & Environmental Diagnosis

This phase focuses on the systematic identification of health practices and other factors which seem to be linked to health problems defined in Phase 2 above. This step includes non-behavioral causes (personal and environmental factors) that can contribute to health problems, but are not controlled by behavior. These could include genetic predisposition, age, gender, existing disease, climate, and workplace, the adequacy of health care facilities, etc. Also assessed are the behaviors which cause health problems in the target population. Another important component of this phase is the determination of the importance and relative changeability of each behavioral cause. It is critical that a behavioral diagnosis is completed for each health problem identified on Phase 2. This will allow all the planners to choose target behaviors which will become the focus of specific educational interventions.

Behavioral Diagnosis is the analysis of behavioral links to the goals or problems that are identified in the epidemiological or social diagnosis.

Environmental Diagnosis is a parallel analysis of factors in the social and physical environment other than specific actions that could be linked to behaviors.

Methods used for behavioral diagnosis may be one or more of the following: community forums, nominal groups, focus groups, surveys, and interviews. Community forums are a way to obtain public opinion regarding a topic by allowing anyone from the community to attend and participate. Typically the researcher presents the topic to the audience and the audience is then able to respond with questions or feedback. Community forums are similar to “Town Hall” meetings (Green, 1980). Nominal and focus groups can also be used to obtain feedback and information from the target population. Nominal and focus groups are used to gain insight in to the perceptions, beliefs, and opinions of the target population (Goldman and Schmalz, 2001). Nominal and focus groups are designed to create a non-threatening environment for participants to speak freely and openly about the topic. Nominal and focus groups encourage the participants to express and defend their opinions (Goldman and Schmalz, 2001). Surveys and interviews function similar to forums and groups as a means of gathering information. Surveys are written materials given to participants that usually contain questions regarding the topic. Participants respond to these questions and return the surveys to the researcher. Interviews are face-to-face, one-to-one interactions between the participants and the researchers. In interviews the researcher will ask the participant specific questions regarding the topic and will take notes on the participant’s responses and other feedback.

Phase 4 Educational Diagnosis

This phase assesses the causes of health behaviors that were identified in Phase 3. Three kinds of causes are identified - predisposing factors, enabling factors, and reinforcing factors.

The critical element of this phase is the selection of the factors which if modified, will be most likely to result in behavior change. This selection process includes identifying and sorting (positive and negative) these factors in appropriate categories, prioritizing factors among categories, and prioritizing with categories. Prioritization of factors is based on relative importance and changeability. Learning objectives are then developed which focus on these selected factors.

Educational diagnosis pinpoints the factors that must be changed to initiate and maintain behavioral change. It is during this phase that specific intervention objectives are created and the intervention itself will be implemented.

Educational and organizational diagnosis looks at the specifics that hinder or promote behaviors related to the health issue, such as predisposing factors, enabling characteristics, and reinforcers.

Predisposing factors are any characteristics of a person or population that motivates behavior prior to the occurrence of that behavior including the person's knowledge of their health problems, the person's beliefs and values can motivate the person to guide their health care behavior, and the person's attitude about their health condition can aid the person in their treatment.

Enablers are characteristics of the environment that facilitates action and any skill or resource required to attain specific behavior. For example, the person's accessibility to health care resources, the person's availability to work with their treatment team, the person's skills that they have learned in treating their disease, and local, state, and federal laws that allow the person to have access to appropriate medical treatment and patient education information.

Reinforcers are rewards or punishments following or anticipated as a consequence of a behavior. Reinforcers serve to strengthen the motivation for behavior. Family members, peers, and significant others play an important role in reinforcing the patient's health care behavior.

Methods used for obtaining educational diagnosis include community forums, nominal groups, focus groups, surveys, and interviews.

Phase 5 Administrative & Policy Diagnosis

This phase focuses on the administrative and organizational concerns which must be addressed prior to program implementation. This step includes the assessment of resources, budget development and allocation, development of an implementation timetable, organization or personnel within programs, and coordination of the program with all other departments, and institutional organizations and the community.

Administrative Diagnosis is the analysis of policies, resources and circumstances prevailing organizational situations that could hinder or facilitate the development of the health program.

Policy Diagnosis assesses the compatibility of your program goals and objectives with those of the organization and its administration; does it fit into the mission statements, rule and regulations.

Focus Groups. The PRECEDE program planning model proposes the use of focus groups in order to obtain feedback and information from the target population. A focus group is defined as an interactive strategy to gain insight in to the perceptions, beliefs, and opinions of representatives of the target population about specific issues, programs, or services through a 60 to 120 minute guided discussion facilitated by a

skilled investigator (Goldman and Schmalz, 2001). There have been a variety of focus group methodologies that have been used.

There are a number of reasons why program developers use focus groups in program planning. First, focus groups are designed to create a nonthreatening setting for the participants to speak freely about the topic. Second, focus groups stimulate participants to express and defend their opinions and encourage others with differing opinions to respond. Third, focus groups can foster consensus as well (Goldman and Schmalz, 2001). Fourth, focus groups have been more helpful than individual interviews at eliciting valuable information. At last, focus groups have been a valuable source for obtaining information in program development by eliciting broad and general information about the proposed programs as well as what impact the program may have on the target population (Goldman and Schmalz, 2001).

The steps involved in facilitating a focus group include participant recruitment, logistics coordination, survey or questionnaire development, facilitation by group leader, and recording and transcription of the discussion (Goldman and Schmalz, 2001). Focus groups typically include approximately eight to 15 participants. Recruitment is done about one to three weeks in advance of the actual group date. The group will last about 60-120 minutes. The facilitator will conduct the group by first discussing the purpose, then getting in to the specific questions prepared for the focus group topic. The focus group will be recorded and transcribed in order to obtain all feedback, opinions, and information provided by the participants (Goldman and Schmalz, 2001). Once all focus groups are concluded the information obtained will be integrated in to the development of the proposed program. The drawback to facilitating a focus group is that the exact

percentage of people who hold a particular belief or opinion about the topic is difficult to obtain, therefore, the results may not be able to be generalized to all people in the target population (Goldman and Schmalz, 2001).

Application of the PRECEDE Model

The PRECEDE planning model has been applied to several different disease management and prevention programs. The PRECEDE planning model has been applied to assessing or influencing the health promotion practices of other clinical health workers including; physicians, nurses, dentists, dieticians, physical therapists, pharmacists, and health care educators (Green and Kreuter, 2005). This planning model has been used to increase physician-patient communication by creating primary prevention programs that incorporate computer-generated appointment and prescription reminders. The PRECEDE model has been used in hospital settings when planning programs on how to increase physician compliance with best practice treatment guidelines (Green and Kreuter, 2005). This planning model has been applied to disease management and prevention programs including hypertension, obesity, arthritis, asthma, smoking cessation, heart disease, medication compliance, and patient education programs using mass media. By applying this planning model to disease management programs several factors are taken in to account including race, gender, age socioeconomic status, motivation and readiness to change, and attitudes toward health care behavior (Green and Kreuter, 2005).

This planning model was followed to construct patient education modules in the diabetes disease management website that will integrate the cognitive and behavior change theories to enact greater patient adherence to their diabetes management protocol.

This planning model can be applied to chronic disease management because of its multi-phasic approach to understanding and breaking down all facets of disease state. For example, Phase 1 would define the quality of life of patients with diabetes. Focusing on the patient's overall physical health, self-worth, confidence in managing their diabetes, quality of health care providers, and productivity (number of days missed at work due to complications of diabetes). Phase 2 would focus on ranking and prioritizing the health goals or concerns that impact their poor quality of life. These goals or concerns would include the complications of diabetes (end-stage renal disease, retinopathy, foot infections, and neuropathy). Once these health concerns are prioritized, the plan moves in to Phase 3 where the behavioral and environmental factors are assessed. Phase 3 will focus on the risk factors of diabetes and the complications. When these risk factors are defined then the plan will move to the next phase. Phase 4 focuses on the educational and ecological assessment. This assessment includes determining what patients know about how to manage their diabetes and their confidence level to manage it effectively on their own. Providing patient education and feedback from health care providers about patient's blood glucose monitoring, medication, routine physician appointments, and assessing for complications will help to reinforce the patient's efforts in managing their diabetes. Finally, in Phase 5, the program will need to assess the administrative and/or organizational roadblocks that may hinder the development of the disease management program. There may also be administrative and organizational support and resources that may be available to promote the disease management intervention.

Learning Modules

Four learning modules developed for the Diabetes Disease Management Program, include foot care, weight management, glucose monitoring and insulin therapy, and routine physician visits. Example topics for foot care may include daily exam of feet and general guidelines about what to look for, obtaining help from a spouse/friend/caregiver, daily care (cleansing, lotion, appropriate foot wear); educational information including risk factors, scope of foot problems, and treatment of foot complications. Example topics for the weight management module may include American Diabetes Association diet guidelines, carbohydrate counting/carbohydrate to insulin ratio, exercise regimen, food log. Example topics for the glucose monitoring and insulin therapy module may include daily glucose checks 4-8 times per day, chart glucose readings, carbohydrate to insulin ratio, injection sites (Upper arm, upper leg, stomach, buttocks), and/or oral medications for Type 2 diabetes. Educational information would include what to do when blood glucose readings are too high or too low and/or what type of insulin/oral medication should be used and how much to give. Example topics for the routine physician visits module may include scheduling quarterly visits with an endocrinologist, scheduling quarterly visits with an eye doctor, completing blood work prior to physician appointments (Hemoglobin A1C), and monitoring blood pressure routinely. The learning modules and suggested topics for each module were identified through reviewing the literature concerning medical complications associated with diabetes, treatment adherence, and health behavior change.

These learning modules are anchored in Cognitive-behavioral Theory and mirror Cognitive-behavioral interventions. Beck (1995) developed Cognitive-behavioral

interventions in the 1960s as a structured, short-term, and present-oriented treatment strategy for depression. Cognitive-behavioral interventions focus on modifying irrational thinking and problem-solving (1995). Cognitive-behavioral Theory proposes that irrational or dysfunctional thinking is common in most people and influences overall mood and behavior (1995). Beck states evaluating and modifying irrational thoughts can improve mood and behavior (1995). Cognitive-behavioral interventions include building a strong alliance between the patient and therapist, collaboration, problem identification, skills training, and homework. The therapist works to help the patient identify automatic thoughts, intermediate beliefs, and core beliefs (i.e., irrational thoughts or perceptions, and negative self statements) (1995). As these thoughts and beliefs are identified, the therapist works to help the patient to modify them in to more rational and positive thoughts whereby, helping the patient to cope with and change negative behavior and improve mood.

The learning modules integrate the aspects of Cognitive-behavior theory to aid in health behavior change. Cognitive-behavioral interventions aid in improving problem-solving and decision-making skills and provide feedback to patients (1995). Cognitive-behavioral treatment can also include role playing, relaxation skills training, and activity monitoring and activity scheduling (1995). Patients accessing the learning modules obtain assistance in problem-solving, decision-making, and receive feedback based on their responses. The learning modules construction focuses on modifying behavior, improving mood and motivation to increase treatment adherence and improving overall quality of life. Interactive, theory-driven modules provide more than just patient information. Patients will be able to access each module and navigate through

educational information and vignettes receiving feedback to their responses. Feedback aids in modifying irrational thoughts and learning new problem-solving and decision-making techniques that are essential in behavior change.

Purpose

This doctoral dissertation intends to supplement the Saint Clare's Health System website with a link to the "Diabetes Disease Management Program," which would then be accessed through an Internet connection with a User Identification name and password. The program includes patient education information (i.e. national standards for diabetes self-management), anecdotal vignettes regarding topics of treatment adherence, health behavior change, glucose monitoring, weight management, and foot care. This website has specific objectives including structured interventions to aid patients in managing their diabetes. These structured interventions help to increase adherence to their treatment regime by increasing diabetes health literacy through patient education. These interventions based on cognitive-behavioral and health behavior change theories, (i.e. the Theory of Planned Behavior, the Theory of Reasoned Action, the Transtheoretical Model, Self-Determination theory, and Social Cognitive theory) target changes in the patients' thoughts and behavior regarding their management of diabetes. The cognitive-behavioral and behavior change theories used to develop this disease management program for people with diabetes to help increase treatment adherence, facilitate cognitive and behavioral change, and to sustain preventative health behavior. This intervention integrates these theories in to a patient education and interactive program using the Internet. Patients have access to a personally tailored website in order to learn better ways to manage their diabetes by learning how to change their

health care behavior. Patients have access to patient education materials and interactive vignettes designed to teach and challenge the patient's knowledge of diabetes. This program will help to determine the patient's level of motivation and confidence to manage their diabetes effectively in order to improve adherence to treatment and increase their quality of life.

The Diabetes disease management program will include information adapted from the Project LEAP (Lower Extremity Amputation Prevention) manual (Birke and Rolfsen, 1998). The Lower Extremity Amputation Prevention (LEAP) Program was developed in 1992 at the Gillis W. Long Hansen's Disease Center. This program was developed to reduce the incidence of lower extremity amputation by educating patients and doctors about how to screen for loss of protective sensation in the feet of patients with diabetes as well as to educate patients on proper foot care and hygiene. The LEAP program screens for foot sensation loss by using a monofilament to test foot sensitivity. Birke and Rolfsen (1998) published a study in *Diabetes Care* that found diabetes patients who participated in the LEAP program had reduced the incidence of sensation loss and amputation. The LEAP program is currently run by the Bureau of Primary Health Care in Bethesda, MD and continues to educate patients and physicians through national, state, and local collaboration.

The Internet-based diabetes disease management program provides patient education information to increase health care literacy. Through an Internet-based diabetes disease management program the patient can access educational information regarding: monitoring blood glucose levels, advice on medication dosing, and insulin administration (Funnell, 2004). Patient education will not be limited to the patient. The

patient's family members and support system will be involved as well. Family members and others that are assisting in the patient's care can access information regarding diabetes self-management along with other information about diabetes that will help family members to understand what the patient's needs are and to ensure these needs are being met (Funnell, 2004). Patients will have instant access to specific patient education materials linked to the disease management site. Rothman, et. al. (2004) found that a comprehensive diabetes disease management program benefited patients with low health care literacy. Low health care literacy is defined as patients having poor knowledge of their disease and how to manage it. By providing patient education information, patients with low literacy were able to improve their knowledge base about blood glucose monitoring, weight management, and blood pressure through consistent access to educational information and communication with health care providers (Rothman, et. al., 2004).

Physicians and patients will be better able to monitor the disease state as well as to communicate more effectively with each other in order to maintain a more goal-oriented approach to disease management. Anticipated limitations might be a decrease in physician-patient communication, difficulty accessing a disease management website, and disease management websites may be inappropriate for patients with severe and uncontrollable illnesses (Joch, 2000 and Managed Care Week, 2000).

Rationale

This doctoral dissertation adhered to the PRECEDE planning model to develop this Internet-based diabetes disease management program. The Social Diagnosis proposed the patient's quality of life can be obtained through focus groups and key

informant interviews with patients with diabetes as well as staff members from the Regional Diabetes Center at St. Clare's Health System. The focus groups concentrated on the feasibility of an Internet-based disease management program as well as obtaining the patients' perception of their diabetes and quality of life.

The Epidemiological Diagnosis proposed that diabetes and the complications of diabetes result in a poor quality of life for these patients. These complications and poor quality of life factors will be prioritized by ranking the importance and severity. Also, epidemiological data was compiled from the New Jersey State Department of Health. This data includes rates of disability, morbidity and mortality of diabetes in three counties that St. Clare's Health System serves (Morris, Sussex, and Warren).

The Behavioral and Environmental Diagnosis proposed that both patient behavior and genetics play key roles in the diagnosis and treatment of diabetes. These behavioral and genetic factors were obtained through interviews with patients and staff members at the St. Clare's Health System Regional Diabetes Center.

The Educational Diagnosis proposed that there are three factors that influence health care behavior. These factors are predisposing, enabling, and reinforcing. More specific instances of these factors were obtained through focus groups, key informant interviews, and surveys of the patients and staff members at the St. Clare's Health System Regional Diabetes Center.

The Administrative and Policy Diagnosis proposed that staff members and administrators of the Regional Diabetes Center were consulted in order to obtain information on any hospital policies or procedures that may hinder the development of

the proposed Internet-based diabetes disease management program using the St. Clare's Health System web site.

This doctoral dissertation developed an Internet-based disease management program that replicates key elements of other nationally accredited and funded Internet-based programs that have been empirically validated. Once developed, evaluation research methodologies could be used to determine the effectiveness of this proposed disease management program and its interventions.

CHAPTER 2

Methods

Participants

Twenty participants were selected from current members of the St. Clare's Health System Regional Diabetes Center Education Program. Participants were recruited by word of mouth, by the Regional Diabetes Center staff to participate in two focus groups and three key informant interviews held at the St. Clare's Health System Regional Diabetes Center. Participants also completed the MDRTC Diabetes Knowledge Test and Diabetes Self-Management Profile upon entering the Regional Diabetes Center Education Program. These surveys functioned as a needs assessment to determine the participant's knowledge of diabetes and diabetes treatment. In addition, twenty-five of the MDRTC Diabetes Knowledge Test and twenty-four of the Diabetes Self-Management Profile surveys were used in this need assessment to determine the participant's level of knowledge of diabetes. This archival information was collected by copying these completed surveys.

Six questions were formulated to facilitate the focus group. The questions were geared toward obtaining the participants' opinions regarding the feasibility of conducting patient education and diabetes disease management over the Internet as well as to determine the level of diabetes health care literacy among the participants. (See Table 2 in Appendix). The PRECEDE program planning model was used to help develop the six focus group questions. Questions were formulated using each phase of PRECEDE. The first two focus group questions were formulated from the Social Diagnosis and Epidemiological phases that focus on quality of life. Question three was formulated from

the Behavioral and Environmental Diagnosis phase that focused on patient behavior. The fourth and fifth questions were formulated from the Educational Diagnosis phase that focuses on factors that influence health care behavior. The sixth question was formulated from the treatment adherence and theoretical literature reviewed that focuses on confidence and knowledge levels and how these levels influence patient behavior and decision-making.

Procedure

The PRECEDE planning model was followed to obtain data for each step of the model (Social, Epidemiological, Behavioral/Environmental, Educational, and Administrative and Policy).

Social Diagnosis. The Social Diagnosis data was obtained through conducting a focus group(s)/key informant interviews. The focus group(s) and key informant interviews consisted of current and former patients that participated in the St. Clare's Health System Regional Diabetes Center Education Program. Participants were asked six questions from a questionnaire developed for this study. The data obtained focused on the participant's quality of life, health care and Internet literacy, the feasibility of developing a diabetes disease management program for the Internet, and to assess the benefits and risks of such a program. The focus groups and key informant interviews were facilitated by the primary investigator.

Epidemiological Diagnosis. The Epidemiological Diagnosis data was obtained through accessing vital statistical information from www.census.gov, the New Jersey State Department of Health, and archival data from the St. Clare's Health System Regional Diabetes Center. The data included rates of disability, morbidity, mortality,

prevalence, incidences, poverty levels, socioeconomic status, quality of life, years of potential life loss, and the age and gender of patients with diabetes in the counties that St. Clare's Health System serves (Morris, Sussex, and Warren).

Behavioral and Environmental Diagnosis. The Behavioral and Environmental Diagnosis and the Educational Diagnosis data were obtained from the participants in the focus groups and key informant interviews conducted at the St. Clare's Health System Regional Diabetes Center using the questions in Table 2. This data included the participants' opinions regarding the feasibility of conducting a diabetes disease management program on the Internet, determining the participants' level of health care literacy, determining the predisposing, enabling and reinforcing factors of their health care behavior, and determining the participants' own confidence levels to co-manage their diabetes with the physicians and other health care providers.

Administrative and Policy Diagnosis. The Administrative and Policy Diagnosis data was obtained through interviews conducted with the administration of St. Clare's Health System to determine the hospital's organizational readiness to implement an Internet-based diabetes disease management program to its patients. A business plan may need to be developed in order to assess the financial risks and benefits for establishing and maintaining this program. The St. Clare's Health System Information Technology department was consulted to discuss implementation and maintaining this program on the hospital's home web site.

Other archival data previously collected by St. Clare's Health System Regional Diabetes Center staff pertaining to the participant's level of diabetes knowledge was reviewed. These surveys include the MDRTC Diabetes Knowledge Test and Diabetes

Self-Management Profile (Harris, et. al., 2000 and Fitzgerald, et. al., 1998). Admission into the diabetes educational program includes patients being asked to complete surveys including the MDRTC Diabetes Knowledge Test and the Diabetes Self-Management Profile. The MDRTC Diabetes Knowledge Test is a 23-item survey geared toward determining the patient's overall knowledge of diabetes. Studies using this survey indicated that scores increased as the number of years of formal education increased, and those who attended diabetes education classes scored higher than those who had not (Fitzgerald, et. al., 1998). The Diabetes Self-Management Profile is a survey that can be used as a semi-structured interview. This survey includes sections that focus on exercise, hypoglycemia, diet, blood glucose testing, and insulin. The Diabetes Self-Management Profile is a 23-item survey that focuses on treatment adherence over five variables (exercise, hypoglycemia, diet, glucose testing, and insulin). Each variable had between three to nine questions each. The participant's responses had a score correlated with it and the scores were added together to obtain a total score for each variable. The total scores from each variable were added to obtain a total score for overall adherence. The higher score correlated to better treatment adherence whereas the lower scores meant less adherence. The purpose of this survey was to obtain the patient's overall self-management ability and adherence to treatment regimen (Harris, et. al., 2000).

Internet-based Disease Management. This diabetes disease management program integrates the information and feedback from the focus groups as well as survey and intake data obtained through the St. Clare's Health System Regional Diabetes Center educational program. This information was integrated with the cognitive-behavioral and behavior change theories in the development of the learning modules. Once

implemented, the diabetes disease management program can be accessed through the St. Clare's Health System homepage at www.saintclares.org. A link to the diabetes disease management program will be created. When a patient clicks on this link they will be asked to enter a user name and password. If this is the patient's first visit to the program (s)he will be asked to create a user profile including background and demographic information (i.e. name, address, telephone number, e-mail address, number of years with diabetes, what type of diabetes, name of treating physician, etc). Once the profile is created the patient will enter their username and password. This allows the program to be individually tailored to each patient. When a patient accesses the program it will greet them and ask questions regarding last blood glucose reading and what they ate at their last meal or snack. If the patient enters a higher or lower than normal blood glucose reading the program will prompt the patient to either inject insulin to decrease their blood glucose or to have a snack to increase a lower than normal reading. Patients can then navigate through the modules within the program. Each module includes patient education information and interactive vignettes that were developed by integrating Cognitive-behavioral and other behavior change theories with the feedback obtained from the focus groups and key informant interviews. Information regarding the barriers and reinforcers to their health care behavior, quality of life, and patient's self-confidence and self-efficacy to manage their diabetes effectively has been integrated in to each module. This information aids the patient in becoming an active member of the treatment team as well as adhering to medical regime.

The web-site contains four learning modules, as mentioned earlier, covering several topics under each module including foot care, weight management, glucose monitoring and insulin therapy, and routine physician visits.

