

11-16-2004

# African American Women With Type 2 Diabetes: Understanding Self-Management

F Bridgett Rahim-Williams  
*University of South Florida*

Follow this and additional works at: <https://scholarcommons.usf.edu/etd>

 Part of the [American Studies Commons](#)

---

## Scholar Commons Citation

Rahim-Williams, F Bridgett, "African American Women With Type 2 Diabetes: Understanding Self-Management" (2004). *Graduate Theses and Dissertations*.  
<https://scholarcommons.usf.edu/etd/1208>

This Dissertation is brought to you for free and open access by the Graduate School at Scholar Commons. It has been accepted for inclusion in Graduate Theses and Dissertations by an authorized administrator of Scholar Commons. For more information, please contact [scholarcommons@usf.edu](mailto:scholarcommons@usf.edu).

African American Women With Type 2 Diabetes:

Understanding Self-Management

by

F. Bridgett Rahim-Williams

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
Department of Anthropology  
University of South Florida  
Tampa, FL

Major Professor: Michael V. Angrosino, Ph.D.  
Jay Sokolovsky, Ph. D.  
Nancy Romero-Daza, Ph.D.  
Lois LaCivita Nixon, Ph.D.  
Wayne Westhoff, Ph.D.  
Howard N. Jacobson, M.D.

Date of Approval:  
November 16, 2004

Keywords: minority health, women's health, health education,  
health communication, glucose control

© Copyright 2004 F. Bridgett Rahim-Williams

## DEDICATION

I dedicate this dissertation to my mom, Mrs. Uradell Newkirk, my best mentor and role model, my children, Ameenah and Jamil and my sister, Mrs. Derrell Newkirk White all for their encouragement, unconditional love, support and enduring patience that sustained me through this process.

In loving memory of my dad, Mr. Osby A. Nekwirk, the inspiration for this research, I wholeheartedly dedicate this dissertation.

## ACKNOWLEDGEMENTS

I would like to especially thank the women, diabetes educators, and staff of the diabetes education programs for their participation and support in making this study possible. My heartfelt gratitude extends to Ms. Dinah Hilditch, Director of the Diabetes Program at the St. Petersburg Free Clinic and Ms. Bettye Burnett Scott, Director of the Diabetes Intervention and Prevention Program. Special thanks to Dr. Carrie Nero, Director of the Office of Minority Health, Ms. Johnester Andrews, and Assistant Director, Dr. Claude Dharamraj with the Pinellas County Health Department.

I extend gratitude to Mr. Rod Hale, USF Multi-cultural Graduate Programs for the fellowship and grant funding that supported this research. Likewise, I acknowledge the assistance of Ms. Marsha Stepelton with Keystrokes Secretarial Services and Ms. Rita Rincon Joyner for their transcription and formatting expertise.

I am grateful for the enduring encouragement and intellectual inspiration from Ms. Christine McDonald Robinson and Dr. Ray E. Moseley.

Lastly, I would like to express my utmost gratitude to the members of my dissertation committee for their mentorship and support of my academic and professional maturation.

## TABLE OF CONTENTS

LIST OF TABLES	vi
LIST OF FIGURES	vii
LIST OF TERMS	viii
ABSTRACT	xi
CHAPTER I INTRODUCTION	
STATEMENT OF THE PROBLEM	1
PURPOSE OF THE RESEARCH	3
RESEARCH QUESTIONS	4
SIGNIFICANCE OF THE STUDY	4
CHAPTER II LITERATURE AND CONCEPTUAL ORIENTATION	
A. CONCEPTUAL ORIENTATION	7
Cultural Construction of Health and Illness	8
Explanatory Model	10
Health Belief Model	12
B. LITERATURE REVIEW	16
Introduction	16
Anthropology and Diabetes	17
Epidemiological Diabetes Mellitus	23
Type 2 Diabetes	25
African Americans and Diabetes	28
Diabetes Mellitus and African American Women	32
Self-Management	36
Patient Health Education	40
Diabetes Self-Management Education	41
Standards for Self-Management Education	44
Religion and Health	45
Beliefs about Blood	48
Conclusion	49

CHAPTER III METHODOLOGY	
Introduction	51
Research Design	53
Choosing Participants	54
Research Participants	55
Data Collection	57
The Women	58
Participants' Profile	59
The Women	60
Semi-structured, In-depth Interviews—Qualitative	60
Self-Management Survey/Questionnaire—Quantitative	61
Survey/Questionnaire Pilot Testing	64
Diabetes Self-Management Health Educators	66
Diabetes Self-Management Health Educator Self-Profile	67
Direct and Participant Observation	67
Recording and Transcription	74
Reliability and Validity	75
Data Management	76
Protection of Human Subjects	77
Summary	78
CHAPTER IV DATA ANALYSIS	
Introduction	79
SECTION I. African American Women with Diabetes Mellitus	81
Demographics	81
SURVEY/QUESTIONNAIRE RESULTS—Quantitative	82
Research Question 3	82
General Management of Diabetes	83
Personal Management of Diabetes	85
Easy Self-Management Beliefs	85
Difficult Self-Management	86
Lifestyle Behavior Change	88
Patient Self-Management Responsibility	88
Patient Education	89
Helpful Class Attendance	90
Location of Class Attendance	90
Support Systems and Self Management	91
Exercise/Physical Activity and Self Management	93
Blood Glucose Monitoring and Hemoglobin Test	95
Medication Use	96
African American Women Constructing Diabetes	99
Introduction	99
Research Question 1	99
Self-Management Treatment Behaviors—Qualitative	104
Introduction	104
Research Question 2	104

Nutritional/dietary change	104
Exercise	106
Medications	107
Blood Glucose Monitoring	108
Interaction With Physicians	109
Patient Education	110
Spirituality/Religion	111
Support Systems	111
Summary of Women's Interviews	113
Participant Observation	114
Experience of Mock Diabetic	114
Researcher as Diabetes Educator	117
SECTION II. DIABETES EDUCATORS AND SELF-MANAGEMENT PROGRAMS	118
Educator Demographics	118
Self-management Educators Constructing Diabetes	119
Prescribed Self-Management Treatment Behaviors	123
Research Question 4	123
A. DIABETES EDUCATORS	123
Nutrition	125
Exercise	126
Blood Glucose Monitoring	126
Medications	127
Support Systems	128
Spirituality/Religion	128
Interaction with Health Care Provider	129
Patient Education	130
Summary of Educator Interviews	131
B. DIABETES EDUCATION PROGRAMS	133
Cultural Awareness and Sensitivity	133
Self-Management Program Participant Observation	134
Community-based Program—D.I.P.P.	134
Community-based Clinic—SPFC	135
Hospital-based Programs	137
A. Morton Plant/Joslin	137
B. Diabetes Care Institute	138
University-based Clinic—USF	139
Summary of Class Observations	140
SECTION III. COMPARATIVE FINDINGS	142
Research Question 5	142
Cultural Construction of Diabetes	142
Concordance	142
Discordance	142
Self-Management Treatment Behaviors	143

Concordance	143	
Discordance	143	
MODEL OF BALANCED SELF-MANAGEMENT	146	
MODEL OF INTERRUPTION	146	
Summary of Findings	147	
Cultural Construction of Diabetes	147	
Self-Management Treatment Behaviors	147	
CHAPTER V DISCUSSION AND CONCLUSIONS		
Introduction	151	
Discussion of Findings	152	
Intra-cultural Variation	153	
Discordance	156	
Research Question 1	158	
Self-Efficacy	160	
Research Question 2	162	
Self-Management Behaviors of the Women	162	
Exercise/Physical Activity	163	
Blood Glucose Monitoring	163	
Glucose Monitoring Supplies	163	
Nutrition	165	
Medication	166	
Family and Friends	166	
Religion	166	
Mock Diabetic Experience	168	
Patient Education	174	
Prescribed Self-Management Treatment Behavior	175	
Research Question 3	175	
Concordance/Discordance	178	
Research Question 4	178	
Barriers	180	
Relationship to Other Studies	181	
Contributions to Theory	190	
Contributions to Applied Anthropology	192	
Contribution to Public Health	196	
Limitations	198	
Implications and Recommendations	201	
Future Research	204	
REFERENCES CITED	207	
APPENDICES	225	
Appendix A	Recruitment Letter	226
Appendix B	Letter to Churches and Community	227
Appendix C	Participant's Profile Sheet	228

Appendix D	Health Educator's Profile Sheet	230
Appendix E	Informed Consent—The Women	231
Appendix E.1	Informed Consent—Diabetes Health Educators	236
Appendix F	Self-Management Survey/Questionnaire	241
Appendix G	Interview Guide—The Women	248
Appendix G.1	Interview Guide—Diabetes Health Educators	249
Appendix H	University of South Florida IRB Approval Letter	250
Appendix I	Weight Status of Study Participants	251
Appendix J	Diabetes Jeopardy Game	253

About the Author

## LIST OF TABLES

Table 1	General Management of Diabetes	84
Table 2	Things I Do to Manage Diabetes	85
Table 3	Things That Make It Easy to Manage Diabetes	86
Table 4	Things That Make It Difficult to Manage Diabetes	87
Table 5	Diabetes Education Acquisition	90
Table 6	Location of Diabetes Class Attendance	91
Table 7	Support Systems	93
Table 8	Exercise Activity	94
Table 9	Hemoglobin A1c Test	96
Table 10	Medication Use	97
Table 11	Barriers	181

## LIST OF FIGURES

Figure 1	MODEL OF BALANCED SELF-MANAGEMENT	146
Figure 2	MODEL OF INTERRUPTION	146

## LIST OF TERMS

The following terms are used as operational definitions for the purposes of this dissertation.

### Diabetes Mellitus:

A group of metabolic conditions characterized by high blood sugar or hyperglycemia, and by both under-and-over secretion of insulin, the hormone that transports glucose across cell membranes (Lieberman 2004:335; Cox et al 2004:156; Ritenbaugh and Goodby 1989:230; Norris et al 2002:39). It is a chronic disorder of carbohydrate metabolism resulting from insufficient production of insulin or from inadequate utilization of this hormone by the body's cells.

### Type 2 Diabetes

Formerly called non-insulin-dependent diabetes mellitus or adult-onset diabetes (Norris et al 2002:39) is characterized by insulin resistance and relative insulin deficiency (Task Force on Community Preventive Services 2002:10). It is the more common form of diabetes where the pancreas is able to manufacture insulin but the body tissues do not respond normally to it (Bailey 2000:Skelly 1992:2).

### Self-management/Self-Care:

The performance of preventive or therapeutic health care activities, often in collaboration with health care professionals (Skelly 1992:19); paramedical professionals such as nurses, pharmacists, physiologists who are consulted informally about health problems (Furnham 1994:715). A term used widely to describe patient behaviors, patient education, and health promotion programs (Lorig and Holman 2000:1). Also defined as "self-care" (Schoenberg and Drungle 2001:446).

### Health Belief Model:

Behavioral science theory that posits individuals will take action to ward off, to screen for, or control an ill-health condition if: (1) they regard themselves as susceptible to the condition, (2) if they believe it to have potentially serious consequences, (3) if they believe that a course of action available to them would be beneficial in reducing either their susceptibility to or the severity of the condition, and (4) if they believe that the anticipated barriers to (or costs of)

taking the action are outweighed by its benefits (Strecher and Rosenstock 1997:44; Redding et al 2000:Redding et al 2000:181; Carroll et al 2003:355; Spikmans et al 2003:152).

### Health Education

Any combination of learning opportunities designed to facilitate voluntary adaptations of behavior (in individuals, groups, or communities) conducive to good health (Turnock 2001:329).

### Public Health

Activities that society undertakes to assure the conditions in which people can be healthy. These include organized community efforts to prevent, identify, and counter threats to the health of the public (Turnock 2001:337).

### Beliefs

Propositions accepted as true (Chrisman and Johnson 1996:104).

### African American/Black

People having origins in any of the black racial groups of Africa (Grieco and Cassidy 2001:2).

### Native American/American Indian/Alaska Natives

People having origins in any of the original peoples of North and South America (including Central America), and who maintain tribal affiliation or community attachment (Grieco and Cassidy 2001:2). For this study, tribes include Choctaw, Metis, Pima, Dakota, Ute, Navajo, Cree, Ojibwa.

### Latino/Hispanic

A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race (Grieco and Cassidy 2001:2).

### Asian American

People having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent (Grieco and Cassidy 2001:2).

### Caucasian/white

Whites are people having origins in any of the original peoples of Europe, the Middle East, or North Africa (Grieco and Cassidy 2001:2).

### Grounded Theory

Identifying categories and concepts that emerge from text and linking the concepts into substantive and formal theories (Bernard 2002:462).

### Reliability

Dependability; making the same measurement again and again in hopes of getting the same result (Babbie 1992:306).

### Validity

Validity concerns whether measurements actually measure what they are supposed to rather than measuring something else (Babbie 1992:306). It refers to the credibility, goodness, and quality of the research (LeCompte and Schensul 1999:94).

### Self-efficacy

The belief that one can successfully execute the behavior required to produce the outcomes are grounded in the model (Strecher and Rosenstock 1997:44)

### Triangulation

Confirming and cross-checking the accuracy of data obtained from one source with data collected from other, different sources (LeCompte and Schensul 1999:131),

### Snowball Sampling

Sampling in which one person selected for participation in a study recommends for inclusion others who, in turn, indicate others, and so on (Hahn 1999:369).

### Church

That population as any functional body of practicing Christians (Angrosino 2001:ix).

### Disease

Deviations from a biomedical norm (McElroy and Jezewski 2000:191).

### Illness

The lived experience of culturally constructed categories (McElroy and Jezewski 2000:191).

### Sickness

Patients' roles. (McElroy and Jezewski 2000:191).

African American Women With Type 2 Diabetes:

Understanding Self-Management

F. Bridgett Rahim-Williams

ABSTRACT

Prescribed self-management behaviors have been found to be important factors affecting the rates of morbidity and mortality in multiple medical conditions including chronic diseases such as diabetes, a condition that disproportionately affects high health risk populations such as African Americans.

This study focused on understanding health behaviors, beliefs, and associated factors such as support systems and access to care that played a role in diabetes self-management and glucose control. The study also explored diabetes self-management education and its role in diabetes self-management. The research conducted in Pinellas and Hillsborough counties in Florida, included twenty-five African American women between the ages of forty-six and eighty-seven, with self-identified diabetes mellitus (type 2 diabetes). The study also included seven diabetes self-management educators consisting of nutritionists, a nurse educator, physicians, and an exercise physiologist—key members of the diabetes self-management team. Additionally, five diabetes education programs were observed.

Methods included semi-structured qualitative interviews, with direct and participant observation of the Diabetes Intervention Prevention Program (DIPP), the St. Petersburg Free Clinic Diabetes Program, and the Morton Plant Meese/Joslin Diabetes Program in Pinellas County. Hillsborough County sites included the USF Diabetes Program, and University Community Hospital's Diabetes Care Program. Site selection included a cross-section of program types: non-clinic/community-based, community-based clinic, hospital-based, and university clinic-based.

The study also utilized a thirty-nine question survey designed to elicit information about self-management beliefs and behaviors.

Results revealed several self-management behavioral variables affecting glucose control: (1) nutritional/dietary changes, (2) exercise, (3) medication use, (4) blood glucose monitoring, (5) physician-patient interaction, (6) support systems, and (7) patient education/knowledge. Results also identified access to care as a contributor to self-management. Two models of diabetes self-management emerged from the findings: a *model of balanced self-management* held by the diabetes educators and self-management programs, and a *model of Interruption* practiced by the women.

Recommendations highlighted the need for the awareness of socio-cultural factors affecting self-management, the elimination of barriers affecting access to care, improvement in physician-patient interaction, provision of culturally aware patient education, and stronger community and family support systems.

## CHAPTER I

### INTRODUCTION

Diabetes mellitus is a disease that was relatively uncommon among African Americans at the beginning of the twentieth century, is a major clinical and public health problem in the African American community (Elders and Murphy 2001:226). According to Blackhealthcare.com (n.d.), the disease is one the most serious challenges facing the more than 30 million African Americans in the United States. Blackhealthcare.com reports that in 1993, 1.3 million African Americans were known to have diabetes, a number almost three times that of African Americans who were diagnosed with diabetes in 1963, and that African Americans with diabetes are more likely than white Americans to develop complications and experience greater disability from those complications..

In 1995, diabetes was seventh among the top ten causes of death for African Americans (Bailey 2000:61). Elders and Murphy (2001) report that more recently, it is the third leading cause of death from disease in African Americans.

#### I. STATEMENT OF THE PROBLEM

Among African American women, diabetes is considered epidemic; the rate is 11.8% among women  $\geq$  20 years of age, and 25% among women  $>$ 55 years of age (Auslander et al 2002:809), or according to BlackHealthCare.com (2002),

one in four black women 55 years of age or older. According to the National Women's Health Information Center, Office of Women's Health, Department of Health and Human Services (DHHS), 2002, diabetes is sixty percent more common among African American women than among white women. Moreover, data from 1995 reveal that diabetes was the fourth leading cause of death, out of the top ten, for African American women (Bailey 2000:61). A more recent study by Auslander et al (2002:809) reports that the overall mortality rate among African American women is forty percent higher compared with their Caucasian counterparts.

Prevention of Type 2 diabetes among African American women is critical because of the high rates of diabetes-related mortality and morbidity in this population (Auslander et al 2002:809). Self-management plays an important role in reducing the morbidity and mortality of diabetes, because self-management is vital in preventing diabetes complications (Ellison and Rayman 1998:325). However, Ellison and Rayman (1998:325) report that even though the importance of self-management of diabetes mellitus is well known, the literature is replete with studies documenting poor adherence to practically every aspect of diabetes care. For example, Ellison and Rayman (1998:325; Nelson, Reiber and Boyko 2002:1722) found that patients have done poorly with physical exercise and with managing a proper diet. The latter may be understandable because Helman (1990:32) states that dietary beliefs and practices are notoriously difficult to change. Such results are problematic because high dietary fat intake

(Auslander et al 2002:809), and low prevalence of physical activity (Hays and Clark 1999:706) are two major risk factors for Type-2 diabetes. Similarly, Li and Deng (1995) report that increase of total caloric intake, change of life style, e.g. urbanization, mental stress, and ageing of the population are factors that influence the increasing prevalence of diabetes mellitus.

## II. PURPOSE OF THE RESEARCH

The dissertation is a descriptive, qualitative study that incorporates the use of an ethnographic questionnaire/survey. The study was designed to illustrate and illuminate the ways African American women with Type 2 diabetes manage and understand their disease. The Department of Health and Human Services (HHS), Office of Minority Health (OMH) recommends that preventive interventions, such as those directed at preventing diabetic complications, target high-risk groups. The OMH recognizes African American as individuals at high risk for diabetes. To reduce complications, the OMH recommends careful control of blood glucose levels, improved care, and diabetes self-management education. Self-management for the purposes of this study included health beliefs, health behaviors (monitoring of blood glucose, physician visits, nutrition, exercise/physical activity, spirituality/religion, oral and injection medicines), support systems and educational interventions.

The research also elicited information about the perceptions of diabetes self-management health educators: nurse educators, exercise physiologists/specialists, nutritionists, and certified diabetes educators providing

diabetes self-management education classes, and health care activities to African American women with Type-2 diabetes. Lastly, to understand the knowledge and education involved in diabetes self-management, the study included direct and participant observation of five diabetes self-management education programs.

### III. RESEARCH QUESTIONS

The research questions for this study were:

1. What is the cultural construction of diabetes mellitus among African American women with the disease?
2. What treatment behaviors do African American women utilize to manage diabetes?
3. What self-management treatment behaviors are prescribed by diabetes educators and self-management programs?
4. What is the concordance/discordance that exists between self-management treatment behaviors of the women and prescribed behaviors of diabetes educators and self-management programs?

### IV. SIGNIFICANCE OF THE STUDY

Patients' perceptions and experiences with many important aspects of self-management have not been well documented (Ellison and Rayman 1998:325). As such, this research was designed to contribute knowledge to understanding patient self-management practices, behaviors, and beliefs of African American women with Type-2 diabetes, a high-risk population adversely affected by diabetes. This understanding has the potential to influence the delivery of health prevention, education and promotion activities, as well as the delivery of health care services.

Moreover, this research has the potential to offer insights into and knowledge of intra-cultural variation in the self-management experiences that may be present within the African American women under study. This is significant because the African American population includes many individuals who have immigrated to the United States from other parts of the Americas, particularly the Caribbean, about whose diabetes status little is known (Tull and Roseman 1995:613).

This research is also important for health educators, community-based health programs, policy makers, program planners, and health care providers facing the challenge of reducing racial and ethnic health disparities such as diabetes among minority populations.

Bailey (2000) reports that there are distinctive differences between African Americans and European Americans in the prevalence and hospitalization rates associated with diabetes. He states that research is needed to determine if any other factors, such as social and cultural may be contributing to the large disparity of diabetes-related problems (Bailey 2000:73). Livingston (1994) indicates that the overall gap in our knowledge is with respect to how diabetes affects African Americans. The lack is identified in the areas of (1) risk factor identification and prevalence, (2) factors contributing to increased diabetes-related morbidity and mortality, and (3) socio-cultural factors and health outcomes (Livingston 1994:105).

Lastly, the Department of Health and Human Services Administration reports

that research dedicated to a better understanding of the relationships between health status and different racial and ethnic minority backgrounds will help us acquire new insights into eliminating disparities (*The Initiative to Eliminate Racial and Ethnic Disparities in Health*, 2003). To reduce the burden of diabetes within the African American community, research is needed to assess the behavioral, social, and environmental correlates associated with the disproportionate burden (Burrus, Liburd, and Buroughs 1998:15).

Chapter two of this dissertation highlights the literature and conceptual orientations that provides the framework for this dissertation. The literature review focuses on (1) anthropology and diabetes; (2) epidemiological diabetes; (3) diabetes and African Americans; (4) diabetes and African American women, (5) spirituality and health, (6) health/patient education, and (7) self-management and (8) self-management education. The conceptual orientation includes the cultural construction of health and illness and the Health Belief Model (HBM). Chapter three presents the methodological approaches used for this study. Chapter four provides the analysis of the qualitative and quantitative data. The discussion of the findings is presented in chapter five. The chapter also includes the contributions to anthropology, theory, and public health. Chapter five concludes with recommendations for practice, research, education, prevention and intervention.

CHAPTER II  
LITERATURE AND CONCEPTUAL ORIENTATION  
A. CONCEPTUAL ORIENTATION

Introduction

The Cultural Construction and Explanatory Model of health and illness, and the Health Belief model formed the study's conceptual framework. A Grounded Theory approach provided the mechanism for data analysis that identified categories and concepts that emerged from interviews, and linked the concepts into substantive and formal theories (Bernard 2002:462)

The participants in this study were on the one hand African American women with type 2 diabetes (diabetes mellitus), and on the other hand, health care providers (nurse educators, the dietician/nutritionist, the exercise physiologist, and physicians) who comprised the diabetes self-management team, and who facilitated the diabetes self-management education programs. Though a diverse group, these individuals respectively shared a set of learned values, behavior, and beliefs that are characteristic of a particular society or population (Corin 1995:273; Ember and Ember 1988:527; Hahn 1995:66). These learned and shared behaviors as social constructions, what people know and believe to be true about the world as they interact with one another over time in specific social

settings (LeCompte and Schensul 1999:48) become institutionalized in our patterns of thinking and behavior (Angrosino 2001:40), and such interpersonal relationships provide the context for reinforcing shared beliefs and behaviors, and for encouraging persistence of group norms (Trotter and Schensul 1998:699). Thus, health and health practices are part of the inmost complexities of social existence, permeating the domains of politics, economics, and religion and almost always connected with dimensions that go beyond the body, such as interpersonal, family, and community relations (Kleinman and Petryna 2001:2).

### Cultural Construction of Health and Illness

A patient's beliefs about health and illness provide individual and collective reasons for acting, justify prior actions, and call for future actions (Charmaz 2000:279). Explanations of the causes and patterns of health and disease often convey value judgements, senses of right and wrong and of accountability and blame, as well as reveal what is morally at stake in definitions of health and its failures (Kleinman and Petryna 2001:2).

The construction of health can be understood from both a bio-cultural and an interpretive frame (Corin 1995:273). A bio-cultural focus concentrates on the way bodily processes influence people's behavior (Corin 1995:273). For example, the concept of heredity posits a dormant potential for disease, a latent threat of physical treachery, but does not explain why some people in a family suffer terribly from diabetes while others are spared (Hunt, Valenzuela, and Pugh 1998:965). An interpretive ideology shifts the focus from disease as a biological

entity to the experience of illness in a given social and cultural context. Corin (1995:274) posits that the construction of health takes place at the individual, cultural, and the macrosocial level, and includes social structure. No single definition fully conveys what health really is (Spector 2000:5). However, the World Health Organization taking a comprehensive perspective to health defines the concept as, “not merely the absence of disease but a state of complete physical, mental and social well-being (Turnock 2001:41). Anthropologists recognizing a wide spectrum of illness and wellness definitions find it helpful to distinguish three categories: *disease* (deviations from a biomedical norm), *illness* (the lived experience of culturally constructed categories, and *sickness* [patients’ roles] (McElroy and Jezewski 2000:191).

Kleinman (1980) believes that the construction of the illness experience is a health care function. Sickness, he says, is a “natural” phenomenon that is cast into a particular cultural form through the categories that are used to perceive, express, and evaluate symptoms. The cultural construction of illness then is frequently a personally and socially adaptive response (Kleinman 1980:74) created by human beings in particular social settings and at particular times (Lindenbaum and Lock 1993:3). Spector (2000) states that the experience of an illness is determined by what illness means to the sick person. Contextual factors are important in accounting for variation found in illness experience (McElroy and Jezewski 2000:191). Class, gender, ethnicity, educational level, age, and social support especially influence risk of illness, access to care,

economic constraints, and the probability of resolving a health problem (McElroy and Jezewski 2000:191). Hunt, Valenzuela, and Pugh (1998:959) believe that in order to better understand patients' illness orientations, it is important to examine the relationship between their reasoning and their experiences with the illness and its treatment. By considering how patients interpret and evaluate the impact of their action or inaction on their illness state, Hunt, Valenzuela, and Pugh (1998:959) suggest that we can better understand the decisions patients make about illness-related behaviors.

### Explanatory Model

In an explanatory model, processes are described by which individuals explain events in their lives as they try to make sense of the world around them (Glanz, Lewis, and Rimer 1990:35). The models are sets of beliefs or understandings that specify for an illness episode its cause, time, and mode of onset of symptoms, patho-physiology, course of sickness, and treatment (Rubel and Hass 1996:121). According to Glanz, Lewis, and Rimer (1990) individuals develop personal cognitive explanations about factors affecting their levels of health or illness. These cognitions then influence health-related behaviors (Glanz, Lewis, and Rimer 1990:35).

Chen, Kleinman, and Ware (1992) state that the explanatory model focuses on the patient's and family's conceptions of the nature of a particular illness episode, its causes and effects, expected and/or desired treatment, and apprehensions about outcome. It is grounded in culturally defined systems of

meaning, crystallizing out of local beliefs about the nature of the body, of suffering, and of the person. Chen, Kleinman, and Ware (1992) say that the explanatory model is informed by cultural categories that organize various types of illness and methods of treatment, and it finds expression in particular episodes of illness. Similarly, illness usually begins with the sick person's attention to and perception of the early manifestations of disease (Kleinman 1980:75; Angel and Thoits 1987:477) as individuals may do with the onset of diabetes.

For Thompson and Gifford (2000) the explanatory model highlights the specific culturally mediated meanings of health and illness. The assumption they propose is that people incorporate experiences and understandings of new illnesses into existing cultural frameworks and symbolic meaning systems.

Schoenberg, Amey, and Coward (1998) propose that explanatory models or commonsense models also involve comprehending symptom labeling and identifying perspectives on origin, consequences, illness time line and lay treatment strategies of disease. It is said that the explanatory method is a useful theoretical foundation in understanding individual health behaviors and how people respond to symptoms and diagnoses of illness (Thompson and Gifford 2000:1463). This illness behavior, according to Chen, Kleinman, Ware (1992), represents the constellation of activities and beliefs exhibited by an individual and his or her social circle in response to bodily indications perceived as symptoms. Chen, Kleinman, Ware (1992) suggest that in a given individual or social network, illness behavior involves the definition of symptoms, the monitoring of

the body (to see if the symptoms change or progress), and remedial or “treatment” action—utilization of lay or professional help to rectify the perceived abnormality. This illness behavior is influenced by one’s belief system related to ill health.

Schoenberg, Amey and Coward (1998) found that informants’ perspectives on etiology and the relationship between perceived etiology of non-insulin dependent diabetes mellitus and treatment revealed factors such as poor former dietary practices, diabetes “runs in the family,” personal risk factors, and being currently overweight, as accounting for the onset of their diabetes. “Onset” is when the person experiences the first symptoms of a given problem (Spector 2000:19). The onset can be slow and insidious such that the patient may not be conscious of symptoms, or may think that with waiting the discomfort will go away (Spector 2000:19). On the other hand, the onset may be rapid and acute where the person is positive that she or he is ill, and knows that immediate help must be sought (Spector 2000:19).

The relationship of patient attitudes and patient behavior has been central in both the health belief model and in the theory of reasoned action (Fitzgerald et al 2000:1); theories demonstrating relevance for this study.