CHAPTER 3

Results

This program development dissertation focused on the need for development of an Internet-based disease management program for people with diabetes. The following data shows that patient education; patient knowledge of diabetes, and treatment adherence needed improvement. In order to develop this disease management program, patients from the St. Clare's Healthcare System Regional Diabetes Center provided input by participating in focus groups, key informant interviews, and completing two surveys (MDRTC Diabetes Knowledge Test and Diabetes Self-Management Profile). See Tables 3 and 4 in appendix for sample surveys. The information and data gathered from these qualitative and quantitative methods provided the necessary data in order to tailor the educational content areas, and health behavior change strategies proposed for the diabetes disease management website.

Focus Group Data

Focus groups were facilitated over the telephone with volunteers from the St. Clare's Healthcare System Regional Diabetes Center educational classes. Participants were asked six questions (See Table 2 in Appendix) and their responses and feedback were written down by the facilitator. The total number of focus group participants/key informant interviews was 20 and the total number of focus groups facilitated was three and key informant interviews were three. Fourteen participants participated in the focus groups and six participants participated in the key informant interviews. Focus group 1 was facilitated on 9/19/05 from 9:45 to 10:30 am Eastern time, focus group 2 was facilitated on 9/21/05 from 1:30 to 2:15 pm Eastern time, key informant interview 1 was

facilitated on 9/28/05 from 1:30 to 2:00 pm Eastern time, key informant interview 2 was facilitated on 10/17/05 from 9:30 to 10:00 am Eastern time, key informant interview 3 was facilitated on 10/19/05 from 4:45 pm to 5:00 pm Eastern time, focus group 3 was facilitated on 11/04/05 from 12:00 pm to 2:00 pm Eastern time. The following is the narrative from each focus group and key informant interview.

Qualitative Results from Focus Group 1

Question 1. In managing your diabetes to stay as healthy as you can, how has this impacted your “quality of life” in either a positive or negative way?

Participant 1. “Not so negative. My father, mother, brother, and sister have diabetes. I have a positive attitude. But it has been hard. Most of my family still lives in Trinidad. I have neuropathy and I’m in pain.”

Participant 2. “I’ve been in denial for a long time. My mother and husband both had diabetes and they have both passed away. It’s been hard without them. I have Type II and I cannot believe it. I’m depressed and I want to be left alone. I take Effexor for my depression. I have high blood pressure as well. The golden years have turned rusty. I also have arthritis and fibromyalgia.”

Participant 3. “I would say negative. I have neuropathy and I’m in a lot of pain. I’m also depressed like participant number two, but I’m angry on top of that.”

Question 2. What are some behaviors or attitudes you will need to change in order to have a fulfilling life with diabetes?

Participant 1. “I need to lose weight and have better eating habits, especially at night. I need to get more active. I want to be totally off of these Type II medications.”

Participant 2. “Eating habits, I go without breakfast most days and I sleep a lot. I need to exercise. I’m late to appointments because I’m sleeping late. I also have problems with my testing materials; you know using the meter and the strips.”

Participant 3. “I have a poor or bad attitude. I’m in therapy right now for domestic violence and I’m a recovering alcoholic. I’m pissed off and I blame myself for everything. Everyone is always yelling at me. I need to eat better and right now I’m struggling to learn all I can about my diabetes.”

Question 3. What are some barriers (weaknesses or limitations) that may hinder your ability to manage your diabetes effectively? (i.e., money problems or limited social support)

Participant 1. “I have an ok social support from my daughter, but I would like to have more money for all of the supplies.”

Participant 2. “Doctors and physicians seem to generalize and don’t give much individual attention. I feel that my doctor and most doctors aren’t very empathic. I think if I felt that they were more empathic and treating me like a person I’d do better. I also need to learn how to cook better for myself and learn to buy proper food.”

Participant 3. “I’m tired of defending myself to my daughter. I have a limited social support in my life and I’m exhausted. I’m on pain meds and I have some vision problems. Money is a problem and I worry about the cost of the supplies, medication, and medical care. I think therapy with a psychiatrist would be helpful for me to learn to accept having diabetes.”

Question 4. What are some reinforcing factors (strengths or assets) that may help you in managing your diabetes effectively? (i.e., social and family support)

Participant 1. “My daughter is supportive. I work here at St. Clare’s and this helps me because I always feel supported. The diabetes center staff and the other participants support me. The diabetes classes are helpful to learn about diabetes and learning about what questions to ask my doctor and to learn and understand my blood test results and labs. I have my grandchildren that support me too, they keep me going.”

Participant 2. “I’m fortunate to be in the diabetes center program. They are knowledgeable and patient. The staff is very supportive. It’s good to know that I’m not alone in this. I have support from the staff even after my four weeks here is done.”

Participant 3. “I go to AA meetings. I come here for the diabetes education classes. I think the staff here is supportive and my family doctor is very supportive. My daughter has been supportive and has given me a lot of encouragement.”

Question 5. What are the contributing factors (positive or negative) that will affect your management of diabetes?

Participant 1. “For the positive I would say the classes here because I’m learning how to test my blood sugar. I’m learning about meal plans and I’m just learning more about my diabetes. On the negative side I think it is going to take me a lot of time to learn all of these things.”

Participant 2. “Positives for me would be coming here because I’m getting up to date information in these classes and the staff are helping me to understand it. But I don’t see any real standard for this information and there is so much of it. My doctors have been a problem because, like I said before, they generalize things too much. Some other negatives for me would be my forgetfulness, fear, and trust in my doctors.”

Participant 3. “A positive for me is my daughter and my friends. They provide me with a lot of encouragement. But I think getting misinformation, my lack of education, misleading TV and media advertisements, and cost of everything are the negatives for me. I’m on Medicaid, I have high co-pays for my supplies and prescriptions, and the cost of buying the right food for my diet is going to be a problem for me.”

Question 6. Overall, how would you rate your current knowledge about diabetes and your current confidence level in your ability to manage your diabetes?

Participant 1. “For knowledge I think I’m about halfway there and I have high confidence in my ability to handle my diabetes.”

Participant 2. “My knowledge is excellent and my confidence level is high as well.”

Participant 3. “My knowledge level is ok and I’m confident that I can hold my own. I’m scared and I need to commit to beating my diabetes.”

Qualitative Results from Focus Group 2

Question 1. In managing your diabetes to stay as healthy as you can, how has this impacted your “quality of life” in either a positive or negative way?

Participant 4. “Positive, it made me take action and to pay attention to losing weight.”

Participant 5. “Positive, I now have some answers to the symptoms I’ve been having and my weight loss.”

Participant 6. “Positive, I’m focusing on things that will help me in the future. I’m exercising more over the past six months and I’m focusing more on food choices.”

Question 2. What are some behaviors or attitudes you will need to change in order to have a fulfilling life with diabetes?

Participant 4. “Being more consistent with exercise. I think about it but I don’t do it as much as I should. I need to take more time for myself. Recognize my symptoms and feelings and make myself a higher priority.”

Participant 5. “I’m a single mom and having diabetes is a lifestyle change for me. I need to cook better for me and my family and exercise more.”

Participant 6. “I don’t feel like I need to change a whole lot. Portion control at meals. Food is the focus in my family; I’m Italian so food is a big thing.”

Question 3. What are some barriers (weaknesses or limitations) that may hinder your ability to manage your diabetes effectively? (i.e., money problems or limited social support)

Participant 4. “Mostly my attitude about dieting and changing my life. I’m a stress eater. I eat fast food a lot and need to eat on the run. I feel down about having diabetes and I’m feeling sorry for myself. I need a better attitude toward diet and exercise.”

Participant 5. “Stress management! I’m a single mom, I’m working and I eat a lot of fast food. I need to make better food decisions and not skip meals like I was doing before.”

Participant 6. “Myself, just doing what I know I need to do. Putting what I’ve learned in to action.”

Question 4. What are some reinforcing factors (strengths or assets) that may help you in managing your diabetes effectively? (i.e., social and family support)

Participant 4. “Diabetes classes, my husband is supportive, and the Internet, diabetes.org. My family doctor is supportive. I have supportive friends and good social support.”

Participant 5. “Diabetes classes, social support at home and work. There are some co-workers that have diabetes and we help each other.”

Participant 6. “Family support from my wife and adult children. My career is less stressful and I have less everyday stress. I’m gathering as much information as possible.”

Question 5. What are the contributing factors (positive or negative) that will affect your management of diabetes?

Participant 4. “The positives for me are my desire to be healthy, weight loss, and exercise. The negatives are stress from work, home, school, and family and my attitude toward having diabetes.”

Participant 5. “Positive is that I’m exercising more and I joined a gym. The negative for me is making multiple food choices, food decisions.”

Participant 6. “Positives are having an active lifestyle, my attitude, and learning about diabetes. Negatives would be just portion control at meals.”

Question 6. Overall, how would you rate your current knowledge about diabetes and your current confidence level in your ability to manage your diabetes?

Participant 4. “My knowledge is 5 out of 10. I need to know more and understand more especially the psychological aspects of diabetes. I’ve been on meds now for five weeks and I was diagnosed in August of 2005. My confidence level is a five to six out of 10.”

Participant 5. “My knowledge is five to six out of 10. I’ve had diabetes for seven years and I’m still finding new and different information and some of the blood glucose guidelines are changing. I would say that I’m pretty confident in managing my diabetes.”

Participant 6. “Knowledge, I’m fairly knowledgeable already, I’ve learned a lot in the diabetes classes. I like to keep it simple. I feel very confident in my ability to manage my diabetes.”

Qualitative Results from Key Informant Interview 1

Question 1. In managing your diabetes to stay as healthy as you can, how has this impacted your “quality of life” in either a positive or negative way?

Participant 7. “In a positive way because I exercise more now. I watch my diet and I take Glucophage.”

Participant 8. “Neither, I just have to do it. If anything it is negative because I have to do it.”

Question 2. What are some behaviors or attitudes you will need to change in order to have a fulfilling life with diabetes?

Participant 7. “Hard, because I over-eat. I’m setting my mind to eat right. Self-control has been a problem and I need to be tougher on myself.”

Participant 8. “More structured, my life is very unstructured. Regiment my life and decrease my stress. Some times I skip lunch. Most times I skip lunch. So I need to get up at a more consistent time in the morning.”

Question 3. What are some barriers (weaknesses or limitations) that may hinder your ability to manage your diabetes effectively? (i.e., money problems or limited social support)

Participant 7. “My home environment. I’m retired and my husband always would bring me sweets. I’m trying to get my household on the same page.”

Participant 8. “The time factor. I could have everything planned and it could all change in a minute. I have a lot of people that depend on me and it is hard to plan things because it could change quickly. I care for my 83 year old mother and my daughter is living at home with me and her two kids.”

Question 4. What are some reinforcing factors (strengths or assets) that may help you in managing your diabetes effectively? (i.e., social and family support)

Participant 7. “I have a treadmill in the house. I do yoga and “Better Bones” exercise and I’ve been meeting new people. I listen to music and I take more time to get things right.”

Participant 8. “I don’t get depressed, I’m motivated. I have some good support from others especially my family at home. I adjust well and I take things in stride. I’m a problem-solver.”

Question 5. What are the contributing factors (positive or negative) that will affect your management of diabetes?

Participant 7. “Positives are attending support groups, watching TV shows about diabetics. Negative things would be having sweets at home and stress at home from family.”

Participant 8. “The positives would be that I have good follow through, money is not an issue, my support system is flexible, and I go with the flow. The negatives are my lack of schedule at home because things are constantly changing.”

Question 6. Overall, how would you rate your current knowledge about diabetes and your current confidence level in your ability to manage your diabetes?

Participant 7. “I’m about 90% knowledgeable, knowledge is power. I’m about 85% confident in managing my diabetes.”

Participant 8. “Knowledge, not good. I was diagnosed about one month ago. I understand the food part, but I really don’t understand the medication part. I don’t like taking that much medication. I’m 70% confident, but I try 100%.”

Qualitative Results from Key Informant Interview 2

Question 1. In managing your diabetes to stay as healthy as you can, how has this impacted your “quality of life” in either a positive or negative way?

Participant 9. “Neither it’s the testing that has changed things. Well I guess positive because I’m eating better.”

Participant 10. “Positive because I’m more active now. I cut down on portion size and have learned to balance my meals.”

Question 2. What are some behaviors or attitudes you will need to change in order to have a fulfilling life with diabetes?

Participant 9. “Exercising more, it’s hard with my arthritis and back pain.”

Participant 10. “Exercise is what I need and I’m limited because of spine problems. Eating out and eating at other’s homes is a problem for me. I need to limit what I eat and walk away from stress.”

Question 3. What are some barriers (weaknesses or limitations) that may hinder your ability to manage your diabetes effectively? (i.e., money problems or limited social support)

Participant 9. “Nothing, my spouse is my support system. Our spouses help us out (talking to other participant).”

Participant 10. “I agree with what she said our spouses support us and help us out.”

Question 4. What are some reinforcing factors (strengths or assets) that may help you in managing your diabetes effectively? (i.e., social and family support)

Participant 9. “Support is wonderful and I’ve been walking away from stress.”

Participant 10. “My wife is supportive and she’ll keep me in line. I’ll be able to help my son, daughter, and son-in-law. They all have diabetes and my wife is pre-diabetic.”

Question 5. What are the contributing factors (positive or negative) that will affect your management of diabetes?

Participant 9. “Negative, dining out is hard, the holidays, not always wanting to eat right and over indulging. But on the positive side, I walk, exercise, I handle stress better, and I have a more balanced diet.”

Participant 10. “Again I have too agree with her. Dining out, the holidays, and not always wanting to follow the diet make it hard sometimes. I love ice cream and I over indulge some times. The positives

for me are about the same as her, I walk and exercise more frequently, I handle stress better, and I have a balanced diet.”

Question 6. Overall, how would you rate your current knowledge about diabetes and your current confidence level in your ability to manage your diabetes?

Participant 9. “Better than before since I was diagnosed. Fine 10 out of 10. I have no problem with it. But I wish that I didn’t have to have it.”

Participant 10. “My knowledge increases daily. I should’ve known a lot more. If I knew then what I know now, I could have avoided this. My son is Type I and I should’ve known more. My confidence level is very high because of the support I have at home and here at the Diabetes Center.”

Qualitative Results from Key Informant Interview 3

Question 1. In managing your diabetes to stay as healthy as you can, how has this impacted your “quality of life” in either a positive or negative way?

Participant 11. “Actually in a positive way. It has forced me to eat healthier and to exercise. I exercise twice a day now and I feel better because of it. Overall, it’s made a difference in how I feel.”

Participant 12. “Better because I’m eating healthier foods and eating less. If I wasn’t diagnosed and going the way I was going I might not even be here. I guess it’s positive. It has prompted me to learn more about nutrition than I knew before.”

Question 2. What are some behaviors or attitudes you will need to change in order to have a fulfilling life with diabetes?

Participant 11. “Not sure. I have a positive attitude about it. It runs in my family and I know a lot about it. Maybe just reinforcing my positive attitude.”

Participant 12. “I guess I’m trying to do a lot like more exercise, I just have to get up and do things. It is hard. I’m having a problem at work with my boss. I want to walk and see people and he just wants me to e-mail them. I’m trying to eat more decreased sugar and glyceric foods and watching and counting carbs, and not over-doing it. It is a continuous learning process. I really do like to swim and be outdoors and I like to have excuses to do it.”

Question 3. What are some barriers (weaknesses or limitations) that may hinder your ability to manage your diabetes effectively? (i.e., money problems or limited social support)

Participant 11. “A lot of stress hinders it. I hope I won’t get any physical injuries that would limit my exercise. Exercise helps me to control stress and without exercise my stress might increase.”

Participant 12. “Money is always a problem whether you are diabetic or not. I work and I have health insurance and without health insurance treatment would be a problem and it would be hard to pursue. My husband is relatively supportive. He tries hard not to have foods at home

that I shouldn't have. Sometimes I feel deprived, but you still have to count the carbs, but sometimes I want more."

Question 4. What are some reinforcing factors (strengths or assets) that may help you in managing your diabetes effectively? (i.e., social and family support)

Participant 11. "The biggest strength comes from feeling better, lowering and controlling my blood glucose, exercise, weight loss, having responsible behavior in handling my treatment of my diabetes, and the support from my friends and my family. A weakness is wanting some sweets sometimes."

Participant 12. "That's a rough one. I rub shoulders with people who are more supportive rather than less supportive. I hate when people say, "you can't have that!" and I say, "What do you know about it." A strength is that I'm curious and read a lot about diabetes and I enjoy being active and getting outdoors to walk, swim, and ski. My strengths are my curiosity to know what is best for me and to do it. Coming to the support group helps a lot in order to get better ways to handle situations we face."

Question 5. What are the contributing factors (positive or negative) that will affect your management of diabetes?

Participant 11. "I answered it in the last question. Treating my diabetes is not a choice and I need to do it. The weight loss and blood glucose control is a nice side benefit, but I need to do it. Managing my diabetes is not a choice, I just do it. Not managing it is not an option."

Participant 12. “I really don’t know. I’m not sure. The positives are my exercise and the negatives are having too much carbs. I’m human and sometimes I just want to say the heck with it.”

Question 6. Overall, how would you rate your current knowledge about diabetes and your current confidence level in your ability to manage your diabetes?

Participant 11. “I think that I have all the fundamental knowledge I need to manage my diabetes, but I like coming to the support group to learn more. I’m 75% confident in managing my diabetes. I just started medication in April and I’m about 75% confident. The program at the hospital is beneficial to the people that have been diagnosed with diabetes and it helps to put people on the right track. I feel sorry for those who don’t use it.”

Participant 12. “At the moment my knowledge level is pretty good and my confidence is a little shaky, but mostly pretty good.”

Qualitative Results from Focus Group 3

Question 1. In managing your diabetes to stay as healthy as you can, how has this impacted your “quality of life” in either a positive or negative way?

Participant 13. “I just found out and I just started taking pills about two weeks ago. I’ve probably had Type 2 for years, but now it is confirmed. I really don’t want to face it and now I need to get serious about it. I did have gestational diabetes with my pregnancies. Overall it is negative. But it is also positive because I’m addressing it. Realizing it now makes me more serious about it and that’s a positive.”

Participant 14. “Change of diet is the biggest one. It is unpleasant but it is a good thing. I exercise a bit more now. I’m a little more aware about what I eat.”

Participant 15. “Negative, it has been hard to accept this diagnosis and I was very angry at first, why me. It’s silly to be mad, it is not life threatening, but I think why me.”

Participant 16. “Positive way when I choose to do it. When I’m following the guidelines and when I put me mind to it.”

Participant 17. “Negative way, I feel that I can’t do the things I probably could do. I think I could do more without diabetes. I probably passed on a lot of opportunities because of the diabetes and I chose to be a stay-at-home mom and I think about that a lot. It was hard earlier because of my lack of knowledge. I didn’t know as much about the meters and that restricted what I did.”

Participant 18. “It has made it more difficult. You have to watch what you eat. So I need to eat better. In a positive way, being able to understand and empathize with others that have chronic diseases. The negatives are the stigma about my weight and insulin usage and having diabetes is extremely stressful.”

Participant 19. “I’ve had it for five-six months or so. I was overweight and I didn’t want to believe it. I was in denial for a while. Both of my parents had Type 2 diabetes. The pills are working for me. My blood

sugars are good and my blood work is good. I get my eye sight checked frequently, but I do need to lose weight.”

Participant 20. “Positive, because it has shown me that I should watch and plan my diet. I used to skip breakfast and lunch. Now I have breakfast and I still skip lunch at times, but I’m not as hungry at night or at dinner where I would stuff myself and gain weight as a result. Now I regiment myself with regard to the carbs, bread, and butter, and especially ice cream. But I do keep a log of my food and exchanges. My hemoglobin A1C is around six and my monthly blood sugar average is 110. I have lost weight by changing my diet. I still occasionally splurge but I know my sugars will be high and I’ll need to adjust what I eat. I have a better understanding of what affects my sugar and how to keep it down.”

Question 2. What are some behaviors or attitudes you will need to change in order to have a fulfilling life with diabetes?

Participant 13. “Overall health issues like diet and exercise. I have an 11 year old daughter and it could be a positive thing for her in terms of diet because we weren’t eating very healthy and maybe now we will, I hope.”

Participant 14. “I have a pretty fulfilling life as it is. I’m not sure to be honest. The only thing I can think of is that I dislike vegetables in my diet so if I could incorporate vegetables in to my diet that could be one. A less hectic lifestyle would allow more fulfillment in terms of disease management, but that’s really all I can think of.”

Participant 15. “Definitely my acceptance attitude. I’ve been working on it. It is not the end of the world. I’ve been getting better. But I wish I didn’t have to fart around with it.”

Participant 16. “I don’t feel that my diabetes has changed my life all that much. It is not a hindrance. It has just been a kick in the pants to become healthier.”

Participant 17. “I really don’t know. I think maybe I should go back to school now. I feel much better now than I ever have before.”

Participant 18. “Stop over-eating, increase exercise, more appropriate carb to insulin ratio. More frequent blood sugar testing. Leading an overall healthier lifestyle.”

Participant 19. “I guess right now I’m not doing much to manage my diabetes. I have two artificial knees, I’m tired, and I need to lose weight. I’d rather enjoy my life and outside of that I don’t care. I just don’t like being told “no.””

Participant 20. “Accept that I need to maintain blood sugar control. I’ve accepted it and I test twice a day. It doesn’t really impact me that much because I’ve been in control for a while. But if it did get out of control I would need to eat less or exercise more. I do take pills. I’ve taken them without fail for the past couple of months since being diagnosed. I know I need to manage my diabetes because if I don’t my blood sugar will go up.”

Question 3. What are some barriers (weaknesses or limitations) that may hinder your ability to manage your diabetes effectively? (i.e., money problems or limited social support)

Participant 13. “I’m not positive if this is something I shouldn’t do, but I like a lot of carbs. I need to learn to limit my carbs. So learning more about it will help me. I had a mental block about taking pills and now I have too. I was taking nothing now I’m on a bunch of pills. So accepting that I need to take the pills, I guess.”

Participant 14. “The biggest challenge for me is to take the time and energy to do things properly. I don’t make time for exercise or to plan meals. I’m busy with my kids and that takes time away from exercise and I’m inclined to eat the foods that I shouldn’t be.”

Participant 15. “Probably my overall acceptance of it. I’m trying to work on it. I truly haven’t accepted it. I’m smart, I know about it and what I need to do, but I can’t accept it right now.”

Participant 16. “I think because it is all self, it is an internal problem and with me the problem is I like food and I over eat and was inactive. This diagnosis showed me how much I’ve over eaten and helped me to become more active.”

Participant 17. “I don’t know. I’m doing well now. When I was first diagnosed I didn’t have a meter so I didn’t know if my blood sugar was high or low. It was a guessing game. Now I’m doing well with a meter. Going out to dinner and traveling is a pain because I have to give myself

insulin injections. So it can be hard to find a bathroom or private place to do it. It is embarrassing to pull out a syringe in front of others. But I have no problem managing it.”

Participant 18. “Stress, full-time job, being on-call at work, finding time for myself, being over-weight as a child has hindered my control as an adult.”

Participant 19. “School is a problem because I need to have a snack when I’m able. I eat breakfast at 5:30 am; I have a snack around 11 am and lunch at 1:30 pm. It is not always easy to make a good lunch. I try to eat a lot of light foods. I do what I want and if the light food tastes good I’ll eat it.”

Participant 20. “The cravings for ice cream and the other foods that I really like. I’ve decreased my salt intake and I use a salt substitute. But I need to keep my blood sugar below 115 every day.”

Question 4. What are some reinforcing factors (strengths or assets) that may help you in managing your diabetes effectively? (i.e., social and family support)

Participant 13. “I have a good doctor; I have fear that if I don’t do it, I’ll have worse problems. Taking control of my diabetes means I’ll be healthier. Secretly, I’m wishing that if I take care of this that I may not need to take the pills down the road. I’m being optimistic, I guess.”

Participant 14. “Check my blood sugar every day. My wife and parents are very persistent. I have a friend I workout with three times a week. I have a great doctor, she is a big asset. The healthcare system I’m in is

great. I get the meds I need and the staff are helpful. I know enough about nutrition to eat right, but I don't always do what I should."

Participant 15. "Definitely the excellent care from my primary care doctor. The one I had before wasn't that good. I started going to diabetes classes, but stopped because I couldn't accept it. Now I want more information about food and diet and reinforcement in these areas. I'm still in a denial phase. I take all the medication, but that's about it. I do feel guilty because I don't share much about my denial with my primary doctor. I don't want to disappoint her."

Participant 16. "I have to say that I think better support groups that are age appropriate would help me the most. All of the local ones have people that are 20-30 years older than me. It seems all the community groups and hospital groups are all geared toward older diabetics."

Participant 17. "The meters, you know when your high or low. I'm trying to get an insulin pump and my primary care doctor is helping me with that."

Participant 18. "Family is important. A better understanding from doctors is important. If the doctor understands diabetes it makes it easier. More community involvement in terms of support groups and other activities."

Participant 19. "People have been supportive, but they don't hound me about it. Once I get over being mad about it, it will be ok."

Participant 20. “Wanting to be healthy and having a positive attitude. I want to maintain my new weight loss since I’ve lost a lot of weight. I want to stay healthy and I don’t want to keep buying new clothes. These are positive changes and I want to keep it that way. Plus people tell me how good I look now and that feels good. By controlling my blood sugar I should live longer too.”

Question 5. What are the contributing factors (positive or negative) that will affect your management of diabetes?

Participant 13. “My mom is diabetic and knowing it is in the family, I know that I need to deal with it. I have some friends on dialysis and I don’t want to be on it and my diabetes hasn’t affected my kidneys or liver yet. So I’m trying to stay on top of it.”

Participant 14. “My general outlook on things had a lot to do with it. When things are going good I don’t think about it as much. But when I’m down it gets harder to manage. But when I’m managing it well I tend to forget about it and it gets out of control then I need to focus on it more. It’s a cycle. I have some arthritis problems and that hinders my exercise and other secondary health concerns that hinder my management sometimes.”

Participant 15. “My work, there is always stuff there to eat. There is always snacks, treats, and sweets there. Time is a barrier. I get home late. I don’t cook much and I eat a lot of convenience food. Lack of energy to want to prepare a decent meal. All these I would say are negative factors.”

Participant 16. “You know, you mean what helps or doesn’t? My family, my five year old son. They are positives. The negatives are the way I was brought up and my over-eating and inactive lifestyle. I’m a rules person so I strive to make sure I follow them.”

Participant 17. “Eating right is a positive thing. Picking the right foods and not over eating, and exercising. The negatives are parties, like knowing what to eat there and stuff like that.”

Participant 18. “Stress is a big negative, being female; you know having a period is a negative. A positive is having a supportive family that is knowledgeable and can help me do better. Other negatives are our society is a fast food oriented and it is hard to stay on my diet when I need to eat on the run.”

Participant 19. “Well, there was a period of time where I was depressed and I was focused on it. Now I’m back to work and it is hard to stay focused. Once I retire I will probably do better.”

Participant 20. “Positives are my motivation and dedication to manage my diabetes, my motivation to live a longer and healthier life. I’m doing pretty good for being 67 years old compared to others my age.”

Question 6. Overall, how would you rate your current knowledge about diabetes and your current confidence level in your ability to manage your diabetes?

Participant 13. “My knowledge so far is not good, I’m just learning. My confidence level is right in the middle, about 5 out of 10.”

Participant 14. “Current knowledge could be better. I’ve been told a lot and learned a lot, but there is a lot of information out there. It is sufficient but I could learn more especially about the three meds I’m on. I have a degree in biology and know a little about these meds, but I need to ask more questions sometimes.”

Participant 15. “Fair. Fair also, very fair. I purchased the home test kit a while back and haven’t used it once. I’m not sure I even know how to use it. I’ve been in such denial about this and I’m not sure if this will lead to insulin dependence rather than controlling it on oral medication. I just want to keep that from happening.”

Participant 16. “As far as my knowledge of diabetes I’m lacking in that. I’m not as well informed about it as I should be. I know there is a lot of information out there, but I should know more. I’m very confident, even though I don’t know as much. But my blood sugars are good, I’ve lost some weight, and I feel healthier.”

Participant 17. “I’ve had it for over four or five months and I’m hoping that I know what I’m doing. The problem is learning about the new things and being informed about the new stuff when it is available. I think my confidence is very high with all the new stuff out now. It is very easy for me to manage it. Things are getting better and easier for me.”

Participant 18. “My knowledge about diabetes is excellent. My confidence level is good.”

Participant 19. “I understand it pretty well. I know what I should do, what I should eat, and that I should exercise. I know I need to lose weight and decrease my sugar intake. My blood sugar has been good and I test all the time. I just deal with it. I can do it when I want to. I’m confident that I can do what I need to. I’m a happy camper right now.”

Participant 20. “I think I have excellent knowledge about my diabetes, plus my daughter has diabetes so I feel very knowledgeable about diabetes. I understand how high and low blood sugars can affect me and how to control it. I do read about diabetes as much as possible to stay on top of any new developments and hopefully there will be a cure. My confidence level is excellent. I have no problem taking care of myself. I’ve missed my medication on a few occasions, but overall, I think I manage it pretty well. I can recognize and predict when my blood sugar will be high or low. I can feel it.”

Summary of Focus Group and Key Informant Qualitative Data

There were 20 participants that participated in a combination of focus groups and key informant interviews. Fourteen of the twenty participants participated in three focus groups, while six were interviewed. The three separate focus groups conducted consisted of: Focus Group 1 - three participants; Focus Group 2 - three participants; and Focus Group 3 - eight participants, respectively. There were also three separate key informant interviews that were facilitated that included two participants within each session. It was difficult to schedule participants within the focus group format due to time constraints experienced by the participants attending the diabetes education classes at St. Clare’s

Regional Diabetes Center. In an effort not to be intrusive, key informant interviews were scheduled with the participants at a convenient time on three occasions. Due to difficulty in obtaining an adequate number of participants to attend the scheduled focus groups, the “nominal group process” methodology could not be followed. In total, there were 16 female participants and four male participants. Eighteen of the participants had Type II diabetes and two participants had Type I. Nineteen of the participants described their ethnicity as white and one participant described themselves as being from Trinidad. Thirteen of the participants described their socioeconomic status as “middle”, four as “high”, and three as “low”. There were nine participants from the 56-65 age range, five from 46-55 years, three from 36-45 years, two over 65 years of age, and one from 26-35 years. All participants acknowledged having used the Internet and had Internet access at home, work, or other locations.

Themes of Focus Group and Key Informant Qualitative Data.

Question 1. In managing your diabetes to stay as healthy as you can, how has this impacted your quality of life in either a positive or negative way?

In response to the first question, three overall themes emerged including how having diabetes had a positive impact on the participant’s quality of life, how having diabetes had a negative impact on the participant’s quality of life, and how having diabetes had little to no impact on the participant’s quality of life.

Regarding the first theme, positive impact was defined by the participants as losing weight (Participant 4 and Participant 5), understanding symptoms and treatment options (Participant 5, Participant 13, and Participant 16), and increasing exercise,

making positive food choices, and overall eating healthier (Participants 6, 7, 10, 11, 12, 14, and 20).

For the second theme, negative impact was defined by the participants as having physical and mental health problems as a result of the diabetes diagnosis. Physical health complaints included neuropathy (Participants 1 and 3), arthritis (Participant 2), high blood pressure (Participant 2), fibromyalgia (Participant 2), and loss in physical ability to do things (Participant 17). Mental health issues included feelings of depression (Participants 2 and 3), feelings of anger (Participants 3 and 15), denial (Participants 13 and 19), and increase in stress (Participant 18).

Lastly, two participants (1 and 8) felt that the diagnosis of diabetes had little to no impact on their overall quality of life.

Question 2. What are some behaviors or attitudes you will need to change in order to have a fulfilling life with diabetes?

Overall the majority of participants reported that diet and exercise were the two areas where behavior change could help them have a more fulfilling life with diabetes. Diet was defined by the participants as eating healthier, making better food choices, portion control, self control, and not skipping meals (Participants 1, 2, 3, 5, 6, 7, 8, 10, 12, 13, and 18). Exercise was defined by the participants as either starting an exercise program or increasing exercise (Participants 2, 4, 5, 9, 10, 12, 13, and 18).

Regarding attitude, four participants (3, 15, 19, and 20) felt they currently had a poor attitude toward their diabetes diagnosis as well as having a more difficult time accepting this diagnosis. Two participants (11 and 17) felt that they had an overall positive attitude toward their diabetes diagnosis and two participants (16 and 18) reported

having the motivation to be healthier. Four participants (8, 10, 14, and 18) discussed if they could manage their stress levels more effectively they could have a more fulfilling life with diabetes. Three other areas of behavior and attitude change were noted, including self blame (Participant 3), taking time off for self (Participant 4), and having more structure in life (Participant 8).

Question 3. What are some barriers (weaknesses or limitations) that may hinder your ability to manage your diabetes effectively? (i.e., money problems or limited social support)

Overall the majority of the participants felt that food preparation/diet and weight management were the most significant barriers that hindered their ability to manage their diabetes effectively. Food preparation/diet was defined by the participants as buying the right food, making positive food choices and portion size. Weight management was defined by the participants as how following a diet or not affects their weight (Participants 2, 4, 5, 8, 12, 13, 14, 16, 18, 19, and 20).

The second barrier identified was stress management. Stress management was defined as the participant's inability to manage stress successfully and that stress was coming from home, work, family, and having diabetes (Participant 5, 8, 11, 14, 18).

Participants reported that money for diabetic supplies (Participants 1, 3, and 12) and limited social support (Participants 3, 7, and 8) is a barrier. Participants reported that having a negative attitude (Participants 4 and 15) and decreased motivation toward treatment (Participants 6 and 16) is a barrier. And one participant endorsed each of the following as barriers, poor physician/patient relationship (Participant 2), medication compliance (Participant 13), and feelings of embarrassment for taking insulin injections

in public (Participant 17). Three participants (9, 10, and 17) felt that they had little or no barriers for their diabetes management.

Question 4. What are some reinforcing factors (strengths or assets) that may help you in managing your diabetes effectively? (i.e., social and family support)

The majority of the participants reported that social support was the most significant reinforcing factor that helped the participants to manage their diabetes effectively. They defined social support as support from family including spouses or significant others (Participants 1, 3, 4, 6, 8, 9, 10, 11, 14, 18, and 19), friends (Participants 4, 11, and 14), co-workers (Participants 1 and 5), the St. Clare's Diabetes Center classes and staff (Participants 1, 2, 3, 5, 12, 14, 15, 16, and 18), and support from their primary care doctor (Participants 3, 4, 13, 14, 15, and 18). Other reinforcing factors that were endorsed included having an increase in knowledge about diabetes (Participants 6, 12, 15, and 17), exercise (Participants 7, 11, and 12), improved glucose control (Participants 11, 14, and 20), weight loss (Participants 11 and 20), having a positive attitude and motivation toward treatment (Participants 8 and 20), decreasing stress (Participants 6 and 9), and obtaining diabetes information from the Internet (Participant 4).

Question 5. What are the contributing factors (positive or negative) that will affect your management of diabetes?

In response to this question, two general themes that emerged, including positive contributing factors and negative contributing factors that affected the management of diabetes. Positive contributing factors that the participants felt affected their diabetes management included, exercise (Participants 4, 5, 6, 12, and 17), motivation toward

treatment (Participants 4, 8, 13, and 20), diabetes knowledge (Participants 2, 6, 7, and 18), social support (Participants 3, 8, 16, and 18), diet (Participants 1, 9, 10, and 17), weight loss (Participants 4 and 11), improved blood glucose testing (Participants 1 and 11), attending the St. Clare's Regional Diabetes Center program (1 and 7), and improved stress management (Participants 9 and 10).

Two main negative contributing factors were difficulty maintaining diet and stress management. The participants defined difficulties in maintaining diet as poor food choices, over-eating, not taking the time to prepare meals, eating too much fast food, skipping meals (Participants 5, 6, 7, 9, 10, 12, 15, 16, 17, and 18). Stress management was defined by the participants as a decrease in their ability to cope with stress (Participants 4, 7, 8, 15, and 18). Other negative contributing factors were endorsed including negative attitude toward treatment (Participants 4 and 19), lack of knowledge (Participants 1 and 3), decreased motivation toward treatment (Participants 14 and 19), financial issues (Participant 3), and poor relationship with doctor (Participant 2).

Question 6. Overall, how would you rate your current knowledge about diabetes and your current confidence level in your ability to manage your diabetes?

In this question the participants are asked to rate their current levels of diabetes knowledge and confidence in their ability to manage their diabetes. Regarding knowledge, the majority of the participants felt they had adequate knowledge about their diabetes and how to manage it. Participant responses were as follows, "so/so", "ok" "50-50", or "5 out of 10" (Participants 1, 3, 4, and 5). "Excellent" (Participants 2, 18, and 20). "Pretty good" or "fairly good" (Participants 6, 9, 10, 12, 15, 17, and 19). "Ninety

percent” (Participant 7). “Fundamental knowledge” (Participant 11). “Could be better” (Participants 12, 17, and 19). “Not good” (Participants 8, 13, and 16).

As for confidence level, the majority of participants felt they were confident in their ability to manage their diabetes effectively. Participants’ responses were as follows, “Excellent or very high” (Participants 1, 2, 6, 9, 10, 16, 17, and 20). “Good” (Participant 18). “Eighty-five percent” (Participant 7). “Seventy-five percent confident” (Participant 11). “Seventy percent confident” (Participant 8). “Confident” (Participants 3, 14, and 19). “Pretty confident” (Participants 5 and 12). “Five or six out of 10” (Participants 4, 13, and 15). “Shaky” (Participant 12).

Results from the MDRTC Diabetes Knowledge Test and Diabetes Self-Management Profile

The two surveys used to assess patients’ needs in this program development dissertation were surveys that were collected from patients as part of the intake process by the St. Clare’s Regional Diabetes Center staff. New patients completed the MDRTC Diabetes Knowledge Test and the Diabetes Self-Management Profile. St. Clare’s Regional Diabetes Center staff explained that each survey was distributed to each new patient, but it has been difficult to have the completed surveys returned. Of each survey, approximately 45 were distributed at intake. Twenty-four of the MDRTC Diabetes Knowledge Test was returned and 24 of the Diabetes Self-Management Profile were returned.

The MDRTC Diabetes Knowledge Test was scored to determine participants’ pre-intervention knowledge levels about their diabetes. This survey included 23 variables related to diabetes treatment. These variables included diet, highest carb, highest fat, free

food, HgbA1c (hemoglobin A1c), testing BG (blood glucose), juice and BG, tx (treatment) low BG, exercise, infection, feet, heart disease, nerve disease, lung disease, keto (ketoacidosis), flu, insulin reaction 1, forgot insulin, insulin reaction 2, low BG, skip a meal, high BG, and insulin reaction 3. As can be seen in Table 11, the variables that fell below the mean of .60 included Insulin Reaction 3 ($M = .32$; $SD = .48$), Insulin Reaction 1 ($M = .41$; $SD = .50$), Keto ($M = .50$; $SD = .51$), Highest Fat ($M = .56$; $SD = .51$), and High BG ($M = .58$; $SD = .50$). The overall diabetes knowledge score was $M = .82$; $SD = .11$. Each mean is equivalent to the percentage correct out of 100 for each variable.

Table 11

Mean and Standard Deviations for the Variables of the MDTRC Diabetes Knowledge Test

Variable	M	SD	Variable	M	SD
Diet	.96	.20	Nerve Disease	.96	.20
Highest Carb	.80	.41	Lung Disease	.96	.20
Highest Fat	.56	.51	Keto	.50	.51
Free Food	.80	.41	Flu	.92	.28
HgbA1c	.88	.33	Insulin Reaction 1	.41	.50
Testing BG	.88	.33	Forgot Insulin	.74	.45
Juice & BG	.76	.44	Insulin Reaction 2	.79	.42
Tx Low BG	.72	.46	Low BG	.76	.44
Exercise	.84	.37	Skip a Meal	.74	.45
Infection	.88	.33	High BG	.58	.50
Feet	.96	.20	Insulin Reaction 3	.32	.48
Heart Disease	.92	.28			

n = 25

* Each mean or percent below .60 was significant.

For Insulin Reaction 3, participants had difficulty understanding what situations may cause an insulin reaction (low blood glucose levels). The main situation that may cause an insulin reaction is heavy exercise. For Insulin Reaction 1, participants had difficulty identifying when they may have had an insulin reaction after taking intermediate acting insulin (NPH or Lente). An insulin reaction is when a person experiences physical symptoms associated with having low blood glucose levels. For

Keto (ketoacidosis), participants had a difficult time understanding what symptoms were associated with ketoacidosis. This condition is caused by an excessive amount of protein that builds up due to poor insulin production. The body's inability to break down these proteins leads to an acid build up referred to as ketones and can cause physical symptoms including nausea and vomiting. For Highest Fat, participants had a difficulty understanding what foods contained the highest fat content. This is important in terms of making food choices that will affect the participant's blood glucose level. Finally, for High BG, participants had difficulty identifying what causes high blood glucose. Food choices, exercise, the amount of insulin taken, and illness are all factors that can cause blood glucose levels to increase.

As seen in Table 11, eighteen variables including diet, highest carb, free food, HgbA1c, testing BG, juice and BG, tx low BG, exercise, infection, feet, heart disease, nerve disease, lung disease, flu, forgot insulin, insulin reaction 2, low BG, and skip a meal were above the mean of .60. The diet variable included that participants' ability to understand how the American Diabetes Association (ADA) is helpful in managing blood glucose levels. The highest carb variable focused on the participants' understanding of what foods contain the most carbohydrates. The free food variable focused on the participants' understanding of what is a "free" food. A free food is a food choice that contains less than 20 calories and will not affect blood glucose levels. The hemoglobin A1c (HgbA1c) variable focused on the participants' understanding of what HgbA1c measured and how often this blood test is needed. The testing BG variable focused on having the participants' identify the most accurate method of testing blood glucose levels. The juice and BG variable had participants' decided whether or not sweetened fruit juice

raises or lowers blood glucose levels. The tx low BG variable focused on the participants' understanding of what type of food or drink will help to raise blood glucose levels. The exercise variable focused on the participants' understanding of how exercise affects blood glucose levels. The infection variable focused on the participants' understanding of how infection will affect blood glucose levels. The feet variable focused on the participants' understanding the best way to care for their feet. The heart disease variable focused on the participants' understanding how a diet low in fat will decrease heart disease. The nerve disease variable focused on the participants' understanding the symptoms of nerve disease. The lung disease variable focused on the participants' understanding what other types of diseases or complications that are associated with diabetes. The flu variable focused on the participants' understanding what they should do to maintain blood glucose levels when ill. The forgot insulin variable focused on the participants' understanding what to do when they forgot to take their insulin. The insulin reaction 2 variable focused on the participants' understanding what they should do when they are beginning to feel that their blood glucose levels are low. The low BG variable focused on the participants' understanding what causes low blood glucose levels. The skip a meal variable focused on the participants' understanding how their blood glucose levels will be affected when they take their insulin but skip a meal.

Diabetes Self-Management Profile was developed to determine the participants' level of adherence to the complex treatment regimen. Diabetes Self-Management Profile contains six variables including exercise, hypoglycemia, diet, blood glucose testing, insulin, and total adherence. The exercise variable contained three questions that focused

on the participants' level adherence to an exercise plan. The hypoglycemia variable contained three questions that focused on the participants' understanding of treating low blood glucose. The diet variable contained nine questions that focused on the participants' adherence to diet and understanding of how diet affects blood glucose levels. The blood glucose testing variable contained four questions that focused on the participants' adherence to and understanding of the frequency of blood glucose monitoring. The insulin variable contained four questions that focused on the participants' adherence to and understanding of taking insulin injections. The total adherence variable was the sum of the previous five variables. Each variable's total scores were broken down in to three ranges (low, middle, and high). Low adherence is equivalent to a score of $M = 1$, middle or moderate adherence is equivalent to a score of $M = 2$, and high adherence is equivalent to a score of $M = 3$. Similar to the knowledge test, percentages for each variable were obtained. As seen in Table 12, the results for each variable as well as total adherence include; exercise ($M = 1.86$; $SD = .77$), hypoglycemia ($M = 2.32$; $SD = .72$), diet ($M = 2.13$; $SD = .69$), BG testing ($M = 1.50$; $SD = .72$), insulin ($M = 5.79$; $SD = 3.3$), and total adherence ($M = 1.92$; $SD = .65$). It should be noted that most participants were diagnosed with Type II diabetes and did not use insulin, and therefore did not respond to the questions in the insulin variable.

Table 12

Means and Standard Deviations for the Variables of the Diabetes Self-Management Profile

Variable	M	SD
Exercise	1.86	.77
Hypoglycemia	2.32	.72
Diet	2.13	.69
BG Testing	1.50	.72
Insulin	5.79	3.3
Total Adherence	1.92	.65

n = 24

Integrating Psychological Theory to Diabetes Disease Management

This diabetes disease management program followed the PRECEDE program planning model and integrated the strategies and interventions of Cognitive-behavioral and behavior theory. Cognitive-behavioral theory and treatment focuses on identifying problem areas, problem-solving, education, collaboration, and feedback to address a variety of psychological issues (Beck, 1995). Integrating the core aspects of Cognitive-behavioral theory to diabetes disease management helps to produce lasting changes in thought and behavior that results in improved adherence to treatment. The four main theories that contributed the most to the construction of the learning modules were the Social Cognitive Theory (self-efficacy), Health Belief Model, the Transtheoretical Model (stages of change), and Self-Determination Theory. Both the Theory of Reasoned Action and the Theory of Planned Behavior made minor contributions to the learning modules.