### Health Belief Model

Behavioral science theory such as the Health Belief Model (HBM) has relevance for this research on diabetes self-management behaviors and health beliefs because it provides a framework for recognizing and explaining the ways

that individuals go about maintaining their health, for explaining the relationship between perceived health benefits and a patient's success with self-management (Clarke, Crawford and Nash 2002:77), and for identifying factors influencing people's perceptions of individual risk and their likelihood of adopting risk-reducing behaviors (Carroll et al 2003:355). The model posits that individuals will take action to ward off, to screen for, or control an ill-health condition if: (1) they regard themselves as susceptible to the condition, (2) if they believe it to have potentially serious consequences, (3) if they believe that a course of action available to them would be beneficial in reducing either their susceptibility to or the severity of the condition, and (4) if they believe that the anticipated barriers to (or costs of) taking the action are outweighed by its benefits (Strecher and Rosenstock 1997:44; Redding et al 2000:Redding et al 2000:181; Carroll et al 2003:355; Spikmans et al 2003:152). Perceived severity and susceptibility to disease are the expected negative physical outcomes, and perceived benefits are the positive outcomes (Bandura 2004:145). These concepts of perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy, the belief that one can successfully execute the behavior required to produce the outcomes are grounded in the model (Strecher and Rosenstock 1997:44) with self-efficacy being one of the most consistent predictors of successful self-care behavior (Skinner 2003:78), and one of the mechanisms through which self-management programs demonstrate success (Lorig and Holman 2000:1). Self-efficacy is also a function of an individual's

attitudes, beliefs, characteristics, and innate abilities, as well as education, knowledge, training, and learned skills (National Chronic Care Consortium 1999:3). However, modifying behaviors that may be life-long habits such as eating and exercise may be more difficult to surmount (Strecher and Rosenstock 1997:47) because diabetes self-care requires more frequent monitoring and sustained adherence to medication, diet, and exercise regimens in order to achieve the desired level of glycemic control (Clarke, Crawford and Nash 2002:78). For instance, a person with diabetes must be willing to inject insulin and/or puncture a finger to check blood glucose levels in public, and must maintain a very steady activity routine and be ready to adjust medications accordingly whenever activities change (Romeo 2000:353). Also, a person with diabetes can no longer run into a restaurant to have a quick meal because this person must now cope with strict dietary guidelines and specific mealtimes (Romeo 2000:353). Applying the health belief model to dietary change, if a patient believes themselves to be at risk of complications (perceived vulnerability) related to diabetes and believes these complications to be serious (perceived severity), and believes that diet is an important means to avoid these risks (outcome efficacy), the patient will be more likely to consult a dietitian/nutritionist (Spikmans et al 2003:152). Thus, as indicated by the health belief model, for behavioral change to succeed, people must feel threatened by their current behavioral patterns (lack of exercise, nutritional habits, lack of blood glucose monitoring) and believe that change of a specific kind (exercising, eating

smaller portions more frequently, monitoring, consulting a nutritionist, acquisition of diabetes education) will be beneficial by resulting in a valued outcome (glycemic control, prevention of complications, weight loss) at an acceptable cost (family/friend support), and must also feel themselves competent to overcome perceived barriers to taking action (Strecher and Rosenstock 1997:47). But, observable actions such as an individual watching their diet and consuming no more than 30-20 percent of calories from fat based upon a criterion that professionals agree will reduce the risk of disease (Prochaska, Redding and Evers 1997:63), or as Jewler (1991) indicated—attending diabetes education classes, starting an exercise/fitness/weight loss program, and/or changing nutritional habits such as eating more fiber and consuming less cholesterol, could be perceived as barriers to self-management. Overcoming these barriers may be difficult because achieving the best outcomes places increased burdens on the diabetic patient, physician and health care system alike given that diabetes is one of the most psychologically and behaviorally demanding of the chronic medical illnesses (Clarke, Crawford and Nash 2002:78).

As one of the most commonly used models of individual health behavior change, the health belief model serves as a guide for understanding of health behavior, for guiding research and intervention development (Redding et al 2000:181).

Using the theoretical orientations outlined above, this dissertation investigates the self-management beliefs and behaviors of African American

women with type 2 diabetes, and the self-management education efforts of diabetes educators, and self-management programs that assist diabetic individuals with acquisition of the knowledge and behavioral actions required to initiate and adhere to the recommended diabetic regimen; a regimen that includes dietary changes, exercise/physical activity, blood glucose monitoring, and oral or injection medication use. The regimen when adhered to is reported to reduce diabetes related morbidity and mortality. As such, a conceptual framework that focuses upon the relationship of health beliefs and behaviors is appropriate for this study.

The following section reviews the relevant literature for this research. The review focused on (1) anthropology and diabetes; (2) epidemiological diabetes; (3) diabetes and African Americans; (4) diabetes and African American women, (5) spirituality and health, (6) patient health education, and (7) self-management and (8) self-management education.

## B. LITERATURE REVIEW

### Introduction

Learning about people's beliefs and behaviors is the core of applied medical anthropology (Mull 1993:610). Medical anthropology is concerned with the occurrence and expression of illness in diverse populations, the symbolic meaning attached to illness, beliefs about the human body, the comparative study of professional healers and curing practices, the management of sickness, and the relationship of illness to social and political dynamics in the community

(Carrese and Marshall 2000:298; Morsy 1996:27). The research for this dissertation endeavored to gain in-depth, qualitative understanding of how a selected group of African American women understood diabetes and diabetes self-management. As a primary focus, the study endeavored to understand what African American women do to manage diabetes in the course of their everyday lives.

### Anthropology and Diabetes

Diabetes mellitus is not a single disease but a group of metabolic conditions characterized by high blood sugar or hyperglycemia, and by both under-and-over secretion of insulin, the hormone that transports glucose across cell membranes (Lieberman 2004:335; Cox et al 2004:156; Ritenbaugh and Goodby 1989:230; Norris et al 2002:39). It is a chronic disorder of carbohydrate metabolism resulting from insufficient production of insulin or from inadequate utilization of this hormone by the body's cells (Bailey 2000:72; Skelly 1992:2). The disease is characterized as two major types— type 1 and type 2. Type 1 diabetes mellitus is a chronic metabolic disorder and is one of the most common chronic diseases in childhood (Thompson, Auslander, and White 2001:7). In type I or juvenile diabetes the insulin-producing beta cells of the pancreas are attacked by the individual's system resulting in a decrease in insulin production (Lieberman 2004:335). Type 1 is also designated as an auto immune disease, may have a genetic basis, and accounts for approximately 5-10% of the cases of diabetes worldwide (Lieberman 2004:335; Norris et al 2002:39). Type 2 diabetes formerly

called non-insulin-dependent diabetes mellitus or adult-onset diabetes (Norris et al 2002:39) is characterized by insulin resistance and relative insulin deficiency (Task Force on Community Preventive Services 2002:10), and is the more common form of diabetes where the pancreas is able to manufacture insulin but the body tissues do not respond normally to it (Bailey 2000:Skelly 1992:2).

Wiedman's (2001) research reveals that over the past quarter century anthropologists have contributed to the advancement of knowledge about this disease in such areas as genetics, metabolism, obesity, nutrition, modernization, research methods, cultural models, culturally competent care, patient-provider relations and community interventions.

Lieberman (2004) reports that since the 1960s anthropologists have published on a diversity of topics related to type 2 diabetes. She refers to research by Wiedman (2001) that lists approximately 130 plus articles, chapters, and books published from 1975 to 2001 by anthropologists that have appeared in anthropology, medical, epidemiology, and nutritional science journals (Lieberman 2004:339). However, Lieberman (2004) states that the majority of research on diabetes by anthropologists has occurred in a very limited number of societies, primarily in Canadian Native and North American populations. For example, the focus in Canada has been on the Dogrib in the Northwest Territory, Sandy Lake Cree, Anishinaabe Ojibway, the Metis, urban Indians in Toronto, and the Inuit and non-Inuit Indians in the Canadian Arctic (Lieberman 2004:338).

In the Continental United States, extensive multidisciplinary studies have

been made with the Pima Indians of Arizona, the Zuni, Yuman tribes, Oklahoma Cherokee and Kiowa Apache, Oklahoma Choctaw, Florida Seminole, North Dakota Sioux, Seneca of New York, and the Oregon Kalamath (Lieberman 2004:338). Additional multidisciplinary research has been completed on Japanese Americans, Mexican Americans, and for Australia, New Zealand, the Pacific Island, and among Australian Aborigines (Lieberman 2004:338). .

Little work has been done by anthropologists or with an anthropological perspective in Mexico, Latin America, the Caribbean, and little to no research has been conducted in Asia, African, the Middle East, India or Europe, Asia, and Korea (Lieberman 2004:339). The records Lieberman (2004) cites document only four instances of diabetes among African Americans being studied by medical anthropologists. A 2002 search of the Human Relations Area Files (HRAF), a collection of ethnography, indicated only 46 documents with brief references to diabetes (Lieberman 2004:338). This minimal attention suggests the need for additional research on diabetes in the African American community by anthropologists especially given the incidence and prevalence of the disease among this population.

In anthropology, an extensive representation of research related to diabetes mellitus is seen within biological/physical anthropology. Examples include, but are not limited to, research in (a) *Journal of Physical Anthropology*, (b) *Journal of Ethno-pharmacology*, (c) *Human Heredity*, (d) *American Journal of Human Biology*, (e) *Annals of Human Genetics*, and (f) *Journal of Medical*

*Genetics* (Sabu and Kuttan 2002; Koley and Shrivastava 1997; Singh and Rosen 2001; Jouad et al 2001; Hegele et al 2001; Acosta-Patino et al 2001; Navas et al 2000; Lee 2000; and Weiner 1999).

Similarly represented are many anthropological studies that direct attention to the socio-cultural aspects of diabetes. For example, in the research on the lived experiences of diabetes and lay meanings of risk among Aborigines living in Melbourne, Australia, Thompson and Gifford (2000) found that Melbourne Aborigines see non-insulin dependent diabetes mellitus as the result of living life out of balance, a life of lost or severed connections with land and kin and a life with little control over past, present or future.

A research focus has also been upon Native American populations where non-insulin dependent diabetes mellitus has been recognized as a growing health problem since the early 1960s (Ritenbaugh and Goodby 1989:227). Examples of anthropological studies along this line reflect Lang's (1989) research on the Dakota (Sioux) community in North Dakota. She discovered from interviews conducted with Dakotan who were affected with diabetes, that the concern with diabetes was part of larger, self-reflective narratives that involved not only individual, but also community identity, and cultural heritage (Lang 1989:305).

Bruce's research (2000) with the Native American Metis of Western Canada revealed that diabetes was significantly associated with age, sex, obesity, and level of education (Bruce 2000:542). On the other hand, Olson

(1999:185) found that ethnicity, acculturation, history of prejudice, and social position are essential factors to consider for fully understanding diabetes and why American Indians are experiencing the disease disproportionate to other populations. Her reasoning is that factors such as ethnicity, history of prejudice, and social position affect the experience of a health problem, and the overall quality of health (Olson 1999:185). Carson-Henderson's (2002) research with Choctaw elders proposed that the varied beliefs about how diabetic patients and providers respond to the disease constitute both a communication and behavioral barrier to optimal management of the disease and reduction of morbidity and mortality. According to the Indian Health Service, there is excess morbidity and mortality associated with the disease of diabetes within the population of American Indians (Carson-Henderson 2002:1). Possible hypotheses for this excess morbidity and mortality include insufficient education about the disease, structural and cultural barriers to health care access, the existence of extensive symptom tolerance, and a culturally constructed concept of the disease that may impede care-seeking and compliance.

Research in China by Li and Deng (1995) identified factors that also influenced the prevalence of diabetes mellitus. They found an increase of total calorie intake (2680 kcal/day in 1990-close to the average world level), inappropriate high carbohydrate diet habit, change of life style, e.g. urbanization, mental stress, and ageing of the population (Li and Deng 1995: 1185).

Anderson et al (1995) approached the issue of how Euro-Canadians and

Chinese-Canadian women living with diabetes experienced and managed their illness. These authors noted factors such as diet, exercise, medication and blood testing. They found that how a woman managed her illness was not reducible to her ethnicity (Anderson et al 1995:181).

Schoenberg, Amey and Coward (1998) investigated adherence to dietary recommendations, contending that adherence represents one of the most challenging lifestyle modifications. Their findings from interviews with 51 women over the age of sixty-five with diabetes and their physicians revealed that women who indicated former dietary practices, currently being overweight, or having improper bodily functions were more likely to follow a standard recommended diet for individuals with diabetes (Schoenberg, Amey and Coward 1998:2113).

Wiedman's 1989 study of Oklahoma Native Americans sought to discover factors that accounted for the increase in type II diabetes mellitus when populations acculturate to an industrial technology (Wiedman 1989:237). He found that the diabetic epidemic among Oklahoma Native Americans could not be accounted for by only the increase in longevity associated with industrialization. Rather, adiposity resulting from the change in technology, nutrition, and lifestyle was a major factor for the diabetic epidemic (Wiedman 1989:250). Wiedman (1989) recommended weight loss as the primary control mechanism of type II diabetes.

In their study on Latino beliefs about diabetes, and heterogeneity in beliefs across different groups, Weller et al (1999) reported that Latino cultural beliefs

about diabetes were concordant with the biomedical model. Variation in responses tended to characterize less knowledge or experience with diabetes and not different beliefs (Weller et al 1999:722).

Also an anthropological inclusion is Bailey's (2000) qualitative and quantitative research that examined the relationship between health beliefs and health care-seeking pattern of African Americans and Euro-Americans, two populations with non-insulin dependent, diabetes mellitus who were characterized as economically similar but culturally distinctive. Findings from this study indicated that it was important to assess health care issues of the African American diabetic patient such as (1) perceived cause of diabetes, (2) the lifestyle and dietary pattern of each patient, and (3) the perceived seriousness of the diabetic condition to the patient (2000:187). Bailey suggests that all three health care issues influence the ability of the African American patient to adhere to the prescribed diabetic regimen.

Taking a somewhat different approach, Thompson and Gifford (2000) proposed the need for a more comprehensive epidemiological approach towards understanding risks for diabetes (Thompson and Gifford 2000:1457).

### Epidemiological Diabetes Mellitus

Diabetes is one of the most vexing problems confronting modern medicine and society (Urdaneta and Krehbiel 1989:221). Approximately 15.7 million people (6-7 %) in the U.S. have diabetes (Brownson, Remington, and Davis 1998: 421), with an estimated 23 million people to be affected within 10 years

(Olefsky 2001: 628). The disease is one of a number of non-infectious diseases the rates of which continue to rise, bearing a heavy impact on mortality and morbidity (Thompson and Gifford 2001:1459; Rock 2003:131). The rate of increase has tripled during the past 30 years (Tull and Roseman 1995:613). Some 800,000 new cases are diagnosed each year, or 2,200 per day (Florida Policy Exchange Center on Aging, Healthy People 2010-Diabetes-Conference Edition, and the prevalence of diabetes could double within the next 20 years (Uusitupa 2002:1651). The Pima Indians of Arizona have the highest diabetes rate in the world, with fifty percent of the adult population over the age of 35 afflicted with the disease (Carson-Henderson 2002:43).

Biologically, diabetes mellitus is a chronic disorder of carbohydrate metabolism resulting from insufficient production of insulin or from inadequate utilization of this hormone by the body's cells (Bailey 2000:72; Bradley 1997:2; Pierce and Armstrong 1996:91; Williams 1990:168). The disease hinders the way the body uses food, thereby causing high blood sugar levels (Williams 1990:168). Under normal circumstances, the metabolism of sugars and starches in the body produces glucose, which is converted into energy (Skelly 1992:1). The disturbance in the metabolism of sugars and starches leads to the accumulation of glucose in the blood and the excretion of glucose into the urine (Skelly 1992:1).

Olefsky's (2001) research documents that diabetes mellitus is the sixth leading cause of death in the United States. Alarming are statistics that reveal

death rates due to diabetes having increased by about 30% in the past 12 years, and that the life expectancy for persons with diabetes is approximately 15 years less than those who do not have diabetes (Olefsky 2001:628).

Urdaneta and Krehbiel (1989) explain that what has limited our understanding of this serious degenerative disease is the limited scope of diabetes studies; studies that have mostly focused on etiological roots (Urdaneta and Krehbiel 1989:221). The bio-cultural view of medical anthropology; a perspective that examines the interactions between all the determinants of the disease—environmental, cultural, and biological—provides the answer for understanding and solving the diabetes problem (Urdaneta and Krehbiel 1989:221).

### Type-2 Diabetes

Type 2 diabetes, or non-insulin dependent diabetes mellitus (NIDDM), or adult-onset diabetes is the kind of diabetes that medical anthropologists, working in other cultures, usually write about (Bradley 1996:2). It is characterized by hyper-insulinism in response to the resistance of target tissues to the transport of glucose into cells (Lieberman 2004: 335). The pancreas is able to manufacture insulin, however for reasons not clearly understood, the tissues do not respond normally to it (Skelly 1992:2).

The world is experiencing an epidemic of Type 2 diabetes (McDermott 1998:2; Cooper, et al 1997:343; Uusitupa 2002:1651), which accounts for 90% to 95% of all participants with diabetes (Olefsky 2001: 630; Lieberman 2004:335), and is one of the most serious public health challenges facing the United States

(National Institutes of Diabetes and Digestive and Kidney Diseases, National Institutes of Health; Florida Policy Exchange Center on Aging; Department of Health and Human Services, Office of Minority Health). Statistics reveal that approximately 10 million individuals are suffering from NIDDM, while 5.5 million persons are estimated to have the disease but are undiagnosed (Ferzacca 2000:1; Florida Policy Exchange Center on Aging,).

Type 2 diabetes is the most common form of diabetes among minority groups in the United States (Davidson 1991:153). All minorities in the United States, except natives of Alaska, have a prevalence of non-insulin dependent diabetes that is two to six times greater than that of white persons (Carter, Pugh, and Monterrosa 1996:221; Hosey, Gordon and Levine 1998: 108). Type 2 is more common and disproportionately affects minority populations such as Hispanics, Asians, African Americans and Native Americans in the U.S. (Keyserling et al 2002:1576; Florida Policy Exchange Center on Aging; Hunt, Valenzuela, and Pugh 1998:959; Bradley 1996:2). For example, the prevalence in Hispanics is nearly double that of whites (Gilbert and Sawyer 2000:242; Carter, Pugh, and Monterrosa 1996:222), with mortality due to diabetes being twice as high among Mexican Americans and Puerto Ricans as it is for non-Hispanic whites (Weller et al 1999:722), and diabetes affects American Indian populations at higher rates than any other population in the world (Olson 1999:185).

The specific cause of diabetes mellitus is unknown (Livneh and Antonak 1997:208). It actually may be caused by more than 50 specific factors (Lieberman

2004:336). Non-behavioral causes of the disease are personal factors that are least controllable by individual or collective action, but that do contribute to health problems (Ferzacca 2000:1). For example, the etiology has been linked to an association between familial aggregation, genetic admixture, genetic markers and diabetes (Uusitupa 2002:1650; Thompson and Gifford 2000:1459; Leonetti, Fujimoto, and Wahl 1989:345). As a heterogeneous, polygenic disorder, the responsible genes have been identified in selected subtypes of the disease (Olefsky 2001:630).

Research by Livneh and Antonak (1997) identifies behavioral causes that may be associated with diabetes. Their psychological studies suggest an association with the onset and chronic course of the disease being related to increased anxiety, depressive mood, social withdrawal, rebelliousness, insecurity and denial among children and adults (Livneh and Antonak 1997:208). Other studies identify environmental factors such as advancing age, physical inactivity, sedentary lifestyle, and obesity (Ferzacca 2000:1; Centers for Disease Control and Prevention, National Institutes of Diabetes and Digestive and Kidney Diseases; Garro 1995:37; Bruce 2000:542; Olefsky 2001: 630; Thompson and Gifford 2001:1459). Obesity is considered as probably the major environmental factor contributing to the increasing incidence of type 2 diabetes (Olefsky 2001:630). More than 80% of new cases of type 2 diabetes are associated with obesity (2004:341). Bailey (2000) however, reports that in a 1996 study by Hargrove and Keller, African American women considered being “overweight or

fat” as an older individual an expectation, and/or see being overweight as a sign of being healthy; being slim or skinny is looked upon as being sickly. African American women are not alone in this view of being overweight as healthy. Carson-Henderson (2002) reported a similar view held by populations she described as American Indians. She found that weight gain is considered a sign of health and well being among some American Indians, and that weight loss may be a cause for concern (Carson-Henderson 2002:47). Tripp-Reimer et al (2001) state that it is a common belief among many ethnic groups that a heavier physique is indicative of health. For example, they point out that in the United States, Navajo and Utes believe a heavy body indicates both health and happiness, the Hmong regard fat as one of two essential elements that provide vitality for the body, and that some Chinese people may believe that extra weight is a blessing related to wealth and prosperity (Tripp-Reimer 2001:5).

#### African Americans and Diabetes

Diabetes mellitus is a major clinical and public health problem in the African American community (Bailey 2000:73). Surveillance data from the Centers for Disease Control and Prevention have shown that the prevalence is substantially higher among blacks than whites (Elders and Murphy 2001:226). For example, research indicates that the diabetes rate is 33% greater for African Americans than whites (Lieberman 2004:344; Spector 2000:226; Skelly 1992:3), and estimated reveal that African Americans are 1.7 times as likely as Caucasians to have NIDDM as the general population (Schoenberg and Drungle 2001:445).

According to the National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health, for every six white Americans who have diabetes, ten African Americans have diabetes. Bailey (2000) reports that African American men have a prevalence of diabetes that is 80% higher than that for European men, while African American women have a prevalence 90% higher than that for European American women. Additionally, African Americans aged 20 years and older are twice as likely to have type 2 diabetes as whites of similar age, and they experience greater morbidity and mortality from the disease (McBride Murray et al 2003:167). Furthermore, estimates by the American Diabetes Association indicate that diabetes is twice as common among African Americans aged forty-five to sixty-five as among whites in the same age-group, and three times more common after age 65 (Davidson 1991:153). Diabetes also appears to have a greater impact and run a more serious course in African Americans compared with whites (Skelly 1992:3).

In an interview with Dr. James R. Gavin II, chair of the American Diabetes Association's (ADA) African American Program, Dr. Gavin stated that the ADA's research revealed that African Americans are acutely aware that diabetes is a serious disease (Jet Magazine 1996:36). Likewise, they know that people of color are at a greater risk for developing it. However, Dr. Gavin stressed that even with this knowledge, fifty percent of African Americans in a survey conducted by the ADA don't believe that they themselves are at risk, and often had a fatalistic attitude about diabetes, believing that there was nothing that they can do to avoid

it. Such a fatalistic attitude is unfortunate given data from the National Diabetes Information Clearinghouse, National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK) of the National Institutes of Health that illustrates the magnitude of Type-2 diabetes among African Americans:

- 2.3 million African Americans have diabetes.
- Most African Americans (about 90 percent to 95 percent) with diabetes have Type II diabetes.
- For every six white Americans who have diabetes, 10 African Americans have diabetes.
- African Americans with diabetes are more likely to develop diabetes complications and experience greater disability from the complications than their white American counterparts with diabetes.
- Death rates for people with diabetes are 27 percent higher for African Americans compared with whites.
- African Americans are at increased risk for a chronic disease such as diabetes due to dietary patterns that include higher consumption of fat and calories and lower consumption of fruit and vegetables (Haire-Joshu et al 2001:140).

The National Diabetes Information Clearinghouse, National Institute of Diabetes, Digestive and Kidney Diseases (NIDDKD) of the National Institutes of Health indicate that if African Americans can prevent, reverse, or control diabetes, their risk of complications will decrease. To do this, the NIDDKD recommends the adoption of healthy lifestyles, such as eating healthy foods and getting regular exercise. Additional studies concur that the main treatment behaviors for controlling diabetes include: taking medications, exercising, monitoring blood sugar, and dietary changes (Uusitupa 2002:1650; Hunt, Valenzuela, and Pugh 1998:962; Davidson 1991:158; Hamburg, Elliott, and Parron 1982:13; Weiss et al 1989:290; Task Force on Community Preventive Services 2002:10, Lorig et al 2001:256). Ideal glycemic control or hemoglobin

A1c (HbA1c) is <7.0% (Norris et al. 2002:39). An advisory note about the recommendation on dietary changes is worth considering. While food is an essential part of the way that any society organizes itself—and the way that it views the world it inhabits, cultural groups differ markedly from one another in many of their beliefs and practices related to food (Helman 1990:31). Thus, it seems important for diabetes health educators and health care service providers to be mindful of Helman's (1990:31) point that diet may be based on cultural, and not just nutritional criteria, because food patterns are learned in the family context and have highly symbolic and affective associations (Tripp-Reimer 2001:6).

Information on diabetes in African Americans from the National Diabetes Information Clearinghouse, National Institute of Diabetes, Digestive and Kidney Diseases (NIDDKD) of the National Institutes of Health reports that African American adults have substantially higher rates of obesity than white Americans, with the location of the excess weight being a risk factor for Type II diabetes. The information states that excess weight carried above the waist is a stronger risk factor than excess weight carried below the waist. Likewise, the NIDDKD reports that African Americans have a greater tendency to develop upper-body obesity, which increases their risk of diabetes. Among people known to have type 2 diabetes, obesity is found in 82% of African American women compared with 62% of white women (Davidson 1991:154). McBride Murry et al (2003) propose that the differential effects of diabetes on African Americans may be

attributed to the fact that this population must balance the demands associated with managing a major chronic illness in the midst of multiple stressors occurring in several domains of their lives.

Rock (2003) argues that to counter the trend in increasing weight and incidence of Type-2 diabetes among adults and children across North America, it is important to consider the place of certain foods and their consumption in real time and place. She suggests that it is important to consider how the organization of societies affects consumption and physical activity (Rock 2003:162).

#### Diabetes Mellitus and African American Women

Women in particular are disproportionately likely to have NIDDM and to live with the disease significantly longer than their male counterparts, and they also tend to operate with more co-morbidity and fewer economic resources (Schoenberg and Drungle 2001:448). However, diabetes is considered to be epidemic among African American women (Taylor 2001:51; Auslander et al 2000:78; Auslander et al 2002:809), a relatively unstudied group (Skelly 1992:14). African American women are more than twice as likely as Caucasian women to be diagnosed with diabetes, amounting to fifty-one cases of diabetes per 1000 African American women, compared to 23 per 1000 Caucasian women (Schoenberg and Drungle 2001:444). Skelly (1992) reports that Black women have a fifty percent greater incidence of diabetes than white women. For African American women fifty-five years and older, the prevalence of NIDDM is one in

four (Auslander et al 2002:809). Overall, African American women are more likely to be diagnosed with diabetes (Schoenberg and Drungle 2001:444), bearing a disproportionate burden of type 2 diabetes, and also its associated risk factors and complications such as eye disease, kidney failure, and lower extremity amputations (Liburd 2003: 160; Auslander et al 2002:809). As such, the prevention of type 2 diabetes among African American women is critical because of the high rates of diabetes-related mortality and morbidity in this population (Auslander 2002:809).

A major reason for the unequal distribution of diabetes among African American women is a high prevalence of obesity, a primary risk factor for type 2 diabetes (Liburd 2003:160; Davidson 1991:153), related to the higher amount of dietary fat consumed by African Americans when compared with Caucasians in the United States (Auslander 2002:809). African American women are a special population because they have the highest prevalence of obesity, and the third highest prevalence of type 2 diabetes (Lieberman, Probart and Schoenberg 1999:131). The 1999-2000 NHANES indicates that among African-American women aged forty and older, the rate of obesity, a body mass index greater than or equal to thirty is now more than 50%, and the combined rate of overweight and obesity is currently >80% compared to 61% for non-Hispanic white women aged fifty and older (Liburd 2003: 160). Bailey (2000) provides a cultural perspective on obesity as it relates to African American women. He cites a 1997 study conducted by Fitzgerald et al that found among African American women,

the motivation to lose weight often was not for health reasons but for improved appearance (Bailey 2000:73). In this case, the Fitzgerald study de-emphasized the importance of weight loss to one's diabetic condition, and placed more value upon losing weight for improved appearance (Bailey 2000:73). Carson-Henderson's (2002) research on Choctaw elders reveals that obese patients with diabetes usually have a high rate of insulin resistance, and that this means that much more insulin is needed in order to lower blood sugar than those whose weight is normal.

Carson-Henderson (2002) explains that obesity is a consequence of lifestyle, and therefore is subject to the influence of cultural and socioeconomic patterns. She reports that levels of food intake may be socially and culturally determined, noting that food has cultural dimensions (Carson-Henderson 2002:47). Owens (2003) believes that perceptions of food and cultural meanings attached to food are concerns that should be addressed, especially for adult women with type 2 diabetes. For African American women with type 2 diabetes, modifying their diet may be difficult given the deeply rooted experiences, historical meaning of food, and traditions, across generations, surrounding food in the African American culture (Owens 2003:147). Deviating from the traditional food experiences in one's family may be perceived negatively by family members and can result in conflict for the people with diabetes (Owens 2003:147). Yet, making healthy choices when preparing and consuming foods is important for maintaining control of diabetes (Owens 2003:147).

Family may not be the only factor influencing food choices and experiences. Carson-Henderson (2002) states that low socioeconomic status (SES) plays a role in food choices, and that low SES has been associated in many studies with calorie-dense, high fat, and refined carbohydrate diets.

Also reported in the Fitzgerald et al study was that an individual's negative attitudes and beliefs decreases motivation and promotes a "why bother" attitude if weight loss does not occur thereby leading to non-adherence to the dietary regimen for diabetes (Bailey 2000:73). Urdaneta and Krehbiel (1989:279) point out that a patient's understanding of diabetes, her/his expectations for treatment, and the motivation to comply are all tied to the patient's particular cultural matrix. As such, recognizing the impact of culture in disease management and self-care practices is important for improving diabetes care (Hosey, Gordon, and Levine 1998:108). Additionally, to prevent serious physical and mental complications in African American women with diabetes, there is a need to better understand how they meet the challenge of managing their diabetes (McBride Murry et al 2003:167), yet few research data are available on the self-care practices of black women with non-insulin dependent diabetes mellitus (Skelly 1992: 15). Much of the literature on black women and diabetes points to the importance of screening and early detection of diabetes among high risk women and the need for improved quality of care and for patient education services appropriate to the needs of these women (Taylor 2001:51).