The Social Cognitive Theory states people that have a sense of self-efficacy to perform a behavior will perform that behavior (Bandura, 1986). Research conducted using Social Cognitive Theory found that people with a high sense of self-efficacy tended to show higher rates of adherence to diabetes treatment protocol. The core aspects of Social Cognitive Theory are embedded throughout the questions and situations of all four learning modules. For example, in each module when an incorrect response is made, prompts appear stating that the response was incorrect and then provides educational information about why the response was incorrect. Also, when a correct response is made, praise is given. By providing helpful and positive feedback, learning can occur which aids in improving self-efficacy. The Health Belief Model states that people tend to engage in preventative health behaviors when the severity and susceptibility of acquiring an illness is known (Rosenstock, 1974). Studies reviewed for this program development study have shown when there are positive changes in the beliefs about diabetes and diabetes treatment, adherence to treatment regimen increase. Each learning module provides useful educational information regarding ways that quality of life can improve. For example in the weight management module, information is provided showing how diet and exercise are important factors in controlling diabetes. By helping make a shift to a more positive perception of diabetes management, treatment adherence improves. The Transtheoretical Model states that people progress through five stages when changing a behavior precontemplation, contemplation, preparation (readiness), action, and maintenance (Prochaska and DiClemente, 1984). Depending on which stage a person is in determines how quickly a behavior may be changed. This model focuses on the readiness to change by concentrating on current beliefs and tailoring treatment strategies

to promote adaptive behavior change. For example, in the weight management module and the glucose monitoring and insulin therapy module, links are provided to information such as exercise information, food logs, and glucose monitoring logs. This information aids in tailoring treatment strategies to correspond the current stage of change the user may be in. Self-Determination Theory focuses on how personal choice and environmental factors influence treatment adherence (Williams, Rodin, Ryan, Grelnick, and Deci, 1998). Research conducted using Self-Determination Theory showed that when people displayed confidence, motivation, and received positive social support, adherence to treatment improved. For example in the foot care module, a question is asked concerning whether or not a spouse, family member, or caregiver is available to help assess if there are any foot problems. Also in the glucose monitoring and insulin therapy module there is a situation that describes an event where a personal decision needs to be made, by making the correct decision the level of self-confidence increases.

The two behavioral theories used in the development of the learning modules were The Theory of Reasoned Action and the Theory of Planned Behavior. The Theory of Reasoned Action states that all behaviors are based on the person's intention to perform the behavior. This theory states that the immediate cause for any behavior is the person's intentions to engage in or refrain from that specific behavior (Ajzen and Fishbein, 1980 and Ajzen and Fishbein, 1975). For example, in the foot care module, information is provided on how to check feet and what to look for when checking for foot problems or infection. Also, the glucose monitoring and insulin therapy module provides information regarding frequency of checking blood glucose levels as well as when to administer insulin if needed. These examples show the benefits of performing diabetes

management behaviors. The Theory of Planned Behavior integrates perceived behavioral control as a determinant of intention and behavior in addition to attitude and social norms. Perceived behavioral control is defined as the person's perception of the ease or difficulty involved in performing a behavior. The Theory of Planned Behavior states that the belief that the person is able to perform the behavior is as important as the actual performance of the behavior (Ajzen, 1991 and Rhodes, Fishbein, and Reis, 1997). For example in the weight management and glucose monitoring and insulin therapy modules, links are provided to food logs, glucose monitoring logs, and exercise information. By providing user-friendly worksheets it makes it easier to perform diabetes management behaviors and aid in forming positive beliefs about performing these behaviors.

While aspects of each of the Cognitive-behavioral and behavior theories were used in the development of the learning modules, collaboration with St. Clare's Regional Diabetes Center staff, participants, and the PRECEDE program planning model helped to identify the areas of need and, consequently, each area was given its own learning module. Each learning module includes educational information as well as situations to test knowledge and aid in problem-solving. Praise is given following each correct response to provide support and positive feedback to the participant. After each incorrect response, feedback is provided to help the participant to learn from each mistake. Figure 1 and 2 provides an example of the development of the questions and situations used in the learning modules. Following each learning module, participants are asked to return to the beginning to retest their knowledge. This pretest-posttest design aids in acquiring new knowledge about diabetes and practicing newly formed behaviors. As the

participants learn more about how to best manage their diabetes and practice new behaviors, adherence to treatment regimen and quality of life will improve.

Figure 1.

Structure of the questions and situations in the learning modules.

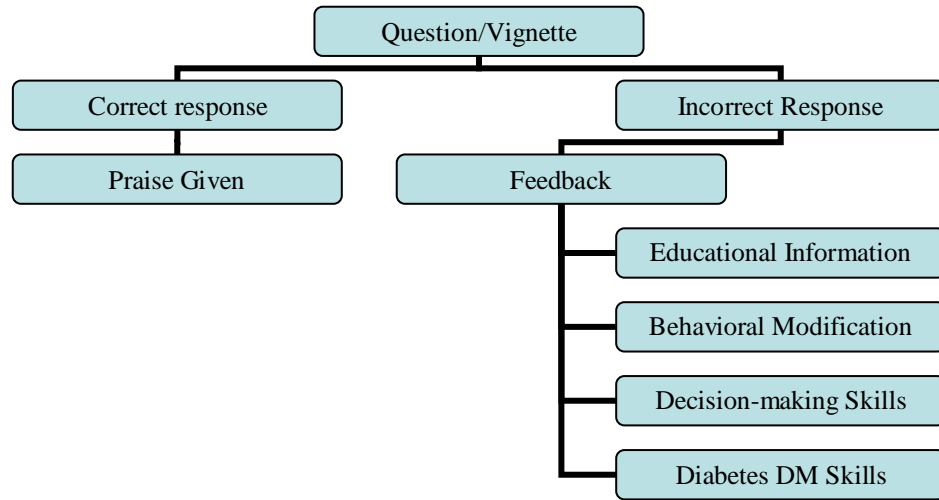
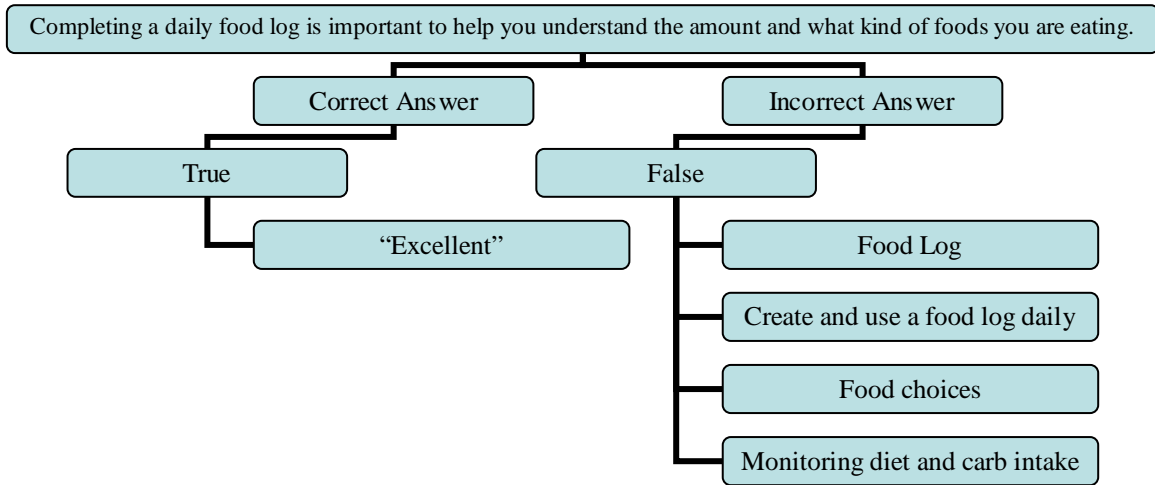


Figure 2.

Learning module setup example from the weight management module.



Learning Modules

The learning modules developed, followed the PRECEDE program development and planning model and integrated the feedback from the focus groups, key informant interviews, and archival survey data. The learning modules developed are geared toward improving treatment adherence and compliance by integrating cognitive-behavioral and behavior theory and patient education to motivate patients toward health behavior change by helping the patient to feel more confident in their ability to manage their diabetes effectively. The questions and situations created for each module were developed by integrating prior literature on diabetes treatment adherence and disease management, patient education, focus group and survey data, and cognitive-behavioral and behavior theory. Each learning module was designed to be interactive, and presented in a pretest-posttest design. Patient responses to each question and situation are designed to promote

patient education, self-efficacy and self confidence, in addition to improving treatment adherence. This design helped in improving diabetes knowledge as well as enacting a positive health behavior change to increase adherence to treatment regimen. In turn, patients decreased their risk for medical and psychological complications associated with diabetes and increased their ability to manage diabetes more effectively.

Patients had access to patient education information as well as suggestions for improving diabetes disease management. Links are provided throughout each module, to help guide the patient to obtain additional information and definitions of medical terminology. Patients are able to view and print information that is helpful in diabetes disease management including skin and foot care, exercise, sample food logs, sample glucose monitoring logs, and sample daily record sheets.

Foot Care

“This section focuses on your feet and how you care for them. Foot care is very important for people with diabetes. Diabetes can cause a decrease in circulation to your feet over time, especially if your blood glucose levels are not controlled. If any foot problem is not addressed it may lead to more severe problems or amputation. Therefore it is important to contact your primary care doctor or podiatrist when you notice a foot problem. This section includes educational information, sample questions, and some everyday situations that you may experience.”

Question 1. Should you check your feet everyday?

Yes or No

If “Yes” is selected a prompt appears stating, “You’re right!”

If “No” is selected a prompt appears stating, “It is important for you to check your feet everyday. Things that you should look for when checking your feet include blisters¹, dryness², infected toenails³, cuts⁴, or abrasions⁵. If you find any of these problems you should contact your podiatrist or primary care doctor for treatment. Common treatments include topical creams or lotions⁶, and oral medication. Always avoid applying lotion or cream between your toes, this habit can lead to infection.”

Question 2. Does someone (family member, spouse, caregiver, or friend) help you to check your feet?

Yes or No

If “Yes” is selected a prompt appears stating, “Great job!”

If “No” is selected a prompt appears stating, “It is important to have someone to help you check your feet, especially if you have any difficulty checking your feet on your own. If no one is able to help you, you can use a mirror to check your feet. Checking your feet each day helps to prevent future foot problems. It is important to have someone to support you in your management of diabetes and foot care.”

¹ Blisters are defined as a collection of fluid underneath the top layer of skin or epidermis.

² Dryness can be caused by a dry climate, winter weather, deficiency of vitamin A, systemic illness, overexposure to sunlight, or medication. The skin loses moisture. It may crack and peel. Or it may become irritated, inflamed, and itch. Bathing frequently, especially with soaps, can contribute to dry skin.

³ Infected toenails - Nails that are infected with a fungus may become discolored (yellowish-brown or opaque), thick and brittle, and may separate from the rest of the nail. In some cases, the nail may crumble. The dark, moist and warm environment of shoes can promote fungal growth. In addition, an injury to the nail can put you at risk for a fungal infection. Fungal nail infections are difficult to treat. Medications applied directly to the nail are available, but they only help a small number of fungal nail problems. Oral medications (pills) may need to be prescribed by your doctor. Treatment also may include periodic removal of the damaged nail tissue.

⁴ Cuts are defined as severed skin. Washing a cut or scrape with soap and water and keeping it clean and dry is all that is required to care for most wounds. Putting alcohol, hydrogen peroxide, and/or iodine into a wound can delay healing and should be avoided. Seek medical care early if you think that you might need stitches. Any delay can increase the rate of wound infection. Any puncture wound through tennis shoes has a high risk of infection and should be seen by your healthcare professional. Any redness, swelling, increased pain, or pus draining from the wound may indicate an infection that requires professional care.

⁵ Abrasions are defined as scrapes or burns that do not break the skin, but are red, irritated and may itch.

Question 3. Should you clean and care for your feet everyday?

Yes or No

If “Yes” is selected a prompt appears stating, “Excellent!”

If “No” is selected a prompt appears stating, “It is important to clean and care for your feet each day. Cleaning and caring for your feet is important and includes washing, using lotion for dryness, and wearing appropriate shoes and/or foot wear. If you are having problems finding the right foot wear contact your podiatrist and (s) he can fit you with the right shoes.”

“This next section includes some possible everyday situations that you may find yourself in. Read each paragraph and select your answer according to how you would act in each situation.”

Situation 1. During a daily foot exam you see some cracking on both feet and both feet are dry. What should you do?

- Do Nothing.
- Soak your feet.
- Clean feet and apply cream or lotion.

If “Do Nothing” is selected a prompt appears stating, “Incorrect, because your feet are cracking and dry it may lead to bleeding and put you at risk for infection.”

If “Soak your feet” is selected a prompt appears stating, "Sorry, soaking your feet may actually make the cracking and dryness worse.”

⁶ Creams or lotions refer to a water-soluble preparation applied to the skin. An ointment differs from a cream in that it has an oil base.

If “Clean feet and apply cream or lotion” is selected a prompt appears stating, “Super! But be sure to avoid applying lotion between your toes, this habit could lead to infection.”

Situation 2. Because of some physical and vision problems it has become difficult for you to check your feet. What should you do?

- Do Nothing
- Go to the doctor
- Have your spouse, a friend, another family member, or use a mirror to help you check your feet.

If “Do Nothing” is selected a prompt appears stating, “Incorrect, because it is important to check your feet each day and you will need to find someone to help you.”

If “Go to the doctor” is selected a prompt appears stating, “Your doctor or podiatrist will not be able to see you everyday for foot exams. So it is better for you to find someone at home who may be able to help you or use a mirror if no one is available to help you. You should still see your primary care doctor and/or podiatrist frequently for check ups.”

If “Have your spouse, a friend, another family member, or use a mirror to help you check your feet” is selected a prompt appears stating, “Good for you!”

Situation 3. Your shoes have been causing your feet to hurt and you find that some blisters have formed and burst as a result. What should you do?

- Clean your feet, call your doctor or podiatrist, and change your footwear.
- Change your footwear.
- Do Nothing

If “Clean your feet, call your doctor or podiatrist, and change your footwear” is selected a prompt appears stating, “Perfect!”

If “Change your footwear” is selected a prompt appears stating, “Changing your footwear alone will not solve the problem.”

If “Do Nothing” is selected a prompt appears stating, “If you do nothing your foot pain will continue to get worse and the blisters will continue to form and burst. As this continues you are becoming at risk for infection.”

Situation 4. You notice that your right foot is [swollen](#)⁷. You remember that you tripped over some furniture two days ago. You have done nothing to treat the swelling. What should you do?

- Elevate your foot, apply ice, and call your primary care doctor.
- Continue to go about your daily activities.
- Do Nothing

If “Elevate your foot, apply ice, and call your primary care doctor” is selected a prompt appears stating, “Outstanding!”

If “Continue to go about your daily activities” is selected a prompt appears stating, “Continuing to go about your daily activities and not relaxing, your foot may continue to swell and become more painful.”

If “Do Nothing” is selected a prompt appears stating, “By not treating the injury your foot pain and the swelling will get worse and you may require medical attention.”

⁷ Swelling is defined as the inflammation of soft tissues as a result of excess water accumulation due to injury or infection.

Situation 5. You have been treating a foot infection with a prescription topical cream.

After several days you notice that the infection has not gotten any better. What should you do?

- Continue to apply the cream as prescribed.
- Apply twice as much cream each day.
- Call your primary care doctor or podiatrist for an exam.

If “Continue to apply the cream as prescribed” is selected a prompt appears stating, “Incorrect, it is better to call your primary care doctor for an exam because it appears that the cream is not working to treat the infection.”

If “Apply twice as much cream each day” is selected a prompt appears stating, “Not quite right, if the cream does not seem to be working then just using more will not help to cure the infection.”

If “Call your primary care doctor or podiatrist for an exam” is selected a prompt appears stating, “Nice job! Your doctor may prescribe a stronger cream or an oral medication.”

When the module is completed a prompt appears stating, “Thank you for completing this section. If you would additional information on basic foot care [click here](#). (See Table 5 in Appendix). Before moving on to the next modules take a moment to go back through this module to test your foot care knowledge.”

Weight Management

“This section focuses on how you manage your weight. Weight management is very important for people with diabetes. By losing weight, treating your diabetes can become easier, however continuing to gain weight can cause an increase in complications associated with diabetes. Weight management is also important in managing your blood

glucose levels. This section includes educational information, sample questions, and some everyday situations that you may experience.”

Question 1. Does the American Diabetes Association (ADA) have guidelines for proper nutrition and food choices for people with diabetes?

Yes or No

If “Yes” is selected a prompt appears stating, “Correct!” Click here for more information

www.diabetes.org

If “No” is selected a prompt appears stating, “The American Diabetes Association (ADA) does have guidelines for proper nutrition that is geared toward providing you with the right amount of protein and carbohydrates in your diet. This diet will help you to better control your weight and blood glucose levels. You should also consult with a registered dietitian or certified diabetes educator (CDE) to discuss your personalized diet plan.”

Question 2. Where can you go to find the American Diabetes Association (ADA) dietary guidelines?

- Ask your primary care doctor or the doctor that is treating your diabetes.
- Call the American Diabetes Association (ADA) at 1-800-342-2383
- Go to the American Diabetes Association’s (ADA) website; www.diabetes.org
- All of the above are right.

If any of these answers are selected a prompt appears stating, “Way to go! All of the other answers are good ways of getting this information.”

Question 3. What is meant by the [carbohydrate](#)⁸ to [insulin](#)⁹ ratio?

- The amount of carbohydrates that were in the meal or snack you just ate.
- The amount of carbohydrates in a meal or snack to the amount of insulin you should inject in order to cover the carbohydrates.
- The amount of protein in the meal or snack you just ate.

If “The amount of carbohydrates that were in the meal or snack you just ate” is selected a prompt appears stating, “Not quite right, for every meal or snack you have it is important to know how much carbohydrates there are in order to give yourself enough insulin to cover those carbs.”

If “The amount of carbohydrates in a meal or snack to the amount of insulin you should inject in order to cover the carbohydrates” is selected a prompt appears stating, “You’re right!”

If “The amount of protein in the meal or snack you just ate” is selected a prompt appears stating, “Incorrect, protein does not affect your overall blood glucose level.”

Question 4. Having a daily exercise plan is important to managing your diabetes?

Yes or No

If “Yes” is selected a prompt appears stating, “Great job!” If you would like additional information on exercise [click here](#). (See Table 6 and Table 7 in Appendix).

⁸ Carbohydrates (carbs): Mainly sugars and starches, together constituting one of the three principal types of nutrients used as energy sources (calories) by the body. Foods that contain carbohydrates include bread, cereal, rice, and pasta. These foods contain mostly [carbohydrates](#). The foods in this group are made mostly of grains, such as wheat, rye, and oats. Starchy vegetables like potatoes, peas, and corn also belong to this group, along with dry beans such as black eyed peas and pinto beans. Starchy vegetables and beans are in this group because they have about as much carbohydrate in one serving as a slice of bread.

⁹ Insulin: A natural [hormone](#) made by the [pancreas](#) that controls the level of the sugar glucose in the blood. Insulin permits cells to use [glucose](#) for energy. Cells cannot utilize glucose without insulin.

If “No” is selected a prompt appears stating, “It is important to exercise each day in order to help control your blood glucose level as well as to lose weight. You should talk to your doctor prior to starting any exercise program.”

Question 5. Losing weight can help you to better manage your diabetes.

True or False

If “True” is selected a prompt appears stating, “Super!”

If “False” is selected a prompt appears stating, “Losing weight can help you control your blood glucose levels and you may be able to take less insulin or oral medication. Of course there are healthy and unhealthy ways to loss weight so it is important to talk with your doctor about a weight management program that is right for you.”

Question 6. Completing a daily food log is important to help you understand the amount and what kind of foods you are eating.

True or False

If “True” is selected a prompt appears stating, “Excellent!” For sample daily food logs and daily record sheets [click here](#). (See Table 8 and Table 10 in Appendix).

If “False” is selected a prompt appears stating, “Completing a daily food log will help you understand what kind of food and the amount of food you are eating at each meal or snack. The type and the amount of food you eat affect your blood glucose levels. It is important to have a balanced diet with the right amount of carbohydrates and protein.”

“This next section includes some possible everyday situations you may find yourself in. Read each paragraph and select your answer according to how you would act in each situation.”

Situation 1. You have been overweight most of your life and you have a family history of diabetes. You have been diagnosed with Type II diabetes about one year ago, but you have not done much to change your lifestyle. What is one thing that you could do right now to start treating your Type II diabetes?

- Start walking 30 minutes a day.
- See your primary care doctor only.
- Do nothing.

If “Start walking 30 minutes a day” is selected a prompt appears stating, “Good for you, that is a great start! Be sure to talk with your doctor prior to starting any exercise program.”

If “See your primary care doctor only” is selected a prompt appears stating, “Not quite, by only seeing your doctor will not do much right now to jump start your treatment of your Type II diabetes.”

If “Do nothing” is selected a prompt appears stating, “Incorrect, by doing nothing you are putting yourself at risk for future health complications.”

Situation 2. You have just started keeping a food log. You notice that most of your food choices include several servings of carbohydrates like bread and pasta. What should you do to balance your diet?

- Decrease the amount of carbohydrates only.
- Increase the amount of fruits and vegetables only.
- Do nothing.
- Balance the amount of carbohydrates, fruit, vegetables, dairy products, and protein.

If “Decrease the amount of carbohydrates only” is selected a prompt appears stating, “By only decreasing the amount of carbohydrates in your diet you will help to lower your blood glucose level in the short-term. By balancing your diet with servings of dairy products, protein, fruits, and vegetables you will have better long-term results.”

If “Increase the amount of fruits and vegetables only” is selected a prompt appears stating, “By only increasing the amount of fruits and vegetables in your diet you will see some benefit, but you should add protein and dairy products as well.”

If “Do nothing” is selected a prompt appears stating, “Continuing to have a diet high in carbohydrates will cause problems with high blood glucose levels and may contribute to weight gain.”

If “Balance the amount of carbohydrates, fruit, vegetables, dairy products, and protein” is selected a prompt appears stating, “Perfect! You should also talk with a registered dietitian or certified diabetes educator to come up with a personalized diet plan.”

Situation 3. You have Type I diabetes and require insulin injections or a bolus from an [insulin pump](#)¹⁰ to control your blood glucose level. The amount of carbohydrates you eat at a meal or snack will affect your blood glucose level. How do you know how much insulin to take?

Guess

¹⁰ Insulin pump is a pump for delivering insulin in order to achieve tight blood sugar control and lifestyle flexibility while minimizing the effects of low blood sugar (hypoglycemia). The pump is composed of a pump reservoir similar to that of an insulin cartridge, a battery-operated pump, and a computer chip that allows the user to control the exact amount of insulin being delivered. The pump is attached to a thin plastic tube (an infusion set) that has a soft cannula (or needle) at the end through which insulin passes. This cannula is inserted under the skin, usually on the abdomen. The cannula is changed every 2-3 days. The tubing can be disconnected from the pump while showering or swimming. The pump is used for continuous insulin delivery, 24 hours a day. The amount of insulin is programmed and is administered at a constant rate (basal rate). Often, the amount of insulin needed over the course of 24 hours varies depending on factors like exercise, activity level, and sleep. The insulin pump allows for the user to program many different basal rates to allow for this variation in lifestyle. In addition, the user can program the pump to

Take as much insulin in order to get your blood glucose level back within the normal range.

Take enough insulin to cover the grams of carbohydrates you just ate.

If “Guess” is selected a prompt appears stating, “By guessing, you may give too much or too little insulin causing your blood glucose level to become too low or too high.”

If “Take as much insulin in order to get your blood glucose level back within the normal range” is selected a prompt appears stating, “By taking as much insulin to get your blood glucose level into the normal range and not accounting for the additional carbohydrates, you risk keeping your blood glucose levels high because you just ate carbohydrates and you have not taken enough insulin to cover these carbohydrates.”

If “Take enough insulin to cover the grams of carbohydrates you just ate” is selected a prompt appears stating, “Good for you!”

Situation 4. Since being diagnosed with Type II diabetes one year ago, you have started a food log, you exercise on a daily basis, you have lost some weight, you watch your carbohydrate and sugar intake, and you have been following the American Diabetes Association’s (ADA) diet as best you can. However your recent blood lab work shows an increase in your [Hemoglobin A1c \(HgbA1c\)](#)¹¹. What should you do?

See your primary care doctor only.

Continue to do everything that you have been and contact your primary care doctor.

Give up.

deliver a "bolus" during meals to cover the excess demands of carbohydrate ingestion. The pump is currently the closest device on the market to an artificial pancreas.

¹¹ Hemoglobin A1c is a blood test that shows the average level of sugar (glucose) in your blood over the last 12 weeks. This blood test will give your doctor a snapshot of your blood sugar readings for the past couple of months and will help to determine if treatments are working or if they need to be modified. This test should be performed two to three times per year or as recommended by your doctor. The target HgbA1c is a score of 7 or below.

If “See your primary doctor only” is selected a prompt appears stating, “By seeing your doctor (s)he may help you to better understand why your HgbA1c went up, but you should continue to do all of the things you have been in order to lower your HgbA1c. Your doctor may discuss the possibility of oral medication that will help you to control your Type II diabetes.”

If “Continue to do everything that you have been and contact your primary care doctor” is selected a prompt appears stating, “Outstanding!”

If “Give up” is selected a prompt appears stating, “If you give up your HgbA1c and blood glucose levels will become difficult to manage and will put yourself at risk for health complications.”

Situation 5. Sample food log

Monday

Breakfast – Cereal, milk, banana

Lunch – Soup, one slice of bread, yogurt, apple

Snack – Large piece of chocolate cake

Dinner – Pasta with tomato sauce, salad with dressing, cheese, vegetable

Where could you have made a better food choice or substitution?

- Breakfast
- Lunch
- Snack
- Dinner

If “Breakfast” is selected a prompt appears stating, “This looks good.”

If “Lunch” is selected a prompt appears stating, “This looks good.”

If “Snack” is selected a prompt appears stating, “By making a better snack choice or substituting the chocolate cake with a more nutritious snack with less sugar and carbohydrates you will help to balance your diet as well as to help keep your blood glucose levels within the normal range.”

If “Dinner” is selected a prompt appears stating, “This looks good.” For additional information on daily food logs [click here](#). (See Table 8 in Appendix).

When the module is completed a prompt appears stating, “Thank you for completing this section. Before moving on to the next module, take a moment to go back through this module to test your weight management knowledge.”

Glucose Monitoring and Insulin Therapy (Oral Medication)

“This section focuses on how you monitor blood glucose levels, use insulin, and/or oral medication. Glucose monitoring and insulin and oral medication therapy are very important for people with diabetes. By checking your blood glucose levels frequently each day this process will help to know how much insulin you need as well as to determine the effectiveness of the oral medication. Checking your blood glucose levels frequently each day helps you to better manage your diabetes as well as decrease the risk of future health complications associated with diabetes. This section includes educational information, sample questions, and some everyday situations that you may experience.”

Question 1. True or False: There is no right or wrong time to check your blood glucose level.

If “True” is selected a prompt appears stating, “Correct, mainly people with diabetes will check their blood sugar levels in the morning before breakfast, before dinner, or after

exercise. It is also recommended to check your blood sugar two hours after a meal, if you feel that your blood sugar is high or low, and check more often when you are sick.”

If “False” is selected a prompt appears stating, “Not quite, everyone will have a different monitoring schedule. This schedule will be based on the type of diabetes you have as well as your eating and exercise habits. It is important to check your blood sugar at least twice a day.”

Question 2. Should you write down your daily blood glucose readings?

Yes or No

If “Yes” is selected a prompt appears stating, “Way to go!”

If “No” is selected a prompt appears stating, “You should write down your blood glucose readings each time you check. This helps to know where there are any highs or lows during the day. This habit helps you to decide where to make changes in your diet or exercise plan to keep your blood glucose level within the normal range.” Click here for a [sample glucose monitoring log](#). (See Table 9 in Appendix).

Question 3. What does the carbohydrate to insulin ratio mean?

- The amount of insulin you should take to cover the carbohydrates you have eaten.
- The relationship between insulin and carbohydrates.
- Both are correct.

If “The amount of insulin you should take to cover the carbohydrates you have eaten.” is selected a prompt appears stating, “You’re right! “

If “The relationship between insulin and carbohydrates.” is selected a prompt appears stating, “This is also correct. Because the amount of carbs you eat directly affects how

much insulin you will need to give yourself to keep your blood sugar within the normal range.”

If “Both are correct.” is selected a prompt appears stating, “Yes, both answers are correct. You should take enough insulin in order to cover the amount of carbs in a meal and the amount of carbs you have will help you to determine how much insulin you will need to keep your blood sugar within the normal range. By talking with your doctor, you may be able to determine an appropriate carbohydrate to insulin ratio that will help to keep your blood sugar within the normal range.”

Question 4. Being diagnosed with Type I diabetes; you need to inject insulin or bolus insulin from an insulin pump to control your blood glucose level. If you take insulin injections, what are some good sites on your body to inject the insulin?

- Upper arm.
- Upper leg or thigh.
- Stomach or Hips
- Buttocks
- All of the above

If any answer is selected a prompt appears stating, “Yes, this is a good site to inject insulin.”

If “All of the above” is selected a prompt appears stating, “All of these are good sites for insulin injection. Each site may vary in how fast the insulin is absorbed in to your body. Insulin is absorbed more quickly in to your body when injected in to fatty areas such as your buttocks, hips, upper leg or thigh, and stomach.”

Question 5. You have Type II diabetes and in addition to diet, exercise, and weight loss, you are taking an oral medication. How often should you take your oral medication?

- As prescribed by your primary care doctor.
- When you think you need it.
- When your blood glucose level is low.

If “As prescribed by your primary care doctor” is selected a prompt appears stating, “Great job!”

If “When you think you need it” is selected a prompt appears stating, “Incorrect, when you are prescribed an oral diabetes medication, you should take it each day as recommended by your doctor.”

If “When your blood glucose level is low” is selected a prompt appears stating, “Not quite right, because taking your oral diabetes medication only when you feel low will not raise your blood glucose level. It is important to take your oral diabetes medication as prescribed by your doctor in order to help you to control your blood glucose levels.”

Question 6. What are some good times to check your blood glucose level?

- When you wake up.
- Before you go to bed.
- At 12pm (Noon)
- Two hours after meals.

If “When you wake up” “Before you go to bed” or “At 12pm (Noon)” is selected a prompt appears stating, “only checking your blood glucose level once a day will not help you to maintain your blood sugar. By checking it two hours after meals you will know what to eat and/or how much insulin to take (Type I). If you have Type II diabetes,

checking your blood glucose level two hours after meals can help you to make proper food decisions. It is important to check your blood sugar at least twice a day.”

“This next section includes some possible everyday situations that you may find yourself in. Read each paragraph and select your answer according to how you would act in each situation.”

Situation 1. You have Type I diabetes and you and your spouse are going to a wedding reception. Your blood glucose levels have been running high all day. It is time for cake loaded with sugar and rich frosting. What should you do?

- Check blood glucose and have some cake no matter what the reading is.
- Eat the cake and guess on how much insulin to give.
- Decide not to have any cake right now and take some home for later.

If “Check blood glucose and have some cake no matter what the reading” is selected a prompt appears stating, “It is great that you checked your blood glucose level and the reading should help you to decide whether or not to have the cake. If you decide to have cake you should take enough insulin to cover the sugar and carbohydrates in the cake.”

If “Eat the cake and guess how much insulin to give” is selected a prompt appears stating, “Incorrect, by eating the cake and giving insulin without knowing your blood glucose level may cause either an increase or decrease in your blood glucose level. It is important to check your blood glucose level before and two hours after meals and snacks.”

If “Decide not to have any cake right now and take some home for later” is selected a prompt appears stating, “Excellent!”

Situation 2. You have Type I diabetes and you have been writing down your blood glucose readings every day. You take seven readings a day. The readings in the morning

are 80 and 90. The readings in the afternoon are 200 and 185. The readings in the evening are 86, 95, and 100. What can you do in order to decrease your afternoon blood glucose levels?

- Have less carbohydrates at lunch.
- Skip lunch.
- Have smaller portions at lunch.
- Adjust your insulin injections to regulate your blood glucose at lunch.
- Two of the above are right.

If “Have less carbohydrates at lunch” is selected a prompt appears stating, “Having less carbohydrates may decrease your blood glucose level in the short-term, but may cause it to rise later.”

If “Skip lunch” is selected a prompt appears stating, “By skipping lunch your blood glucose level may decrease drastically and you may need to eat foods with high amounts of sugar and/or carbohydrates to increase your blood glucose level shortly after skipping lunch.”

If “Have smaller portions at lunch” “Adjust your insulin injections to regulate your blood glucose at lunch” or “Two of the above are right” is selected a prompt appears stating, “Your right, great job!”

Situation 3. You have Type I diabetes and you take insulin injections at different sites on your body. You use your upper arm and upper leg (thigh). You notice that the absorption of the insulin has been slowing down. Are there other sites on your body that you could use that might have faster absorption?

- Stomach, hips, and/or buttocks.

Lower arm, lower leg.

If “Stomach, hips, and/or buttocks” is selected a prompt appears stating, “Good for you!

These sites may increase absorption because of the higher fat content in these areas.”

If “Lower arm, lower leg” is selected a prompt appears stating, “These sites are not recommended for insulin injection because they have less fat and the absorption is decreased.”

Situation 4. You notice that you are feeling dizzy, nausea, headache, and blurred vision.

You are also very thirsty. These are all symptoms of high and low blood sugar. How do you know if you are high or low and what can you do to treat it?

You check your blood glucose level and it is low. You should eat and drink something that is high in sugar and/or carbohydrates like orange juice and peanut butter crackers.

Do nothing and wait for the symptoms to go away on their own.

Call your doctor.

You check your blood glucose level and it is high. You should take the amount of insulin you need to lower your blood glucose back in to the normal range.

Two are correct.

If “You check your blood glucose level and it is low. You should eat and drink something that is high in sugar and/or carbohydrates like orange juice and peanut butter crackers” or “You check your blood glucose level and it is high. You should take the amount of insulin you need to lower your blood glucose back in to the normal range” or “Two are correct” is selected a prompt appears stating, “Nice job! By first determining if you are high or low that will help you to decide how to treat the symptoms. If your blood sugar is low it is recommended that you follow the rule of 15. That means that you

should eat/drink 15 grams of fast acting carbs like orange juice and wait 15 minutes.

After 15 minutes test your blood sugar and if is still low you would eat 15 grams of slow acting carbs like peanut butter crackers. Wait 15 minutes and continue checking your blood sugar until the reading remains above 70.”

If “Do nothing and wait for the symptoms to go away on their own” is selected a prompt appears stating, “By doing nothing you are at high risk for either high blood sugar (hyperglycemia) or low blood sugar (hypoglycemia) that can cause you to faint and require medical attention.”

If “Call your doctor” is selected a prompt appears stating, “By contacting your doctor (s) he may not be able to provide you with immediate help. Therefore, you should be ready for the extreme highs and lows. Your doctor can provide you with some suggestions for these situations.”

Situation 5. Both you and your spouse have Type II diabetes. You have had Type II diabetes for five year and have been taking a high dose of an oral medication to treat your diabetes. Your spouse was diagnosed with Type II diabetes six months ago. You both see the same primary care doctor. Your spouse was told to follow the American Diabetes Association (ADA) diet and to exercise. Your spouse tells you that (s) he feels that diet and exercise is not working and (s) he wants to take some of your medication. What should you do?

- Give your spouse some of your medication.
- Have your spouse go to your primary care doctor.
- Tell your spouse to stop the diet and exercise program all together.

If “Give your spouse some of your medication” is selected a prompt appears stating, “Incorrect, by giving your spouse your medication it may put spouse at risk for health complications because it may not be the right dose for your spouse and it could interfere with other medications that your spouse may already be taking.”

If “Have your spouse go to your primary care doctor” is selected a prompt appears stating, “Perfect! It is important for the doctor to evaluate your spouse and determine whether or not to prescribe any medication.”

If “Tell your spouse to stop the diet and exercise program all together” is selected a prompt appears stating, “Incorrect, it is important for your spouse to continue to follow the ADA diet and to exercise regularly even though it may be frustrating and your spouse may not be feeling any benefits from this program.”

When the module is completed a prompt appears stating, “Thank you for completing this section. Before moving on to the next modules take a moment to go back through this module to test your glucose monitoring and insulin therapy (oral medication) knowledge.”

Routine Physician Appointments-Patient as Member of Treatment Team

“This section focuses on how your regular primary care doctor appointments and how you can be an active member in your diabetes disease management. It is very important for people with diabetes to have routine doctor visits (primary care doctor, podiatrist, eye doctor), blood lab work, and to follow all doctor’s, nurse, diabetes educator, and other healthcare professional’s recommendations. By being an active member in your diabetes treatment you will increase your knowledge and confidence for managing your diabetes. By following a treatment program that you work out with your

doctor, you will decrease the health complications associated with diabetes and increase your quality of life. This section includes educational information, sample questions, and some everyday situations that you may experience.”

Question 1. What is the name of the specialist that mainly works with people who have diabetes?

- Internist
- Endocrinologist
- OB/GYN
- Pathologist

If “Internist” is selected a prompt appears stating, “Not quite, an Internist can work with people with diabetes, but that is not their specialty.”

If “Endocrinologist” is selected a prompt appears stating, “Outstanding! An Endocrinologist has specific training in diabetes and it’s complications as well as other endocrine system diseases.”

If “OB/GYN” is selected a prompt appears stating, “Sorry, an OB/GYN works with women and pregnancy.”

If “Pathologist” is selected a prompt appears stating, “Incorrect, a Pathologist works mainly with skin and tissue samples to determine what type of disease or illness a person may have.”

Question 2. How often should you schedule appointments with your endocrinologist or primary care doctor for check ups?

- Once a year
- Twice a year

- Four times a year
- Only when you have a problem

If “Once a year” is selected a prompt appears stating, “It is important to see your endocrinologist or primary care doctor at least four times a year for check ups. If you are in very good control of your diabetes and blood glucose levels you may only need to see your doctor twice a year.”

If “Twice a year” is selected a prompt appears stating, “It is important to see your endocrinologist or primary care doctor at least four times a year for check ups. If you are in very good control of your diabetes and blood glucose levels you may only need to see your doctor twice a year.”

If “Four times a year” is selected a prompt appears stating, “You’re right! As you become better at managing your diabetes you may not need to see your doctor as often.”

If “Only when you have a problem” is selected a prompt appears stating, “No, that may be too late. It is very important for you to have regular appointments with your doctor in order for both of you to work together in managing your diabetes and to prevent the health complications associated with diabetes.”

Question 3. How often should you have blood lab work completed to monitor your hemoglobin A1C (HgbA1c)?

- Once a year
- Twice a year
- Four times a year

If “Once a year” is selected a prompt appears stating, “Not quite right, you should have your HgbA1c checked at least twice a year, sometimes more often if your diabetes is not under control or is recommended by your doctor”

If “Twice a year” is selected a prompt appears stating, “Great job! You may need to have your HgbA1c checked more often if your diabetes is not under control or is recommended by your doctor.”

If “Four times a year” is selected a prompt appears stating, “This may be too much. You would need to have your HgbA1c checked four times a year if your diabetes is not under control or is recommended by your doctor.”

Question 4. How often should you schedule appointments with your ophthalmologist (eye doctor) for vision exams?

- Once a year
- Twice a year
- Only if you have vision or eye problems

If “Once a year” is selected a prompt appears stating, “Super! You may need to have more frequent eye exams depending on how well you have been managing your diabetes or if you have been experiencing vision problems.”

If “Twice a year” is selected a prompt appears stating, “It is recommended that you have at least one eye exams per year. You may need more frequent eye exams depending on how well your diabetes is controlled or if you are experiencing vision changes or problems.”

If “Only if you have vision or eye problems” is selected a prompt appears stating, “Incorrect, it may be too late once you start to have problems. It is good to see the eye

doctor between visits if you experience some problems, although it is better to have regular appointments in order for you and the doctor to monitor your vision.”

Question 5. How often should you schedule appointments with your podiatrist (foot doctor) for foot exams?

- Once every two years
- Once a year
- Only when you have foot problems

If “Once every two years” is selected a prompt appears stating, “Not quite right, you should have at least one foot exam per year or possibly more if your diabetes is not under good control or you are experiencing frequent foot problems.”

If “Once a year” is selected a prompt appears stating, “Good for you! Usually if you are not experiencing any foot problems having one appointment per year is fine.”

If “Only when you have foot problems” is selected a prompt appears stating, “Incorrect, it may be too late. It is important for you to have at least one foot exam per year. You should also have additional exams if you are experiencing any problems.”

Question 6. Which of the following is a recommended hemoglobin A1C (HgbA1c) level that you should be working toward as you manage your diabetes?

- Between 4 and 7 percent
- Between 8 and 10 percent
- Above 10 percent

If “Between 4 and 7” is selected a prompt appears stating, “Way to go! By keeping your HgbA1c between 4 and 7 you are preventing the health complications associated with

diabetes and this also means that your blood glucose levels are mostly within the normal range over the last three month period.”

If “Between 8 and 10” is selected a prompt appears stating, “These values are a little too high. This means that your blood glucose levels over the last three months are mostly higher than normal and that you should make changes to your diet and exercise plan in order to keep your blood glucose levels within the normal range.”

If “Above 10” is selected a prompt appears stating, “Incorrect, this is too high. This reading means that your blood glucose levels over the last three months are mainly outside the normal range. The higher the HgbA1c the greater your risk is of developing complications. Therefore, making changes to your diet and exercise plan may be needed in order to have your blood glucose level fall into the normal range.”

“This next section includes some possible everyday situations that you may find yourself in. Read each paragraph and select your answer according to how you would act in each situation.”

Situation 1. Since being diagnosed with diabetes 6 months ago you have been feeling overwhelmed by all of the changes you need to make and you are confused about what you need to do. You have some information and you want to have access to additional information but you are unsure where to get it. What things can you do to feel less overwhelmed and confused?

- Prepare questions for your doctor.
- Contact the American Diabetes Association (ADA) and have information mailed to you. You can call 1-800-342-2383 or go to their website www.diabetes.org

Attend diabetes education classes or diabetes support groups that are offered at local hospitals.

All of the above

If “Prepare questions for your doctor”, “Contact the American Diabetes Association (ADA) and have information mailed to you. You can call 1-800-342-2383 or go to their website www.diabetes.org”, “Attend diabetes education classes or diabetes support groups that are offered at local hospitals”, and/or “All of the above” is selected a prompt appears stating, “Yes you’re right! Any of these choices are a good way to get more information about diabetes and how to make changes to your lifestyle.”

Situation 2. You have been seeing your primary care doctor on a regular basis for check ups. You have been with this doctor for about three years, but you do not feel like you have a good relationship with him/her. At each appointment you prepare questions, but really never get to ask them because the doctor seems to only tell you about your blood lab work and asks if there are any problems. The appointment seems to last only a few minutes before you leave. What can you do in order to feel that you are a part of your diabetes treatment and to have a good working relationship with your doctor?

Discuss these concerns with your doctor.

Change doctors

Insist that time be set aside for you to discuss your questions with the doctor during each appointment.

All of the above

If “Discuss these concerns with your doctor”, “Change doctors”, “Insist that time be set aside for you to discuss your questions with the doctor during each appointment”, and/or

“All of the above” is selected a prompt appears stating, “Great job! You need to be an active member in your diabetes management. By doing any one of these choices you are showing your doctor that you want to be involved and that you are following the doctor’s recommendations. If all else fails and you are not confident with the relationship you have with your doctor it might be time to change doctors. Overall, you want to feel confident in your ability to manage your diabetes and you need to be part of the treatment team with the doctors, nurses, and other health care providers.”

Situation 3. You have been attending a diabetes education class and you have been using the Internet to find information on diabetes and diabetes treatment. You have gotten a lot of information that is confusing and sometimes conflicts with each other. What can you do to clarify this information so that you can use it to help in your diabetes management?

- Ask other people in your diabetes education class.
- Present the information to your doctor for clarification.
- Present the information to a diabetes educator at the class.
- Two are correct.

If “Ask other people in your diabetes education class” is selected a prompt appears stating, “Not quite right. The other people in the diabetes education class might have similar questions about this information and therefore cannot help you. Or you might get more conflicting information leading to more confusion.”

If “Present the information to your doctor for clarification” or “Present the information to a diabetes educator at the class” is selected a prompt appears stating, “Nice job! Either of these is a good source of information and should be able to clarify this information for

you as well as to point you in the right direction to obtain less confusing diabetes patient education information.”

If “Two are correct” is selected a prompt appears stating, “Right! By talking with your doctor and/or a diabetes educator they will be able to explain this information in a less confusing way as well as to give you other helpful information so that you can manage your diabetes the best way you can.”

Situation 4. Since being diagnosed with diabetes you have noticed that you have been feeling depressed and stressed out. Both of these feelings have been interfering in your diabetes management and your motivation and confidence levels are low. You have never felt this way before and are wondering how you can better deal with these feelings. What can you do to start addressing these feelings so that you can feel more confident and motivated to manage your diabetes?

- Talk about your feelings with friends and/or family members.
- Talk to your primary care doctor about your feelings of depression and stress.
- Just wait for these feelings to go away on their own.
- Two are correct

If “Talk about your feelings with friends and/or family members” or “Talk to your primary care doctor about your feelings of depression and stress” or “Two are correct” is selected a prompt appears stating, “Super! By getting support from others and talking about your feelings you may begin to feel less depressed and stressed out. Also others may be able to give some suggestions for dealing with these feelings. However, if your depressed feelings and stress continue to worsen you may want to see a counselor, therapist, psychologist, or psychiatrist in order to discuss these feelings. These

professionals can provide treatment as well as suggestions in order to help you to deal with these feelings and to find out where these feelings are coming from. Sometimes people need to take medication in order to decrease their depression and stress.”

If “Just wait for these feelings to go away on their own” is selected a prompt appears stating, “Incorrect, it is important for you to address these feelings because by doing nothing these feelings may worsen. As your depression and stress levels increase you will become less confident and less motivated in managing your diabetes. This will put you at risk for complications associated with diabetes. You will want to be as motivated and confident as you can in order to manage your diabetes. Having diabetes is not easy and you can have a fulfilling life in spite of it as long as you stay motivated and confident in your ability to overcome it.”

Situation 5. You have been recently diagnosed with diabetes and you are going to your first follow-up appointment with your primary care doctor. You completed blood lab work prior to this appointment to see what your hemoglobin A1C (HgbA1c) level is. You have had other doctor appointments in the past, but because of the new diabetes diagnosis you are anxious about this office visit. What things do you think will happen during this office visit?

- Your doctor will explain your HgbA1c results with you.
- Your weight and blood pressure will be checked.
- You will be given patient education information about diabetes as well as information about blood glucose monitoring and information about oral medication or insulin.
- You may be given a referral to an Endocrinologist, who is a specialist in treating people with diabetes.