#### Self-Management

Self-management has been defined as the performance of preventive or therapeutic health care activities, often in collaboration with health care professionals (Skelly 1992:19), or paramedical professionals such as nurses, pharmacists, physiologists who are consulted informally about health problems (Furnham 1994:715). Self-management is also a term that has been used widely to describe patient behaviors, patient education, and health promotion programs (Lorig and Holman 2000:1). For people with chronic disease, self-management is widely recognized as a necessary part of treatment (Lorig and Holman 2000:1).

For this study, self-management is behaviors, beliefs and patient education enacted as a part of the diabetic regimen. Specific behaviors included glucose testing/monitoring, nutritional/dietary changes, physical activity/exercise, foot care, medication taking, and symptom recognition and management, health care provider interactions, and support systems. Beliefs involve perceptions of self-efficacy in, benefits of, and barriers to caring out the required diabetes self-management treatment behaviors. Access to care includes the costs of medications, and testing supplies such as lancets, syringes, monitors, and test strips, and costs of health care treatments.

Self-management, also called self-care, is the performance of preventive or therapeutic health care activities, often in collaboration with health care professionals (Schoenberg and Drungle 2001:446; Skelly 1992:19). This self-management is conceptualized as activities undertaken by individuals to promote

health, prevent disease, limit illness, and restore health (Schoenberg and Drungle 2001:4465). There is no standard behavioral prescription that can be given to the diabetic patient because self-care is a fluid rather than static state (Kimble 2000:25). However, the main treatment behaviors recommended for controlling diabetes include: dietary changes, taking medications, exercising, foot care, monitoring blood sugar, and interaction with health care providers (Schoenberg, and Drungle 2001:446; Hunt, Valenzuela and Pugh 1998:964; Davidson 1991:158; Hamburg et al 1982:13; Weiss et al 1989:289; Lorig et al 2001: 256). Secondary treatment activities identified by Schoenberg and Drungle (2001) for diabetes self-management involve recognizing and responding to symptoms, seeking information, managing diagnosed conditions through home appliances, using over-the-counter medicines, or implementing changes in activities. The patient is often required to make complex treatment decisions and vary self-management behavior from situation to situation (Kimble 2000:25). This self-management by individuals with diabetes is reported to be modest, yet appropriate self-management is the cornerstone of glycemic control (Schoenberg and Drungle 2001:443). Skelly (1992) in a similar vane, agrees that self-monitoring is the cornerstone of self-management today. Davidson (1991) though believes that the cornerstone of diabetes management is proper nutrition. Skelly (1992) however, points out that dietary compliance is often the most difficult component of diabetes self-management. Though the “cornerstone” may be viewed differently, it is essential for effective diabetes self-management

because diabetes is serious, largely self-managed, and a personal responsibility (Funnell and Anderson 2002:3) that requires individuals with diabetes to exert this personal responsibility over the day-to-day maintenance of their disease if they are to achieve a stable state of health (Skelly 1992:4). The performance of regimen behaviors also requires problem-solving skills to manage daily barriers to regimen adherence and to make appropriate adjustments to the self-care regimen (Hills-Briggs 2003:182). The management of the disease thus relies largely on behavior modifications on the part of the patient (Urdaneta and Krehbiel 1989:279), and compliance with a therapeutic regimen in order to prevent or delay the onset of complications (Skelly 1992:5). It is a self-management regimen that the individual engages in for the remainder of one's lifetime, both in the presence and absence of current symptoms (Schoenberg and Drungle 2001:443).

As a complex task, the self-management regimen touches nearly every important aspect of daily life (Schechter and Walker 2002:170; Tripp-Reimer et al 2001:147). For example, Hunt, Pugh, and Valenzuela (1998) found in their work with Mexican Americans aged 29-69, that even though all patients tried to control their diabetes, none of them followed recommendations completely. Instead, they adapted self-management behaviors to the exigencies of everyday life such as what to eat, whether to exercise, when to take medications, available resources, priorities, social responsibility and level of autonomy (Hunt, Pugh, and Valenzuela 1998:207).

Research conducted within the Melbourne Aboriginal community by Thompson and Gifford (2000) revealed that when Melbourne Aborigines talk about trying to manage their diabetes, it is not only their sugar that is out of control, it is their whole life. When they talk about stabilizing their sugar, their discourses are woven into wider narratives about individual and community struggles to maintain a sense of coherence, control and stability over present life circumstances (Rock 2003:1459).

Urdaneta and Krehbiel (1989:279) report that compliance largely depends on developing management programs that incorporate, rather than pre-empt a patient's culture. Compliance with an overall treatment regimen, as well as intervention and prevention are important in diabetes self-management because NIDDM, with its complications, represents the leading cause of blindness, kidney failure, heart disease, strokes and amputation (Bruce 2000:542; Ferzacca 2000:1; Weiss et al 1989:283). Yet, complications of diabetes can be prevented or delayed by controlling risk factors such as hyperglycemia, and hypertension (Zgibor and Songer 2001: 23). Some individuals though do require insulin therapy to maintain normal blood glucose levels (Ferzacca 2000:12); an injection therapy likewise important in preventing complications.

Self-efficacy is an important and central concept in self-management (Bodenheimer et al 2002:2469). Self-efficacy is the confidence to carry out a behavior necessary to reach a desired goal, and is enhanced when patients succeed in solving patient-identified problems (Bodenheimer et al 2002:2469).

Groups can assist in this endeavor because groups offer a forum for people with diabetes to gather and to learn (Mensing and Norris 2003:96).

Even though participants' concepts about the relationship between their behavior and illness may not so much determine their self-care activities, they may reflect their experiences in trying to gain control over their disease (Hunt, Valenzuela, and Pugh 1998:964). For people with non-insulin dependent diabetes mellitus, self-care remains the core of control and containment of the disease (Schoenberg and Drungle (2001:446). The best disease control is achieved when those with type 2 diabetes have positive attitudes, good meal plan adherence, few perceived barriers to physical activity, and a high degree of knowledge of diabetes (Cox et al 2004:155).

#### Patient Health Education

Health education is education about health (Gilbert and Sawyer 2000:3). Weiss et al (1989) see the initial and most important ongoing therapeutic modality when treating diabetes mellitus as patient education. They believe that a patient who understands their disease and who participates in the therapeutic and goal-setting decisions is much more likely to follow the therapeutic program than a patient who is simply told what to do (Weiss et al 1989:289).

The principal tool of health educators is knowledge, and the sought outcomes are often behavioral (Gilbert and Sawyer 2000:3). Interventions include modifying such behaviors as diet/nutrition and exercise/physical activity (Green and Kreuter, 1999:129), and may also include, but are not limited to health

promotion, early identification and treatment, and disability limitation (Turnock 2001:265).

Research suggests that preventive interventions should target high-risk groups (Gilbert and Sawyer 2000:243; Uusitupa 2002:1651). Green and Kreuter (1999) point out that among the least modifiable or controllable personal factors are genetic pre-disposition, age, gender, and places of residence that encompass various social and environmental factors beyond the control of the individual.

Urdaneta and Krehbiel (1989:221) state that only by examining the interactions between all the determinants of the disease—environment, cultural, and biological—can we hope to understand and solve the diabetes problem. However, because biomedicine privileges white, middle class ideals of self-control and individualism while de-valorizing worldviews such as those prominent in marginalized neighborhoods where social interdependence is vital, such a focus within health education masks the economic, political, and racial inequalities beyond the clinic that create barriers to self-care (Miewald 1997:353).

### Diabetes Self-Management Education

Diabetes self-management education (DSME) is the process of teaching people to manage their disease (Norris et al 2002:39), and providing them with self-regulation skills (Skelly 1992:50). Educating and supporting patients in managing their daily life with diabetes mellitus are important goals of diabetes care today (Wikblad 1991:837); goals that are to optimize metabolic control and quality of life and to prevent acute and chronic complications while keeping costs

acceptable (Norris et al 2002:39). A common problem in diabetes patient education content though is that health professionals provide too much detail regarding patho-physiology and too little regarding the daily management of illness (Tripp-Reimer et al 2001:8)

Self-management education complements traditional patient education in supporting patients to live the best possible quality of life with their chronic condition (Bodenheimer et al 2002:2469). A distinction between traditional patient education and self-management education is that traditional patient education offers information and technical skills, while self-management education teaches problem-solving skills, and integrating self-management into daily life improves health outcomes for individuals with diabetes (Bodenheimer et al 2002:2469). Carson-Henderson (2002) believes that the assessment of patient beliefs and current practices within their lived experience is crucial to formulating effective diabetes education strategies.

Brown et al (2002) found that culturally competent self-management education such as accessible community-based sites and offering activities that reflected cultural characteristics and preferences of Mexican American participants, improved health outcomes of Mexican Americans, particularly those individuals with HbA(1c) levels >10%. Ideal glycemic control is <7.0% (Norris et al. 2002:39). The Task Force on Community Preventive Services (2002), a task force supported by the Centers for Disease Control and Prevention, (CDC), recommends using alternatives to clinical sites for the provision of diabetes self-

management education. These sites include community gathering places such as community centers, libraries, and places of worship (Task Force on Community Preventive Services 2002:10). Additionally effective are strategies reported by Urdaneta and Krehbiel (1989) for reaching adults with poor literacy skills. The authors cite (1) the use of teaching methodologies that incorporate a personal approach, (2) an eclectic manner of compiling information, (3) experiential learning through the use of the senses and work, (4) reiteration of facts for reinforcement, (5) an emphasis on cooperation and group support, and (6) work with familiar things (Urdaneta and Krehbiel 1989:278). Carson-Henderson (2002) adds that materials and practices that have been seen to be effective in one population may not be effective in another, such that education programs must be compatible with both the knowledge and cultural background of the patient group. Conversely, research by Cox et al (2004) found that self-management education for type 2 diabetes does not need to be different for African Americans versus Caucasians in southern states. But, low-income individuals may not understand or follow the education provided for diabetes self-management, if that education does not take into account the patient's prior knowledge, understanding, beliefs, attitudes, and barriers be they real or perceived (Cox et al 2004:157).

While the foundation of diabetes management is the self-care behavior of the patient (Anderson 2003:134), diabetes self-management success also requires an alliance between patients and their health care providers, one or more from a

team including physicians, nurses, dietitians, diabetes educators, pharmacists, and other specialized health professionals (Schechter and Walker 2002:170) such as podiatrists, ophthalmologists, psychologists, diabetologists, and internists (Spikmans et al 2003:152; Romeo 2000:354).

### Standards for Diabetes Self-Management Education

The “Task Force to Review and Revise the National Standards for Diabetes Self-Management Education (DSME) Programs” reviews current DSME standards for their appropriateness, relevancy, and scientific basis, and to be sure the standards are specific and achievable in multiple settings. The task force developed ten (10) guidelines that represent the cornerstone of care for all individuals with diabetes who want to achieve successful health-related outcomes (Mensing et al 2000:682). The national standards define quality diabetes self-management education that can be implemented in diverse settings and that will facilitate improvement in health care outcomes (Mensing et al 2000:682). The standards are divided into three categories—structure, process and outcomes. Pertinent areas are:

- The DSME will recognize and support quality DSME as an integral component of diabetes care.
- The DSME entity will determine its target population, assess educational needs, and identify the resources necessary to meet the self-management educational needs of the target population.
- An established system (committee, advisory board) involving professional staff and other stakeholders will participate annually in a planning and review process that includes data analysis and outcome measurements, and addresses community concerns.
- The DSME entity will designate a coordinator with academic and/or experiential preparation in program management and the care of individuals with chronic disease.
- The DSME will involve the interaction of the individual with diabetes with a

multi-faceted education instructional team, which may include a behaviorist, exercise physiologist, ophthalmologist, optometrist, pharmacist, physician, podiatrist, registered dietitian, registered nurse, other health care professionals, and paraprofessionals.

- The DSME instructors will obtain regular continuing education in the areas of diabetes management, behavioral interventions, teaching and learning skills, and counseling skills.
- A written curriculum, with criteria for successful learning outcomes shall be available.
- An individual assessment, development of an educational plan, and periodic re-assessment between participant and instructor(s) will direct the selection of appropriate educational materials and interventions.
- There shall be documentation of the individual's assessment, education plan, intervention, evaluation, and follow-up in the permanent record.
- The DSME entity will utilize a continuous quality improvement process to evaluate the effectiveness of the education experience provided, and determine opportunities for improvement

Mensing et al (2000) believe that demographic variables, such as ethnic background, formal education, reading ability, and barriers to participation in education must be considered to maximize the effectiveness of diabetes self-management education.

### Religion and Health

Religion, "a system of symbols which acts to establish powerful pervasive and long lasting mood and motivations in men by formulating conceptions of a general order of existence, and clothing these conceptions with such an aura of factuality that the moods and motivations seem uniquely realistic" (Bharati 1971:237) helps people face life crises, and provides consolation (Angrosino 2001:48). According to anthropologist Anthony F.C. Wallace, religion is the "belief and ritual concerned with supernatural beings, powers, and forces (Kottak 2002:488; Haviland 2002:364). Haviland (2002) posits that when individuals

participate in religious ceremonies, they obtain a personal lift—a wave of assurance, and security. Ellison’s (1998) research explains that religious practices, rituals, and beliefs may provide specific coping resources for African Americans (Ellison 1998:3). He found a positive relationship between “church” attendance and life satisfaction patterns in older, non-Southern African Americans, yet not among their more religious, southern counterparts (1998:3). Similarly, Tripp-Reimer et al (2001) report that trusting in God and prayer are common treatments for diabetes among rural Southern African Americans. Mattis (1997) reported that among elderly African American adults, women are more likely than Black males to engage in formal religious practices, and more likely to make use of religious materials and private prayer. Prayer, specific beliefs, and cognitions about God and the meaning of life, are particularly important in Black women’s efforts to cope with difficult life events; it is one of their most important coping strategies (Mattis 1997:3), and is the most common and frequently cited method of treating illness in African American communities (Spector 2000:219).

Perrin and McDermott (1997) report that numerous studies document that religion, or one of the dimensions of religion, has a positive impact on mental health or psychological well being in adulthood. Their research on spiritual health identified several meanings of this dimension. These are: (a) a unifying force within individuals which integrates all the other dimensions (physical, mental, emotional and social) and therefore, plays a vital role in determining the state of well-being of the individual; (b) a meaning and purpose in life; (c) a

common bond between individuals; and (d) individual perceptions of faith (Perrin and McDermott 1997:90).

The spiritual dimension enhances a person's health when spirituality includes: (a) personal belief or faith that extends beyond one's self and provides a sense of well-being, (b) a locus of control and empowerment for self-realization, (c) a system of unconditional meaningfulness that provides a personal sense of positive direction and fulfillment, and (d) peace and tranquility in the face of stressful situations (Perrin and McDermott 1997:90).

Religious involvement may also have a beneficial influence on health and well-being by (a) shaping behavioral patterns and lifestyles in ways that reduce the risk of chronic and acute stressors, (b) by generating relatively high levels of social resources, and (c) by providing specific cognitive resources that are useful in the problem-solving or emotion-regulating aspects of coping with stressors (Ellison 1998:3).

Perrin & McDermott (1997) state that health care professionals are beginning to consider that optimal health may require a spiritual as well as social, behavioral, and physical balance. However, even though a large body of literature suggests that aspects of religious involvement have beneficial implications for physical health and may reduce mortality risk, few studies focus squarely on African Americans (Ellison 1998:2).

## Beliefs about Blood

Beliefs are propositions believed to be true (Chrisman and Johnson 1996:104). The human experience of blood—as a vital liquid circulating within the body, and which appears at the surface at times of injury, or illness, provides the basis for lay theories about a variety of illnesses (Helman 1990:26). In general, these illnesses are ascribed to changes in its volume, consistency, temperature, quality or polluting power (Helman 1990:90). According to Helman (1990:26) these lay concepts of blood also provide a potent image of things social, psychological and physical. Snow (1993:97) suggests that blood responds to many things, and is in a constant flux, responding to internal and external stimuli. Among the external factors she cites that cause blood to change are: occurrences triggering strong emotional states in the individual; failure to keep the body clean; and even seasons of the year. Internal change factors that Snow (1993:98) identifies include the use of remedial measures to restore health; failure to keep the body clean internally; the disruption of normal processes when one becomes ill, and a factor as simple as what one eats for breakfast. Consideration of what causes blood to change may also be affected by age and gender (Snow 1993:98).

Matthews, Lannin and Mitchell (1994:793) suggest that the reference to bad or dirty blood refers directly to a more inclusive system of beliefs about health and disease common to many African Americans in the South. This belief system attributes good health to the maintenance of balance in the blood (Matthews,

Lannin and Mitchell 1994:793). Snow (1993) also recognizes the important symbolism of blood in African American life. She believes that “blood as the shimmering red symbol of life itself,” is of immense importance in African American traditional medicine (Snow 1993:97). Helman (1990:26) advises clinicians to be aware of the possible hidden symbolism in any lay conceptualization of blood. However, because of contrasting ideas about the blood and its functions between physicians and African American patients in clinical settings, misunderstandings do occur in the interaction between the two (Snow 1993:97). Snow (1993:97) suggests that the prescriptive and proscriptive measures whose aim is keeping the blood just right require constant attention when the goal is to maintain a balance between factors impinging on the state of the blood and their presumed effect. Rock (2003:131) adds that research and interventions focused on the sweetness of blood would benefit from rethinking intersections between diabetes, duress, and distress.

### Conclusion

The literature and methods delineated in this chapter formed the foundation for the data collection and data analysis of this research. The literature documents the seriousness of non-insulin dependent diabetes mellitus for African Americans and African American women in particular. The literature also clearly indicates the importance of self-management and self-management education for the prevention of diabetes complications, morbidity and mortality for the women participants of this study. Similarly, the literature documents that managing

diabetes is a complicated task involving a myriad of on-going daily activities vital to health of the diabetic individual. Unfortunately, the literature reports that individuals overall have a difficult time with diabetes self-care/management, especially adhering to dietary and physical activity regimens.

The applied theories support the relevance for understanding health beliefs, behavior and behavior change processes and how these processes may have facilitated and/or hindered the desired action for diabetes self-management.

Lastly, and a significance for this study, the literature documents the dearth of self-management research on the most vulnerable groups with disproportionately high prevalence of non-insulin dependent diabetes mellitus (NIDDM)—older adults, women and in particular African American women (Schoenberg and Drungle 2001:448). This research endeavored to provide some insight into self-management practices of African American women with diabetes mellitus because self-management practices among ethnic minority groups are insufficiently understood (Schoenberg and Drungle 2001:448).

CHAPTER III  
METHODOLOGY  
Introduction

The inquiry of this study focused on diabetes health beliefs and self-care behaviors. The inquiry is guided by a search for participant's explanations of their experiences in treating the health problem of this study—diabetes self-management.

The conceptual framework as informed by the cultural construction of health and illness and Health Belief Model guided both the data collection and Grounded Theory approach to data analysis of sorted and coded text data. A Grounded Theory approach provided a technique for identifying categories and concepts that emerged from interviews, and linked the concepts into substantive and formal theories (Bernard 2002:462) such as described in Chapter two.

The methods and analysis utilized presented an avenue for discovering the women's self-management behaviors, health beliefs, support systems, and diabetes knowledge and education of twenty-five African American women with diabetes mellitus. The analysis also looked for constructs associated with diabetes self-management as reported by the seven self-management educators, and five diabetes education programs. Such constructs included

nutrition, exercise, medications, weight reduction, foot care, elimination of stress, blood glucose monitoring, and diabetes education.

The research for this study involved the use of qualitative and quantitative methods in order to gather data on health beliefs, diabetes knowledge, and self-management behaviors. The qualitative interviews were conducted first followed by the quantitative questionnaire. The study utilized semi-structured, in-depth interviews direct and participant observation, and a survey /questionnaire. Combining several such data collection strategies provided data triangulation (Berg 2001:28), confirming and cross-checking the accuracy of data obtained from one source with data collected from other, different sources (LeCompte and Schensul 1999:131), in hopes that the multiple sources all converge to support a particular theory (Leedy and Ormond 2001:105).

The methods selected provided the data to answer the research questions:

1. What is the cultural construction of diabetes mellitus among African American women with the disease?
2. What treatment behaviors do African American women utilize to manage diabetes?
3. What self-management treatment behaviors are prescribed by diabetes educators and self-management programs?
4. What is the concordance/discordance exists between self-management treatment behaviors of the women and prescribed behaviors of diabetes educators and self-management programs?

## Research Design

This study was designed as a descriptive, qualitative inquiry into (a) the ways in which African American women with type 2 diabetes manage and understand their disease, and (b) the perceptions of diabetes self-management as understood and practiced by diabetes self-management health educators, important team members in diabetes self-care, and self-management programs. Thus, this research looked for variations, as they may have existed between the women with diabetes, the diabetes self-management health educators, and the programs. For this study, diabetes self-management was three factors: (1) health beliefs, (2) behaviors and (3) patient education. Self-management behaviors included but were not limited to, glucose monitoring, exercise/physical activity, patient education, nutrition/diet modification, use of medications, physician-patient interaction, social systems such as family, friends and religion.

The problem identified for the present study was the epidemic rate, and disproportionate burden of type 2 diabetes and its associated risk factors and complications for African Americans in general, and African American women in particular (Lieberman 2004:335; Cox et al 2004:156; Lieberman, Probart and Schoenberg 2003:79; Liburd 2003:160; Auslander et al 2002:809; Bailey 2000:61; Tull and Roseman 1995:613).

The women with diabetes interviewed for this study all lived in Pinellas County, with the majority residing in St. Petersburg, Florida. According to the 2000-2001 Comprehensive Assessment for Tracking Community Health Report

(CATCH), prepared by the University of South Florida's Center for Health Outcomes Research, (CHOR), District 7 in Pinellas County (St. Petersburg, Florida), has a consistent pattern that reflects very unfavorable health status for several indicators. These include: maternal and child health; social and mental health; health status; and sentinel events. The report identifies the District 7 area as being characterized by having the highest percentage of African American residents (23%) in the county; a finding, the reports says, that is consistent with the strong association found between health status, race and poverty throughout the United States.

The present study focused on the experiences of self-management as an important aspect of diabetes care because self-management is vital in preventing diabetes complications (Ellison and Rayman 1998:325).

### Choosing Participants

Non-probabilistic, snowball sampling served as the primary and most effective strategy for choosing participants for this study. Through word of mouth, and the availability of participants in diabetes self-management education classes, I was able to gain access to and interview African American women with type 2 diabetes. During interviews, many of the women shared that they knew of other African American women who were also diabetic. To respect the privacy of the potential new contact, I requested that the interviewee first contact the friend or family member to ascertain their interest in being interviewed. The phone call or face-face conversation was also to find out whether the interviewee was

permitted to give me the name and phone number of the potential new interviewee. A second strategy was to see whether the new contact preferred to call me to schedule an interview. In the majority of the referral contacts, the new interviewee did grant permission for the informant to pass along the contact information to me. I made the contact, and scheduled the interview. By asking the first subjects for referrals of additional women with type 2 diabetes, the sample eventually snowballed from a few subjects to many subjects (Berg 2001:33). This technique allowed for the continuous accrual of related research respondents with one or more common characteristics within a large unknown universe of individuals (Trotter and Schensul 1998:705). The size of the sample was dependent on how homogenous the population was—how alike its members were with respect to the characteristics of the research interest (Leedy and Ormond (2001:218).

### Research Participants

Researchers choose individuals (case selections) to study because they possess characteristics that match those of interest to the researcher (LeCompte and Schensul 1999:113). As such, the participants of this research were (a) African American women ages forty-six to eighty-seven with a self-reported diagnosis of type 2 diabetes, and (b) diabetes self-management health educators. The literature identifies the onset of diabetes as usually occurring in persons who are in the middle and later stages of life (Urdaneta and Krehbiel 1989:277). For this reason, and because the women who primarily attended the

sites where data collection occurred were forty years of age or older, and were within the age for diabetes onset of in middle to later years of life, this study focused upon the accessibility and availability of this population.

The women in this study were recruited through (1) diabetes self-management education classes in St. Petersburg, and Safety Harbor, Florida, (2) family members, (3) friends of diabetic women, (3) interviewee referrals, (4) a by hand, researcher distributed recruitment letter to African American women in the St. Petersburg area (Appendix A), (5) letter to churches (Appendix B), and (6) distributing investigator business cards to potential participants. The second population under study for this research included seven professionally diverse diabetes self-management health educators. These individuals were selected based upon the National Standards for Diabetes Self-Management Education (DSME) programs which recommend that diabetes self-management education involve the interaction of the individual with diabetes with a multi-faceted education instructional team, which may include a behaviorist, exercise physiologist, ophthalmologist, optometrist, pharmacist, physician, podiatrist, registered dietitian, registered nurse, and other health care professionals. Additionally, Davidson (1991) informs us that ongoing patient care involving a team composed of, at a minimum, a physician, nurse, and dietician can prevent unsatisfactory outcomes. Given these recommendations, this study included two registered nurses, one licensed practical nurse, one nutritionist, one exercise physiologist, and two physicians. They were recruited through researcher phone

contact, and attendance at diabetes self-management programs in St. Petersburg, and Tampa, Florida. Prior to participation in the study, the research was explained to all participants, and written informed consent (Appendix E) was obtained from all participants who agreed to be in the study.

### Data Collection

This study utilized a detailed set of questions, and procedures for conducting the research (LeCompte and Schensul 1999:61), and used the most practical, efficient, feasible, and ethical methods for collecting the data (Marshall and Rossman 1994:105). The study included an eleven item demographic participant profile of the women (Appendix C), a eight item health educator self-profile (Appendix D). It also included a thirty-nine item self-administered, and researcher assisted questionnaire (Appendix F). The use of the mixed qualitative and quantitative methods produced a large body of data that generated categories, themes, and patterns (Neuman 2000:420; Marshall and Rossman 1994:112) of diabetes beliefs and self-management behaviors. Through inductive reasoning (from particular to general), this large body of data were reduced to a small set of themes (Leedy and Ormond 2001:158; Creswell 1998:152), recurring ideas, and patterns (Marshall and Rossman 1994:114) to make transformed data more readily accessible, and understandable (Berg 2001:35). This process enabled a description and understanding of diabetes self-management, health beliefs, knowledge, and behaviors between the women themselves, and the associated convergence or divergence from perspectives of diabetes self-

management health educators. Data collection began in November 2003 and concluded in May 2004.

### The Women

Twenty-five African American women ages forty-six to eighty-seven with type 2 diabetes participated in this study. Average age was sixty-four. Diagnosis of diabetes ranged from three months to forty-one years. Two women were in their forties, seven women were in their fifties, nine women were in their sixties, six women were in their seventies, and one woman was in her eighties. Nine of the women were married, nine of the women were widowed, four were divorced, two were separated, and one never married. Educational levels ranged from high school graduate to doctoral degree.

Ten women did not report income specific data. However, they did report having Social Security, Social Security Disability, Medicaid, Medicare, or a combination of this type of assistance. Two women reported receiving Social Security only, but did not provide the amount. For women who did report an annual income, two women reported income between \$10,000-19,000. One woman reported her income between \$20,000-29,000 from retirement. One woman indicated annual income between \$30,000-39,000, another between \$40,000-\$49,000 and three women indicated annual income between \$75,000-100,000. Five women did not provide income, or any other type of financial assistance information.

Self-identified religious affiliation revealed that sixteen (64%) were Baptist, eight (16%) were Pentecostal, two (8%) were Methodist, one (4%) was a member of the Church of God in Christ, and one (4%) was Non-denominational, and one (4%) was Presbyterian.

Family history of diabetes was very prevalent among the women. Twenty four (96%) of the twenty five women reported knowledge of at least one family member presently with diabetes, or at least one deceased family member who had diabetes. Only one woman reported not being aware of anyone in her family with or who had diabetes. Twenty four (96%) of the women reported being overweight at the time of diagnosis. All of the women had attended a diabetes self-management class at least once since being diagnosed. Seven women were presently attending classes at the time of this study.

Because some people of African origin living in the United States might not choose to refer to themselves as African American (LeCompte and Schensul 1999:26), all women self-identified their ethnic affiliation. For this study all women self-identified as African American on the survey instrument (Appendix F).

#### Participants' Profile

A demographic profile (Appendix C) was completed with each woman. The participant's profile captured data on age, height, weight, marital status, occupation, education, city of residence, type of insurance, religion, length of diabetes diagnosis, and attendance at diabetes self-management education

classes. The demographic profile was completed as part of the semi-structured, in-depth interview session.

## The Women

### Semi-structured, In-depth Interviews -- Qualitative

Semi-structured, in-depth interviews were conducted from December 2003 through April 2004 with each woman. The interviews were conducted with the use of an interview guide (Appendix G). An interview guide includes a list of questions and topics that need to be covered (Bernard 1994:209). The interviews also took on an approach reflective of Bernard's (1994) description of unstructured interviewing—interviews conducted with a clear plan in mind [interview guide], but with a minimum of control over the informant's responses.

Twenty-four of the interviews were conducted on a face-to-face basis. One interview was conducted by phone because of what the participant described as her "busy schedule." Twenty-one of the interviews were held in the homes of the women. Two interviews were held at places of employment, one at the site of, and after a diabetes self-management education class. The total number of interviews for this study was based upon a percentage of the number of women attending community and clinic-based diabetes education classes included in this research. I originally anticipated conducting interviews with approximately fifteen percent of the total population of the African American women with Type-2 diabetes attending the diabetes education that classes I observed. However, I conducted interviews with thirty-two percent, or 8 women who attended classes.

The remaining sixty-eight percent, or 17 women agreed to participate in the study as recruited by word of mouth.

On average, class attendance of women was approximately eleven women per month between the two community-based sites where the majority of the direct and participant observation occurred. Many of these women were the same women who attended self-management classes at the same location more than once per month.