All of the above will likely occur during this office visit.

If “Your doctor will explain your HgbA1c results with you” or “Your weight and blood pressure will be checked” or “You will be given patient education information about diabetes as well as information about blood glucose monitoring and information about oral medication or insulin” or “You may be given a referral to an Endocrinologist, who is a specialist in treating people with diabetes” or “All of the above will likely occur during this office visit” is selected a prompt appears stating, “Excellent! Each of these things will likely occur during this office visit. Your first office visit can be anxiety provoking because of your uncertainty about what will happen as well as all the new information you will be given in order for you to manage your diabetes. You should feel less anxious at each office visit after this as long as you are being an active member of the treatment team and following the recommendations of your doctor.”

When the module is completed a prompt appears stating, “Thank you for completing this section. Before moving on to the next modules take a moment to go back through this module to test your routine physician appointments-patient as member of treatment team knowledge.”

Proposed Program Evaluation Design

Patient focus group(s) were facilitated prior to the development of the Internet-based program to determine need, feasibility, and desirability. This feedback was compiled and included in the development of the disease management program. The actual evaluation of this program is beyond the scope of this study and is a topic for future research.

CHAPTER 4

Discussion

In 2001, Americans spent \$1.4 trillion on healthcare services, which was approximately 14% of the gross domestic product for the United States (Godin, 2005). Costs of providing health care services are rising between 8% to 12% annually, causing economic strain on business and industry (Godin, 2005). If these costs are not contained healthcare expenditures are estimated to approach 20% of gross domestic product by 2015 (Borger, Smith, Truffer, Keehan, Sisko, Poisal, Clemens, and Godin, 2006). The nation cannot tolerate the constant increase in costs.

Diabetes is a major contributor to these ever increasing healthcare costs. Diabetes is a chronic disease that has no cure and causes serious physical limitations and death. The medical treatment for diabetes and its complications are extremely costly. The cost to treat diabetes including the loss of productivity is estimated at \$102 billion per year and on average people with diabetes missed 8.3 days of work per year (Ciechanowski, Katon, Russo, and Walker, 2001 and Feifer and Tansman, 1999). The nationwide cost for treating late diabetic complications is over \$5 billion per year. These costs are predicted to rise as the baby boomer generation (people born between 1948 to 1963) ages, become at risk to be obese, and are more likely to be diagnosed with diabetes. Diabetes in the baby boomer generation and the elderly is emerging as one of the most significant health care problems of the 21st century (Kesaveadev, Short, and Nair, 2003). According to the Centers for Disease Control and Prevention (2003), the national cost to treat diabetes in the year 2050 is an estimated \$102 billion.

Because of the nature of chronic diseases such as diabetes, disease management varies over time, with treatments being adjusted to meet the needs of the patient's ever changing symptoms and therefore causing an increase in nonadherence (Warsi, Wang, LaValley, Avorn, & Solomon, 2004). Nonadherence is the main contributor to rising healthcare costs. Examples of nonadherence include poor motivation toward treatment protocol, poor attitude, limited understanding of disease state, limited ability to access disease management and patient education information, limited access to support groups or educational programs, poor self-efficacy to manage disease symptoms, limited transportation to appointments, and poor patient-physician communication (Grey and Barry, 2004; Gonder-Fredrick, Cox, and Ritterband, 2002; Feifer and Tansman, 1999; Cox and Gonder-Fredrick, 1992). According to Warsi, et al., (2004) strategies to reduce health care costs included decreasing the number of physician appointments, reducing the number of emergency room visits and hospital stays, increase patient productivity (i.e. taking less sick time off from work), increasing the patient's health literacy, increasing treatment adherence, and increasing the patient's motivation toward treatment. The development of an Internet-based disease management program for people with diabetes is needed to improve treatment adherence, health outcomes, and overall quality of life.

The Internet is emerging as a cost effective tool for health care providers to develop disease management programs to help reduce health care costs (Bush, Bowen, Wooldridge, Ludwig, Meischke, and Robbins, 2004). The Internet-based diabetes disease management program has been developed to improve adherence to treatment, provide patient education to increase the person's knowledge of diabetes and its complications, and to increase the person's confidence level in their ability to manage

their diabetes effectively. Healthcare costs may be reduced as a result of the development of the Internet-based diabetes disease management program. Healthcare costs can be reduced by decreasing the number of healthcare professional visits, hospital stays, and prescription costs. Traditional disease management companies spend approximately \$300-\$1000 per patient per year, while an Internet-based program may cost only around \$50 (Managed Care Week, 2000). Godin, Truschel, and Singh (2005) indicate the Internet has become a primary source of information for most people, young and old. The Internet has been used increasingly to obtain medical information on a variety of illnesses and disorders. This increased Internet usage for patient education information has spurred the development of disease management programs for medical conditions including cancer, hypertension, arthritis, etc. and has sparked greater understanding of disease symptoms and treatment (Godin, Truschel, and Singh, 2005). The Internet has become a tool for all ages to have immediate access to information 24 hours a day, seven days a week. Bush et. Al. (2004) stated as of March 2004, two-thirds or 66% of adults have Internet access. The US Department of Commerce (2004) reported that adults use the Internet to search for information on health services and practices 41.6% of the time when online. This is an increase from 34.1% in 2001. By harnessing the power of the Internet, people with diabetes can have unlimited access to patient education information whenever they need it.

Kim and Ladenson (2002) reviewed several Internet-based diabetes disease management programs and found that most web sites simply provided patient education information. The American Diabetes Association's web site includes patient education information on diagnosis and treatment. The National Institute of Diabetes and Digestive

and Kidney Diseases (NIDDK) web site provides information on diagnosis, treatment, monitoring, complications, experimental treatments, and alternative therapies.

The Joslin Diabetes Center's web site offers information to patients newly diagnosed with diabetes. The Diabetes Monitor web site provides general information about diabetes, types of diabetes, complications, coping strategies, medication, monitoring, and research. The Diabetes Monitor includes a "Diabetes 123" section that has answered 8000 specific questions about diabetes that have been screened by their team of specialists (Kim and Ladenson, 2002).

Diabetes Portal: Diabetes Living web site offers basic information about diabetes, diabetes management, parenting and children, complications, coping, and new research information. The New York Online Access to Health Project's web site contains information on care and treatment of diabetes, complications and related concerns, and information resources (Kim and Ladenson, 2002).

The Diabetic Gourmet Magazine's web site provides information on food selection and preparation. The Canadian Diabetes Association's web site offers a full color booklet and PDF version that clearly illustrates how to draw, mix, and inject insulin. The Children with Diabetes web site focuses on insulin pump therapy and provides information for and against insulin infusion therapy. The National Eye Institute's web site provides patient education information regarding diagnosis and treatment of diabetic retinopathy (Kim and Ladenson, 2002).

The Diabetes Resource Center's web site includes specific patient education information regarding basic foot care and prevention for foot ulcers and lower limb amputation. The Diabetes News web site focuses on maintaining an updated list of full-

text patient education articles focusing on the treatment of diabetes and its complications (Kim and Ladenson, 2002).

These programs provide a wealth of educational information, but lack the theory-driven, interactive nature to spur effective modifications in health behavior. Internet technology provides the power to develop programs that are interactive. The above mentioned programs are only using part of the total power that the Internet possess as a tool to develop more effective diabetes disease management programs. By integrating psychological theory with the interactive power of the Internet, diabetes disease management programs can be developed that will increase adherence to treatment protocol, increase patient education and empowerment, and decrease healthcare costs.

Application of the PRECEDE Planning Model to Diabetes Disease Management

By following the PRECEDE program planning model, problems were identified through the use of the focus groups, key informant interviews, and surveys. The learning modules were developed to address the problem areas and St. Clare's Health System Regional Diabetes Center staff were consulted to discuss the validity of the content of the learning modules and to determine how helpful each module would be in improving each problem area. By integrating Cognitive-behavioral and behavior theory in to each module, participants should begin to feel more confident in their ability to manage their diabetes. Participants should then begin to make positive changes in lifestyle through more adaptive health behavior and therefore, improving health outcomes. This improvement in self-efficacy, self-confidence, and self-esteem leads to greater adherence to treatment regimen, a reduction in medical complications, reduced healthcare costs, and overall improvement in the quality of life of people with diabetes.

In conversations with case managers, diabetes educators, and nurses at St. Clare's Health System Regional Diabetes Center, it was discovered that when participants complete the diabetes education classes, it has been difficult to monitor treatment adherence. By providing an educational program over the Internet linked to the St. Clare's Health System's website, diabetes center staff members could better monitor the progress of past participants as well as provide continued diabetes education within an interactive Internet-based program.

The Internet-based disease management program for people with diabetes that was developed followed the PRECEDE program planning model in order to integrate the needs of Saint Clare's Regional Diabetes Center and the needs of the participants. Participants from the St. Clare's Health System Regional Diabetes Center participated in focus groups and key informant interviews in order to determine the barriers, reinforcers, benefits, and consequences regarding ability to manage diabetes effectively. Participants completed two surveys that focused on diabetes knowledge and treatment adherence upon intake in to the diabetes center program. This information was synthesized and the problem areas were identified and integrated in to interactive learning modules that could be adopted by the St. Clare's Health System Regional Diabetes Center. As a result of the focus groups, key informant interviews, and surveys areas of need were identified including adherence to treatment regimen and basic knowledge about diabetes and its complications. Each learning module was developed to improve on the problem areas using cognitive-behavioral and behavior theory to increase the participants' adherence to treatment, boost their self-confidence to manage their diabetes effectively, and improve their quality of life.

The learning modules were developed using cognitive-behavioral and behavior theory. The cognitive-behavioral theories including the Social Cognitive Theory, Health Belief Model, the Transtheoretical Model, and the Self-Determination Theory heavily influenced the development of the learning modules. The most influential theories included the Social Cognitive Theory, the Transtheoretical Model, and the Self-Determination Theory. The behavior theories including the Theory of Reasoned Action and Theory of Planned Behavior made minor contributions to learning module development. The PRECEDE program planning model includes five content areas including Social Diagnosis, Epidemiological Diagnosis, Behavioral and Environmental Diagnosis, Educational Diagnosis, and Administrative and Policy Diagnosis. The Social Diagnosis focused on the patient's quality of life and was obtained through focus groups and key informant interviews with patients with diabetes as well as staff members from the Regional Diabetes Center at St. Clare's Health System. The Epidemiological Diagnosis focused on incidence and prevalence of diabetes and how the complications associated with diabetes can result in a poor quality of life for these patients. Complications and poor quality of life factors were prioritized by ranking the importance and severity. Complications included foot infection, kidney disease, heart disease, and nerve problems. This information was gathered through focus groups and key informant interviews. The Behavioral and Environmental Diagnosis focused on how both patient behavior and genetics play key roles in the diagnosis and treatment of diabetes. This information was gathered through the focus groups, key informant interviews, and survey data. The Educational Diagnosis assessed three factors that influence health care behavior. These factors are predisposing, enabling, and reinforcing. Predisposing factors

include pre-diagnosis health and exercise regimen (i.e., diet and weight management). Enabling factors include poor lifestyle, enabling relationship with family and friends, and poor attitude toward treatment. Reinforcing factors include positive aspects of diabetes disease management such as family support, adherence to diet and exercise programs, and positive attitude toward treatment. These factors were obtained by focus groups, key informant interviews, and surveys. The Administrative and Policy Diagnosis was obtained through conversations with staff members and administrators of the Regional Diabetes Center in order to obtain information on any hospital policies or procedures that may hinder the development of this Internet-based diabetes disease management program using the St. Clare's Health System web site.

The results of the focus groups and key informant interviews showed specific themes where the participants were struggling with their diabetes disease management. Problem areas identified from the first focus group question were physical and mental health complications such as nerve problems, high blood pressure, depressive symptoms, and stress. These complications may be integrated in to future modules and this website could include social support through "chat rooms" or a "buddy program" chat room. Areas of concern identified from the second focus group question included compliance to an exercise program and poor attitude toward adhering to treatment protocol. Areas of concern identified in the third question were weight management, stress management, and motivation toward treatment. The fourth question focused on the participant's strengths and reinforcing factors that aid in diabetes management. These factors include weight management, stress management, and social support. The fifth question identified both positive and negative contributing factors that affect diabetes management. Positive

contributing factors included exercise, motivation toward treatment, and diabetes knowledge. The negative contributing factors included poor diet, stress, and poor attitude toward treatment. The final question identified the participant's overall level of knowledge of diabetes and overall level of confidence to manage diabetes. Most participants felt they had adequate knowledge about diabetes and felt confident in their ability to manage diabetes. These findings are consistent with the conclusions of Buffler, England, and Fleming (2001) as well as Nichols-English and Poirier (2000). Both of these studies identified several areas of diabetes disease management that required improvement including patient education, improving hemoglobin A1c levels, vision care, foot care, and blood glucose monitoring. Both studies also indicated a need for greater adherence to diabetes treatment regimen in order to decrease complications and improve overall quality of life.

Given the results of the MDRTC Diabetes Knowledge Test participants struggled with identifying and understanding the symptoms and events associated with high and low blood glucose levels as well as how a high fat diet may cause physical complications and increase blood glucose. These findings are consistent with the conclusions of Cradock (2004) who found poor rates of adherence to blood glucose monitoring, and adherence to diet and exercise plans. The focus of the learning modules was to include questions and situations geared toward providing educational information in addition to attempting to enact health behavior change through improving self-efficacy and self-confidence.

The Diabetes Self-Management Profile results showed participants displaying low to moderate levels of adherence to all aspects of diabetes treatment regimen. These

results are consistent with the diabetes nonadherence studies of Cradock (2004), Buffler, England, and Fleming (2001), and Nichols-English and Poirier (2000). Each of these studies found poor rates of adherence to several aspects of diabetes disease management and treatment including diet, exercise, foot care, and blood glucose monitoring. The learning modules focused on improving adherence to treatment protocol by providing educational information with the goal of enacting positive health behavior change. Adherence to treatment protocol is required to reduce disability and physical complications of diabetes.

Flesch-Kincaid grade level readability statistics were conducted on the learning module information that would be presented to the user. The grade average of the learning modules was 9.1. The modules could be modified and major medical terms could be deleted. Since commonly known medical terms such as “diabetes” tend to inflate the readability index of health education material, these medical terms were removed to obtain a second readability assessment. When this was done, the grade level was reduced to 8.6. Therefore, users with an eighth grade education would be able to understand the material presented in the learning modules. Also this website could be developed to include a way to increase the font size to make the text larger to accommodate users with vision difficulties.

Limitations

The limitations of this program development dissertation include being unable to facilitate the focus groups and key informant interviews in-person; this information was gathered over the telephone. Forty-five of each survey was distributed and only 25 of the MDRTC Diabetes Knowledge Test and 24 of the Diabetes Self-Management Profile were

returned. Only 20 participants from the St. Clare's Health System Regional Diabetes Center volunteered to participate in the focus groups and key informant interviews with 19 reporting their ethnicity as "white". Participants were recruited by Regional Diabetes staff members to volunteer for the focus groups and key informant interviews and having 20 participants makes it difficult to generalize these findings to the population of people with diabetes. Therefore, the results may not be able to be generalized to racial and ethnic populations diagnosed with diabetes. These findings are particular to the patients from St. Clare's Health System and the development of future programs would need to collect data to access the needs of their local community. Finally, of the 20 participants, 18 were diagnosed with Type II diabetes and two were diagnosed with Type I diabetes. This causes some conflict because the treatment for Type II diabetes differs in terms of oral medication versus insulin injections as a primary treatment strategy. Therefore when insulin usage questions were raised in the surveys those participants diagnosed with Type II diabetes skipped those items causing some over-reporting of problems in insulin therapy.

The Internet itself can be a limitation as it lacks the personal touch of face-to-face interactions with healthcare providers. Some people with diabetes may not have access to the Internet or understand how to navigate the Internet to get the information they are seeking. Also, the quality and accuracy of information on the Internet is cause for concern. Many healthcare related websites are sponsored by major medical and pharmaceutical companies and therefore may only present information that is supportive of their products or hypotheses. Many of these healthcare websites are not monitored closely for accuracy of information and this lack of regulation leads to the presentation of

biased and faulty information. It should be noted that when considering medical and healthcare information from the Internet it is important to check to see who is sponsoring the information and if questions arise, it is recommended that patients discuss them with healthcare professionals. The learning modules developed for this Internet-based diabetes disease management program has a grade reading level range of 8.6 to 9.1 meaning that those with less than a ninth grade education may have difficulty understanding some of the material that is presented.

Iddekinge, Raymark, and Roth (2005) and Naquin and Paulson (2003) found that patients tended to respond to interview and assessment questions more honestly and accurately when these questions are presented on a computer compared to when the same questions are asked face-to-face by an interviewer. Therefore a lack of face-to-face interactions with physicians and other healthcare providers may be beneficial.

Implications

The implications of this program development dissertation can be far reaching. There are approximately 100 million Americans that suffer from some type of chronic disease and more than \$650 billion is spent each year managing these diseases (Centers for Disease Control and Prevention, 2003). Mukhtar, Jack, Martin, Murphy, and Rivera (2006) reported in their *Healthy People 2010* article that the national average of people diagnosed with diabetes continues to rise since their last survey in 2000. The *Healthy People 2010* diabetes objectives include annual foot exams, hemoglobin A1c tests, and annual eye exams (2006). The development of Internet-based disease management programs for chronic diseases such as diabetes is emerging as an effective tool to reduce increasing national healthcare costs. Currently, major pharmaceutical companies are

researching and developing Internet-based disease management programs on a much larger scale with large budgets. Many of these disease management programs provide only patient education information. This diabetes disease management program was developed using a pretest-posttest design integrating Cognitive-behavioral and behavior change theory with patient education information presented in an interactive manner. The learning modules that were developed can also be expanded upon and new modules can be added in order to meet the ever changing patient needs. The integration patient education information with Cognitive-behavioral and behavior change theory increases the level of patient self-efficacy and self-confidence, therefore, improving adherence to treatment regimen. There is a growing body of research focused on the application of psychological theory to diabetes disease management. Alfred Bandura's Social Cognitive/ Social Learning Theory have been applied to diabetes treatment adherence. Norris, Engelgau, and Narayan (2001) showed that integrating Social Cognitive Theory with diabetes patient education information improved compliance to treatment regimen and patients displayed greater knowledge about diabetes. Von Korff, Gruman, Schaefer, et. al. (1997) and Anderson (1990) showed that by incorporating Social Cognitive and Social Learning Theory to diabetes disease management, patients' self-efficacy to self-manage diabetes increased and showed improvement in quality of life. Bernal, Woolley, Schensul, and Dickinson (2000) and Chang and Lin (1997) showed that patient reports of self-efficacy and self-confidence increased when educational information was integrated with positive feedback from diabetes educators and healthcare professionals. Wagner, Austin, and Von Korff (1996) and Mullen, Green, and Persinger (1985) found that patient's self-efficacy or confidence to manage their chronic disease increased as a result

of integrating social cognitive and social learning concepts to disease management. Po (2000) showed the use of telecommunication strategies as a means of providing patient education to increase patient self-efficacy. Po found that by altering the delivery of diabetes patient education information, self-efficacy and self-management increased as a function of patients having greater access to information.

Directions for Future Research

Future research using Cognitive-behavioral and behavior theories can be applied to disease management and should focus on the relationship between patient motivation and compliance to treatment. Goldring, Taylor, Kemeny, and Anton (2002) studied the Health Belief Model and found a relationship between patient motivation and treatment adherence. When patients are motivated to make positive healthcare decisions, adherence increases. Skinner, Hampson, and Fife-Schaw (2002) integrated the Health Belief Model to diabetes treatment and found when patients displayed a positive perception of diabetes their motivation and adherence to treatment were higher compared to those with a negative perception.

Cognitive-behavioral and behavioral interventions integrated with patient education has helped to change patient health care behavior as well as to make the patient a more active member in their diabetes disease management. Cognitive-behavioral interventions have helped patients to develop coping skills, competence, and mastery in managing their diabetes (Grey and Barry, 2004). This improvement has been made possible by retraining patients to develop and replace their maladaptive health care behavior and attitudes with more adaptive ones. This change in behavior and attitude has helped patients to better self-manage their diabetes (Grey and Barry, 2004). Krichbaum,

Aarestad, and Buethe (2003) found that by combining Cognitive-behavioral and behavioral interventions with diabetes patient education that patients became more motivated to care for themselves, actively sought out additional information about diabetes, and adjusted their behavior to improve their lifestyle. These improvements increased patient self-efficacy and self-management. Finally, Steed, Cooke, and Newman (2003) found that patients with diabetes had co-morbid psychological problems including depression, anxiety, adjustment issues, and quality of life issues. Patients that participated in Cognitive-behavioral and self-management patient education programs decreased their symptoms of depression and anxiety. Patients also experienced a decrease in adjustment issues and improved quality of life (Steed, Cooke, and Newman, 2003). After considering these findings, psychologists and health psychology can have an important impact on diabetes and chronic disease management. Psychological interventions can be used to increase treatment adherence and modify health behaviors, and reduce emotional complications associated with diabetes and chronic disease. Integrating psychological interventions in to primary care and medical settings can help to reduce overall healthcare costs.

This program development dissertation was conducted using a much smaller segment of the population diagnosed with diabetes. This Internet-based diabetes disease management program was developed to aid the surrounding community served by St. Clare's Health System Regional Diabetes Center. The staff from the Regional Diabetes Center hopes that when this Internet program is implemented they will have greater ability to monitor former participants and these former participants will have greater

access to diabetes disease management and patient education information. These former participants will also have access to the Regional Diabetes Center staff through e-mail.

The actual implementation and evaluation of this diabetes disease management program is beyond the scope of this dissertation and should be the basis of future research in diabetes disease management. Future efforts involving the staff at St. Clare's Health System Regional Diabetes Center could focus on the pilot implementation and preliminary evaluation of this program which could include patient feedback. Once programmatic changes are made, a comparison study could be conducted, comparing traditional disease management approaches to this Internet based diabetes disease management program. This type of study could be funded by the St. Clare's foundation; possible outcomes (dependent variables) could be patient satisfaction, diabetes knowledge, as well as self-efficacy to self manage diabetes, treatment adherence, and overall complications with diabetes.

This Internet-based diabetes disease management program can be modified to include artificial intelligence to prompt patients with questions about their diabetes management and direct them to modules that may be beneficial to the patient. This diabetes disease management program could also be implemented in kiosks to be located within waiting rooms at physician offices and diabetes education settings. Future additional module development could occur regarding nerve problems, high blood pressure, stress, and depressive symptoms based on additional needs assessment feedback from patients. Last, additional modules could be provided to educate family members and significant others related to the diabetes self management and the need for social support in effective familial management of diabetes.