The total number of women with Type-2 diabetes included in this study was limited to twenty-five based upon the anticipated large amount of narrative material generated by semi-structured interviews. Additionally, with twenty-five interviews, saturation of the data occurred whereby the information on self-management beliefs, and behaviors became redundant.

#### Self-Management Survey/Questionnaire—Quantitative

A qualitatively informed, thirty-nine items questionnaire/survey was researcher designed, and used as an extension of the semi-structured, in-depth interviews. The survey was administered during April and May of 2004 after the interviews were completed as a procedure to follow-up on the in-depth interviews. The interviews were conducted from December 2003 through April 2004. The survey was designed based on data from the interviews, and served to confirm the interview statements of the women informants (LeCompte and Schensul 1999:69). While the survey was based primarily on information

obtained from the semi-structured, in-depth interviews, six questions were selected from the Centers for Disease Control and Prevention's (CDC), 2002 Behavioral Risk Factor Surveillance Survey (BRFSS). Since 1984, the CDC has administered the BRFSS. The instrument is designed to collect data on behaviors that would be useful for planning, initiating, supporting, and evaluating health promotion and disease. An additional purpose of the CDC survey is to monitor the state-level prevalence of major behavioral risks among adults associated with premature morbidity and mortality. Questions from the BRFSS used for this study were taken from sections on (a) diabetes, (b) fruits and vegetables, (c) exercise/physical activity, (d) pills/insulin, and (e) weight control.

In a similar procedure as with this study, Cox et al (2004) used a cross-sectional survey in their study on self-management of type 2 diabetes in low income African American and Caucasian adults. Their *Diabetes Patient Questionnaire* (DPQ) is a modified version of the *Diabetes Care Profile* (DCP) designed by Fitzgerald et al (1996). Considered valid and reliable, DCP is a self-administered instrument consisting of ten scales that measure social, psychological, health, dietary, and physical activity factors related to diabetes management (Cox et al 2004:158). Questions from the DCP utilized by Cox et al (2004) in their study addressed perceived health status, diabetes control, perceived knowledge of diabetes care, attitudes toward diabetes, physical limitations, meal plan adherence, and exercise barriers. Other questions in the twenty-five item, DPQ interview protocol collected data similar to the present

study. For example, the DPQ questions collected data on demographics, previous diabetes instruction, extent to which diabetes recommendations were being followed, and physical activity (Cox et al 2004:159).

A study by Zgibor and Simmons (2002) likewise used a qualitative survey. Their comparative study investigated barriers to blood glucose monitoring, and diabetes care among Europeans, Maori and Pacific Islanders. Zgibor and Simmons' (2002) research also considered variables such as (a) self-efficacy, (b) health beliefs, (c) psychosocial environment, (d) co-morbidities (e) finance/access to care, and (f) knowledge of diabetes as they relate to barriers to diabetes care/ services.

Questions from the Cox et al (2004), Zgibor and Simmons (2002), or the Fitzgerald et al (1996) study were not used in this study because the CDC's BRFSS is a nationally recognized, used, cited, and readily accessible instrument. Additionally, it adequately met the needs of this study for initial survey design.

The survey for this research used multiple choice, true-false, yes-no, and agree-disagree Likert-type scale responses. The questions were designed to elicit force-choice responses with response categories predetermined by the researcher (Angrosino 1987:173). The personal survey solicited the respondent's own views and opinions in order to explore the extent of variables involved in the broadly defined issue (Angrosino 1987:173) of diabetes self-management.

The survey built on the semi-structured interviews and observations

(Schensul, Schensul and LeCompte 1999:166), and from the 2002 BRFSS, provided objective and quantifiable data on the interviewees' assessment of their own self-management practices and behaviors. The questions and response values were used to measure the construct—self-management, and to identify variables such as nutrition, physical activity, medications, health education classes, glucose monitoring, family/peer support, cost of supplies, insurance coverage etc., that may be associated with it, thus making it possible to target health education, health promotions and interventions to the issues that are important to the women.

#### Questionnaire/Survey Pilot Testing

Before administering the survey, the instrument was submitted for review, pilot testing, and approval. The initial draft of the survey was first submitted to officials at two pilot test sites for review and approval; first, to the director of the Pinellas County Health Department's Office of Minority Health, and the Diabetes Intervention and Prevention Program (DIPP) director, and second to the self-management education class director at the St. Petersburg Free Clinic-James B. Sanderlin site. Approval of the instrument, and permission to conduct the pre-testing was received from program officials at each site. Thus, two (2) pilot-test sessions were conducted with participants in two diabetes self-management education classes. A total of ten African American individuals, both men and women between the ages of forty-eight to sixty-five were pilot-tested at the DIPP community-based, non-clinical diabetes self-management education class. The

second pilot testing occurred at the St. Petersburg Free Clinic's Diabetes Program—James Sanderlin site. A total of thirty-four individuals participated in the pilot testing during one of the monthly diabetes self-management education classes held during the time period of the study. Demographics included both males and females between the ages of fifty and sixty-nine, with diverse ethnic identities. Self-identified ethnicities included Native American, African American, Caucasian, and Latino. Nine individuals self-identified as African American. Between the two sites, the instrument was piloted with approximately forty-four individuals with type 2 diabetes. Like the Cox et al (2004) study, the pilot testing in this study was initiated to solicit comments on the clarity of the questions, wording, and to obtain suggestions for question additions and/or deletions. Thus, the piloting was done to test the construct, content, and face validity and reliability of the survey; to assess the clarity of the questions, the timing of the administration, sequencing, flow and skip patterns, language use, comprehension, length, and reliability before using the questionnaire (Schensul, Schensul and LeCompte 1999:190). Based on positive comments that the survey was easy to read, understand, and that it addressed important issues in diabetes self-management, the survey was finalized with a total of three new questions added. The survey was submitted to and received approval from the University of South Florida's Institutional Review Board.

The final survey (Appendix F) was hand delivered or mailed to each of the twenty-five women participating in the study. Twenty of the twenty-five women

returned the survey for an eighty percent response rate.

### Diabetes Self-Management Health Educators

This research also included semi-structured, in-depth interviews and a self-profile (Appendix D) of seven professionally diverse diabetes self-management health educators. For this study, these individuals were defined generically as persons who were involved in providing diabetes education, intervention and prevention classes, or health care services to individuals with diabetes. These individuals either taught diabetes self-management education classes on a regular basis (twice per month or once per week), or were guest presenters in classes held at community, clinic or university-based locations. They represented a professionally, ethnically, and gender diverse group of individuals. The composition included two registered nurses (RNs), one licensed practical nurse (LPN), one exercise physiologist, one nutritionist who has written a book and created a pyramid about “Soul Food,” one endocrinologist who worked in a university-based, adult diabetes clinic, and one internal medicine physician who also practiced holistic medicine. One registered nurse was also a registered dietician (RD), and an American Diabetes Association (ADA) certified diabetes self-management educator. The exercise physiologist was also an American Diabetes Association certified diabetes self-management educator. To become an ADA certified diabetes self-management educator, individuals must have a Bachelor’s degree, a minimum of one thousand hours of teaching diabetes self-management education, and pass a written exam.

The number of diabetes health educators who were interviewed was based on the type of educators who make up the diabetes self-management team, e.g. physicians, nutritionist/dietician, nurse educator, and occasionally an exercise/physiologist. The selection of diabetes educators was also based on an interest in examining any differences and similarities in perspectives from the diverse professionals involved in diabetes self-management.

Ethnicity of the diabetes health educators included three African American females, two Caucasian females, and two Caucasian males.

#### Diabetes Self-management Health Educator Self-Profile

All of the diabetes self-management health educators completed a “Self-Profile” (Appendix D) during the semi-structured, in-depth interview. This eight item tool captured such information as (1) the number of years providing diabetes self-management education, (2) the location of the classes taught, (3) the duration of the classes, (4) the profession of the diabetes educator, (5) the educational level, (6) certifications/licenses held, (7) gender, and (8) ethnicity.

#### Direct and Participant Observation

##### Diabetes Self-Management Education Classes

Participant observation is the foundation of cultural anthropology (Bernard 1994:136). Using participant observation provided an avenue for learning through exposure to, and involvement in the activities of the participants in this study (Schensul, Schensul and LeCompte, 1999:91). The primary research sites

and settings for direct and participant observation were two programs providing community-based diabetes self-management education classes in St. Petersburg, Florida. One program was located within a community-based site (The Enoch D. Davis Center), while the other program was located within the community, but in a clinic-based facility—the St. Petersburg Free Clinic, housed within the James B. Sanderlin Center.

Participant observation also provided an opportunity to get close to the participants, in hopes of making them feel comfortable enough with my presence so that I could observe and record information about their lives (Bernard 1994:136; Marshall and Rossman 1994:79). To understand the participants, they were studied in their particular cultural environment of the diabetes community-based classes (Kleinman 1980:8), in an effort to go from being an outsider to being an accepted insider (Creswell 1998:123). Participation in class activities involved taking written pre-post tests about diabetes, joining in with exercise classes, being measured for body mass index (BMI) assessment (height and weight proportion), glucose testing, high blood pressure screening, nutritional label reading, and responding in question and answer sessions.

An additional aspect of participation was that of my experience as a “mock” diabetic. Daily behaviors were initiated to comply with self-management instructions provided by the diabetes health educators and programs. These instructions included daily glucose monitoring, daily exercise for at least thirty (30) minutes, reduction in the portion sizes of foods eaten, eating four to five

small meals a day, and two to three nutritious snacks. Recommendations were to eat something nutritious (e.g. carrots, salad, bell peppers, fresh fruit, pumpkin or sunflower seeds, low-carb protein bar) every two hours, keep a glucose monitoring log, test before a meal in the morning, two hours after a meal, monitoring my weight, drink at least eight glasses of water daily, keep something sweet like a small piece of candy readily available (to raise glucose levels should the level seem to drop), count and reduce simple carbohydrates (e.g. sodas, cakes, cookies, white rice, candy), estimate serving sizes (e.g., one half cup of oatmeal, one half of a banana or apple), use sugar substitutes such as Splenda. Equal, Sugar Twin, Sweet 'N Low, feet checks with a mirror for cuts and bruises, awareness of physiological changes that may suggest glucose levels that were either too high or too low (light-headedness, dizziness, excessive tiredness, blurry vision, disorientation).

Further participant observation included volunteering at both of the primary sites for data collection: the Pinellas County Health Department's Office of Minority Health (PCHD/OMH), and with the St. Petersburg Free Clinic's Diabetes Program.

The PCHD/OMH desired to reduce ethnic and racial minority health disparities such as diabetes. As such, it provided diabetes education classes through the Diabetes Intervention Prevention Program (DIPP); a component of the Health Department's Health and Human Services (HHS) funded Steps to a HealthierUS (STEPS) Project. Volunteer activities at the PCHD/OMH allowed for access to

the program director of the DIPP. With the permission of the Director of the Office of Minority Health, and the DIPP director, access was granted to the diabetes self-management classes and to participants in the classes. The DIPP classes were free, open to the public, and held once a week for two hours. An introduction of the study afforded the opportunity to recruit women for this study. The DIPP was selected as a recruitment site because the African American women desired for this study were attendees at the classes held by DIPP. Additionally, the DIPP class held at the Enoch Davis Center was located in a high minority health disparity geographical area that included diabetes as an indicator. One woman with diabetes and one diabetes health educator from DIPP volunteered to participate in this study.

The DIPP program not only provided access to African American women with type 2 diabetes, but also to other health professionals attending classes as guest speakers. For example, guest presenters included a gastroenterologist, and a podiatrist. Likewise, access to self-management education materials was readily available. These materials included print and video materials.

Another venue for participant observation included attendance at, and volunteering with St. Petersburg Free Clinic's diabetes self-management education classes. These clinic-based classes were held at the Free Clinic's James B. Sanderlin Center site twice a month for one hour each. Researcher activities involved guest diabetes lecturer, and assisting at the front desk with attendee sign in for class sessions, collecting the one dollar donation for the

class (participants could attend the class without a donation), and distribution of diabetic supplies such as test strips, monitors, lancets, syringes, and alcohol wipes. As with the DIPP, the class director introduced the study and researcher to the attendees. Five women from the St. Petersburg Free Clinic's class participated in the study.

Observations of diabetes self-management classes were conducted for six months—from November 2003 to May 2004, and were conducted across several program types, locations, and times. These included:

1. University Community Hospital (UCH)—Diabetes Care Program—Tampa
2. University Clinic—Diabetes Education Center—USF, Tampa
3. Hospital-based—Morton Plant Mease Hospital, Joslin Center—Clearwater
4. Community-based Center--DIPPER/DIPP—St. Petersburg
5. Community-based Clinic—St. Pete Free Clinic—James B. Sanderlin Center—St. Petersburg.

Estimated attendance ranged from eight to twenty women of mixed ethnic/racial composition at each session. The representation of African American women in the classes varied depending upon location, but was always no more five at the university and hospital-based classes. Community-based class attendance averaged eight to fifteen African American women per session. Community-based classes that offered free testing supplies such as monitors, strips, lancets, and free syringes, had larger numbers of participants than classes that did not offer such participant incentives. Additionally, community-based classes were free or accepted minimal monetary donations (one dollar), and offered free supplies and/or food had larger attendance than university and hospital-based clinic diabetes education classes observed. One hospital-based

program had good overall participant attendance (25 total individuals), but still low attendance of African American women (5 persons). Cost of the class may have been a factor for the lower attendance at university and/or hospital-based diabetes self-management education classes. This cost ranged from approximately \$500-700 dollars for the class. Classes were held for five hours each day over a two-day period, or four sessions in one month for two hours each session. The cost of the class was covered under health insurance through Florida Law, Chapter 96-279, that required coverage for medically necessary diabetes supplies and self-management training. However, participants could be assessed some cost for what insurance did not cover. Some programs offered scholarships to help defray the cost for individuals with low-incomes or no health insurance coverage.

The Diabetes Intervention and Prevention Program (DIPP) and the St. Pete Free Clinic's diabetes self-management education classes were chosen as the primary sites for direct and participant observation based on easy access to, and more availability of the women desired for this study.

Data were collected from field notes, tape-recorded in-depth, semi-structured interviews, direct and participant observations, participant profiles, self-management educator profiles, and the survey, and reviewed for information related to the research questions. The study used researcher-constructed typologies to locate naturally occurring variations in the observations to identify salient, grounded categories of meaning held by the participants (Marshall and

Rossman 1994:114). The data were marked, labeled, and sorted in order to find relationships between categories, and/or similarities or dissimilar statements, themes or behavior.

Several categories were created based upon the research questions and themes that emerged from the data. These categories were created to code the data initially for subsequent analysis. Such categories included, but were not limited to (1) diabetes knowledge, (2) diabetes beliefs, (3) self-management treatment behaviors that included exercise/physical activity, meal planning/nutrition, medication use, blood glucose monitoring, interaction with health care providers, support systems (family, friends, religion/spirituality), and self-management education classes. Alternative explanations for the data and the linkages among them were described when found (Marshall and Rossman 1994:116). This critical analysis assisted in facilitating explanations that were the most plausible of all (Marshall and Rossman 1994:116). As new ideas, concepts and themes emerged, the data were recoded. The degree of the coding was based on three factors offered by Neuman (2000:420). These factors were the research question (s), the richness of the data, and the research purposes.

After the initial open coding process of locating themes and assigning the initial codes or labels in an effort to condense the large set of data into categories, axial coding was performed (Neuman 2000:423). Transcripts were read and re-read, initial codes were reviewed, and key concepts re-organized into categories or concepts that clustered together and linked concepts and

themes (Neuman 2000:421; Leedy and Ormond 2001:161).

The analysis of the data from the survey/questionnaire was performed using the SPSS 11.5, Statistical Program for the Social Sciences, program. This tool allowed for the production of frequencies for each of the variables in the study (LeCompte and Schensul 1994:195). Simple descriptive statistics such as means, medians, and percentages were performed. Due to the small sample size of twenty-five women, and lack of access to confidential medical records of the women for assessing clinical glucose control, the study did not lend itself to statistically correlated analysis of the relationship between self-management behaviors of the women and glucose control levels (HbA1c). Instead, the study addressed the association of self-management behaviors in which the women engaged, and their self-reported glucose control as indicated in the interviews and survey questionnaire.

#### Recording and Transcription

All interviews were tape-recorded except for one that was completed by telephone due the interviewee's schedule. Permission to record the interview was received and recorded as part of the interview session. The interviews were recorded for later indexing and extraction of data. The length of all interviews range in duration from one to two (1-2½) hours, with the content based upon self-management knowledge, beliefs, behaviors, and practices of the women, and the education information shared by the diabetes self-management educators. Additionally, the length of the interviews was based upon the scope and nature of

the information shared by each interviewee.

The services of a typist were used for transcribing the majority of the interview tapes. This researcher also assisted in transcribing the tapes. The tapes were transcribed verbatim by the typist. The need for the protection of the privacy of the women was explained to the typist who agreed to confidentiality of the data.

### Reliability and Validity

Validity concerns whether measurements actually measure what they are supposed to rather than measuring something else (Babbie 1992:306). It refers to the credibility, goodness, and quality of the research (LeCompte and Schensul 1999:94). Reliability is a matter of dependability; making the same measurement again and again in hopes of getting the same result (Babbie 1992:306). The use of multiple data-gathering techniques to investigate the same phenomenon is interpreted as a means of mutual confirmation of measures and validation of findings (Berg 2001:5). Triangulation, the process of creating redundancy (LeCompte and Schensul 1999:131) of the methods, such as, semi-structured, in-depth interviews, direct and participant observation, and survey/questionnaire administration involved repeated questions, observations, looking for the information on the same treatment behaviors, health beliefs, and education/knowledge in order to confirm and cross-check the accuracy of the data that was obtained from the women, educators and self-management programs, in order to create redundancy in self-management and self-management treatment behaviors. Triangulation of the information on the same

topic from different data sources (the women, diabetes educators, and self-management programs) was critical for the validity and reliability of the research (LeCompte and Schensul 1999:144)

Generalizability refers to whether specific research findings apply to people, places, and things not actually observed (Babbie 1992:306). Because of the small sample size, sampling method, the uniqueness of the inner-city, urban community where this study was undertaken, and the use of the non-probabilistic, snowball sampling strategy, this qualitative study did not presuppose generalizability to all African American women with type 2 diabetes, nor to all diabetes self-management health care educators and programs.

#### Data Management

Interview data were transcribed as recorded. A typist was used to assist the researcher with the transcription. Data collected in this research (print and audio-taped) were secured in a locked file cabinet in the researcher's home. Data transported back and forth from fieldwork was kept locked in the researcher's car until needed for use. After use, materials were transferred to the secured file cabinet where it was filed. Informed consent forms were kept in a separate locked file away to protect the privacy of the study participants. Additionally, confidentiality was maintained by keeping interview data in a locked file when not in use. These data will be disposed of by shredding at five years after completion of this study.

## Protection of Human Subjects

This research adhered to the professional guidelines and codes of ethics for the protection of human subjects. These included informed consent, confidentiality and personal rights to privacy, and minimizing harm and maximizing benefits; beneficence, respect, and justice. Ervin (2000:30) states that when research is being done, the subjects should be fully aware of it; anthropological work should not be clandestine. Permission to proceed must be sought (Ervin 2000:30; Marshall 1991:214; Marshall and Rossman 1994:109). A belief that individuals have the capacity to be autonomous agents is essential in an adequate representation of respect for persons (Marshall 1991:214). The purpose of the research was explained to all participants. Each was provided an opportunity to ask questions, and to voluntarily participate in the research. The right to autonomy was respected for those individuals who did not wish to participate. Those who did agree were provided with the written informed consent form that explained the research, and the right of the participant to opt out of participating at any point in the research. Each participant's signature was obtained for those agreeing to be included in the study.

Actual names of the participants were not used. Ervin (2000:34) advises that when informants' comments or behaviors are described in reports, they should be disguised so that the identities of individuals cannot be guessed. Alpha-numeric pseudo identifiers, and semi-fictional characters were used to protect the privacy of participants. The data will remain confidential with access only to me,

the dissertation committee if needed, and as specified by IRB guidelines.

### Summary

This chapter delineated the qualitative and quantitative methods used in this study on diabetes self-management behaviors, and beliefs of twenty-five African American women with type 2 diabetes. The methods included semi-structured, in-depth interviews, direct and participant observation, participant profiles, mock diabetic experience, researcher as diabetes educator and questionnaire/survey administration.

This study followed research ethics in its use of informed consent, confidentiality, autonomy, and security of participant data. Likewise, this chapter addressed the issues of data generalizability, validity and reliability as evidenced in the triangulation of data collection methods, and analysis. Results of the data are presented in Chapter four.

CHAPTER IV  
DATA ANALYSIS  
Introduction

Analysis is the search for patterns in the data (Bernard 2002:429). The literature and conceptual orientations, Cultural Construction/Explanatory Model of Health and Illness, and the Health Belief Model cited in Chapter two, the methods noted in chapter three, and the four research questions were combined with a Grounded Theory approach for the data analysis of diabetes health beliefs, self-management behaviors, and knowledge. Through using the explanatory model of illness one can elicit information about the individual's beliefs and preferences (Rundle, Carvalho and Robinson 1999:xxv). Application of the Health Belief Model to the analysis was relevant because it is essential to remember that a patient's and his or her perception and understanding of origin and meaning of well-being, illness and recovery can be major factors in the health care recovery process (Rundle, Carvalho and Robinson 1999:xxi). Using a Grounded Theory approach provided a means for identifying categories and concepts that emerged from the text, and linking those concepts into substantive and formal theories (Bernard 2002:622). The analysis was conducted with the goal of answering the research questions for this study:

1. What is the cultural construction of diabetes mellitus among African American women with the disease?

2. What treatment behaviors do African American women utilize to manage diabetes?
3. What self-management treatment behaviors are prescribed by diabetes educators and self-management programs?
4. What is the concordance/discordance exists between self-management treatment behaviors of the women and prescribed behaviors of diabetes educators and self-management programs?

The results presented here are delineated in three sections. Section I reports the quantitative and qualitative findings from the research with the women. It also includes the experiences of the researchers as a mock diabetic and diabetes educator. Demographics of the women are provided along with the results focusing on (1) the cultural construction of diabetes among the women, and (2) the action taken in the form of treatment behaviors based upon the health beliefs the women understand to initiate, and report they enact as self-management behaviors in response to their diabetes diagnosis.

Section II reports the findings from the diabetes educators and diabetes education programs. Demographics of the educators and program characteristics are provided. The section presents findings focusing on treatment recommendations from both the educators and diabetes programs.

Section III presents a comparative model analysis. Findings address the concordance/discordance in diabetes and self-management behaviors between the diabetes self-management educators, programs and the women. A summary concludes the chapter.

## SECTION I

### African American Women with Diabetes Mellitus

#### Demographics

Twenty-five African American women ages forty-six to eighty-seven with type 2 diabetes participated in the study. Average age was sixty-four. Diagnosis of diabetes ranged from three months to forty-one years. Two women were in their forties, seven women were in their fifties, nine women were in their sixties, six women were in their seventies, and one woman was in her eighties. Nine women were married, nine women were widowed, four were divorced, two were separated, and one never married. Educational levels ranged from high school to doctoral degree.

Ten women did not report specific income data. However, they did report having Social Security, Social Security Disability, Medicaid, Medicare, and or a combination of this type of assistance. Two women reported receiving Social Security only, but did not provide the amount. For women who did report an annual income, two women reported income between \$10,000-19,000. One woman reported her income between \$20,000-29,000 from retirement. One woman indicated annual income between \$30,000-39,000, another between \$40,000-\$49,000 and three women indicated annual income between \$75,000-100,000. Five women did not provide income, or any other type of financial assistance information.

Self-identified religious affiliation revealed that sixteen were Baptist, four were Pentecostal, four were Methodist, one was a member of the Church of God in Christ, one was Non-denominational, and one was Presbyterian. Family history of diabetes was very prevalent among the women. Twenty-four (96%) of the women reported knowledge of at least one family member presently with diabetes, or at least one deceased family member who had diabetes. Only one woman reported not being aware of anyone in her family with or who had diabetes. Twenty-four (96%) of the women reported being overweight at the time of diagnosis (Appendix I). All of the women had attended a diabetes self-management class at least once since being diagnosed. Eight women (32%) were attending classes regularly at the time of this study.

## SURVEY/QUESTIONNAIRE RESULTS—Quantitative

### Research Question 3

#### WHAT TREATMENT BEHAVIORS DO THE WOMEN UTILIZE TO MANAGE DIABETES?

Twenty women (80%) of the twenty-five responded to questions surveying their diabetes treatment behaviors. Five women (20%) did not return the questionnaire. Two of these women reported illness hospitalizations, two women reported experiencing vision difficulties, and one woman indicated being ill but did not require hospitalization. Follow-up phone and letter contact was conducted to elicit a response from all of the women. Those women who responded to the questionnaire addressed nutrition/diet, exercise, blood glucose

monitoring, diabetes education, medicines, general diabetes management, diabetes knowledge, and support systems.

Although some survey questions included items from the CDC's Behavior Risk Factor Surveillance Survey (BRFSS), the survey questions were primarily designed based upon information from the in-depth interviews in order to develop an instrument that addressed the specific issues of the women themselves rather than an instrument from other researcher constructed tools (e.g. Diabetes Care Profile) based upon different populations. As such, the questionnaire in the present study reflected the culture specific data from the women participants themselves as taken from the qualitative interviews, and participant observations. Such a culture-specific approach was valuable for assessing and understanding factors that were germane to the women. As a researcher preference, the survey was administered after the interviews.

Thirteen women (65%) believed that if diabetes "runs in the family", other family members would be diagnosed with diabetes. Analysis revealed similar levels of beliefs by the women regarding whether diabetes could be prevented if there was a genetic component. Responses to the statement, "if diabetes runs in the family the condition cannot be prevented," indicated that seven women (35%) agreed, and a combined thirty percent of the women disagreed with the statement (three [15%] disagreed, and three [15%] strongly disagreed).

### General Management of Diabetes

Table 1 reveals the frequency distribution of the women's response to how

diabetes is generally managed. Results revealed that fourteen women (70%) believed that diabetes was generally managed through nutrition. Fourteen women (70%) believed that diabetes was generally managed by exercising. Medications were identified as important and thirteen women (65%) selected this behavior.

TABLE 1 In General, Diabetes is Managed By N=20				
BEHAVIOR	NUMBER SELECTING BEHAVIOR	PERCENT	NOT SELECTING ITEM	PERCENT %
Nutrition/Diet Change	14	70	6	30
Meal Planning	14	70	6	30
Exercise	14	70	6	30
Medication	13	65	7	35
Glucose Monitoring	16	80	4	20
Keeping Glucose Log	14	70	6	30
Physician Visits	14	70	6	30
Diabetes Classes	12	60	8	40
Weight Loss	10	50	10	50
Spirituality/Religion	8	40	12	60
Family Support	11	55	9	45
Friends	9	45	11	55

## Personal Management of Diabetes Mellitus

Table 2 shows the frequency distribution of the things the women responding to the survey reported personally doing to manage diabetes.

TABLE 2		Things I Do to Manage Diabetes			N=20
BEHAVIOR	NUMBER SELECTING BEHAVIOR	PERCENT	NOT SELECTING ITEM	PERCENT	
Nutrition/Diet Change	16	80	4	20	
Exercise	16	80	4	20	
Medication	16	80	4	20	
Glucose Monitoring	15	75	5	25	
Keeping Glucose Log	12	60	8	40	
Physician Visits	15	75	5	25	
Diabetes Classes	5	25	15	75	
Weight Loss	12	60	8	40	
Spirituality/Religion	11	55	9	45	
Family Support	9	45	11	55	
Friend Support	9	45	11	55	
Reduce Stress	13	65	7	35	
Foot Care	10	50	10	50	

### Easy Self-Management Beliefs

Ten (50%) of the twenty respondents agreed that it was easy to manage diabetes. Additionally, the frequency distribution revealed that three (15%) of the women strongly agreed that it was easy for them to manage diabetes. Thirteen (65%) expressed no difficulty managing diabetes. Only three (15%) of the women considered managing diabetes to be somewhat difficult, while two (10%) disagreed, and 1(5%) strongly disagreed. Four women (20%) had no response. Frequency distribution of the reported activities and behaviors that made it easy

for the women to manage diabetes is represented in Table 3.

TABLE 3 Things that Make it Easy for Me to Manage Diabetes N=20				
BEHAVIOR	NUMBER SELECTING BEHAVIOR	PERCENT	NOT SELECTING ITEM	PERCENT
Nutrition/Diet Change	12	60	8	40
Exercise	15	75	5	25
Medication	17	85	3	15
Changing Eating Habits	14	70	6	30
Talking With Physician	8	40	12	60
Talk with Diabetic Family Member	10	50	10	50
Diabetes Classes	9	45	11	55
Weight Loss	9	45	11	55
Spirituality/Religion	13	65	7	35
Talk with Diabetic Friend	14	70	6	30
Talk with Non-Diabetic Family Member	5	25	15	75
Reduce Stress	14	70	6	30
Friend without Diabetes	4	20	16	80
Having Insurance	8	40	12	60

#### Difficult Self-Management

Twelve (60%) of the women responding to what made it difficult to manage diabetes reported that they did not find it difficult to manage diabetes implying a

sense of self-efficacy. On the other hand, as indicated in Table 4, eight (40%) of the women agreed that diabetes was difficult to manage.

When diabetes was considered difficult to manage, thirteen (65%) of the women identified giving up foods they liked as the primary difficulty they had. Six (30%) women reported changing their eating habits, the cost of medications, and the cost of supplies as posing some difficulty though minimal. Five (25%) of the women reported losing weight, daily glucose testing, and reducing stress were problematic.

TABLE 4 Things that make it difficult for me to manage diabetes N=20				
BEHAVIOR	NUMBER SELECTING BEHAVIOR	PERCENT	NOT SELECTING ITEM	PERCENT
Giving Up Enjoyed Foods	13	65	7	35
Costs of Medication	6	30	14	70
Cost of Supplies	6	30	14	70
Losing Weight	5	25	15	75
Daily Glucose Testing	5	25	15	75
Stress	5	25	15	75
Cost of Foods	3	15	17	85
Exercise	2	10	18	90
Lack of Insurance	2	10	18	90
Insurance Co-payment	2	10	18	90
Cost of Insurance	1	5	19	90
Not Enough Insurance	1	5	19	95
Talk with Physician	1	5	19	95

### Lifestyle Behavior Change

Seventeen (90%) of the women believed that making lifestyle behavior changes would reduce their complications from diabetes. Ten (50%) of the twenty women strongly agreed that lifestyle behavior change would make a difference, seven (35%) agreed, and three (15%) had no response.

Lifestyle behavior change would also make a difference in the overall health of the women. A total of sixteen (80%) believed their health outcomes would improve with lifestyle modifications. Seven (35%) agreed, nine (45%) strongly agreed, one woman (5%) strongly disagreed, and three women (15%) did not respond.

### Patient Self-Management Responsibility

Primary responsibility for self-management is with the patient/individual. Fifteen (75%) of the 20 women identified the individual with diabetes as the most important person on the self-management team. This team generally is comprised of the primary care physician, nurse, nutritionist/dietician, diabetes educator who may or may not be a nurse and/or nutritionist, an exercise physiologist, and in some instances, the team may include a psychologist/mental health professional. One woman (5%) disagreed that the patient/individual was the most important part of the diabetes management team, and two persons (10%) did not respond.

## Patient Health Education

Even though diabetes education was reported by the women as an important contributor to diabetes self-management for glucose control, frequency distribution of the women's responses, as indicated in Table 5, revealed that most of the women did not receive a referral to either classes or a nutritionist/dietician from their primary care physician.

Eleven (55%) of the twenty women responding received no physician referral to diabetes self-management classes. Seven women (35%) stated that they did receive a referral, and two women (10%) did not remember whether they had received a physician referral.

Eleven (55%) of the twenty women responding received no physician referral to a nutritionist/dietician. Eight women (40%) stated that they did receive a referral, and one woman (5%) did not remember whether she had received a physician referral. However, in the past eighteen (90%) of the women reported that they had received diabetes education from their physician. Fourteen (70%) of the women indicated that they read brochures, books and/or pamphlets to obtain diabetes information. Twelve (60%) of the women received education from a nutritionist, and eleven (55%) talked with a friend with diabetes and obtained diabetes information. Acquiring education from a family member with diabetes, or a nurse was represented by eight (40%) of the women.

TABLE 5		Diabetes Education Acquisition			N=20
Source	Number Receiving Education	Percent % Receiving Education	# Not Indicating source	Percent % Not Indicating Source	
Physician	18	90%	2	10 %	
Reading	14	70%	6	30%	
Nutritionist	12	60%	8	40%	
Diabetic Friend	11	55%	9	45%	
Diabetic Family Member	8	40%	12	60%	
Nurse	8	40%	12	60%	
Non-Diabetic Family Member	7	35%	13	65%	
Non-Diabetic Friend	5	25%	15	75%	
Exercise Physiologist	5	25%	15	75%	
No Education	1	5%	19	95%	

#### Helpful Class Attendance

For women who did attend classes, thirteen (65%) of them indicated that the classes helped. Four women (20%) did not know if the class(es) helped, three women (15%) believed that the classes did not help them to manage their diabetes.

#### Location of Class Attendance

Table 6 reveals the location of diabetes education class attendance reported by the women. An equal number of women, four (20%), identified previously attending community-based center and community-based clinic classes. Three women (15%) attended hospital-based classes, and two women (10%) attended

hospital- based clinic classes. University-based clinic attendance was minimal with only one woman reporting having received education at this type of program site. No women reported attending diabetes classes held at a church/religious program site.

Ten (50%) of the surveyed women reported not having attended any diabetes self-management classes in the past. However, present class attendance had increased by thirteen percent at community-based center, and community-based clinic sites. Attendance at hospital and hospital-based clinic declined, and the number of women who were presently attending classes increased by fourteen percent over past attendance.

TABLE 6 Location of Diabetes Education Class Attendance					N=20
Site	Past # Attending	% Past Attending		Present # Attending	% Presently Attending
Community Center	4	20%		6	33%
Community-based Clinic	4	20%		6	33%
Hospital	3	15%		1	5%
Hospital-based Clinic	2	10%		1	5%
University-based Clinic	1	5%		0	0%
Church	0	0%		3	15%
None	10	50%		8	44%

## Support Systems and Self-Management

Eighteen (90%) of the women indicated that they received their initial knowledge about diabetes self-management from their primary care physician. Seventeen (85%) of the women indicated that support systems were important for managing diabetes. Nine (45%) of the women strongly agreed and eight (40%) agreed that support systems were important to them for diabetes management. None of the women indicated disagreement or strong disagreement that support systems were important. However, three women (15%) did not respond to this inquiry.

Types of support the women indicated they had for managing diabetes varied as revealed in Table 7. Fourteen (70%) indicated that they had a friend to talk with. Twelve (60%) identified that they had family to talk to. Eight women (40%) revealed support in the form of having access to free glucose monitoring supplies. Seven women (35%) identified self-management education class as support, six (30%) indicated having a walking/exercise partner, and six (30%) of the women revealed talking with their physician as the support they had.

In contrast, the type of support for diabetes management that the women reported needing differed from the support they had. Eleven (55%) of the women identified needing family support. Eleven (55%) of the women indicated they needed assistance with changing their eating habits to include fewer carbohydrates, smaller meals more times a day, and eating more fresh fruits and vegetables. Nine women (45%) desired a walking/exercise partner. Friend

support was needed by eight (40%) of the women, and eight of the women (40%) needed assistance with access to glucose monitoring supplies. Seven women (35%) expressed a need for a support group, and six women (30%) indicated needing help with losing weight.

TABLE 7		Support Systems		N=20	
Women Have	# of Women	% of Women	Women Need	# of Women	% of Women
Friend to talk to	14	70%	Family Support	11	55%
Family to talk to	12	60%	Nutritional change	11	55%
Access to Free Supplies	8	40%	Exercise Partner	9	45%
Self-Management Class	7	35%	Friend Support	8	40%
Exercise Partner	6	30%	Testing Supplies	8	40%
Physician to talk to	6	30%	Support Group	7	35%
Private Health Insurance	5	25%	Weight Loss Help	6	30%
Diabetes Support Group	4	20%	Medical Cost Help	5	25%
Help Losing Weight	3	15%	Education at Home	4	20%

Sixteen (80%) of the women believed that talking within the family about diabetes was important. Six (30%) of the women strongly agreed that family talking is important, and ten (50%) of the women likewise agreed to the importance. Only two women (10%) disagreed that talking within the family about diabetes was important. Two women (10%) did not respond. Of those who did respond, none strongly disagreed about the value of talking within the family.

#### Exercise/Physical Activity and Self-Management

Exercise/physical activity was one of the main prescribed self-management treatments for diabetes. The women in this study indicated several activities in

Table 8 in which they engaged for controlling diabetes. The primary activity of choice was walking outside and twenty (75%) of the women indicated this preference. The next exercise behavior reported was riding a stationary bicycle by seven (35%) of the women. Walking on the treadmill was a method chosen by six (30%) of the women. Five women (25%) selected dancing, and four women (20%) indicated aerobics. Equal numbers of women, three (15%), preferred water aerobics, stair-stepping, and attending the YMCA as exercise/physical activity behaviors for managing diabetes. Lesser activities indicated by the women included lifting weights by two (10%) women, and one woman (5%) each of yard work, swimming, tennis, and riding a bicycle outside.

TABLE 8		Exercise Activity	N=20
Type	# Participating	% Participating	
Walking Outside	15	75%	
Stationary Bicycle	7	35%	
Walk on Treadmill	6	30%	
Dancing	5	25%	
Aerobics	4	20%	
Water Aerobics	3	15%	
Stair-stepping	3	15%	
Gardening	3	15%	
YMCA Attendance	3	15%	
Weight Lifting	2	10%	
Yard Work	1	5%	
Swimming	1	5%	
Tennis	1	5%	
Outside Bicycle Riding	1	5%	
No Exercise	5	25%	

Six (30%) of the women reported engaging in exercise/physical activity for at least twenty minutes each time, two to three times a week. Four women (20%) exercised for twenty minutes each time three to four times a week. The two women (10%) who exercised once a week, and the two women (10%) who reported exercising five or more times a week, indicated that they exercised for at least twenty minutes each time. Five women (25%) reported that they did not exercise. The interview data revealed that barrier factors such as diabetic neuropathy of the feet, arthritis, joint pain, knee problems, finding time due to work schedules and family responsibilities, and a safe place to walk as reasons the women cited for not engaging in physical activity/exercise at all.

#### Blood Glucose Monitoring and Hemoglobin A1c Tests

Nine women (45%) reported checking their blood glucose levels twice a day. Six women (30%) indicated that they tested once per day. One woman (5%) responded that she tested three times a day, and four individuals (20%) responded that they did not check their glucose levels at all.

As indicated in Table 9, a total of sixteen women (80%) reported receiving hemoglobin A1c (HbA1c) blood glucose tests over the previous year. Two women (10%) received the test once in the past year. Four women (20%) indicated having the test twice. Four women (20%) reported receiving the test three times, and five women (25%) indicated they received the test four times

during the past year. One woman (5%) reported having the test more than three times, and three women (15%) did not remember if they had received the test.

One woman (5%) did not respond to this query.

TABLE 9 Hemoglobin A1c Test in the Last Year N=20		
Number of Times Receiving Test in Past Year	Number of Women	Percentage
Once	2	10
Twice	4	20
Three	4	20
Four	5	25
More than four	1	5
Don't know if had test	3	15
No response	1	5

#### Medication Use

Table 10 presents the findings on the types of medication used by the women to manage diabetes. Of the twenty women participating in the survey, fourteen women (70%) took pills, and eight women (40%) reported taking insulin. Seven women (35%) indicated that they only took pills, and four women (20%) revealed that they used both pills and insulin. Likewise, four women (20%) reported using

insulin only. Three women (15%) indicated that they used pills but did not indicate whether they also injected insulin. Two women (10%) reported not using insulin or pills to manage diabetes. They were managing diabetes through nutrition, exercise, weight loss or a combination of these behaviors.

Of the fourteen women who used pills, ten (50%) took pills twice a day, and four (20%) took pills once per day. Of the four women who took only insulin, three (15%) injected insulin twice per day, and one woman (5%) injected insulin once per day. Of the women who took both pills and insulin, two women (10%) took pills twice per day, and injected insulin once per day. One woman (5%) both took pills and injected insulin twice per day, and one woman (5%) both took pills and insulin once per day.

TABLE 10 MEDICATION USE N=20		
Medication Type	Number of Women Using	Percentage
Pills	14	70
Pills Only	10	50
Insulin	8	40
Insulin Only	4	20
Insulin and Pills	4	20
No pills and No Insulin	2	10

The present study was not designed as a life history that captured narrative stories of long term living with and managing of diabetes. However, two women expressed their transition from oral medication to injecting insulin.

“I just started with insulin about two and a half weeks ago. At that time, my glucose level was so high that I had to be put on insulin four times a day. That’s when I started to take it seriously. Up until that point, I did not take it seriously.” Before I would just take the pill and eat anything I saw that would fit in my mouth. I was eating. If it was there and I wanted it, I ate it. I think what really triggered it and ran it up so high was that I ate a whole box of Girl Scout cookies. I didn’t realize the damage I was doing to my body. If I had monitored my food intake and did what I was supposed to do, I would have never had to go on insulin. But because I didn’t, it kept escalating until it got to this point. (Ms. S.)

“I went back up to one pill, to four pills and it stayed like that for a few years. It’s like the pills wasn’t helping anymore, and my sugar started going up. I went to a specialist and he told me that I was going to have to be on insulin. Ever since then, I’ve been on insulin. I take insulin twice a day.” (Ms. D2)

## African American Women Constructing Diabetes

### Introduction

Meaning ascribed to illness influences the course of disease by shaping subjective experience as well as individual and social behavior in response to disease (Corin 1995:274). Kleinman (1980) explains that illness has meaning and that nothing so concentrates experience and clarifies the central conditions of living as serious illness. Findings from the interviews provided the women's thoughts on the nature of diabetes, its causes, and signs and symptoms, beliefs about onset, what makes it easy and difficult to manage diabetes, and their general beliefs about managing diabetes. Their comments served as a means to investigate how the women constructed and understood diabetes.

### Research Question 1

#### WHAT IS THE CULTURAL CONSTRUCTION OF DIABETES MELLITUS BY AFRICAN AMERICAN WOMEN WITH THE DISEASE?

The women were asked five questions to investigate their beliefs about diabetes. The analysis of the interview data revealed that the women's construction, explanation and experiences of diabetes was a multi-faceted phenomenon represented by both lay and biomedical perspectives. The first question asked "*What is diabetes?*" The biomedical perspective revealed variations in the understanding of diabetes, but several of the women shared a

similar awareness of the bio-physiology of diabetes as indicated below.

“From my understanding it is when your body does not produce enough insulin and you have to either end up taking the shots or the pills” (Ms. M.)

“As far as I know it starts in the pancreas—that you don’t have enough insulin in the pancreas for your sugar or too much sugar or something that is causing you to have diabetes from what I understand.” (Ms. S)

“It’s a chronic condition that involves your body not being able to efficiently use what it has in my case. It also involves every organ of the body. The thing is, the insulin isn’t able to put glucose into the cells as it should so you have the insulin and glucose circulating around. But the insulin that your body is producing isn’t able to put that glucose where it’s needed into the cells for energy so you get hyperglycemia.” (Ms. J)

The analysis also revealed a belief among the women that diabetes was associated with age, genetics, weight, and pregnancy.

“I have diabetic two. Diabetic two comes with age or genetic, or you could be obese.” (Ms. D)

“It’s sometimes in the genes. It runs in the family.” (Ms. M2)

“Some people if they are diabetic when they are pregnant, it will go away until later in life. Then sometimes it won’t. (Ms. R.)

Data indicated that some women believed diabetes to be a frightening condition, while other women believed that diabetes was a condition that could be managed.

“Well they say it is the silent killer, and it surely is.” (Ms. H1)

“Diabetes is a nightmare; scary because you always have to be careful of stubbing your toe.” (Ms. D1)

“A curse (laughter).” (Ms. R)

“Diabetes is just a disease that can be controlled. (Ms. M2)

“I understand that it can’t be cured, but it can be controlled.” ( Ms. V)

One informant revealed that her family never discussed diabetes although there were other chronic diseases in the family's history. Data analysis also revealed one woman whose knowledge of diabetes was limited.

“When we were growing up my mother and father they never mentioned about diabetes. Only diseases they would talk about was a heart problem. They did mention that because my father and my grandfather died with a heart problem. My dad had a cousin who had cancer. So, those were the most important two things that they knew of. They never mentioned people with diabetes. Let me see, what did they call it back then? Sugar diabetes, that's what they called it. But our family—nobody was tested for no sugar; no nothing like that.” (Ms. E.)

“You know I really don't know, it means that your body is not, you don't utilize the foods—I think I've gone into Alzheimer's. I can't think of the word, it has something to do with the glucose and there's other terminology but I can't think of it right now.” (Ms. H2)

The next question investigated, *“How did you find out that you had diabetes?”* Data indicated that the personal physician of the women or a hospital physician informed the women of their diabetic status. Analysis found that most of the women experienced serious bodily ailments that were initially puzzling to them, and that required medical attention. Two women developed gestational diabetes during pregnancy. Additionally, data revealed that at the time of diagnosis, some women expressed disbelief at being a diabetic.

“What happened to me was I had started getting real thirsty, and I'd drink so much water that I couldn't drink anymore. I couldn't sleep. I had lost a lot of weight, and I didn't realize it. My friend said you done lost a lot of weight. I lost nineteen (19) pounds in less than a month. I was real sick, and I didn't know what was wrong with me. Right after I got feeling so bad, my eyes puffed up. I hadn't slept in days. I finally left a note for my

daughter that mom was going to the doctor. They tested me and my sugar was like 500. My blood pressure was high. I was dehydrated so they kept me, and pronounced me as a diabetic. But I didn't know it till that day. I was overweight. I was like 280 pounds." (Ms. D2)

"It was August 1996 that I found out I was diabetic, and I was depressed about it. I really was. I really didn't understand. I just thought it was something that you couldn't control, until my doctor called me in his office and he told me that you are full blown diabetic. You're not border-line. He said there is no such thing as borderline." (Ms. M2)

"Diabetes doesn't run in my family. Just came to me and stopped. It's not scientific. I've been thinking about this for years. I remember as a kid I was hit in the abdomen with a bat—not on purpose, but it was swinging a bat, playing ball and I really believe that trauma did something to my insides—injured or whatever and I just believe that helped to facilitate for whatever reason the onset because I am the only one." (Ms. J.)

"I first became diabetic when I was 29. I had gestational diabetes; I was pregnant. I was so fortunate. I got a baby and diabetes (laughter). Diabetes is my twin; my child twin." (Ms. R.)

After gaining insight into how the women defined diabetes and how they discovered they were diabetic, the women were asked to reveal their thoughts about managing diabetes. The third question asked, "*What are your thoughts about managing diabetes?*" Analysis found that the majority of the women demonstrated positive attitudes and a personal resolve toward diabetes management.

"You have to be proactive. Managing diabetes is just like managing your every day diet. You don't want to get too fat. You don't want to get too skinny. You don't want to be tired. You don't want to be too full. You just do it with different foods and in a different manner. Talk to your doctors about what you need to do and live." (Ms. B)

"If my mother could live with it for fifty plus years, then I am sure I can too. I am not going to let becoming a diabetic take over my life." I am not going to give up. I am going to do as the doctors prescribe, and keep on with my life." (Ms. W)

“To manage my diabetes, I follow the doctor’s instructions, and eat healthier.” (Ms. D1)

“I made up in my mind that since I became a diabetic I was going to do what I was supposed to do.” (Ms. E)

“Regular checkups with your doctors are important.” (Ms. P)

Women were asked both “*What makes it difficult and what makes it easy to manage diabetes?*” Consistently, data revealed that the women found nutritional changes to be one of the most difficult aspects of self-management. Exercise, pain, injecting insulin, and health care cost were additional themes of the difficulties inherent in diabetes self-management.

Analysis also found that the women identified few aspects that made it easy to manage diabetes. However, when the women did find diabetes self-management easy, it was due to their expression that having a positive attitude made the difference.

“Certain things that you can’t eat. I used to love sweet potatoes and today I cannot eat them even in a pie. I have heartburn when I eat sweet potatoes. I’m not supposed to eat corn. I don’t eat strawberries. I try to eat the foods that agree with me.” (Ms. E)

“When you go to the hospital, you have to pay fifty dollars every time you go to the hospital for anything, and you have Medicaid and Medicare.” (Ms. R)

“You can get a cut on your toe and not even know it. I had a cut on my little toe, and I didn’t even know I had it. I have peripheral diabetic neuropathy in the feet which is a terrible pain.” (Ms. D1)

“It’s not hard. It’s really not hard. You’ve got to have a high respect for it because the damage it can do to your body it will take your life.” (Ms. B1)

## Self-Management Treatment Behaviors—Qualitative

### Introduction

The main treatment behaviors recommended for controlling diabetes include: (1) dietary changes, (2) taking medications, (3) exercising, (4) foot care, (5) monitoring blood sugar, and (6) interaction with health care providers (Schoenberg, and Drungle 2001:446; Hunt et al 1998:964; Davidson 1991:158; Hamburg, et al 1982:13; Weiss et al 1989:289). Secondary activities identified by Schoenberg, and Drungle (2001) involve (7) recognizing and responding to symptoms, and (8) seeking information. Results from this study also identified social support in the form of friends, family and religion/spirituality as additional factors contributing to self-management of diabetes. Question two investigated the range of the diabetes self-management treatment behaviors in which the women engaged.

### Research Question 2

WHAT TREATMENT BEHAVIORS DO THE WOMEN UTILIZE TO MANAGE DIABETES?

#### 1. Nutritional/Dietary changes

Seven questions revealed the perspectives on self-management. Question one focused on nutritional/dietary changes and asked, *“How does what you eat affect your health?”* Data revealed that food choices, quantity and eating or not

eating would fluctuate the women's blood glucose levels. Women were aware of the need to watch what the foods they ate, and endeavored to make the recommended dietary changes. However, many of the women reported, as likewise noted in Table 4, that it was difficult to give up foods that they liked.

"There are certain things that I know I shouldn't eat, but I do I love pasta. That shoots your glucose level out of the room. It does mine. When I know my glucose level is up, I flood my body with water. You learn that from your nutritionist. That's the best part—my doctor sent me to a nutritionist so she could tell me the number of grams of carbohydrates I should have in a day. So what I do, I count carbohydrates so that I don't go over that." (Ms. B2)

"I don't buy sodas anymore—even diet sodas. No snack foods. I try to keep fruit, but it's hard to keep fruit. Fruit doesn't last long. I eat breakfast. Long as you know what to eat—stay away from fried foods, cereal, and milk. I use olive oil more so than margarine." (Ms. D2)

"It's not easy controlling because there're just so many things you can eat. There's a whole bunch that you can't eat or shouldn't—sweets, carbohydrates and oily foods, fatty foods—stay away from all that stuff. It's not easy staying away from it especially when you've got to buy stuff that's decent for you to eat. It's too expensive to buy. I eat lots of broiled chicken or baked chicken. I don't eat too many eggs. I'll eat an egg every once in a while, not even every week do I eat an egg. But I do eat one every once in a while, and I drink 1% milk or soy milk and I eat Cheerios for the heart. I eat the Special K and Oatmeal. (Ms. J.)

One woman represented a negative case for dietary change.

"I do the same thing I always have done. I eat the same things. A lot of this diabetic salt and stuff, I can't eat food with it on there. Diabetic sugar, I'm not working with that because I don't want it. It doesn't taste good. I just eat what I like to eat. But, the only time that I know that the diabetes is going to bother me is when I don't eat. I get weak and dizzy. Then, I eat something, and I stop being dizzy. I don't like breakfast, but since I got this diabetes, I eat a little something. Before I found out I had diabetes, I hadn't had breakfast since I left Georgia in 1958." (Ms. R.)

## 2. Exercise/Physical Activity

The second question addressed exercise as a part of diabetes self-management. The women were asked, “*What type of exercise/physical activity do you do?*” The analysis found that women recognized the importance of exercise for glucose control, and engaged in some type of physical activity/exercise. For example, women reported going to the YMCA, working in the yard, doing housework, and riding a bicycle. However, factors such as disability, joint pain, work schedules, having an exercise partner, and a safe place to exercise limited the women’s participation in physical activity/exercise. Walking was most frequently identified as the exercise of preference for the women. Data revealed the following perspectives on exercise for self-management.

“The insurance now offer the exercise class for seniors at the Y. It’s free so I went right away and signed up and exercised. I went to the aerobics class yesterday. We have an hour of real aerobics. After that, I went into the dry heat sauna. Got in the pool. I exercised. I say that’s gonna help me.” (Ms. D2)

“My physical activity is out in the yard raking. I rake all my leaves around my house and the main thing is picking them up. When I get through with that I can just feel the muscles in my body. So I pick up all the trash and put it in the garbage can and put it in bags. I’m always fixing my plants. I do lots of stuff in the yard. I even cut my hedges. I can’t handle the lawnmower but I cut the hedges.” (Ms. E.)

“The only thing I do now is clean up the house. I’m a gardener. I guess you can tell from my yard. I had a stationary bike, but it’s not working. I have a bicycle, and I was telling my son to fix it so I can use it. Maybe I can go bicycle riding instead of walking. Walking takes a toll on my knee and it gives out.” (Ms. E2)

“Nothing physical. I’m sedentary because of the arthritis mostly. My legs just won’t allow me to do much physical activity. I hurt all over all the time. The exercise I get is going to the grocery store, and now and then I walk around out in the yard— stuff like that. But I don’t get a whole lot of exercise. I make up for it other ways. I exercise my brain all the time.” (Ms. B)

### 3. Medications

The use of medications was the third factor of self-management investigated. The women were asked, “*What type of medicines do you take to manage diabetes?*” Data revealed that the women used oral and injection medication— insulin. Women either used pills only, insulin only or a combination of pills and insulin. More women used pills only than those using insulin only. Additionally, more women used only pills than those taking the combination of oral medication and injecting insulin. Responses revealed the following use of medications.

“I take the oral insulin once in the morning and once in the evening and then I take the syringe at night before I go to bed.” (Ms. B)

“I take my insulin.” (Ms. E.)

“I got put back on Glucophage. The doctor took me off it, and then I told him when I went back that I had stopped taking it, but I went back on it because my blood sugar was going up and down. So I don’t take it every morning and if I can keep my blood sugar between eighty and a hundred and twenty five, I don’t take it. And, if it goes up to forty or fifty, then I’ll get back on it for a couple of days.” (Ms. V.)

“I take pills once a day.” (Ms. R)

“I went back up to one pill, to four pills and it stayed like that for a few years. It’s like the pills wasn’t helping anymore, and my sugar started going up. I went to a specialist and he told me that I was gonna have to be on insulin. Ever since then, I’ve been on insulin. I take insulin twice a day.” (Ms. D2.)

#### 4. Blood Glucose Monitoring:

*“What are your thoughts about testing, and how often do you test?”* was the fourth question asked regarding self-management. Analysis found that the women did monitor their blood glucose levels, but not everyday, and many times only when they experienced symptoms, e.g. dizziness, weakness, headache. Lack of testing supplies for those not on Medicare was problematic for some women. Free supplies could be acquired through attendance at non-profit, community-based diabetes classes. Of the women injecting insulin, fearful of needles served as a barrier to blood glucose monitoring. Perspectives on glucose monitoring reflected the following comments.

“I test myself about three times a week unless I feel bad. If I have a sick feeling, I’ll test more.” (Ms. D.)

“I stick my finger. I write it down cause you might say, I remember it, and then say I can’t remember what it was, but I have my little book and pencil.” (Ms. E)

“The diabetic testing thing, I’m not doing that because I’m scared of needles. That’s the very reason I don’t puncture myself. I don’t take no tests. No tests at all. To find out how high or low it is, I’m not going to stick myself. My daughter bought me a monitor, and everything I need. The nurse came out to my house two or three days, stuck me, and showed me how to use it. But it didn’t matter because I’m not going to stick myself. The monitor is still in the same box. They think I’m taking it, but I didn’t touch it.” (Ms. R)

“You must eat when you take your medicine because if you don’t your glucose levels drop too low. I have physical signs when my blood sugar is too high or too low, my eyes hurt and my head hurts. What I do is, I take my meter—check the level and see where it is. If it’s too high, I get busy with the water. If it’s too low then I go get me a piece of bread and spread it with some peanut butter because that’s what the nutritionist told me to do—eat it slowly with water and then that brings my sugar levels back up to normal. “ (Ms. B2)

## 5. Interaction with Physician/Healthcare Provider

The interaction with the health care provider was assessed as part of the diabetes self-management regimen. The question that asked, “*What did your doctor, or what does your doctor tell you about diabetes?*” indicated high levels of dissatisfaction by the women with the health communication interaction between themselves and their physicians. Analysis revealed that some of the women believed that physician communication was either non-existent, limited, or unclear regarding the women’s diabetic condition. Data analyzed also revealed that physician feedback on health care test results was desired by several of the women, but not provided by the physician. However, women who reported a good relationship with their physician, indicated being aware of test results, and having a physician who took the time to explain their condition to them and to provide test results. Responses indicating the patient-physician interaction represented the following.

“I blame my doctor because she would tell me watch what you eat—you’re on the borderline. She told me this for 3 years—borderline diabetic. My doctor didn’t explain to me. All she said was, I was borderline—watch your diet, and keep your weight down. Finally, one day then I come up with 800 sugar.” (Ms. E)

“The doctor just asks me how I’m feeling. That’s all the doctor asks, nothing else. They never tell me anything about my test results. They don’t tell me how your sugar is or nothing. They never, never tell me anything. The doctor doesn’t give you any time or nothing.” (Ms. R)

“I wouldn’t have anybody but my doctor. He and I have a very good rapport and I like it because there is no condescension on his part none and I’ve had one or two that I’ve had to correct, listen I’m not your maid and I’m not your mammy. I am an African American elderly woman who is seeking your advice about a certain ailment, now you talk to me about that

on my level. But don't assume I don't understand what you're saying because I'm African American and a woman. We get all that out of the way and all my doctors and I get along well. They are all white except my main doctor who is black. But the other specialists are all white and they all know me. Believe me they know me, and they also know I don't take condescension from anybody not anyone." (Ms. B2)

## 6. Patient Education

The initial and most important on-going therapeutic modality when treating diabetes mellitus is patient education (Weiss et al 1989:289). Question six focused on knowing whether the women had received diabetes education. The women were asked, "*Have you ever attended or been referred to diabetes self-management education classes?*" Over fifty percent of the women reported not being referred by their physician to self-management classes or a nutritionist/dietician. The women reported receiving knowledge of how to manage their condition from primarily reading and from a friend with diabetes. The data indicated the following responses from the women.

"I was never referred to diabetes classes." (Ms. R)

"My physician did not refer me to self-management classes. I know about managing my diabetes from my cousin who is a retired nurse. She works at a free clinic. We talked and she worked with me. I volunteer and go to the Free Clinic classes." (Ms. E2)

"I just went by what the nurses instructed me to do when I came home from the hospital. And, I have a big book and I read that book. Sometimes I can remember the things that I was told to do, and that's how I keep up with what I do." (Ms. E)

"I come to the class here. It helps me out a lot. Remind me of what I need to do. When I come to the class once a month, it reminds me that I'm diabetic. I need to stay on a diet. I need to eat the proper foods." (Ms. D2)

“My doctor had the good sense to send me to a nutritionist so she could tell me the number of grams of carbohydrates I should have in a day. So I count carbohydrates. I had a mother who had good sense who insisted on healthy eating.” (Ms. B)

## 7. Spirituality/Religion

The seventh question as a part of self-management focused on the role of spirituality/religion. The women responded to the question, “*How does religion/spirituality help you to manage your diabetes?*”? All of the women found spirituality/religion to be important to them for dealing with the challenges of managing diabetes, and for help with stress reduction. Data from the in-depth interviews revealed a strong faith in God as a central source of strength and as help for managing diabetes and reducing stress.