References

- Ajzen, I. and Fishbein, M. (1977). Attitude-behavior relations: a theoretical analysis and review of empirical research. *Psychology Bulletin*, 84, 888-918.
- Ajzen, I. and Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. Englewood Cliffs, NJ: Prentice Hall.
- Ajzen, I. (1985). From intentions to action: a theory of planned behavior. In J. Kuhl and J. Beckman (Eds.), *Action-control: From cognition to behavior* (pp. 11-39). Heidelberg, Germany: Springer.
- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, 50, 179-211.
- Albarracin, D., Johnson, B. T., Fishbein, M., and Muellerleile, P. A. (2001). Theories of reasoned action and planned behavior as models of condom use: a meta-analysis. *Psychological Bulletin*, 127, 142-161.
- Aljaseem, L. I., Peyrot, M., Wissow, L., and Rubin, R. R. (2001). The impact of barriers and self-efficacy on self-care behaviors in type 2 diabetes. *Diabetes Education*, 3, 393-404.
- American Diabetes Association. (1997). National standards for diabetes self management education programs and American Diabetes association review criteria. *Diabetes Care*, 20, S67-S70.
- American Diabetes Association. (2003). Preventive foot care in people with diabetes. *Diabetes Care*, 26, S78-S79.
- American Diabetes Association. (2003). Diabetic nephropathy. *Diabetes Care*, 26, S94-S98.

- American Diabetes Association. (2003). Standards of medical care for patients with diabetes mellitus. *Diabetes Care*, 26, S33-S50.
- American Diabetes Association. (2004). Third-party reimbursement for diabetes care, self-management education, and supplies. *Diabetes Care*, 27, S136-S137.
- American Diabetes Association. (2004). Physical activity/exercise and diabetes. *Diabetes Care*, 27, S58-S62.
- Armitage, C. J., Sheeran, P., and Conner, M. (2004). Stages of change or changes of stage? Predicting transitions in transtheoretical model stages in relation to healthy food choice. *Journal of Consulting and Clinical Psychology*, 72, 491-499.
- Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review*, 84, 191-215.
- Bandura, A. (1977). Analysis of self-efficacy theory of behavioral change. *Cognitive Therapy and Research*, 1, 287-308.
- Bandura, A. (1986). *Social foundations of thought and action*. Englewood Cliffs, NJ: Prentice Hall.
- Bandura, A. (1997). *Self-efficacy: the exercise of control*. New York: Freeman.
- Bate, K. L. and Jerums, G. (2003). Preventing complications of diabetes. *MJA*, 179, 498-503.
- Beck, J. S. (1995). *Cognitive therapy: basics and beyond*. New York: Guildford Press.
- Berardis, G. D., Pellegrini, F., Franciosi, M., Belfiglio, M., Nardo, B. I., et. al. (2004). Physician attitudes toward foot care education and foot examination and their correlation with patient practice. *Diabetes Care*, 27, 286-287.

- Bernal, H., Woolley, S., Schensul, J. J., and Dickinson, J. K. (2000). Correlations of self-efficacy in diabetes self-care among Hispanic adults with diabetes. *Diabetes Education*, 4, 673-680.
- Birke, J. A. and Rolfsen, R. J. (1998). Evaluation of a self-administered sensory testing tool to identify patients at risk of diabetes related foot problems. *Diabetes Care*, 21, 23-25.
- Blanchard, C. M., Courneya, K. S., Rodgers, W. M., Daub, B., & Knapik, G. (2002). Determinants of exercise intention and behavior during and after phase 2 cardiac rehabilitation: an application of the theory of planned behavior. *Rehabilitation Psychology*, 47, 308-323.
- Bodenheimer, T. (2003). Strategies to improve diabetes care. Retrieved on January 14, 2005, from <http://www.aafp.org/afp/20031015/editorials.html>
- Borger, C., Smith, S., Truffer, C., Keehan, S., Sisko, A., Poisal, J., Clemens, M. K., and Godin, S. (2006). Health spending projections through 2015: changes on the horizon. *Health Affairs*, 2, 61-73.
- Bush, N. E., Bowen, D. J., Wooldridge, J., Ludwig, A., Meischke, H., and Robbins, R. (2004). What do we mean by Internet access? A framework for health researchers. *Preventing Chronic Disease Public Health Research, Practice, and Policy*, 1, 1-17.

- Centers for Disease Control and Prevention. (2001). Strategies for reducing morbidity and mortality in diabetes through health-care system interventions and diabetes self-management education in the community. Retrieved on January 14, 2005, from <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5016a1.htm>
- Centers for Disease Control and Prevention. (2003). Preventing diabetes and its complications. Retrieved on March 27, 2003, from http://www.cdc.gov/nccdphp/pe_factsheet/pe_ddt.htm
- Centers for Disease Control and Prevention. (2003). Diabetes: a serious public health problem. Retrieved on March 27, 2003, from http://www.cdc.gov/nccdphp/bb_diabetes/
- Chang, F. T. and Lin, C. C. (1997). Using self-efficacy in assessing self-care to the IDDM patients. *Kaohsiung Journal of Medical Science*, 6, 351-359.
- Ciechanowski, P. S., Katon, W. J., Russo, J. E., & Walker, E. A. (2001). The patient-provider relationship: attachment theory and adherence to treatment in diabetes. *American Journal of Psychiatry*, 158, 29-35.
- Conner, M., Norman, P., and Bell, R. (2002). The theory of planned behavior and healthy eating. *Health Psychology*, 21, 194-201.
- Corbett, C. F. (1999). Research-based practice implications for patients with diabetes. Part II: diabetes self-efficacy. *Home Healthcare Nurse*, 9, 587-596.
- Courneya, K. S., Friedenreich, C. M., Arthur, K., and Bobick, T. M. (1999). Understanding exercise motivation in colorectal cancer patients: a prospective study using the theory of planned behavior. *Rehabilitation Psychology*, 44, 68-84.

- Courneya, K. S. (1995). Understanding readiness for regular physical activity in older individuals: an application of the theory of planned behavior. *Health Psychology*, 14, 80-87.
- Cox, D. J. and Gonder-Fredrick, L. (1992). Major developments in behavioral diabetes research. *Journal of Consulting and Clinical Psychology*, 60, 628-638.
- Cradock, S. (2004). Helping patients to improve self management of diabetes. *British Heart Journal*, 90, 36-38.
- Day, J. L., Coles, C., and Walford, S. (2003). Self-management in diabetes: training implications for professional careers. *Clinical Medicine*, 3, 338-341.
- Fauci, A. S., Braunwald, E. Isselbacher, K. J., Wilson, J. D., Martin, J. B., Kasper, D. L., et. al. (1998). *Harrison's principles of internal medicine*, 14th ed. New York: McGraw-Hill.
- Feifer, C. and Tansman, M. (1999). Promoting psychology in primary diabetes care. *Professional Psychology: Research and Practice*, 30, 14-21.
- Fishbein, M. and Ajzen, I. (1975). *Belief, attitude, intention, and behavior*. Reading, MA: Addison-Wesley.
- Fishbein, M. (1980). A theory of reasoned action: some applications and implications. In H. E. Howe Jr. & M. M. Page (Eds), *Nebraska Symposium on Motivation*, 1979, 27, 65-116. Lincoln University of Nebraska Press.
- Fitzgerald, J. T., Funnell, M. M., Hess, G. E., Barr, P. A., Anderson, R. M., Hiss, R. G., and Davis, W. K. (1998). The reliability and validity of a brief knowledge test. *Diabetes Care*, 21, 706-710.

Fong, D. S., Aiello, L., Gardner, T. W., King, G. L., Blankenship, G., Cavallerano, J. D., et. al. (2003). Diabetic retinopathy. *Diabetes Care*, 26, S99-S102.

Freudenberg, N., Eng, E., Flay, B., Parcel, G., Rogers, T., & Wallerstein, N. (1995). Strengthening individual and community capacity to prevent disease and promote health: in search of relevant theories and principles. *Health Education Quarterly*, 22, 290-306.

Funnell, M. (2004). Patient empowerment. *Critical Care Nursing Quarterly*, 27, 201-204.

Godin, S. (2005). *Technology applications in prevention: an introduction*. The Haworth Press, Inc.

Godin, S., Truschel, J. & Singh, V. (2005). Assessing quality assurance of self-help sites on the internet. *Journal of Prevention and Intervention in the Community*, 29, 67-84.

Goldman, K.D. and Schmalz, K. J. (2001). Focus on focus groups. *Health Promotion Practice*, 2, 14-19.

Goldring, A. B., Taylor, S. E., Kemeny, M. E., & Anton, P. A. (2002). Impact of health beliefs, quality of life, and the physician-patient relationship on the treatment intentions of inflammatory bowel disease patients. *Health Psychology*, 21, 219-228.

Gonder-Fredrick, L. A., Cox, D. J., and Ritterband, L. M. (2002). Diabetes and behavioral medicine: the second decade. *Journal of Consulting and Clinical Psychology*, 70, 611-625.

- Green, L. W., Kreuter, M. W., Deeds, S. G., & Partridge, K. B. (1980). *Health education planning: a diagnostic approach*. Palo Alto, CA: Mayfield Publishing Co.
- Green, L. & Kreuter, M. (1991). *Health Promotion Planning*. (2nd ed.). Mountain View: Mayfield Publishing Co.
- Grey, M. and Berry D. (2004). Coping skills training and problem solving in diabetes. *Current Diabetes Report*, 4, 126-131.
- Groth-Marnat, G. and Edkins, G. (1996). Professional psychologists in general health care settings: a review of the financial efficacy of direct treatment interventions. *Professional Psychology: Research and Practice*, 27, 161-174.
- Harris Interactive (2000). *Explosive growth of “cyberchondriacs” continues*. New York, NY: Harris Interactive.
- Harris, M.A., Wysocki, T, Sadler, M., Wilkinson, K., Harvey, L., Buckloh, L., Mauras, N., & White, N. H. (2000). Validation of a structured interview for the assessment of diabetes self-management. *Diabetes Care*, 23, 1301-1304.
- Health Promotion Inter-Change (1995). PRECEDE – A powerful planning tool.
- Health Resources and Services Administration (2001). Lower extremity amputation prevention program. Retrieved March 31, 2004, from <http://bphc.hrsa.gov/programs/LEAPprograminfo.htm>.
- Hedeker, D., Flay, B. R., and Petraitis, J. (1996). Estimating individual influences of behavioral interventions: an application of random-effects modeling to the theory of reasoned action. *Journal of Consulting and Clinical Psychology*, 64, 109-120.

- Hess-Fischl, A. (2004). Practical management of patient with diabetes in critical care: from a diabetes educator's perspective. *Critical Care Nursing Quarterly*, 27, 189-200.
- Iddekinge, C. H., Raymark, P. H., and Roth, P. L. (2005). Assessing personality with a structured employment interview: construct-related validity and susceptibility to response inflation. *Journal of Applied Psychology*, 3, 536-552.
- Inzucchi, S. E. (2001). Diabetes facts and Guidelines. *Yale Diabetes Center*.
- Joch, A. (2000). Can the web save disease management. Retrieved January 24, 2003, from http://www.healthcare-informatics.com/issues/2000/03_00cover.htm
- Johnston-Brooks, C. H., Lewis, M.A., and Garg, S. (2002). Self-efficacy impacts self-care and HbA1c in young adults with type I diabetes. *Psychosomatic Medicine*, 1, 43-51.
- Johnston, D. W., Johnston, M., Pollard, B., Kinmonth, A. L., & Mant, D. (2004). Motivation is not enough: prediction of risk behavior following diagnosis of coronary heart disease from the theory of planned behavior. *Health Psychology*, 23, 533-538.
- Jones, L. W., Courneya, K. S., Fairey, A. S., & Mackey, J. R. (2005). Does the theory of planned behavior mediate the effects of an oncologists' recommendation to exercise in newly diagnosed breast cancer survivors? Results from a randomized controlled trial. *Health Psychology*, 24, 189-197.
- Kesavadev, J. D., Short, K. R., and Nair, K. S. (2003). Diabetes in old age: an emerging epidemic. *Journal Association of Physicians India*, 51, 1083-1094.

- Knecht, M.C., Syrjala, A. M., Laukkanen, P., and Knuuttila, M. L. (1999). Self-efficacy as a common variable in oral health behavior and diabetes adherence. *European Journal of Oral Science*, 2, 89-96.
- Kohler, C. J., Fish, L. and Greene, P. G. (2002). The relationship of perceived self-efficacy to quality of life in chronic obstructive pulmonary disease. *Health Psychology*, 21, 610-614.
- Krichbaum, K., Aarestad, V., and Buethe, M. (2003). Exploring the connection between self-efficacy and effective diabetes management. *Diabetes Education*, 29, 653-662.
- Lowe, R., Bennett, P., Walker, I., Milne, S., and Bozionelos, G. (2003). A connectionist implementation of the theory of planned behavior: association of beliefs with exercise intention. *Health Psychology*, 22, 464-470.
- Lox, C. L. and Freehill, A. J. (1999). Impact of pulmonary rehabilitation on self-efficacy, quality of life, and exercise tolerance. *Rehabilitation Psychology*, 44, 208-221.
- Luna, B. and Feinglas, M. N. (2001). Oral agents in the management of type 2 diabetes mellitus. *American Family Physician*, 63, 1747-1780.
- Managed Care Week. (2000). Internet-based disease management poised to take off. Retrieved January 23, 2003, from <http://www.mcareol.com/mcolfree/mcolfre1/artcl604.htm>
- McKenzie, J. F., Smeltzer, J. C., & Neiger, B. L. (2005). *Planning, Implementing, and Evaluating Health Promotion Programs: A Primer*. (4th ed.). San Francisco: Pearson Education Inc.

- Morrison, D. M., Golder, S., Keller, T. E., and Gillmore, M. R. (2002). The theory of reasoned action as a model of marijuana use: tests of implicit assumptions and applicability to high-risk young women. *Psychology of Addictive Behaviors*, 16, 212-224.
- Mukhtar, Q., Jack, L., Martin, M., Murphy, D., and Rivera, M. (2006). Evaluating progress toward healthy people 2010 national diabetes objectives. *Preventing Chronic Disease*, 3.
- Naquin, C. E. and Paulson, G. D. (2003). Online bargaining and interpersonal trust. *Journal of Applied Psychology*, 88, 113-120.
- Nichols-English, G. and Poirier, S. (2000). Optimizing adherence to pharmaceutical care plans. *Journal of American Pharmacology Association*, 40, 475-485.
- Nilasena, D. S. and Lincoln, M. J. (1995). A computer-generated reminder system improves physician compliance with diabetes preventive care guidelines. *American Medical Informatics Association*, 1, 640-645.
- Norris, S. L., Engelgau, M. M., and Narayan, K. M. (2001). Effectiveness of self-management training in type 2 diabetes. *Diabetes Care*, 24, 561-587.
- Norris, S. L., Lau, J., Smith, S. J., Schmid, C. H., & Engelgau, M. M. (2002). Self-management education for adults with type 2 diabetes. *Diabetes Care*, 25, 1159-1171.
- NUA, (2000). *How many online*. Dublin, Ireland: NUA, LTD.
- O'Reilly, M. (1999). Is internet-based disease management on the way? *Canadian Medical Association Journal*, 160, 1039.

- Parmet, S., Glass, T. J., and Glass, R. M. (2005). Diabetic foot ulcers. *Journal of the American Medical Association*, 12, 260.
- Pew Internet and American Life Project (2000). *The online health care revolution: how the web helps Americans take better care of themselves*. Washington, DC: Pew Research Center.
- Po, Y. M. (2000). Telemedicine to improve patient's self-efficacy in managing diabetes. *Journal of Telemedicine Telecare*, 5, 263-267.
- Prochaska, J. O. and DiClemente, C. C. (1983). Stages of processes of self-change in smoking: towards an integrative model of change. *Journal of Consulting and Clinical Psychology*, 51, 390-395.
- Prochaska, J. O. and DiClemente, C. C. (1984). *The transtheoretical approach: crossing the traditional boundaries of change*. Homewood, IL: Irwin.
- Quinn, L. (2004). Educating patients with diabetes about cardiovascular disease risk. *Progress in Cardiovascular Nursing*, 19, 107-113.
- Rhodes, F., Fishbein, M., and Reis, J. (1997). Using behavioral theory in computer-based health promotion and appraisal. *Health Education & Behavior*, 24, 20-34.
- Robert Wood Johnson Foundation (2001). *The e-health landscape*. Princeton, NJ: Robert Wood Johnson Foundation.
- Rosenstock, I. M. (1974). Historical origins of the health belief model. *Health education Monograph*, 2, 328-335.

- Rothman, R. L., DeWalt, D. A., Malone, R., Bryant, B., Shintani, A., et. al. Influence of patient literacy on the effectiveness of a primary care-based diabetes disease management program. *Journal of the American Medical Association*, 292, 1711-1716.
- Sarvela, P. & McDermott, R. (1993). *Health Education Evaluation and measurement*. WCB Brown and Benchmark.
- Schifter, D. E. and Ajzen, I. (1985). Intention, perceived control, and weight loss: an application of the theory of planned behavior. *Journal of Personality and Social Psychology*, 49, 843-851.
- Senecal, C., Nouwen, A., and White, D. (2000). Motivation and dietary self-care in adults with diabetes: are self-efficacy and autonomous self-regulation complementary or competing constructs. *Health Psychology*, 19, 452-457.
- Sheeran, P., Conner, M., and Norman, P. (2001). Can the theory of planned behavior explain patterns of health behavior change? *Health Psychology*, 20, 12-19.
- Skinner, T. C., Hampson, S. E., and Fife-Schaw, C. (2002). Personality, personal model beliefs, and self-care in adolescents and young adults with type 1 diabetes. *Health Psychology*, 21, 61-70.
- Soltis, M. (2002). Upgrading your medical documentation. *Practice Pointers*, 7, 22-26.
- Steed, L., Cooke, D., and Newman, S. (2003). A systematic review of psychosocial outcomes following education self-management and psychological interventions in diabetes mellitus. *Patient Education and Counseling*, 51, 5-15.
- Tufts Managed Care Institute. (2001). Disease management and the internet. Retrieved January 24, 2003, from www.tmci.org

- U. S. Department of Commerce (2004). *A nation online: entering the broadband Age*. Washington DC: Economics and Statistics Administration, National Telecommunications and Information Administration.
- U.S. Department of Commerce (2002). *A nation online: how Americans are expanding their use of the internet*. Washington DC: Economics and Statistics Administration, National Telecommunications and Information Administration.
- Warsi, A., Wang, P., LaValley, M. P., Avorn, J., & Solomon, D. H. (2004). Self-management education programs in chronic disease. *Arch Intern Med*, 164, 1641-1649.
- Whittermore, R., Melkus G. D., and Grey, M. (2003). Promoting lifestyle change in the prevention and management of type 2 diabetes. *Journal of the American Academy of Nurse Practitioners*, 15, 341-349.
- Wilkins, A. S. (1999). Expanding internet access for health care consumers. *Health Care Manage Review*, 24, 30-41.
- Willey, C., Redding, C., Stafford, J., Garfield, F., Geletko, S., Flanigan, T., Melbourne, K., et. al. (2000). Stages of change for adherence with medication regimens for chronic disease: development and validation of a measure. *Clinical Therapeutics*, 22, 858-871.
- Williams, G. C., Freedman, Z. R., and Deci, E. L. (1998). Supporting autonomy to motivate patients with diabetes for glucose control. *Diabetes Care*, 21, 1644-1651.

Williams, G. C., Rodin, G. C., Ryan, R. M., Grolnick, W. S., and Deci, E. L. (1998).

Autonomous regulation and long-term medication adherence in adult outpatients.

Health Psychology, 17, 269-276.

Appendix

Table 2

Focus Group Questions

1. In managing your diabetes to stay as healthy as you can, how has this impacted your quality of life in either a positive or negative way?
2. What are some behaviors or attitudes you will need to change in order to have a fulfilling life with diabetes?
3. What are some barriers (weaknesses or limitations) that may hinder your ability to manage your diabetes effectively? (i.e., money problems or limited social support)
4. What are some reinforcing factors (strengths or assets) that may help you in managing your diabetes effectively? (i.e., social and family support)
5. What are the contributing factors (positive or negative) that will affect your management of diabetes?
6. Overall, how would you rate your current knowledge about diabetes and your current confidence level in your ability to manage your diabetes?

Table 3

MDRTC Diabetes Knowledge Test

Instructions: Read each item carefully and answer truthfully as it applies to you. Do not ask significant others, family members, spouse, or friends for help. Only your honest responses will aid in determining your knowledge about having diabetes.

There are 23 items, please answer each item by circling the letter next to your choice.

1. The diabetes diet is:
 - a. The way most American people eat
 - b. A health diet for most people
 - c. Too high in carbohydrate for most people
 - d. Too high in protein for most people

2. Which of the following is highest in carbohydrate?
 - a. Baked chicken
 - b. Swiss cheese
 - c. Baked potato
 - d. Peanut butter

3. Which of the following is highest in fat?
 - a. Low fat milk
 - b. Orange juice
 - c. Corn
 - d. Honey

4. Which of the following is a “free food”?
 - a. Any unsweetened food
 - b. Any dietetic food
 - c. Any food that says “sugar free” on the label
 - d. Any food that has less than 20 calories per serving

5. Glycosylated hemoglobin (hemoglobin A1) is a test that is a measure of your average blood glucose level for the past:
 - a. Day
 - b. Week
 - c. 6-10 weeks
 - d. 6 months

6. Which is the best method for testing blood glucose?
 - a. Urine testing
 - b. Blood testing
 - c. Both are equally good

7. What effect does unsweetened fruit juice have on blood glucose?
 - a. Lowers it
 - b. Raises it
 - c. Has no effect

8. Which should not be used to treat low blood glucose?
 - a. 3 hard candies
 - b. ½ cup orange juice
 - c. 1 cup diet soft drink
 - d. 1 cup skim milk

9. For a person in good control, what effect does exercise have on blood glucose?
 - a. Lowers it
 - b. Raises it
 - c. Has no effect

10. Infection is likely to cause:
 - a. An increase in blood glucose
 - b. A decrease in blood glucose
 - c. No change in blood glucose

11. The best way to take care of your feet is to:
 - a. Look at and wash them each day
 - b. Massage them with alcohol each day
 - c. Soak them for one hour each day
 - d. Buy shoes a size larger than usual

12. Eating foods lower in fat decreases your risk for:
 - a. Nerve disease
 - b. Kidney disease
 - c. Heart disease
 - d. Eye disease

13. Numbness and tingling may be symptoms of:
 - a. Kidney disease
 - b. Nerve disease
 - c. Eye disease
 - d. Liver disease

14. Which of the following is usually not associated with diabetes?
 - a. Vision problems
 - b. Kidney problems
 - c. Nerve problems
 - d. Lung problems

15. Signs of ketoacidosis include:
- Shakiness
 - Sweating
 - Vomiting
 - Low blood glucose
16. If you are sick with the flu, which of the following changes should you make:
- Take less insulin
 - Drink less fluids
 - Eat more proteins
 - Test for glucose and ketones more often
17. If you have taken intermediate-acting insulin (NPH or Lente), you are most likely to have an insulin reaction in:
- 1 to 3 hours
 - 6 to 12 hours
 - 12 to 15 hours
 - more than 15 hours
18. You realize just before lunch time that you forgot to take your insulin before breakfast. What should you do now?
- Skip lunch to lower blood glucose
 - Take the insulin that you usually take at breakfast
 - Take twice as much insulin as you usually take at breakfast
 - Check your blood glucose level to decide how much insulin to take
19. If you are beginning to have an insulin reaction, you should:
- Exercise
 - Lie down and rest
 - Drink some juice
 - Take regular insulin
20. Low blood glucose may be caused by:
- Too much insulin
 - Too little insulin
 - Too much food
 - Too little exercise
21. If you take your morning insulin but skip breakfast your blood glucose level will usually:
- Increase
 - Decrease
 - Remain the same

22. High blood glucose may be caused by:
- a. Not enough insulin
 - b. Skipping meals
 - c. Delaying your snack
 - d. Large ketones in your urine
23. Which one of the following will most likely cause an insulin reaction:
- a. Heavy exercise
 - b. Infection
 - c. Overeating
 - d. Not taking your insulin

MDRTC Diabetes Knowledge Test Answer Key

- 1. B
- 2. C
- 3. A
- 4. D
- 5. C
- 6. B
- 7. B
- 8. C
- 9. A
- 10. A
- 11. A
- 12. C
- 13. B
- 14. D
- 15. C
- 16. D
- 17. B
- 18. D
- 19. C
- 20. A
- 21. B
- 22. A
- 23. A

Fitzgerald, J.T., Funnell, M. M., Hess, G. E., Barr, P. A., Anderson, R. M.,

Hiss, R. G., & Davis, W. K. (1998). The reliability and validity of a brief

Diabetes knowledge test. *Diabetes Care*, 21, 706-710.