“Because God and I are such good friends, he looks out for me. He always has my back—always. Religion plays a very, very important role in my life with the health problems and all of that and it’s good.” (Ms. B2)

“God is the only one that’s helping me to stay healthy. That’s the only somebody that keep me going.” (Ms. R)

“Religion is a part of your life. Diet is a lifestyle, but your Christianity is even more than that because it’s who you are and who you pattern your life after. So, it plays a very important role. The connection between my religion and my belief and my health or my diet or diabetes is that I am going to need to have my supreme being in order for me to stay on track because I am too weak for this. I can’t do it all by myself.” (Ms. M.)

## 8. Support Systems

The last question regarding diabetes self-management treatment addressed the issue of support systems. The women were asked, “*What type of support do you have or need for managing diabetes?*”? The main support systems identified

included friends, family, and religion with fourteen (70%) of the twenty women reporting a friend to talk to as the primary support system they had. Secondary support systems were access to free blood glucose testing supplies, having an exercise partner, diabetes self-management classes, and a physician with whom to talk. Analysis found a contrast in the type of support the women had and the type of support they wanted. For example, six of the women (30%) expressed a need for help losing weight, but only three (15%) had this help. Seven (35%) needed a diabetes support group, but only four (20%) indicated having this support system. Nine of the women (45%) needed an exercise partner, but only six (30%) women had one. Narrative examples revealed the women's perspective on support systems they had as resources.

"I have 100% support from my family. They watch me like a watch dog. They ask, momma are you supposed to have that? I say, don't come in here with that today. I don't know why he thinks I don't know how to take care of myself. I don't need this doctoring, you know. But, they are only looking out for me." (Ms. M2)

"My girlfriend, she has it (diabetes) too. She has been my support. We've been supporting each other." (Ms. S.)

"The only support I need managing my diabetes is the testing supplies where you don't have to stick yourself." (Ms. R)

"Well, I have a friend who walks with me. She is diabetic too. She is a good support system because she is someone who has experience for a much longer period, so she can give me advice. I have some family members who are diabetic, and I can see and hear what's going on with them." (Ms. M)

## Summary of Women's Interviews

The data from the interviews revealed that the women constructed diabetes in both biomedical and lay terms. They understood diabetes could be caused by a blood glucose imbalance in the body, genetics, age, and that women could be diagnosed with gestational diabetes during pregnancy only to have diabetes to return later in life. Their beliefs about diabetes represented both a fear of the condition and a strength or self-efficacy that although diabetes could not be cured, they could control the disease.

Analysis of self-management treatment behaviors found that the women engaged in behaviors such as nutritional/dietary changes, exercise/physical activity, medication use, and blood glucose monitoring. Findings indicated that all of the women believed it was difficult to adhere to the nutritional recommendations because of the difficulty in giving up foods they liked.

The primary form of exercise identified by the women that they engaged in was walking. However, women also participated in doing yard work, riding a bicycle and going to the YMCA. Several women did not exercise because of disability or bodily pain.

Medication use was divided between those using pills only, insulin only, and insulin and pills only. Needing to inject insulin was not favored by two of four women taking medication by injections. Fear of needles and having difficulty injecting oneself was reported as barriers.

Over half of the women engaged in monitoring their blood glucose levels at

two main times of the day—morning and evenings. However, additional testing occurred when women noticed symptoms such as a headache, dizziness, tiredness, sweating, and palms turning white.

Fifteen of the women expressed displeasure with their physician's lack of information and feedback on the health of the woman, and health care test results. Eleven of the women also expressed concern that their physician did not refer them to a diabetes self-management class.

Religion/spirituality was a main strength for the women in managing diabetes. Likewise, a friend to talk to, and family to talk to were priority support systems for the women. Secondary support systems included access to free blood glucose testing supplies, having an exercise partner, diabetes self-management classes, and a physician with whom to talk.

Discussion of these findings is presented in chapter five.

## Participant Observation

### Experiences of a Mock Diabetic

During this study, participant observation occurred in the form of my experiences as a mock diabetic. My participation in selected activities was undertaken in order to gain insight into and an understanding of behaviors in which the diabetic patient must engage in order to self-manage diabetes. For five months, from December 2003 to May 2004, I engaged in blood glucose monitoring, daily exercise, weight management, interaction with health care

provider, attendance at diabetes self-management education classes, and nutritional/dietary modifications. Taking diabetic medications was not applicable for my experience as a non-diabetic exploring self-management of diabetes. The following activities occurred.

Blood glucose monitoring utilizing the finger stick method was conducted mornings before breakfast, and at two hour intervals after a meal. Testing in the evening was not conducted.

I engaged in several exercise activities four times a week for one to two and a half hours each occurrence. In the gym, I walked the treadmill, used the elliptical cross trainer, stair stepper, stationary bicycle and the weight machines. The two hour gym workout always included a combination of cross-training activities (e.g. elliptical machine, stationary bicycle and weight machines). Outside activities included walking, jogging, and bicycle riding. Duration of these activities lasted from two to two and a half hours with distances ranging from five to seven miles each occurrence. I drank a protein drink or ate a protein bar after exercising.

I attended and participated in diabetes self-management classes four to six times per month for the six months duration of the study. Classes lasted from one hour to two and a half hours each session. My class participation included taking diabetes knowledge pre-tests and post-tests, taking my body mass index measurements as a part of weight control, and learning how to do home blood glucose testing and read the results. Learning included how to read food labels

for serving size, sugar, carbohydrate, fat and sodium content. Class learning also included how to count carbohydrates and calories, learning what were food exchange groups and how to use them, selection and preparation of foods, the bio-physiological, mental and emotional aspects of diabetes.

Additionally, as a part of the mock diabetic experience, I made two visits to a health care provider. One visit was to experience the laboratory testing of blood glucose. The additional visit provided me with an opportunity to ask questions about my blood glucose test results and to gain information about diabetes in general. The visits also allowed me to give attention to the health communication occurring in my physician-patient interaction.

Lastly, nutritional/dietary modifications included the elimination of high fat foods such as fast and fried items. Additional changes included the reduction in quantity or elimination of simple carbohydrates such as pastries, candy, cookies, white rice, pasta, and white potatoes. I gave attention to consumption of green leafy salads, and complex carbohydrates such as fresh fruits and vegetables, whole and multi-grain products, seeds and nuts such as almonds. An example of breakfast three to four times a week included a small bowl of oatmeal sweetened with Splenda, half of a banana, half a glass of 100%, low carbohydrate fruit juice, one eggbeater, two soy breakfast sausages, and a cup of non-sweetened green tea. Lean chicken, fish, and turkey, prepared baked, grilled or broiled, along with beans and soy products served as protein sources. Portion sizes were reduced. Six to eight glasses of water were daily sources of liquid.

A discussion of this mock diabetic participant observation experience is provided in chapter five.

#### Researcher as Diabetes Educator

Teaching a one-hour diabetes self-management class at the St. Petersburg Free Clinic's Diabetes Program was also a part of my participant observation experience. While a class instructor, I was also a peer educator. I was on one hand a participant learning about diabetes and practicing as a mock diabetic, self-managing like the diabetic individuals in the classes I attended. On the other hand, I was also a researcher/educator providing instruction to others about diabetes and diabetes self-management.

My class design utilized an interactive method of instruction. I created a "Diabetes Jeopardy" game (Appendix J) that the participants played. The game board was drawn on the white board in the classroom. Categories and levels were selected by me and the participants. Participants "buzzed" in (raised their hand or enacted a buzzer sound) to respond to questions. Prizes in the form of diabetic body creams, and drinks, samples of sugar substitutes such as Splenda and Stevia, blood glucose monitoring journals, and hot/cold travel thermos were donated by the clinic. Prizes were color-coded to the levels of categories on the game board. Participants won prizes based upon the correct answers to the question at the level of the question asked. For example, level 100 was color-coded as yellow. A participant correctly answering a question at the 100 level received a yellow marker for that prize. At the end of the game, the participant

redeemed the yellow marker for a prize in the yellow category.

Approximately, thirty-five individuals were in attendance of this class where I was being taught as I was teaching.

## SECTION II.

### DIABETES EDUCATORS and SELF-MANAGEMENT PROGRAMS

#### Educator Demographics

Interviews were conducted with seven professionally diverse health care providers who provide diabetes self-management education to individuals with diabetes. Three providers were African Americans, and four were Caucasian. The composition of these individuals included two registered nurses (RNs), one licensed practical nurse (LPN), one exercise physiologist, one nutritionist who has created a “Soul Food” pyramid geared toward healthy nutrition for African Americans, one endocrinologist who worked in a university-based, adult diabetes clinic, and one internal medicine physician who also practiced holistic medicine. One registered nurse was also a registered dietician (RD), and an American Diabetes Association (ADA) certified diabetes educator (CDE). The exercise physiologist was also an ADA certified diabetes educator. To become an ADA certified diabetes self-management educator, individuals must have a Bachelor’s degree, a minimum of 1000 hours of teaching diabetes self-management education, and pass a written exam. The selection of these professionals was based on the literature identifying the membership of the diabetes health care team. They are professionally diverse; yet conceptualized knowledge of diabetes

and its treatment in a similar manner.

### Self-management Educators Constructing Diabetes—Qualitative

The goal of self-management education is to assist patients with the acquisition of knowledge about diabetes and the behaviors that facilitate diabetes care, that prevent complications and reduce diabetes morbidity and mortality. Educators involved in the practice of instructing patients on the care of diabetes provided perspectives on the disease, its causes and its treatments. The qualitative interview data from the health educators revealed their construction of diabetes, their perceptions of what made self-management easy and difficult, and their perceptions of the recommended treatment behaviors for diabetes.

As inquired of the women with diabetes in this study, the first question asked the educators, “*What is diabetes?*” This question investigated their understanding and knowledge of diabetes. Analysis revealed a common biomedical knowledge of diabetes among all of the educators. Educators delineated two main types of diabetes, type 1 and type 2, and causes of disease onset such as obesity, genetics, and gestation. Examples of the homogeneity in the cultural construction of diabetes by educators reflected the following comments.

“Diabetes by definition is elevated blood glucose. Criteria set out by the government and the American Diabetes Association is a fasting blood sugar equal to or greater than 126 on two occasions, or a blood sugar after a glucose challenge test two hours after a meal. Normal blood sugar is now considered up to 100. Between 100 and 125 is impaired glucose.” (E7)

“It’s a it’s a failure of the pancreas to produce insulin and/or else the pancreas is producing the insulin but the cells are unable to take the insulin in so it’s an insulin resistance. So, between the fact that its a lack of insulin or resistance is why they get diabetes; a fasting blood sugar over 126. Between 70 and 126 is normal. The American Diabetes Association says that there is no such thing that someone has border-line diabetes.” (E1)

“Well diabetes is the body’s inability to take the carbohydrates and break them down so the glucose can be used by the body. It’s like a malfunction syndrome. Everything we eat is turned into a glucose molecule and used by the body to let the glucose molecules in the cells so we can use the glucose, sugar, to fuel our body when we most need it. Insulin is a hormone that is naturally made by the pancreas. It’s a function of the pancreas to make insulin so insulin can break down the carbohydrates into glucose to go inside the cells so it can be used”. (E5)

The second question asked the “*causes of diabetes.*” Similar to factors reported by the women in this study, the analysis found that diabetes educators identified, genetics combined with the environment, age, gestation and factors related to one’s lifestyle such as obesity, weight gain, and inactivity as causes of diabetes. However, one educator questioned the over-emphasis on genetics as a primary cause of diabetes. The educator believed that lifestyle modifiable behaviors over which diabetics had control (e.g. diet and exercise) were more dominant reasons for diabetes onset. Educators’ comments revealed the following statements as representative of the causes of diabetes.

“One of the things that leads to diabetes is what’s called—lifestyle, one’s weight, one’s physical activities help to contribute to the factors causing diabetes. It’s a combination of the environment plus genetics.” (E7)

“You will hear this thing about well it runs in the family. It’s that genetics plays a role. Well let me tell you, I think that notion is overplayed. First of all it’s often difficult to separate genetics from your environment. Just because something runs in the family doesn’t automatically mean it’s in the genes. How about it’s in the refrigerator— in the same household generation after generation after generation? How about eating habits are the same and passed on? Shopping habits are the same. The lack of

exercise and the lifestyle in general is the same and passed down from one generation to another. It's over simplified in the lay press. When we talk about it in lay situations, genetics and the role it plays in many diseases is oversimplified and I think over exaggerated. If you examine even the lay press over what people are reading, you will notice doctors are saying a little less of this genetic thing. They are coming out much more freely and saying hey folks it's not rocket science. It's diet and exercise." (E6-1)

"Insulin resistance is one of the primary factors involved in causing diabetes. Weight gain increases the tissues inability to utilize insulin efficiently or increases insulin resistance. If there is diabetes in your family, that doesn't mean that everybody in the family is going to have diabetes. ( E7)

"It is a lot of factors. It could be hereditary, it could be accident where a person could have a gunshot wound or something to the pancreas and the pancreas can't produce insulin, to some other kind of disease process. Sometimes age if you live long enough. Anything could cause it. (E5)

The next two questions investigated what made it easy and difficult to manage diabetes. Having a positive attitude, family support, and being educated about diabetes were factors educators identified as making it easy to manage diabetes. On the other hand, the high cost of supplies and medications, need for lifestyle behavior changes, a negative attitude, and competing life priorities were reasons educators believed diabetes was difficult to manage. Their comments revealed these multiple factors.

As reported by two educators, "A positive attitude; I can do this," (E2), and "family and community support groups" (E5) made it easy to manage diabetes. One educator believed that African Americans were more accepting of diabetes and that was what made it easier for them to manage diabetes than it was for Caucasian Americans.

“I do find that with African Americans having diabetes prevalent in their race, they seem to be more accepting of it. They are a little more willing to take that diagnosis and do something about it. They have seen more than anybody else the devastating side effects of diabetes that is not controlled. Most all of them have grandparents that have died from it and have had amputations. There are awful horror stories that you hear. I think the one advantage of the African American community over the Caucasian community is that they have seen it. They are a little more aware of the fact that they could very easily have it. Most of the people who come to my classes are African American.” (E1)

Some of the difficulties of managing diabetes were described in the following educators' comments.

“I think a lot of it is will power, learning how to control it. We may not have a support group. Also, cost of supplies and this is why I think a lot of people stay unhealthy, and then die from it because your supplies are extremely expensive. Diabetes is one of the most expensive diseases there is to manage because you have a monitoring component that you have to do. (E5)

“The strips cost you about fifty-sixty dollars and you have to do it twice a day. You only get fifty strips inside of a kit that's to last you a month. Now you're talking about somebody making minimum wages. This is why we don't check the blood sugar. If you're talking about insulin, insulin cost you twenty or thirty dollars a bottle. If somebody has to take a shot they may take one shot. They won't take two because they can't afford it especially the working poor people who do not have access to health care. They make too much money to get service, but they don't make enough money, or either they have a job that doesn't offer health care benefits. So these people can't afford to buy insulin to take it properly, you know. You have a choice, you either buy insulin or you buy food. So you buy your food, and instead of taking two shots you may take one shot and then hope that, that helps you.” (E5)

“Not getting the education needed to keep it under control soon enough.” (E1)

“A negative attitude, “This is too hard. I can't do it,” also, limited resources for education, and medications. Insurance pays for education classes and doctor's office knows this. Diabetes is an expensive disease.” (E2)

“They are trying to manage a lot of things. They are trying to manage

their lives, their family and taking care of a lot of people. Unfortunately, they are not taking care of themselves.” (E4)

“It’s a little more difficult for African Americans to make the lifestyle changes because of their culture and the type of diet that they’re used to.” (E1)

## Prescribed Self-Management Treatment Behaviors

### Research Question 4

#### WHAT SELF-MANAGEMENT BEHAVIORS ARE PRESCRIBED BY DIABETES EDUCATORS AND PROGRAMS?

##### A. DIABETES EDUCATORS

Diabetes care is complex because it involves both self-care by the patient and administration of key processes of care by the provider (Chin, Auerbach, and Cook 2000:433). To identify the recommended self-management treatment behaviors for diabetes, educators in the present study were asked to first explain the role self-management played in diabetes control. Second, as asked of the women in this study, educators were asked to identify and discuss the importance of treatment behaviors for managing diabetes. Behaviors discussed were nutrition/dietary changes, exercise, blood glucose monitoring, medications, patient education, health care provider interaction, spirituality/religion, and support systems.

When asked about the role self-management played in diabetes control, educators believed that although self-management involved a health care team approach, the most important self-management team member was the diabetic individual.

“The part that the patient plays, which is essential to true self management, makes all the difference in the level of control.” (E6)

“Physicians are part of the team. The essential person of the team is the individual him/herself. The other members of the team are the primary care doctors, the nurse educators, the dieticians, and then there are a bunch of other people that can be used if necessary—pharmacist, psychologist, and ophthalmologist. But, the principal component of the team is first and foremost the patient, then the nurse practitioner, then the nutritionist, then the primary care physician.” (E7)

Self-management was also explained as having multiple components such as oral and injection medication, education, nutrition, and exercise. Education was a common theme.

“There are many different aspects of treatments. One can break it down into non-drug related and drug-related. Non-drug related is in essence education concerning nutrition, concerning diabetes in general, concerning exercise, how to measure your own blood sugars at home because the greatest majority of treatment is done by the individual. Drug treatment is by tablets or insulin to try to overcome the high blood sugars. (E7)

“In self-management, there is also the association of the primary care physician and hopefully part of the process is education through structured diabetes classes which help the individual learn self-management and in conjunction with the nurse educator and dietician using a plan formulated for each individual.” (E7)

“As a dietician what’s important to me in self-management education is getting our African American clients to have good glucose control by getting diabetic education.” (E4)

Educators were next asked to discuss treatment behaviors involving diabetes self-management. The first question asked the role of nutrition. Analysis revealed that limiting the amount of carbohydrates one ate, decreasing high fat foods, eliminating fried foods, eating more fruits and vegetables, and whole

grains and eating smaller meals more frequently were recommendations for diabetes self-management.

## 1. Nutrition

“Eat a high fiber diet. Most people don’t eat enough fiber. We should get somewhere between twenty-five to thirty grams of fiber per day. Eat whole grain and a lot of fruits and vegetables. Get the healthier mono-saturates and stay away from the trans-fat. Limit your total fat intake, because that’s where your calories are concentrated. People who either have high fat diet frequently don’t eat very healthy because they eat a lot of fried foods, and fatty meats. Dairy products are high in fat. Those fats are saturated fats make the blood cholesterol go up which is another risk factor for people with diabetes.” (E2)

“Carbohydrates are the only things that make your blood sugar go up. You can’t avoid carbohydrates. What you want to do is control the number of carbohydrates that you eat. It’s a matter of learning how to count carbohydrates. It’s a matter of learning how and what particular carbohydrates affect your blood sugar the most. It’s a trial and error situation especially because not everybody’s body works the same as somebody else’s.” (E1)

“A diabetic can have anything and everything that any other person can have. It’s how often you eat it and how much that you eat. They say three meals a day and two snacks, but it actually works out to be about six meals a day they should be eating. Six small meals a day and you can actually lose weight on that. They don’t believe you, but you can lose weight on that.” (E1)

One educator believed that it was not easy to understand dietary/nutritional requirements.

“The diet/nutrition information is probably one of the hardest things to comprehend or understand, for example, what’s a carbohydrate, a fat, what’s a protein?” (E3)

## 2. Exercise

The role exercise played in self-management was next discussed in the interviews. Educators were asked, “*What role does exercise play in diabetes self-management?*” Data revealed that exercise was a very important part of self-management because it assisted with helping to lower blood glucose levels, and to reduce the need for medications. Recommendations were for thirty minutes to one hour of daily exercise. Walking was an exercise suggested. For diabetics with neuropathy, educators believed that alternate exercises performed while seated were doable options.

“Being active thirty minutes a day of walking, brisk activity is probably enough to take care of the exercise issue.” (E2)

“Exercise can help keep glucose levels normal and alleviate the need for insulin and even pills.” Exercise is the most important, and the best medicine for diabetes. It’s as close as we can come to fixing diabetes. The exercise folks need to do is usually approximately 45 minutes to an hour most days of the week. Since many people don’t like to exercise, when the doctor recommends exercise, taking medicine, and backing off of your foods, I think many folks say, I think the medicine will take care of it, and maybe I’ll cut back on my foods a little bit.” (E3)

“The biggest excuse for not exercising is that most diabetics have neuropathy, and it hurts their feet to walk. So, I go over exercises that they can do while they’re sitting down. Even rocking in the rocking chair is exercise.” (E1)

“Exercise specifically is under emphasized. There is not enough discussion about exercise in diabetes. Nutrition which is the word I prefer and exercise go hand in hand.” (E6)

### 3. Blood glucose monitoring

What is the significance of glucose monitoring for self-management? When asked this question, data revealed that monitoring helps diabetics to know how well they are managing their diabetic condition. The hemoglobin A1c (HbA1c) test was identified as the penultimate tool for assessing glucose control.

“Studies have shown that individuals who’ve maintained their blood glucose—the hemoglobin A1c—at seven percent have much better outcome of it. They have many fewer complications than individuals who go above seven. Monitoring on a regular basis is important because if you don’t, you really don’t know how you doing. That tells you how you’re managing as far as the eating habits.” (E2)

“The HbA1c test is used to follow people who have diabetes to see how effective the treatment program is that they are on.” (E7)

### 4. Medications

Data revealed that educators considered medications a part of diabetes self-management. However, medications such as pills and insulin were considered secondary support to nutritional/dietary changes and exercise. Educators also expressed concerns over both the high costs medication and the lack of insurance coverage for medications. This lack was considered a barrier for individuals needing medication as part of the diabetic self-management regimen. Educators responded to the question, “*What part do medications play in self-management?*”

“Diabetes is a progressive disease and everybody will eventually be on insulin. People have that fear of going on insulin to the point of lying about their blood sugar and trying to keep control through oral medications. There are only causing themselves more trouble. The drug manufactures are coming up with this new nasal spray. That’s going to be real good. People are going to be more willing to use the spray than they are to go on the injections.” (E1)

“The health care system does not have reimbursement for any medications. Diabetes is an expensive condition. Pharmacists like to see people with diabetes because they spend 3-5 times as much on medically related devices and medications than someone who doesn’t have diabetes. Medicare will pay for devices such as meters to measure blood sugar, the lancets, and diabetes education, but they will not reimburse for medication.” (E7)

“After exercise, and the patient watching what she/he eats, then if these things aren’t helping enough, then of course we need to consider medication, then stress.” (E3)

## 5. Support Systems

Analysis of responses to the question, “*What type of support is important for managing diabetes?*” educators reported that diabetics needed family, friend, church, and community support. Additional support of a twenty-four hour telephone hotline was also suggested.

“I think they need a strong community support group. I think individuals get to know each other hopefully we can encourage them to take a little step and have an individual or a diabetes sponsor so if a person feels like they want to go off their diet, they want to binge, we can call each other and network. Have a hotline, like a twenty-four hour hotline.” (E5)

“Family support is important because it’s very difficult for a mother who has young children and a husband to try to go on a diet when everyone else in the family is doing whatever they darn well want, especially if she is cooking for them. We encourage family members to be involved in the education process. Families should be educated about nutrition, and the value of exercise. (E7)

“Community health centers, churches and organizations can also help with exercise programs for people who have trouble coping with conditions. Support groups can be quite helpful. Then there are the more structured groups such as the American Diabetes Association and county health departments who have resources for education and information which are available to anyone.” (E7)

## 6. Spirituality/Religion

Educators responded to the question, *“How does religion/spirituality affect self-management?”* Analysis revealed that educators recognized a role for religion/spirituality in diabetes self-management. Faith in God was reported as important for helping to manage stress and for healthier living.

“I do believe that people who are well grounded and have faith and belief in God tend to be healthier and more focused people with their lifestyle and with their health. In my church I am one of the health ministers and I tell persons that God didn’t give us our body to mess it up.” (E4)

“When I think of spirituality, I think in terms of stress management. We also have to take our sitting in church listening to the pastor to a higher level and connect with God who is our help every time and every minute. That Spirit is the help. You have to have faith. You’ve got the help. It’s there.” (E6)

One educator cautioned that individuals managing diabetes and their health should take a logical approach to using God as a single treatment source.

“I think that when people say that God is going to heal them of their diabetes we need to find out what are they are saying. Is God going to heal them, and all they use is God alone, or is God going to heal them with modern technology and medicine? If they say God is going to heal them and God alone, we need tell them when God has given them the wisdom to know that if something is wrong with their body, then God has given man the knowledge and power and wisdom to make medication that will help the process quicker. Don’t they think that God may want them to use the quicker way than the long process? But even with God and praying and all that, it may take days. When we know better we do better.” (E5)

## 7. Interaction with Health Care Providers

Educators were asked about the role health care providers played in self-management. The analysis revealed that physicians are important members of

the diabetes self-management team. However, data indicated that physicians must be more responsive to the needs of their patients. Educators believed that physicians needed to take more time in the health care interaction with patients. Cross-cultural health communication between the patient and physician was also identified as important.

“I think the doctors need to take time to educate the people, and to talk to them. Doctors are highly educated. They have to be able to talk to a person the way that they want to be talked to without putting them down like they are dumb and stupid. A person may not have your vocabulary, but they are not stupid either. You have to find a way to talk to them in the vocabulary that they do understand without putting them down so low as if they are hideous.” (E5)

## 8. Patient Education

The last question addressed patient education. Educators were asked, “*How do you think patient education affects self-management?*” Analysis indicated that education was a vital part of self-management because education provided instruction on treatment behaviors such as nutrition, exercise, blood glucose monitoring, and medications. Families were recommended to be included in instruction level appropriate patient education.

Data revealed that health insurance covered most if not all of the cost of classes when a patient was referred by a physician. Acquiring education was reported as primarily the patient’s responsibility. The physician’s referral was considered only part of the process. Educators believed that through education, patients became knowledgeable about the behaviors necessary to successfully manage diabetes.

“The delivery of the education has to be simple. It’s got to be understood, simple to read, simple to comprehend, and that’s not just specifically for African American women. That’s for African American families. We had to educate the women though so that they can educate their families.” (E4)

“Patients would know about classes through their primary care physician. Most insurance companies will cover the cost or at least part of the cost of education programs. There is a state law in Florida that says the insurance companies need to reimburse for classes. Some programs offer scholarships if people don’t have resources to pay for it. Some hospital programs tend to be fairly expensive. (E7)

“Also, the most important thing is for a person to know as much about his or her diabetes they can because it’s their condition. They are the ones who should be their own best doctor. For that, there’s education including how to monitor your own blood sugar to see how low things are going, knowing what the value of diet and exercise is, and if necessary, the appropriate medications to assist in lifestyle changes. Nurses and dietitians are much better educators by large than physicians are.” (E7)

“When someone is found to have diabetes, the first thing they need to do first is the doctor needs to get them educated. Whether the doctor is going to spend time doing it, or the nurse, or the doctor’s office which isn’t likely going to happen because it’s not practical, the doctor or health care person needs to recommend the patient to learn as much about the disease as possible right from the start because there is no way you are going to take care of it if you don’t have the knowledge that enables people to take care of themselves. It is an illness that almost is entirely up to the patient themselves. Once they get education, hopefully they are going to learn the type of things they need to do to take care of it. The doctor can refer the patient, but the patient has to figure out if it’s something they want to do.” (E3)

### Summary of Educator Interviews

Data analysis revealed that self-management and self-management education were important for diabetes control. The enactment of self-management treatment behaviors was an individual responsibility, however family, friends, religion/spirituality were reported as support systems that made it

easier for patients to manage diabetes. Diabetes was indicated as being difficult to manage when patients had a negative attitude, and when the cost of medications and testing supplies were costly.

Educators reported that several behaviors were needed for managing diabetes. Nutritional changes called for individuals to limit the amount of foods eaten, to reduce carbohydrates and to eat more whole grains, fresh fruits and vegetables. Exercise required exercising daily for thirty minutes. Blood glucose monitoring represented an avenue for assessing levels of glucose in the blood, and as a tool to assist with keeping glucose levels within the recommended ranges.

Medication, such as pills and insulin, was reported as a supplement to nutritional modifications and exercise, two major aspects of self-management. The oral and injection medication was identified as aids that likewise assisted patients with lowering blood glucose levels.

The primary care physician was found to be an important member of the self-management team comprised of a nutritionist/dietician, exercise specialist, nurse educator, psychologist, ophthalmologist, and pharmacist. Interview data revealed a need however for physicians to increase the time spent with patients. Additionally, there was identified a need for physicians to improve the patient-physician health communication.

Patient education was found to be one of the most important aspects of self-management. Insurance covered classes made it possible for patients to obtain

this education. A patient who was educated was considered a patient well-equipped with the self-management knowledge needed to enact the behaviors required for glucose control.

## B. DIABETES EDUCATION PROGRAMS

### Cultural Awareness and Sensitivity

Participant observation and qualitative data revealed that diabetes education was delivered from a biomedicine perspective. Variation that considered sociocultural factors such as age, gender, ethnicity/race, and language was not evident. However, data from interviews with educators revealed an importance for the delivery of culturally aware and sensitive education that included class location, delivery style, indigenous educators, family involvement, and meal preparation—

“When I see a diabetic that is normally discharged from the hospital, they are offered ten or twelve diabetic courses that are paid through the insurance, and most cases they don’t want to go because they said that the teacher is not speaking to them. The teacher is not speaking to them in a language that they can understand. The teacher is not being cautiously sensitive to their culture, their food, their lifestyle and their way of life.” (E4)

“When we teach our classes we teach them at night but we teach them in the faith-based community preferably African American churches so the community can get to the class during either Bible study or choir rehearsal nights or any free night that the church may have so we make it much more accessible for people to attend.” (E4)

“A lot of problems with our education is that people say that I’m going to make those people do right. You can’t make those people—and who are those people? Are you Black? They do have African Americans out there who are trying to talk to African Americans. And then we have some people get out there who forget that we are African Americans. Whoever

is going out there preaching the method must understand the culture of the people. How do you present yourself to a different segment of the culture? ” (E5)

“You have to figure out what is the comfort level of the people you are dealing with. We have to ease ourselves in and be accepted into the environment before we can just start rattling off. But we want to just put our book down and start teaching without taking time to find out what do people know and what do they want to talk about? When you just go up there and start rattling off telling the people what they are going to do, it doesn’t work that way.” (E5)

### Self-Management Program Participant Observation

Direct and participant observation was conducted at five diabetes education programs in the greater Tampa Bay area. The non-random site selections were based on the inclusion of a cross-section of program types in order to gain comprehensive knowledge of diabetes, and to investigate the components of diabetes education. Programs included a community-bases/non-clinic site, a community-based clinic, and two hospital-based programs, and a university clinic-based. Diabetes education content was consistent across all programs. However, length of classes, method of materials presentation, number of attendees, ethnic composition, and educators varied across each program. Descriptions of the programs and class activities observed are outlined below.

#### Community-based Program—D.I.P.P.

The Diabetes Intervention Prevention Program (D.I.P.P.) in St. Petersburg conducted classes every Monday evening for two hours each session. The class used a small, informal discussion, and support group format. Attendance

averaged 15-20 individuals per class, and participants were primarily African American females with diabetes who ranged in age from approximately forty-five to sixty-eight years old. The group also included African American males and Caucasians on occasion, though few in number. Family members and friends of the diabetic individual were also class attendees. The Diabetes Intervention Prevention Program (D.I.P.P.) was funded through a grant from the Pinellas County Health Department.

Classes at the D.I.P.P. were taught by a registered nurse practitioner (RN), and a Nurse Manager, both African American females. Class content included information on (1) the bio-physiological aspects of diabetes, (2) exercise/physical activity, (3) nutrition, (4) stress management, (5) blood glucose monitoring, (6) medications, and (7) cholesterol levels. Materials used included pre-post tests, health videos, and printed literature. Guest presenters for classes included medical/health care providers from health professions such as Podiatry, Cardiology, Internal Medicine, Dentistry, General and Peripheral Vascular Surgery, Chiropractic, and Holistic medicine. Similarly, nutritionists, and exercise instructors were educators for class activities. Light snacks of fresh fruit and vegetables, small meals, health bars, and bottled water were regular offerings to the participants.

A feature of the program was the availability of free health screenings such as blood glucose, cholesterol and blood pressure testing at each class. All classes were free and open to the public.

## Community-based Clinic--SPFC

The St. Petersburg Free Clinic (SPFC) Diabetes Program was located in the James B. Sanderlin Center. At this site, classes were conducted twice a month on Wednesdays for approximately one to one and a half hours. A morning and an evening class were offered. The class used a classroom lecture, question and answer format for dissemination of diabetes and health related information. Classes were taught by a Licensed Practical Nurse (LPN), and included guest speakers on an array of health topics related to diabetes, e.g. nutrition, exercise/physical activity, blood glucose monitoring, medications, foot care, physician care, cholesterol levels and stress management. Videos, a white board, and printed information were also part of the class structure and teaching methodology. The diabetes educator was also a health care professional who provided nursing care to several of the attendees who were patients at the clinic.

Classes averaged forty to forty-five participants per session. Classes were ethnically diverse with self-identification on sign-in sheets noting cultural affiliation such as African American, Caucasian, Latino, East Indian, Native American, Croatian, Jamaican, and Haitian as examples. The majority of attendees were Caucasian, with African Americans second as a group of participants. Gender representation was fairly equitably distributed among the attendees overall, however African American females out-numbered African American males. Age approximated individuals who were forty-five to eighty-six years of age. Classes included clinic and non-clinic individuals, and all classes

were free and open to the public.

A unique feature of the program was its ability to provide free blood glucose monitoring supplies, lotions, nutritional supplements such as Glucerna, and sugar substitutes such as Splenda. Through grant funding, private and corporate as well as participant donations, the program offered glucose monitors, lancets, syringes, test strips, and alcohol wipes to participants at each class on a first come-first served basis. Bottled water was also provided at each session.

### Hospital-based Programs

#### A. Morton Plant Hospital's Joslin Center for Diabetes

Direct and participant observation of Morton Plant Hospital's Joslin Center for Diabetes in Clearwater revealed a formally structured, lecture, question and answer format for class sessions. Participants had the option of attending two, day or four evening classes for a total of ten hours of instruction. Attendees received a detailed notebook which was used in the class for instruction, and which participants were allowed to keep. Sections included (1) Diabetes Overview and Monitoring High Blood Sugar, (2) What Can I Eat, (3) Low Blood Sugar, Medications, and Health Tips, (4) Meal Planning, and (5) Handouts. Handouts included a list of community resources, food label guidelines for diabetes, exercise guidelines, list of resource books, list of diabetes support groups, and tips for handling stress. The program included access to a fully-equipped physical fitness center at the Clearwater Morton Plant Hospital location.

During the time of participant observation, class size was approximately

twenty six individuals. Gender composition was sixteen women, and ten men. Five of the women were African American. The researcher was informed by Joslin diabetes education staff that few African Americans were ever participants in the classes. The educator's perception was that individuals might not be aware of the classes, did not receive a physician referral to the classes, that African American individuals may not be aware that insurance coverage paid for the classes or that the individuals did not have health care insurance. Health care insurance covered the cost of the Joslin self-management education classes at the Joslin center. Medicare covered 10 hours of education, and a physician referral was required.

The uniqueness of the Joslin program was its status as one of the American Diabetes Association (ADA) accredited programs. Educators in ADA programs were Certified Diabetes Educators (CDE). They were nurse educators, exercise specialists and nutritionists. They held a minimum of a Bachelor's degree, had a minimum of 1000 hours teaching diabetes self-management through working with people with diabetes, and had passed a written exam.

#### B. Diabetes Care Institute (DCI) at University Community Hospital

The Diabetes Care Institute at University Community Hospital in Tampa, Florida was also an American Diabetes Association recognized program. Several staff members were Certified Diabetes Educators. These included nurses, nurse practitioners, exercise specialists, and dieticians. The program

provided diabetes self-management education that included a six (6) hour diabetes overview in content areas similar to those taught in the D.I.P.P., SPFC, and Joslin programs. Areas covered nutrition and meal planning, medications, exercise, glucose monitoring, complications, stress management, and foot care.

Staff estimated cost for the six hour class was approximately \$500-\$700. The cost was covered by health insurance. Some financial assistance was available to cover the cost of classes for a limited number of individuals without insurance. Literature provided to participants informed them of Chapter 96-279 of Florida Law that required health insurance policies and HMO contracts sold in Florida to “provide coverage for medically necessary diabetes supplies and self-management training.” Participants were also provided the telephone numbers for the Florida Department of Insurance Consumer Hotline and the Florida Agency for Health Care Administration as follow-up on coverage for supplies and classes. Class size observed was approximately thirteen individuals.

Program literature listed additional supportive services offered at the DCI as “specialized self-management training classes, exercise programs, a weight management program, insulin pump therapy, hospital in-patient and out-patient support for diabetes management and diabetes management support groups.”

#### University-based Clinic Program-USF

The University of South Florida’s (USF) Diabetes Center was located on the campus of the USF Medical Clinic in Tampa, Florida. The Center was an ADA

recognized program with classes taught by Certified Diabetes Educators (CDE) and physicians. One CDE was a master's level trained dietician. One physician educator was an adult endocrinologist. The class that was observed for the present study also included instruction by an exercise specialist, nutritionist/dietician and a nurse educator.

Two morning class sessions covered ten hours of instruction geared toward "newly or previously diagnosed individuals." Insurance was accepted to cover class cost. Within one year from first taking the class, participants were allowed to return to the class without a charge or at a minimal cost.

Class size was limited to approximately ten individuals for each class. Pre-registration was required. Like the Joslin Center program, few African Americans attended the Center's classes. Attendees were primarily Caucasian.

Content for the classes were likewise similar to previous programs mentioned above. Education included pre-post test assessments, overview of diabetes, medications, nutrition, psychosocial issues, exercise, blood glucose monitoring, and personal health care that included care of the feet, skin, teeth and eyes.

#### Summary of Class Observations

All of the observed programs shared teaching comprehensive diabetes knowledge and self-management education. Instructors were both certified and non-certified diabetes educators, and similarly some programs were American Diabetes Association recognized and some were not. Costs of the class

sessions ranged from no cost to approximately \$700.00. Health care insurance covered the class costs, and some programs offered scholarships to help defray the cost for low income, uninsured individuals. Classes were offered both in the day and evening and size varied from ten to approximately forty-five individuals. Except for the two community-based programs, programs had low African American attendance. Staff across programs were unsure of the specific reasons for low attendance, but speculated that reasons were due to non-physician referral, lack of insurance, location, time of class, lack of knowledge about the classes, and lack of follow-through once referred.

Comparative analysis of the data is presented in Section III.

SECTION III  
COMPARATIVE FINDINGS

Research Question 5:

What is the concordance/discordance that exists between self-management treatment behaviors of the women and prescribed behaviors of diabetes educators and programs?

Cultural Construction of Diabetes

Concordance

Findings revealed that the women and educators agreed that managing diabetes was difficult, but that it could be controlled through lifestyle behavior change. Obesity and being overweight were recognized by the women, educators, and programs as factors contributing to diabetes onset. Weight loss, nutritional changes and exercise were identified by both for reducing risk factors and preventing diabetes onset, and for reducing diabetes complications. Genetics and family history of diabetes were also recognized by both educators and the women as a risk factor for onset. Talking within the family about diabetes and having family and friend support were similar themes shared by both the women, educators, and across education programs.

Discordance

Results indicated that knowledge, beliefs about and understanding of diabetes varied among the women. A majority of the women understood diabetes with a lay person's construction of the disease, noting that the disease had "something

to do with the pancreas not working right, and/or with the body either not using or not making enough insulin,” or not knowing at all. On the other hand, diabetes educators and programs shared a professional, academic, detailed and comprehensive biomedical/patho-physiological knowledge and understanding of diabetes and its causes.

### Self-Management Treatment Behaviors

Findings of the prescribed treatment behaviors for diabetes self-management by diabetes educators and programs included in this study were: (1) nutritional changes/meal planning, (2) exercise, (3) use of medications, (4) blood glucose monitoring, (5) stress management, (6) patient education, and (7) support systems (e.g. family, friends, religion).

### Concordance

Findings suggested that the women had knowledge of diabetes treatment behaviors (e.g. nutritional/dietary change, exercise, medications, blood glucose monitoring) and that they initially acquired this knowledge from their primary care physician. Similarly, findings highlighted diabetes educators' identification of the same treatment behaviors as the women for managing diabetes. Barriers such as costs of medications, difficulty changing nutritional habits were identified by both women and educators as an impediment to self-management.

Diabetes educators, self-management programs and the women all agreed that the patient was the number one person on the self-management team. The team consists of physicians, nurses, nutritionist/dieticians, exercise specialists,

diabetes educators, and other health care and mental health professionals.

There was also agreement between the women and the educators that patient education was an important part of the diabetic regimen.

#### Discordance

Findings suggested that the women looked to their primary care physician for on-going self-management education. However, physicians in this study believed that the education was the responsibility of the nurse educator or nutritionist. Even though physicians could make referrals to diabetes education classes, the findings revealed that for the majority of the women, referrals were never made. Women gained their knowledge through reading, and through a nurse or nutritionist/dietician. Such discordance suggests that in the physician-patient interaction where expectations for the delivery of self-management education were not clearly understood or articulated, the women may have lacked the professional level of knowledge needed for managing their condition. Without initial and on-going knowledge of the diabetic regimen for carrying out the prescribed behaviors, the women were placed at high risk for adverse health outcomes related to diabetic complications such as retinopathy, neuropathy, kidney failure, and amputations. A lack of effective diabetes health communication between the patient and physician evidenced the women's dissatisfaction with the physician-patient interaction and their knowledge acquisition of diabetes self-management from friends, reading materials, family and free community-based diabetes self-management classes.

Findings from the study also revealed the emergence of two models as shown in Figure 1 and Figure 2. As represented in Figure 1, self-management education programs emphasized a research informed *model of balanced self-management*—all of the treatment behaviors used and used with consistency. On the other hand, as represented in Figure 2, the majority of the women in the study had *models of interruption*—combinations of selected behaviors with intermittent use due to intervening behaviors and activities, and environmental and structural barriers. For example, as indicated in Table 2, eighty percent of the women reported utilizing nutritional/dietary changes, exercise and medications as a primary model of self-management. Dietary change was fluid, with adherence fluctuating with food choices and amounts, exercise fluctuating with body pain, disability, work schedules and family demands, and medication use varying based upon affordability and access. A second example of a *model of interruption* combined nutritional/dietary change, medications, exercise and blood glucose testing. In this instance, blood glucose monitoring was included as an additional treatment behavior. Monitoring and response occurred primarily with symptom recognition, and not on a consistent daily basis. As with women who primarily practiced fewer behaviors (dietary changes, medication use and exercise, or dietary changes, medication use and blood glucose monitoring), the use and duration of the behaviors practiced by women who included more treatment behaviors as part of their diabetic care regimen (dietary change,

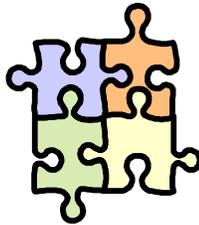
exercise, medication use, blood glucose monitoring) would be affected by intervening factors (support systems, cost of medications, lack of insurance) posing restrictions or barriers to consistent adherence to prescribed treatment regimen.

Reducing the discordance is discussed in chapter five.

### Diabetes Educators and Programs

Figure 1

### MODEL OF BALANCED SELF-MANAGEMENT

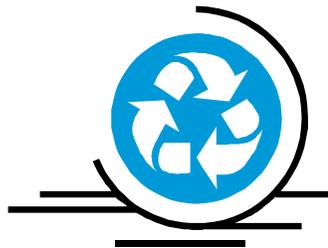


Model of Balanced Self-Management  
Interlocking behaviors used together for a balanced self-management approach.

### The Women

Figure 2

### MODEL OF INTERRUPTION



MODEL OF INTERRUPTION  
Arrows represent consistency in attempted use of prescribed behavior. Squares represent barrier behaviors and/or structural and environmental factors causing intermittent and inconsistent use of prescribed behavior.

## Summary of the Findings

### Cultural Construction of Diabetes

The cultural construction of diabetes applied to the data analysis and discussion of the findings indicated a range of understandings and beliefs about diabetes for the women. Some women were bio-medically knowledgeable about diabetes. Others combined their own understanding of diabetes with basics of biomedical information to form a hybrid (a combination of the two yielding a proximate understanding) of knowledge as a means to understand diabetes. Still others did not know the biomedical, rather conceptualized diabetes in lay terms of meaning and understanding of diabetes as a serious disease affecting the body. On the other hand, diabetes educators and self-management programs constructed diabetes in comprehensive biomedical terms.

### Self-Management Treatment Behaviors

The conceptual underpinnings of the Health Belief Model applied to the data analysis revealed that the women had a belief of susceptibility to diabetes because of a gestational pregnancy, overweight or obese status, susceptibility due to family history (genetics), or a susceptibility to diabetes complications because of difficulty managing the diabetic regimen.

“It (managing diabetes) still comes back to the extra weight that you have on your body. It’s just tearing it down to the point that if I don’t try to do more about getting it down, I may even end up in a wheelchair.” (Ms. M)

From the interviews and questionnaire data, the women also revealed a belief of the serious nature of diabetes—

“Diabetes is scary. It’s a nightmare because with diabetes you have to always be careful of stubbing your toe. You can get a cut on your toe and you don’t even know it. I had a cut on my little toe and I didn’t even know it until I was having this terrible pain in my feet. The pain was so bad. I have diabetic neuropathy in the feet.” (Ms. D1)

“It is a disease that can not be cured, but can be controlled” (Ms. M2)

” Well, they say it is the silent killer and it surely is.” (Ms. R).

Similarly, the women revealed a belief about the outcome of carrying out the recommended behaviors. They believed that to do so would benefit them with glucose control, and thus the prevention and/or elimination of complications. However, the women also believed that barriers to self-management such as fear of needles, could affect the desired outcomes of glucose control and reduction of diabetes complications. From these beliefs about diabetes and beliefs toward the prescribed behaviors, the women made evaluations of the outcomes (prevention and/or elimination of complications or onset of complications), and then initiated or intended to initiate action to carry out the prescribed behaviors (nutritional changes, exercise, blood glucose monitoring, medications, etc).

“After we found out that we could save my kidneys and liver, we realized that I would have to take two glucose level medicines and that’s when he put me on fifteen units of insulin and I don’t mind because it’s just convenient. I only take it once a day at night. An elderly person who has a tendency to be sedentary like I am, your liver overworks at night so we decided I would take the insulin at night to level off the oral. When I get up in the morning my sugar levels are level and healthy.” (Ms. B)

“This diabetic salt and stuff, I can’t eat food with it on there. And the diabetic sugar, I’m not working with that because I don’t want it. You

know, it's not tasting good. And the diabetic testing thing, I'm not using that because I'm scared of needles." (Ms. R)

The beliefs, outcome evaluations, and actions of the women were also based on knowledge and education gained from their primary care physician, nurse educator, nutritionist and/or diabetes educator, along with personal experience.

"When I first discovered that I had diabetes, I took the medicine but I didn't really take it that seriously. My mom was on insulin and I knew I didn't want to be on insulin." (Ms. C)

"I weighed more than I needed to for my height when I was diagnosed. With friends I started participating in exercise routines, you know walking, community exercise classes. I even joined Weight Watchers." (Ms. J.)

Treatment behaviors recommended by educators and programs were nutritional modifications, exercise, blood glucose monitoring, medication use, patient education, stress management, and support systems (family, friends, religion/spirituality). The women in this study practiced the prescribed behaviors but not consistently, and not all of the behaviors.

Two models of self-management treatment emerged: a *model of balanced self-management* held by the diabetes educators and self-management programs, and a *model of interruption* practiced by the women. The existence of two models of self-management –a provider and a patient model, suggested that managing diabetes was a complex and challenging task that required adjustments. Knowledge of self-management did not easily or readily translate into the recommended behaviors by the women. Instead, mediating circumstances such as access to and affordability of medications and diabetic

supplies, disability and bodily pain, vision problems, lack of adequate health insurance, non-referral to self-management classes, intervened to pose barriers and interruptions to the diabetic regimen for the women. As such, self-management required modifications to the biomedical approach of the diabetic regimen in order to adjust for the everyday contingencies in the women's lives.

A discussion of the findings is provided in chapter five.

CHAPTER V  
DISCUSSION and CONCLUSIONS  
Introduction

This study focused on discovering the health beliefs, behaviors, and patient education that impact diabetes care for African American women with diabetes mellitus (type 2 diabetes) because theoretical models document that beliefs, and behaviors are primary factors affecting health (Scheonberg, Amey, Coward: 1998:2113). Political and economic determinants also affect health. However, these determinants were not a major focus of this study, but data indicated that they were secondary factors impacting management behavior of the women. For example, the women and diabetes educators identified economic factors such as costs of medications, and health care treatment costs as factors as having some affect on management behaviors because of income and the costs of treatment. Additionally, health care educators identified the health care system that provides coverage for the costs of diabetes testing supplies, yet not the cost of medications as political factors affecting health outcomes. A political-economy that turns on issues of ideology, power, and conflict (McDonald 2002:vii) was also not the focus of this study although a few women expressed dissatisfaction in the physician-patient health communication interaction. However, this

interaction was perceived as lack of information acquisition more so than a power struggle over a woman's autonomy, and her physician's paternal decision-making control.

In this research, the use of in-depth, semi-structured interviews, direct and participant observations, and Grounded Theory provided a framework allowing for theme identification and categorizations of diabetes health beliefs and self-management behaviors. Additionally, the methods allowed for the identification of two models of self-management, the women and the educators.

In this chapter, the research questions are reviewed as a guide for the discussion of the findings.

### Discussion of Findings

Self-management behaviors are important factors affecting diabetes care and the reduction and increase of morbidity and mortality in health outcomes related to the disease—one that disproportionately affects high health risk populations such as African Americans. Adherence to the prescribed self-care regimen is important for the control of chronic diseases such as diabetes and for the prevention of associated complications such as retinopathy, kidney failure, amputations, and heart problems.

Findings indicated that one's belief in the ability to manage diabetes, the use of recommended behaviors, and an educated patient provided the best regimen for self-management of blood glucose. The primary behaviors identified and used by the women to manage their condition, and that were in concordance with

those prescribed by diabetes educators and self-management programs were: (1) nutritional/dietary changes, (2) exercise, (3) medication use, (4) blood glucose monitoring, (5) stress management, (6) foot care, (7) physician care, (8) losing weight, (9) keeping a blood glucose monitoring log, and (10) having support.

#### Intra-cultural Variation

A significance of this study was its potential to offer insights into and knowledge of intra-cultural variation. Findings revealed that there was more similarity than dissimilarity among the women in the self-management beliefs and behaviors and the factors affecting self-management. For example, there was minimal intra-cultural variation on the perception of how to generally manage diabetes as represented in Table 1. Over fifty percent of the women were knowledgeable on nine out of twelve general ways diabetes is managed. Additionally, the women revealed similarity in the behaviors they reported using individually to manage diabetes as represented in Table 2. Seventy-five percent of the women reported utilizing the same five behaviors for self-management (nutrition/dietary changes, exercise, medication use, blood glucose monitoring, and physician visits), and over fifty percent of the women practiced nine out of thirteen of the same behaviors to manage diabetes. Similar findings were noted for behaviors reported that made it easy for the women to manage diabetes. For instance, in Table 3 over sixty percent of the women identified the same six behaviors that made it easy for them to manage diabetes (nutrition/dietary changes, exercise, medications, spirituality/religion, talking with a diabetic friend,

and reducing stress).

Also, the support systems that women needed were similar as represented in Table 7. These ranged from family support as most needed (55%) to self-management education at home as the least needed (20%).

Another similarity revealed that the women were equally overweight (48%) or obese (48%) at the time of diabetes diagnosis.

Intra-cultural variation was noted in behaviors that made it difficult for the women to manage diabetes as noted in Table 4. While there was one most difficult behavior reported, "giving up foods I like" (65%), responses represented a range of additional diverse factors imposing difficulty on managing diabetes for the women. Five factors identified by twenty-five to thirty percent of the women (costs of medications, cost of supplies, losing weight, daily glucose testing and stress), and seven factors also identified in Table 4 by five to fifteen percent of the women, revealed this variation.

Support systems the women had as noted in Table 7 revealed variation. Similarity was noted with whom the women identified talking, but variation was noted in the additional support systems. For example, more women (70%) had a friend or family (60%) with whom to talk as a support system, while additional types of support that fewer women (thirty to fifteen percent ) had varied from access to free supplies, self-management classes, and an exercise partner, to help losing weight, and a diabetes support group.

Variation was noted in the location of diabetes self-management education.

More women (40%) attended community-based self-management classes than those who attended hospital, hospital-based clinic, and university-based clinic combined (30%) as represented in Table 6. Variation was also noted in the type of exercise the women used. While seventy-five percent of the women in Table 8 were similar in reporting walking as a primary exercise activity, the remainder of the activities represented variation across many types of exercise in which the women engaged.

Lastly, variation was noted in Table 10 in the types of medication (e.g. insulin vs. oral) the women used. More women similarly used oral medication only (50%) than those injecting insulin only (20%). Pills plus insulin use was (20%) revealing a similarity to those women injecting insulin only.

The findings on the intra-cultural variation among the women in this study suggested that the women were more alike than different in their beliefs, self-management behaviors and factors affecting self-management. These findings suggest that what is designed for education, prevention of complications, and health care service intervention can be quite similar, but should remain mindful of adjustments where required. For example, walking as an exercise may be recommended as an activity in which most of the women may participate, but some women will ride a stationary bicycle (35%), and some will walk on a treadmill (30%), but few (5%) will play tennis, swim, do yard work or ride a bicycle outside. Nutritional/dietary changes, exercise, blood glucose monitoring and medications may be recommended as priority behaviors in which the women

(75-80%) may engage, but few (25%) will attend diabetes education classes. However, when they will attend self-management classes, they will do so at a community-based location. More women (70%) will find it easier to talk to a diabetic friend than they (20%) will a friend without diabetes.

The similarity of findings in this study does not suggest that the same homogeneity will be found with all African American women with type 2 diabetes. These results are only applicable to the women under study in this research, and intra-cultural variation may be more evident with a different age, gender, or geographical population.

#### Discordance

There was agreement between the women, educators and programs on the type of treatment behaviors used for self-management. However, findings revealed discordance in regard to the consistent application of the prescribed treatment behaviors between the women, diabetes educators and education programs. Two models emerged: (1) a *model of balanced self-management* held by diabetes educators and education programs, and (2) a *model of interruption* held by the women with diabetes mellitus. The *model of balanced self-management* represents interlocking self-care behaviors used together for a balanced self-management approach to glucose control. The *model of interruption* held by the women represents the attempted continual use of prescribed behaviors interrupted by barrier behaviors and/or structural and environmental factors that may cause intermittent and inconsistent use of the

prescribed behaviors. For example, the prescribed exercise regimen is three times a week for a minimum of 30 minutes each occurrence. As indicated in Table 8, the women participated in a variety of exercise/physical activities. However, five women (25%) reported that they did not engage in any type of exercise/physical activity. Explanations of this interruption of exercise was due to physiological problems such as pain from joint disorders (25%), diabetic neuropathy in the feet (60%), and such social and environmental factors as the need for an exercise partner (45%), and unsafe neighborhoods in which to exercise (20%). Interruptions to the prescribed dietary changes were described by the women in terms of difficulty giving up foods enjoyed, dislike of diabetic foods, and the costs of purchasing and eating the recommended five servings per day of fresh fruit and vegetables. Interruptions to blood glucose monitoring were due to the need for and/or cost of an adequate supply of monthly testing supplies. Patients are often required to make complex treatment decisions and vary self-care behavior from situation to situation (Kimble 2000:25). Anderson et al (1995) believe that diabetes management has to be understood within the mediating circumstances of a woman's life. Thus, the *model of interruption* suggests that non-adherence to the prescribed self-management treatment regimen is beyond the concept of *compliance*. The model suggests that the women tried to manage diabetes, however the comprehensive and complex nature of self-management presented daily living and medical challenges that intervened in the balanced approach to following the recommended regimen.

Reducing the discordance between the models requires a recognition and acknowledgement by educators and programs that managing diabetes involves not only a biomedical approach to self-management, but also an awareness of the psychosocio-cultural index of indicators (e.g. age, gender, education, family structure, religion, career and personal role status), that are a part of an individual's make-up. As a partner, medical care plays an important role in controlling diabetes and in the complications, quality of life and mortality associated with disease (Robbins, Vaccarino, and Zhang 2001:80). While health care providers, educators and programs may not be adequately able to address each patient's individual self-management needs, pre-posttest assessments and program evaluations can provide insight into patient beliefs and behaviors that may facilitate or hinder adherence to the prescribed treatment regimen. This knowledge at the initial point of diagnosis provides a basis for developing and monitoring an individualized, on-going self-management treatment plan. Such a plan has the potential to serve as a proactive cultural intervention tool. The tool may be used by the patient, patient's family or other significant support system and healthcare providers to intercede where interruptions may occur in the treatment cycle.

Additionally, to reduce the discordance between models, utilization of a biopsychosociocultural (holistic) approach to diabetes self-management by diabetes educators and self-management programs can provide an avenue for understanding how these women attempt a holistic approach to self-manage

diabetes in the face of every day living. Application of the biopsychosociocultural approach to the *model of balanced self-management* expands self-management beyond the biomedical model, and into the realm of culture specific dynamics (e.g. family, community, body image, faith community). Such an understanding has potential to improve the patient-provider health care interaction, patient health education, and the design and delivery of education through a culturally aware approach to health care treatment.

#### Research Question 1

The first research question in this study examined the cultural construction of diabetes for the women participants. Explanatory models of illness, or common-sense models, involve comprehending symptom labeling and identifying perspectives on origin, consequences, illness timelines, and lay treatment strategies of disease (Schoenberg, Amey, and Coward 1998:2113). According to Kleinman (1980) the construction of the illness experience is a health care function. He states that sickness is a “natural” phenomenon that is cast into a particular cultural form through the categories that are used to perceive, express, and evaluate symptoms (Kleinman 1980:74). As such, Kleinman (1980) believes that the cultural construction of illness is frequently a personally and socially adaptive response.

Several of the women in this study struggled with defining diabetes in complete biomedical terms. Others constructed the disease in language that

conveyed well-informed knowledge. There were also women who held a mixed knowledge and a general sense of the disease, though their understanding was limited in complete details. On the other hand, the women were able to articulate specific causes of diabetes. They identified obesity, gestational diabetes, nutritional habits, and/or genetic/family history. All of the women were overweight or obese at time of diabetes diagnosis. Three women reported having gestational diabetes before the later diagnosis of diabetes mellitus. All of the women except one, had a known family history of diabetes, and over half of the women believed that if diabetes “runs in the family,” other family members will also be diagnosed with the disease. Many of the women had several family members who were diabetic. An additional observation is that most of the women believed, based on knowledge they had received from their physician, that there is no such thing as a “borderline” diabetic—that one either had diabetes or one did not. This was a belief also shared by the diabetes educators.