Table 4

Diabetes Self-Management Profile

Introduction:

Taking care of diabetes means doing a lot of different things like taking shots, doing blood sugar tests, following a meal plan, getting exercise, and dealing with low and high blood sugars. It's not easy doing all of these things exactly the way doctors and nurses might want. Very few people with diabetes do everything exactly according to plan. Sometimes there are other things that grab your attention or you might just forget to take care of your diabetes, even though you may have wanted to. Most people with diabetes, and their families, develop their own habits for taking care of their diabetes that are comfortable for them. What we're trying to learn in this survey (or interview) is what you and your family usually do to take care of your diabetes. Your answers won't be shared with anyone else, so you can feel comfortable telling me exactly what you do, not just what you think you're supposed to do or what you think I want you to say. So, try to be completely honest with me about what you and your family have usually done in taking care of diabetes in the past three months.

Instructions:

Please read each section carefully and answer the questions following each paragraph by placing an "x" next to your choice. Please answer all questions honestly as it applies to your diabetes care.

Exercise

One part of taking care of diabetes is getting regular exercise, like running, bike riding, and swimming. Some people manage to do this very regularly, while others have a hard time finding the time to get enough exercise. In this part, I'll be asking you about your exercise habits. This could be something like taking part in sports, PE at school, or walking or riding your bike. Try to be honest and accurate as you can about your exercise habits in the past three months.

What kind of exercise do you get?

In the past three months, how often have you gotten one of those kinds of exercise for at least 20 minutes?

ADHERE #1: Exercise

- (4)___ More than 3 weeks
- (3)___ 2 to 3 weeks
- (1)___ 1 month
- (0)___ Less than 1 month

ADH1 = ____ (0-4)

If you get more exercise than usual, or if you plan to get more exercise, do you make changes in your diet or insulin?

If “yes” – what do you do?

ADHERE #2: Exercise, Diet, and Insulin

- (4)___ always eats MORE or gives LESS insulin
- (3)___ frequently eats MORE or gives LESS insulin(2-3 times a wk)
- (2)___ sometimes eats MORE or gives LESS insulin (Once a wk)
- (1)___ occasionally eats MORE or gives LESS insulin(3 times a mon)
- (0)___ eats LESS than usual or gives MORE insulin or does not adjust diet or insulin

ADH2 = ____ (0-4)

If you get less exercise than usual, or if you plan to get less exercise, do you make changes in your diet or insulin?

If “yes” – what do you do?

ADHERE #3: Exercise, Diet, and Insulin

- (4)___ always eats LESS or gives MORE insulin
- (3)___ frequently eats LESS or gives MORE insulin(2-3 times a wk)
- (2)___ sometimes eats LESS or gives MORE insulin (Once a wk)
- (1)___ occasionally eats LESS or gives MORE insulin (3 time a mon)
- (0)___ eats MORE than usual or gives LESS insulin or does not adjust diet or insulin

ADH3 = ____ (0-4)

Hypoglycemia

Everyone with diabetes has low blood sugar reactions now and then. Your doctor and nurses have probably taught you some things to do to keep low blood sugars from happening and to take care of yourself when they do happen. This part is about what you usually do about low blood sugar reactions. Try to be as honest and accurate as you can about what you did about low blood sugar in the past three months.

What do you feel when you have an insulin reaction or when your sugar is low?

How do you tell when your blood sugar is too low? (check the ones that apply to you)

- | | | |
|------------------------------------------------------------------------|-----------------------------------------|-----------------------------------|
| <input type="checkbox"/> trembling | <input type="checkbox"/> fatigue/sleepy | <input type="checkbox"/> crying |
| <input type="checkbox"/> hunger | <input type="checkbox"/> headache | <input type="checkbox"/> weakness |
| <input type="checkbox"/> light-headed | <input type="checkbox"/> queasy stomach | <input type="checkbox"/> sweating |
| <input type="checkbox"/> pounding heart | <input type="checkbox"/> anxious/tense | |
| <input type="checkbox"/> cranky/irritable | | |
| <input type="checkbox"/> can't concentrate/difficulty paying attention | | |
| <input type="checkbox"/> other: _____ | | |

Do you keep something handy in case you have an insulin reaction or your sugar gets too low?

For example, when you are out or at a ball game, or in the car and your sugar gets too low, do you have something handy to eat?

ADHERE #4: Sugar Available

1. YES ___ (1) 2. NO ___ (0)

ADH4 = ___ (0,1)

People manage low blood sugars in many different ways. What do you usually do to treat your low blood sugar reactions?

ADHERE #5: Treating Low Blood Sugar

- (4) ___ careful to quickly take the prescribed amount of carbohydrates (15gm if applicable) and test blood if possible after ten minutes
- (3) ___ take prescribed amount if carbs and goes on (does not test)
- (2) ___ take carbs (not the prescribed amount) without considering how much
- (1) ___ continue treatment until symptoms go away
- (0) ___ ignore symptoms until (s)he gets a chance to do something (waiting until it is convenient to treat symptoms)

ADH5 = ___ (0-4)

Do you wear or carry anything that identifies you as having diabetes, like a card or bracelet?

ADHERE #6: Identification

- (2) ___ wears necklace, bracelet, or charm
- (1) ___ carries billfold identification card only
- (0) ___ no diabetic identification readily available

ADH6 = ___ (0-2)

Diet

Doctors, nurses, and dieticians ask people with diabetes to follow a meal plan and to try to eat about the same each day. Lots of things can get in the way of doing this and, even when they try their best, many people still struggle with eating exactly according to the plan. In this part I'll be asking about your eating habits. Try to be as honest and accurate as you can about your eating habits in the past three months.

Do you weigh your food, count carbs, or use exchanges to figure out how much you should eat, or do you generally eat the same amounts of food without using exchanges or counting carbs? If you use exchanges, what exchanges do you have at breakfast?

ADHERE #7: Measurement of Diet

- (3)___ uses the exchange list or carb counting as a guide and weighs food or reads labels
- (2)___ uses the exchange list or carb counting as a guide, but knows diet well enough so that (s)he can eat the right amounts without weighing or reading labels
- (1)___ eats about the same amounts of food each meal, but doesn't weigh or use exchange list or carb counting
- (0)___ eats the amount (s)he is hungry for and doesn't follow any set patterns of types or amounts of foods

ADH7 = ___ (0-3)

It is not always possible for people to eat at the same time every day. Do you ever "delay" eating or not eat when you should? This does not include times when your sugar is too high and you need to wait before eating. For example, if you were supposed to eat at 12:00 noon and you didn't eat until 12:30 or 1:00.

In the past three months, how many times have you delayed meals when you shouldn't have delayed?

ADHERE #8: Delay of Meals

- (4)___ never delay
- (4)___ seldom delay (1-2 times a quarter)
- (3)___ occasionally (3 times a month)
- (2)___ sometimes (1 time a week)
- (1)___ frequently (2-3 times a week)
- (0)___ almost always (4 or more times a week)

ADH8 = ___ (0-4)

Most people with diabetes have trouble eating all their meals. Are there ever times when you "skip" eating your meals or when you don't eat at all when you should without making adjustments in your insulin? This does not include times when your sugar is too high or when you're sick. This might be when you skip lunch for example.

In the past three months, how many meals have you skipped?

ADHERE #9: Skipping Meals

- (4)___ never skip meals
 - (3)___ seldom skip meals (1 or 2)
 - (2)___ occasionally skip meals (3 or 4)
 - (1)___ sometimes skip meals (5 or 6)
 - (0)___ frequently skip meals (more than 6)
- ADH9 = ___ (0-4)

In the past three months, how many times have you made adjustments to your insulin dose when meals are skipped?

ADHERE # 10: Adjusting Insulin when Meals are Skipped

- (4)___ never skips without adjusting insulin
- (4)___ seldom (1-2 times a quarter) skips a meal without adjusting insulin.
- (3)___ occasionally (few times a month) skips a meal without adjusting insulin
- (2)___ sometimes (1 time a week) skips a meal without adjusting insulin
- (1)___ frequently (2-3 times a week) skips a meal without adjusting insulin
- (0)___ almost always (4 or more times a week) skips a meal without adjusting insulin

There are foods that we all should avoid such as sweets and fatty foods. Eating some of these foods is not necessarily bad for us. However, eating large amounts of sweets and/or fatty foods is not good for us. In the past three months, how often have you eaten excessive amounts (e.g., above and beyond your allotted carbs) of foods like cookies, cakes, ice cream, chips, pizza, French fries, hot dogs, or others?

ADHERE #11: Eats Foods that aren't on Diet Plan

- (4)___ never or hardly ever (1-2 times a quarter)
 - (3)___ occasionally (few times a month)
 - (2)___ Sometimes (once a week)
 - (1)___ frequently (2-3 times a week)
 - (0)___ almost always (4 or more times a week)
- ADH11 = ___ (0-4)

Do you sometimes eat “more” food than what’s on your diet plan (e.g., more carbs than allotted)? This does not include times when you should eat more when you get exercise or when your sugar gets low. This might be when you eat because you’re extra hungry or you might snack before dinner.

In the last three months, how often have you eaten more than what is recommended for your diet plan?

ADHERE #12: Eats More

- (4)___ never or hardly ever (1-2 times a quarter)
 - (3)___ seldom (once a month)
 - (2)___ occasionally (few times each month)
 - (1)___ frequently (2-3 times a week)
 - (0)___ almost daily (4 or more times a week)
- ADH12 = ___ (0-4)

If “yes” for eats more-If you eat more than you normally would, do you make any changes in your insulin or have you usually already given insulin/bolus? What do you do?

ADHERE #13: Eats More and Changes Insulin

- (1)___ gives more insulin when eats more
 - (0)___ gives less
 - (0)___ does not adjust insulin
- ADH13 = ___ (0-1)

Do you sometimes eat “less” food than what’s on your diet plan? This does not include when you exercise changes or when you’re sick or when your sugar is too high. This might be times when you just don’t feel like eating everything on your plate.

In the past three months, how often have you eaten less than what is recommended for your diet plan?

ADHERE #14: Eats Less

- (4)___ never or hardly ever (1-2 times a quarter)
 - (3)___ seldom (once a month)
 - (2)___ occasionally (few times each month)
 - (1)___ frequently (2-3 times a week)
 - (0)___ almost daily (4 or more times a week)
- ADH14 = ___ (0-4)

If “yes” for eats less-If you eat less than you normally would, do you make any changes in your insulin or have you already given your insulin/bolus? What do you do?

ADHERE #15: Eats Less and Changes Insulin

- (1)___ gives LESS insulin when eats less
 - (0)___ gives MORE insulin when eats less
 - (0)___ does not adjust insulin
- ADH15 = ___ (0-1)

Blood Glucose Testing

Some people do all of their blood sugar tests, but lots of others have trouble doing all the tests their doctor and nurses want them to do. Next, I'll be asking about your habits when it comes to testing your blood sugar. Try to be honest and accurate as you can about your testing habits in the past three months.

In the past three months, how often have you tested your blood?

ADHERE #16: Frequency of Blood Testing

- (4)___ 4 or more times daily
 - (3)___ 2 or 3 times daily
 - (2)___ at least once daily
 - (1)___ at least 4 times a week
 - (0)___ does not test, or tests less than 4 times weekly
- ADH16 =___ (0-4)

How often has the doctor suggested that you test?

Doctor Blood Testing: Doctor's Prescription of Blood Testing

- (4)___ at least 4 or more times daily
 - (3)___ at least 2-3 times daily
 - (2)___ at least once daily
 - (1)___ at least 4 times weekly
 - (0)___ does not know
- DBT =___(0-4)
- ADH17 =___ (0-4)

In the past three months, how often have you adjusted your insulin dose, your diet, or your exercise when your blood sugar test results were running high?

ADHERE #18

- (4)___ made an adjustment every time it was needed
 - (3)___ usually made an adjustment when needed (about 75% of the time)
 - (2)___ sometimes made an adjustment when needed (about 50% of the time)
 - (1)___ infrequently made an adjustment when needed (less than 50% of the time)
 - (0)___ never made an adjustment
- ADH18 =___(0-4)

Do you ever test your urine for ketones?

1. YES 2. NO

If "yes"-When do you test?

ADHERE #19: Frequency of Urine Testing

- (3)___ tests when sugar is high OR when sick
 - (2)___ tests only when sick
 - (1)___ rarely tests
 - (0)___ does not test for ketones
- ADH19 =___(0-3)

Insulin

Taking insulin shots includes measuring the doses carefully, taking the shots on time, and maybe changing your dose depending on your blood sugar test result. This is all very complicated and takes time that many people would prefer to spend doing other things. This part is about what you usually do about your insulin shots. Try to be totally honest when you answer these questions.

In the last three months, how often have you delayed taking your insulin? (For insulin pump users) In the last three months, how often have you delayed a bolus when you shouldn't have delayed?

ADHERE #20: Delaying Shots

- (4)___ never, always take insulin on time
 - (3)___ delayed once a month or less (1-3 in a quarter)
 - (2)___ delayed once a week or less
 - (0)___ delayed more than once a week
- ADH20 =___(0-4)

In the last three months, how often have you taken more than the prescribed amount of insulin? (For insulin pump users) In the last three months, how often have you bloused more insulin than you should have bloused?

ADHERE #21: Taking More than Prescribed Insulin

- (4)___ always took prescribed insulin
 - (3)___ took more than prescribed amount (1-3 times)
 - (2)___ took more than prescribed amount (4-6 times)
 - (1)___ took more than prescribed amount (7-10 times)
 - (0)___ took more than prescribed amount more than 10 times
- ADH21 =___ (0-4)

In the last three months, how often have you taken less than the prescribed amount of insulin? (For insulin pump users) In the last three months, how often have you bloused less insulin than you should have bloused?

ADHERE #22: Taking Less than Prescribed Insulin

- (4)___ always took the prescribed amount
 - (3)___ took less than prescribed amount (1-3 times)
 - (2)___ took less than prescribed amount (4-6 times)
 - (1)___ took less than prescribed amount (7-10 times)
 - (0)___ took less than prescribed amount more than 10 times
- ADH22 =___ (0-4)

In the past three months, how often have you missed giving an insulin shot because you forgot or were too busy? (For insulin pump users) In the last three months, how often have you missed a bolus because you forgot or were too busy or failed to give your basal insulin because your pump was not working or inserted?

ADHERE #23: Remembering to Take Shots

- (4)___ never forgot, always take insulin
 - (3)___ forgot once a month or less (1-3 in a quarter)
 - (2)___ forgot once a week or less
 - (0)___ forgot more than once a week
- ADH23 =___ (0-4)

Diabetes Self-Management Profile Score Sheet

Exercise	Hypoglycemia	Diet	Glucose Testing	Insulin
ADH1___	ADH4___	ADH7___	ADH16___	ADH20___
FREQ	EMERG	MEASURE	FREQ	DELAY
ADH2___	ADH5___	ADH8___	ADH17___	ADH21___
MORE	TREAT	DELAY	DIFFER	MORE
ADH3___	ADH16___	ADH9___	ADH18___	ADH22___
LESS	ID	SKIP	ADJUST	LESS
TYPE OF	SYMPTOMS	ADH10___	ADH19___	ADH23___
EXERCISE	trembling	SKIP ADJ	KETONE	SKIP
	light-headed	ADH11___	DBT___**	
	hungry	TABOO	DBT-ADH16=ADH17	
	heart pounding	ADH12___	4 0	
	sweating	MORE	3 1	
	weakness	ADH13___	2 2	
	crying	MORE ADJ	1 3	
	fatigue/sleepy	ADH14___	0 4	
	headache	LESS	**not added to total score	
	stomach upset	ADH15___		
	anxious/tense	LESS ADJ		
	cranky/irritable			
	other			
EXERCISE+HYPOT		+	DIETT+GLUCOSET+INSULINT=ADHT	
___ (0-12)	___(0-7)		___(0-29)	___(0-15) ___(0-16) _____
				(0-79)

Harris, M. A., Wysocki, T., Salder, M., Wilkenson, K., Harvey, L. M.,

Buckloh, L. M., Mauras, N., & White, N. H. (2000). Validation of a structured interview for the assessment of diabetes self-management.

Diabetes Care, 23, 1301-1304.

Table 5

Basic Information and Things I Can Do for Myself (Skin and Foot Care)

Skin and foot care: People with diabetes may be more prone to infections and may have decreased nerve sensations and circulation.

1. Look at your feet daily, including between your toes, for redness, or other changes in color, cracks, or sores that will not heal.
 2. Wash your feet with warm (not hot) water and mild soap; pat dry.
 3. Avoid going barefoot and protect your feet from extremes of hot and cold and other hazards.
 4. File or cut your toenails to follow the curve of your toe. If your nails are too thick for straight pocket clippers, or you have poor eyesight, consult your doctor or nurse.
 5. Use a cream or lotion to keep your skin soft, especially your feet (except between your toes).
 6. Wear Shoes that fit well and wear socks made of natural fibers (cotton, wool) to avoid blisters and other foot problems
-

Adapted from The Michigan Diabetes Research and Training Center
(www.med.umich.edu)

Table 6

Additional Information for Exercise

What kinds of physical activity should be part of my routine?

A comprehensive physical activity routine includes three kinds of activities:

- Aerobic Exercise
- Strength Training
- Flexibility Exercises

Aerobic Exercise

Aerobic exercise increases your heart rate, works your muscles, and raises your breathing rate. For most people, it's best to aim for a total of about 30 minutes a day, at least 5 days a week. If you haven't been very active recently, you can start out with 5 or 10 minutes a day and work up to more time each week. Or split up your activity for the day -- try a brisk 10-minute walk after each meal. If you're trying to lose weight, you may want to exercise more than 30 minutes a day. Here are some examples of aerobic exercise:

- Take a brisk walk (outside or inside on a treadmill)
- Go dancing
- Take a low-impact aerobics class
- Swim or do water aerobic exercises
- Try ice-skating or roller-skating
- Play tennis
- Stationary bicycle indoors

Strength Training

Strength training, done several times a week, helps build strong bones and muscles and makes everyday chores like carrying groceries easier for you. With more muscle, you burn more calories, even at rest. Here are some ways to do it:

- Join a class to do strength training with weights, elastic bands, or plastic tubes
- Lift light weights at home

Flexibility Exercises

Flexibility exercises, also called stretching, help keep your joints flexible and reduce your chances of injury during other activities. Gentle stretching for 5 to 10 minutes helps your

body warm up and get ready for aerobic activities such as walking or swimming. Your health care team can provide information on how to stretch.

Being Active Throughout The Day

In addition to formal exercise, there are many opportunities to be active throughout the day. Being active helps burn calories. The more you move around, the more energy you'll have. These strategies can help you increase your activity level:

- Walk instead of drive whenever possible
 - Take the stairs instead of the elevator
 - Work in the garden, rake leaves, or do some housecleaning every day
 - Park at the far end of the shopping center lot and walk to the store
-

Adapted from www.diabetes.org

Table 7

Exercise: Getting Started

These steps will help you get ready for a routine that's safe and enjoyable.

- Find out which activities will be safe for you. Talk to your health care team about which activities will be safe for you. Your health care provider's advice will depend on the condition of your heart, blood vessels, eyes, kidneys, feet, and nervous system. They may recommend that you have an exercise stress test to see how your heart reacts to exercise. If the tests show signs of disease, ask what physical activities will help you without making your conditions worse.
- Choose what you'll do and make detailed plans. Think about what activities are realistic for you and choose the ones you think you can do. Start slowly. Your activity should be somewhat challenging but not overly difficult. Write down exactly what you'll do, where and when you'll do it, how often, and for how long. Allow yourself to get into a routine. Be flexible and don't get discouraged. For example, I'll get off the bus one stop earlier. Don't be too hard on yourself if you can't. For example, if it's raining, you may not want to walk outside so you can choose a different activity. It's more important to reach your long-term goal than to follow the plan from day to day. Plan how you'll reward yourself for your efforts. For example, some people treat themselves to a movie when they meet their goal for the week.
- Learn your blood glucose response to exercise. Everyone's blood glucose response to exercise is different. Checking your blood glucose before and after exercise can show you the benefits of activity. You also can use the results of your blood glucose checks to prevent low blood glucose or high blood glucose.
- If your blood glucose is high before you exercise (above 300), physical activity can make it go even higher, so be cautious about doing something active. For those with type 1 diabetes, if your fasting glucose level is above 250 and you have ketones in your urine, it's best to avoid physical activity.
- Learn how to avoid low blood glucose (hypoglycemia). - Keep in mind that low blood glucose can occur during or long after physical activity. Low blood glucose is most likely if you:
 - *Take insulin or diabetes pill
 - *Skip a meal
 - *Exercise a long time
 - *Exercise strenuously

- If low blood glucose is interfering with your exercise routine, eating a snack before you exercise or adjusting your medication may help. Talk to your health care team about what is right for you. During activity, check your blood glucose if you notice symptoms such as hunger, nervousness, shakiness, or sweating. If your blood glucose is 70 or below, have 2 to 5 glucose tablets, ½ cup (4 ounces) of fruit juice, or ½ cup of a regular soft drink to raise your blood glucose. After 15 minutes, check your blood glucose again. If it's still below 70, have another serving and repeat these steps until your blood glucose is at least 70.
 - Plan to have water and snacks handy during activity. Drink plenty of water before, during, and after activity. If you are at risk for low blood glucose, always carry a source of carbohydrate so you'll be ready to treat low blood glucose.
 - Wear a medical identification bracelet, necklace, or a medical ID tag to protect you in case of emergency.
 - Decide how you'll keep track of your progress. You may find it motivating to write down what physical activity you've done each day. For example, you can make a note of what you did and how long you did it. Some people enjoy using a step counter, also called a pedometer, to see how far they've walked. Ask your health care team where to get one.
-

Adapted from www.diabetes.org

Table 8

Sample Food Log

Meal	Day # 1	Day # 2	Day # 3
Breakfast	Time: _____	Time: _____	Time: _____
Snack	Time: _____	Time: _____	Time: _____
Lunch	Time: _____	Time: _____	Time: _____
Dinner	Time: _____	Time: _____	Time: _____
Snack	Time: _____	Time: _____	Time: _____
Notes			