### Self-Efficacy

Self-efficacy, the belief that one can successfully execute the behavior required to produce the outcomes (Strecher and Rosenstock 1997:44), was evidenced in the qualitative and quantitative data.

“You can live a normal life if you put your mind to it. I can’t do this, I can’t do that. I never say that. I just go on and do what I have to do.” (Ms. F.)

“If my mother could live with it for fifty plus years, then I am sure I can too. I am not going to let becoming a diabetic take over my life. I am going to do as the doctors prescribe.” (Ms. W.)

“I made up in my mind that since I became a diabetic I was going to do

what I was supposed to do and that's a routine to me." (Ms. E.).

Women identified in the quantitative data lifestyle behavior change, weight loss, patient education, nutritional/dietary changes, exercise, reducing stress, medications and social support such as friends, family and religion/spirituality as factors facilitating their self-management for glucose control. Under circumstances such as a good mental and spiritual attitude, following physician instructions, having family, and friend support, the women believed that managing diabetes could be easy.

Even though the belief that they could successfully carry out the behaviors required to produce the outcome of managing their diabetes was evidenced in the women's belief that they could control diabetes, the women also believed that diabetes was difficult to manage, and expressed the challenges. What made it difficult for the women to manage diabetes was giving up foods they liked, performing the finger prick for blood glucose testing, injecting insulin, foot pain, arthritis, lack of exercise partner, unsafe neighborhoods, and the cost of health care.

"There are certain things that I know that I shouldn't eat, but I do love pasta. So when I eat spaghetti like the other night, I knew my glucose level was going to be high." (Ms. B2)

"It's not easy controlling because there are just so many things you can't eat or shouldn't eat—sweets, carbohydrates and oily foods. It's not easy staying away from it especially when you've got to buy stuff that's decent for you to eat. It's too expensive to buy." (Ms. J.)

"I do the same things I always have done. I just like to eat what I like to eat. The diabetic testing thing, I'm not doing that because I am not going to stick myself." (Ms. R.)

“I don’t really manage it myself good. I need the right machine cause sticking myself I’m not used to it. I’ve always been afraid of needles. I’m a grown, old lady and I’m still afraid of needles. So I give myself shots. I had to learn how to do it. They say stick a grapefruit, but your skin is not like a grapefruit. You can’t feel anything with a grapefruit. Sometimes I hit the wrong spot and it hurts. I need the new model machine where you just touch the skin. I can do that better than I can do sticking.” (Ms. N)

## Self-Management Treatment Behaviors of the Women

### Research Question 2

The second research question addressed the identification of self-management treatment behaviors which African American women with diabetes mellitus utilized to manage diabetes.

Examining patients’ concepts about the association between their own behaviors and health outcomes provides insight into their criteria for evaluating and interpreting their own behavior, which could prove useful in developing strategies for helping inform patients’ decision-making about their self-care ( Hunt Valenzuela, and Pugh 1998:966).

Qualitative and quantitative data revealed that the women in this study knew of the prescribed treatment behaviors (e.g. nutrition/diet changes, exercise, blood glucose monitoring, symptom recognition and response, medications, patient education). However, they followed the prescribed behaviors selectively and inconsistently. But, depending on their behavior (eating a too high carbohydrate food item, or skipping a meal) they too recognized that their blood glucose levels would rise or fall. Such symptom recognition required a response that was in the

form of blood glucose testing, and medication taking ( e.g. oral or injection insulin to lower their blood glucose level if too high, eating a snack, eating a piece of candy if the level is too low).

#### Exercise/Physical Activity

In the present study, women knew that exercise helped to lower blood glucose, and that the recommendation for exercise was three times a week for at least 30 minutes each occurrence. Yet, some women shared stories of not exercising, or not exercising enough. They spoke of experiencing pain and having disabilities as reasons for not exercising. Sometimes it was busy work schedules and family responsibilities that interfered with exercise activities. Other women reported insurance covered membership in the YMCA's fitness program, and the participation in senior aerobics, water aerobics, using the treadmill, stationary bicycle, and weight machines. They reported weight loss results, and feeling better. Liberman, Probart, and Schoenberg (1999) believe that programs should emphasize physical activities since they lead to an increase in caloric expenditure, and increase in lean body mass with metabolically higher levels, an increase in satiety, a decrease in insulin resistance, and an increase in psychological well-being.

#### Blood Glucose Monitoring and Hemoglobin HbA1c Tests

The women in this study also knew the basic recommendation for daily blood glucose monitoring: once in the morning, once in the evening and two hours after a meal. Most of the women tested twice a day, and would also test when they

perceived symptoms of high or low glucose levels, e.g. “dizziness, feeling weak, disoriented.” Unfortunately, some did not test at all because of the pain associated with the finger prick method of testing. They hoped for new technology that would eliminate the need for such a procedure.

Sixteen of the women (80%) reported receiving an HbA1c test over the past year. The HbA1c test measures the average of the blood glucose in the body over the past three months, and ideal glycemic control is <7.0 (Norris et al 2002:39). The number of times each woman was tested varied. Only twenty five percent of the women received the test every three months, or on a regular basis of four times a year. Four women respectively received the test two and three times over the past year, and two women were tested once. Not all of the women were aware of being tested however. Three women (15%) did not know if they had received an HbA1c. The result from the HbA1c test is an important indicator of glycemic control and is a vital part of the diabetic regimen. The score assists the women and the physician with knowing how well the women are managing their condition through such behaviors as nutritional changes, exercise, and medication use. It also may be used to assist with planning modifications that may be needed in the self-management regimen of the women. While quantitative data in Table 9 revealed that some of the women received an HbA1c test, qualitative data findings indicated that the women did not in all cases receive the results of the test. Without knowing and understanding the results, a barrier and interruption to self-management

occurred and the women were placed at a disadvantage for managing their diabetic condition at an optimal level. The findings from the present study suggested the need for physicians and health care providers such as nurses, and physician assistants to communicate test results and the meaning of those results to the women. Without an improved patient-provider health communication for patient health education, the women can only be expected to approximate knowledge of control through daily home blood glucose testing. While a valuable behavioral tool in the diabetic self-management regimen, home glucose monitoring can not be a substitute for the standard HbA1c testing. Additionally, testing alone can not be the end result. The present study speaks to dissemination and understanding of those results as part of the checklist for the diabetic health care visit.

#### Glucose Monitoring Supplies

Lack of the needed testing supplies was another factor that impeded regular testing. For example, the women indicated the out-of-pocket and unaffordable cost of test strips, and lancets if supplies were not covered by insurance. Even with insurance covered diabetic testing supplies, sometimes the number of test strips in a box did not meet the need for the number of times a woman needed to test. As such, a woman could run out of supplies before the end of the month. The cost of additional supplies was at the expense of the woman, unless she attended a program that provided free test supplies to diabetics.

## Nutrition

Where nutrition/dietary changes are concerned, data from the women revealed that all of the women believed that nutritional/dietary change was an important behavior for managing diabetes. But, many of the women struggled to modify their eating habits. Nutritional change was difficult because the women believed that they needed to “give up the foods they liked, reduce portion sizes, count carbohydrates, buy expensive foods, and/or eat diabetic foods.” On the other hand, some of the women continued to eat what they desired, but limited how much of the foods they would eat. This behavior was more in concordance with behavior prescribed by diabetes educators. Patients could eat what they desired; only in moderation, and then as required by their physician if the woman was on a cardiac or other similar diet.

## Medications

Medication use was a treatment behavior some of the women. Combined with nutritional changes, and glucose monitoring, findings suggested that this triad was a common self-management strategy. Medication use, nutritional change, glucose monitoring and exercise were a second combination of behaviors in which the women engaged. The women reported that the costs of medication were expensive. Diabetes educators agreed. Both groups shared concerns that health care insurance did not cover diabetic medicines; only testing supplies. Thus, it was the responsibility of the women to provide for the cost for medicines such as insulin which could cost \$30.00 per vial.

## Family and Friends

The person who had recognizable symptoms turns to friends and family for lay consultation, self medication and lay referral until finally a professional is consulted (Carson-Henderson 2002:114). This support from family and friends was identified as important because intimate relationships have direct effects on health outcomes such as the patient's coping with diabetes and complex daily self-management behavior diabetes demands (Anderson2003:134).

As in the Carson-Henderson study, women in the present study similarly turned to friends with diabetes, and/or family for support in managing diabetes. Data revealed that the women also looked to family members for support and did have some support however the women desired more support from their families. Unfortunately, the diabetes literature revealed that there have been few studies of the impact of social support among adults with type 2 diabetes (Skelly 1992:182).

## Religion

The women also turned to religion/spirituality. Religion assisted the women with stress relief and acted as a comfort medium for managing the difficult times of living with diabetes. Religion was viewed by both the women and educators as an integral part of managing the multiple tasks of the diabetic regimen. Brashears (2000) reports that the church plays a particularly significant role in the lives of elderly African American people, and that of African American adults over fifty-five years of age, eighty percent identify themselves as church members.

The average age of the women in the present study was sixty-five. For elderly African Americans there is significant association between their involvement in church and their physical as well as mental health (Brashears 2000:200). Prayer is a major coping strategy for older African Americans (over the age of sixty), and participation in church communities reduces stress, increases positive self-esteem, and leads to healthier lifestyles (Brashears 2000:200). As such, African American churches and the faith communities can play important roles in the health of women like those who participated in the present study. For example, African American faith communities can be advocates to ensure available, affordable, and adequate medical services, nutrition resources, financial supports, recreational facilities; to work for safe environments and to promote appropriate public policies (Wimberly 2001:145). Likewise, the results from this study offers to faith communities the opportunity to provide diabetes prayer groups, diabetes support groups, diabetes education classes, health forums and screenings for the prevention of diabetes, exercise classes and walking groups, and financial support for the purchase of medications and supplies through religious fundraisers.

#### Mock Diabetic Experience

My experience of managing diabetes as a mock diabetic was challenging, anxiety producing, frustrating, yet provided valuable insights. The participant observation was not without bias. First, I was not a diabetic. As such, I could not

follow all of the prescribed self-management recommendations, e.g. taking medications. However, I could participate as a mock diabetic similar to the two women in the study who did not need to take oral or injection medications rather who managed through nutritional/dietary changes and exercise. Secondly, my experience was biased because although I am an African American woman, I was neither overweight nor obese at the beginning of the study nor at anytime during the research as were the women in the study. My body mass index remained within the normal range for my height and weight continuously throughout the study.

Third, exercise/physical activity was a regular part of my lifestyle behaviors such that to exercise at least thirty minutes a day for three days a week as recommended to the women was less than my regular regimen of four to five days a week for one to two hours at each occurrence.

Lastly, my regular nutritional lifestyle could be classified as being a healthy one. For example, my everyday nutritional preference was already low fat, low cholesterol, moderate carbohydrate, multi and whole grain inclusive, fresh fruit and vegetables, legumes, nuts, seeds, brown rice, soy protein products and lean cuts of chicken, fish and turkey. Standard preparation of meats was to bake, broil or grill. Sweets were minimal, but I did have several treats that I enjoyed. Thus, modifying my diet required few self-management changes.

Managing nutritional intake as a mock diabetic changed how much I ate, when I ate, and some of what I ate. Like the women in this study, one of the

difficulties I encountered was “giving up foods I liked.” I did not eat potatoes, and white rice, and limited sweets such as ice cream, cookies, cakes, pies, etc. When I enjoyed any simple carbohydrate such as the sweets, I limited them to the serving size on the food labels that I learned to read and use as part of the instruction provided in the self-management classes I attended. I attempted to not eat after 8:00pm because some women indicated that they did not eat a meal after this time, and diabetes educators recommended not eating late into the evening. Instead the diabetic could have a snack like a piece of fruit or crackers, or a small sandwich. As such, I did not eat or drink anything after midnight which was difficult to do when I was up late at night working on the dissertation. I ate four to five small meals during the day as recommended in the self-management regimen rather than only breakfast, lunch and dinner. I came to resent not eating and not eating as much of the foods that I liked to eat. However, diabetes education classes that I observed provided instruction that diabetic individuals could eat foods they desired only in small quantities and over time.

Daily blood glucose testing was a challenging, tiring and anxiety-producing experience. I conducted the testing using a donated monitor and test strips. I endeavored to conduct a fasting blood glucose finger prick test every morning before eating, two hours after a meal and when I thought I was experiencing symptoms mentioned by the women in the in-depth interviews, and education classes (headache, tiredness, light-headedness). After two months of the six months experience as a mock diabetic, I tired of the daily routine of testing, and

began periodic testing. I was always apprehensive while waiting for the reading from the glucometer. I initially kept a log of the readings. I stopped keeping the log after two months because of the daily routine required of recording the scores after each test. My testing behavior came to mirror women in the study who reported that they monitored their blood glucose when they recognized symptoms.

“I feel a little giddy, and I get a little headache. My hands turn white, almost as white as this piece of paper her. I take it (blood glucose test) and nine times out of ten, the blood sugar is dropping low.” (Ms. F.)

“I find that if I’m not feeling up to snuff, I’ll take it to see if it’s up or down.” (Ms. H.)

“I test twice—in the morning and in the evening. If I’m feeling funny I will go check it. I have physical signs when my blood sugar is too high or too low. My eyes and my head hurt.” (Ms. B.)

Another aspect of my participant observation was the visitation to local well-known drug stores to assess the cost of test strips. Prices ranged from \$50.00-100.00 for a box of twenty-five to one hundred strips. On a student budget, the cost was prohibitive for my purchase of test strips to use. Additionally, I was not eligible to have free test strips offered by programs providing supplies to Medicare individuals with diabetes.

As part of the health care provider interaction, I scheduled a routine physician visit. As part of the health physical, I requested a metabolic panel screening. This testing provides health readings for several health indicators. My primary interest was for having laboratory testing of blood glucose and cholesterol as part of self-management regimen. My physician informed me that “everything was

fine. All numbers were within the normal range.” I did not receive an explanation of what was the meaning of the “normal” numbers until I asked. My experience echoed some women’s comments that their physician either did not tell them their results or explain to them what the results meant, or results were provided only when requested.

“He’s very nice. If you ask him things he will sit down and explain it to you.” (Ms. F.)

“They don’t never, never tell me anything. I ain’t never known none of the results of my tests.” (Ms. R.)

“They (doctors) never mentioned that to me (HbA1c). They just tell me what the results are. It’s doing real good nowadays.” (Ms. E.)

At another physician visit, I requested an HbA1c test and was told that the test is only provided to individuals who were diabetic. I was not provided the test.

Also as part of my mock diabetic experience, I attended and participated in weekly self-management classes. I attended classes four to five days per month for one to two hours at each occurrence. Some research bias was a part of participation as a class attendee answering questions because of my pre-existing knowledge from extensive reading and literature reviews on diabetes. However, there was always new information that I acquired during the education sessions. The education participation also included learning to read food labels for the serving size, carbohydrate, sugar, sodium, cholesterol, fat, protein, and caloric content.

The experience of being a mock diabetic revealed that managing diabetes is a

constant challenge requiring a serious commitment to the diabetic regimen. In the mock experience for this study, the commitment was to nutrition, exercise, blood glucose monitoring, and self-management class attendance. Having a support system of someone to talk with and as an exercise partner who understood the circumstances of being a diabetic I found to be important, and would have liked to have. I did attend an exercise class at the YMCA as a guest of one of the women in the study.

Although my mock experience was an individual one, when I interviewed the women in this study about managing their diabetes, my experiences seemed to give me an emic or insider's view (Hahn 1999:367) and insight into the challenges the women faced. However, the reality was that I was still a researcher making etic or outsider (Hahn 1999:367) observations on the self-management of a diabetic.

Through my combination of exercise and nutritional modification I did experience weight loss. However, I did not have the circumstance of obesity or overweight to hinder my self-management. I also did not have medications prescribed to work on one health condition (lowering blood glucose levels) while on the other hand causing weight gain thus making the effort to manage diabetes more complicated.

As a graduate student, I had a limited income in which to use for purchasing fresh fruits and vegetables. This budgetary limitation at times made daily eating of five servings of fresh fruits and vegetables recommended by diabetes

educator and self-management programs difficult to adhere to.

The experiences as a mock diabetic provided insight into the self-efficacy, beliefs and behaviors which were important for self-management. I went into the experience with the belief that I could manage diabetes for obtaining the desired health outcome of good glucose control. The trials I encountered with daily blood glucose monitoring, nutritional modifications that included smaller meals more times a day, five daily servings of fresh fruit and vegetables, and giving up and limiting some foods I like posed the greatest challenges for me.

The results from this experience are recommended to health care providers and health educators as an approach for understanding some of the challenges of self-management. There exists the possibility that challenges such as those I encountered in this mock experience as a non-diabetic may provide insights into circumstances that may negatively impact diabetes self-management health outcomes of a true diabetic individual. In the present case, these outcomes are important for reducing the diabetes-related morbidity and mortality for African American women with type 2 diabetes.

#### Patient Health Education

Patient education and interaction with health care professionals such as the primary care physician were expressed by the women and diabetes educators as an important behavior for managing diabetes. The women initially received diabetes education from their physician and absent reading literature, continued to look to their physician for self-care information. Unfortunately, some women

described not getting any information from their physician that would enable them to care for their condition. Physicians in this study considered that due to time constraints, education was more a role for the nutritionist/dietician or diabetes educator. Eleven women (55%) in this study revealed that they were not referred by their primary care physician to either self-management classes or a nutritionist. On the other hand, seven women (35%) were referred by their primary care physician to a nutritionist for assistance with education on dietary modification.

### Prescribed Self-Management Treatment Behaviors

#### Research Question 3

The third question investigated the diabetes self-management treatment practices that are prescribed by diabetes educators and programs.

Health educators are professionals who promote knowledge about health and available treatment, either in individual consultation or at the level of the community (Angrosino 1987:50). Diabetes self-management education (DSME) is the process of teaching people to manage their disease (Norris et al 2002:39), and providing them with self-regulation skills (Skelly 1992:50). This self-care is a complex, interdependent regimen (Skelly 1992:54). Prescribed treatment behaviors identified were (1) nutritional modifications/meal planning, (2) exercise, (3) blood glucose monitoring, (4) medication use, (5) foot care, (6) patient education/seeking information, (7) interaction with health care provider, e.g. physician, nutritionist, and (8) support systems such as the family,

religion/spirituality, and support groups.

Diabetes educators are a range of professionals that include registered nurses, exercise specialists, licensed practical nurses, and nutritionists/dietitians. Other members may include a psychologist, pharmacist, and ophthalmologist. Physicians are also a part of the self-management team and may be the first contact for initial diabetes education.

In the present study, the five diabetes self-management programs all shared in the teaching of prescribed content areas of diabetes care. These areas included an overview of diabetes, nutritional changes/meal planning, exercise, blood glucose monitoring, medication use, stress management, symptom recognition and response, health care follow-up, and support systems. A common problem in diabetes patient education content though, is that health professionals provide too much detail regarding patho-physiology and too little regarding the daily management of illness (Tripp-Reimer 2001:8). Goodall and Halford (1991:77) concur that attempts to improve self-management have relied excessively on providing information.

From researcher observation, education was primarily taught as a lecture. Class sessions were in either two hour, two and a half hours, or five hour sessions. Some classes met weekly, bi-monthly, for two days and for four days. Two day and four day classes were usually the ten-hour insurance covered classes offered by hospital and university clinic-based programs. The classes for these more formal programs were usually one time attendance, with some

exceptions after a year, and with some cost borne by the participant returning to a class. Cost for the university and hospital-based classes ranged from \$500-700 per class session.

Depending on type of program and location, programs had small or large class sizes, and offered day and/or night sessions for the convenience of the participants. The community-based programs appeared to offer more flexibility, accessibility and affordability than university-based or hospital-based programs. The community-based, non-clinic and community-based clinic site offered classes where attendees may participate in unlimited sessions at no cost or for a minimal donation. The community-based programs also offered services that were a part of class activities. For example, body mass index measurements, cholesterol, glucose, and blood pressure screenings were available. Food and drinks were also provided.

Methods of educational delivery included videos, meal planning and goal setting worksheets, printed literature, white boards, pre-post tests, label reading, and health professionals as guest presenters. Programs observed for this study were non-culture specific in their presentation of materials. The primary culture was that of the diabetic, as such the instruction for participants was geared toward diabetes and diabetes care. Programs employed a one-size fit all approach to education delivery. Carson-Henderson (2002) believes that education programs must be compatible with both the knowledge and cultural background of the patient group. But, Cox et al (2004) believe that self-

management education for type 2 diabetes does not need to be different for African Americans versus Caucasians in southern states. However, they state that low-income individuals may not understand or follow the education provided for diabetes self-management, if that education does not take into account the patient's prior knowledge, understanding, beliefs, attitudes, and barriers be they real or perceived (Cox et al 2004:157). Rosenstock (1985) recommends that a variety of interventions be used in patient education, but states that those interventions must succeed in reinforcing relevant health beliefs, behavioral skills, and a sense self-efficacy.

Attendance of the African American diabetic women and African American diabetic patients in general was low in diabetes self-management classes. Explanations from educators suggested that one reason may be due to physician non-referral. This is in concordance with data from the women in this study who revealed that they were not referred by their physician to self-management classes. Additional explanations provided by educators for low class attendance by minority diabetic individuals were the lack of insurance to cover cost of class, lack of personal financial resources to pay for the classes, lack of knowledge about classes, and educators also were not sure why attendance was very low.

#### Concordance/Discordance

##### Research Question 4

The fourth question examined the concordance/discordance in self-management behaviors practiced by the women and the behaviors prescribed by

diabetes educators and programs. The findings indicated that there was concordance between the women, the educators, and the self-management programs in regard to the types of behaviors one utilizes to manage diabetes as listed above.

There was concordance in the belief that the patient was the most important member of the self-management team, a team composed of the primary care physician, nurse educator, nutritionist, diabetes educator, and exercise specialist. Additional members may include, but are not limited to the psychologist, pharmacist, ophthalmologist, and podiatrist.

Concordance between the educators and programs was found in the content of diabetes education, and in the primary focus upon nutritional changes/exercise, blood glucose monitoring, and medications.

Where there was discordance between the women, educators and programs was in the practice of the behaviors. Two models were generated. The women's behavior represented a "*model of interruption*," while the educators and programs had a model that was characterized as a "*balanced self-management*." The *model of balanced self-management* represented all of the treatment behaviors used as required and used consistently as required. Skelly (1992) points out that the ability of patients to follow required regimens is clearly crucial since compliance with therapeutic regimens may prevent or delay the onset of complications.

The *model of interruption* represented the attempted continual use of

prescribed behaviors interrupted by barrier behaviors and/or structural and environmental factors that may cause intermittent and inconsistent use of the prescribed behaviors. Though the model for the behavior of the women could be perceived as non-adherence to the diabetes care regimen, the *model of interruption* posits that the women performed a modified version of adherence to the prescribed treatment based upon factors within and outside of their control; that absent personal, structural and environmental factors, adherence would follow the regimen as prescribed. Effective self-management of chronic illnesses such as diabetes requires not only technical skill to perform regimen behaviors but also problem-solving skills to manage daily barriers to regimen adherence and to make appropriate adjustments to the self-care regimen (Hill-Briggs 2003:182).

### Barriers

Barriers to self-management indicated several factors as listed in Table 11. Such factors as costs of medications and supplies, lack of knowledge of test results, diabetic neuropathy of the feet, arthritis, joint pain (arthritis, knees) finding time due to work schedules and family responsibilities, safe locations to walk, need of exercise partner, family support, and dietary changes were among reported factors impeding adherence to the prescribed diabetic regimen.

Table 11 SELF-MANAGEMENT INDICATOR BARRIERS	
Indicator	Barrier
Nutrition	Change of Eating Habits Cost of Fresh Fruit and Vegetables Access to high fat, fast foods
Exercise/Physical Activity	Exercise Partner Physical disability Safe Neighborhood
Health Care Access	Cost of Medications Access and Affordability of Additional Testing Supplies
Support systems	Family Communication
Self-Management Classes	Physician referral Cost of Classes Insurance Cultural Awareness
Physician-Patient Interaction	Health Communication

### Relationship to Other Studies

The findings in this study were in agreement with findings in other studies on self-management of chronic diseases such as diabetes, health beliefs and attitudes and their impact upon health behavior, and patient education. First, self-management for people with chronic disease is widely recognized as a necessary part of treatment (Lorig and Holman 2000:2), and has been used

widely to describe patient behaviors, patient education, and health promotion programs (Lorig and Holman 2000:2) as the current study does. The self-management theoretical framework used by Schoenberg and Drungle (2001) suggested that personal and contextual factors exert a primary influence on the health knowledge and psychological and material or structural factors that shape self-care behaviors as does the findings of the current study.

Fitzgerald et al (2000) stated that the relationship of culture to health beliefs, attitudes, and behavior is especially important in the treatment of diabetes, which usually involves changing patterns of eating, physical activity and other culturally embedded behaviors. For example, Fitzgerald et al (2000) indicate that research studies have shown that physician attitude at the time of diagnosis was critical in patients' attitudes about the seriousness of diabetes and the patients' subsequent self-management behavior. In the present study, the women received their diabetes diagnosis from their physician. Initially, some women did not believe the diabetes diagnosis and thus did not follow recommended dietary, exercise, monitoring, and medication behaviors. Other women having been hospitalized because of high blood glucose levels at time of diagnosis, made decisions to follow the prescribed behaviors believing that to do so would positively affect their health outcomes.

Carson-Henderson's (2002) research applied as did the present study, cultural construction theoretical frame to her work with Oklahoma Choctaw elders in order to explore and delineate the phenomenon of diabetes mellitus within the

Choctaw population, and to likewise gauge the health care providers' perception of the elder's cultural construction of diabetes mellitus. The use of a cultural construction of health and illness conceptual framework for the present study speaks to the application and usefulness of the approach for understanding cultural health beliefs and behaviors across cultural populations. While Carson-Henderson explored the phenomenon of diabetes in the Choctaw population, and the perception of health care providers interacting with the Choctaw elders with diabetes, the present study, investigated the beliefs and behaviors associated with diabetes self-management and the diabetes educators and diabetes programs providing educational services to diabetic individuals such as the women in this study. The present study suggests the relevance of cultural understanding and provider cultural competency for service delivery cross-culturally as did Carson-Henderson. The present study also indicates the importance of understanding the phenomenon of diabetes mellitus and self-management of African American women with diabetes mellitus in order to tailor interventions and services for the prevention of diabetic complications and reduction of diabetic morbidity and mortality.

In a study by Glasgow et al (1997) on perceived barriers to diabetes self-management among a heterogeneous survey sample of 2,056 adults throughout the U.S., respondents felt that diabetes was a serious disease and that their self-management activities would control their diabetes and reduce the likelihood of long-term complications. The most frequently reported barriers were related to

dietary adherence, followed by exercise and glucose testing barriers (Glasgow et al 1997:556). In the present study, women reported difficulty giving up foods they liked, lack of exercise partners and/or joint pain and lack of access to adequate amounts of testing supplies as barriers to following recommended self-management activities. Schoenberg and Drungle (2001) cite barriers amenable to intervention that support the results of the present study—lack of financial access to health care resources, lack of knowledge for optimal self-care practices, and disability that may impede self-care functioning.

Similarly as results found in this study, Skelly's (1992) research on psychosocial determinants of self-care practices and glycemic control in African American women with diabetes mellitus revealed that the degree of adherence by self-report and self-monitoring, to medication use and home testing was greater than for diet and exercise (Skelly 1992:166). The present study is also in agreement with Liberman, Probart, and Schoenberg (1999) who report that compliance with taking medications is greater than compliance with diet.

Harris' (1991) report on the epidemiological correlates of diabetes mellitus in Hispanics, Caucasians and African Americans found that the major risk factors for diabetes mellitus included a family history of diabetes, increased age (45+), being female, and being overweight. In the present study, all of the women except for one reported a family history of diabetes, all women were 45+ years of age, and all were overweight or obese at time of diagnosis.

In this study, the women, diabetes educators and self-management programs

identify the patient as the most important person of the self-management team. This is a finding that concords with Lorig and Holman's (2000) study documenting that only the patient can be responsible for his or her day to day care over the length of the illness. They identified three sets of tasks commonly dealt with by people with chronic conditions. These are (1) medical management of the condition such as taking medication, adhering to a special diet, or using an inhaler, (2) maintaining, changing, and or creating new meaningful life roles, and (3) dealing with the emotional sequeli of having a chronic condition, which alters one view of the future Lorig and Holman 2000:2).

Results from diabetes educators and programs in this study recommended exercise as one of the key behaviors for blood glucose control. In their study on barriers to weight reduction among African American women with type 2 diabetes, Liberman, Probart, and Schoenberg (1999) likewise recommended physical activities citing that these lead to an increase in caloric expenditure, an increase in lean body mass with metabolically higher levels, an increase in satiety, a decrease in insulin resistance, and an increase in psychological well-being.

Religion was found to be a source of strength and an important coping mechanism for the women in this study. Dye, Haley-Zitlin, and Willoughby (2003) report that willpower, often obtained through a belief in God is necessary for successful behavior change. Bailey (2000) reports that because "African Americans are taught to depend on a supreme being, the Lord, and take their

burdens to the Lord and leave them there,” health care providers should assess the importance of religious beliefs and health outcomes within the African American population. In the present study, religion was viewed by both the women and educators as an integral part of managing the complex task of the diabetic regimen for the women. As such, African American churches and the faith communities can play important roles in the health of these women. For example, African American faith communities can be advocates to ensure available, affordable, and adequate medical services, nutrition resources, financial supports, recreational facilities; to work for safe environments and to promote appropriate public policies (Wimberly 2001:145). The results from this study offer to churches the opportunity to provide diabetes prayer groups, diabetes support groups, diabetes education classes, health forums and screenings for the prevention of diabetes, exercise activities, and financial support for the purchase of medications and supplies through church fundraisers.

Patient education is important for self-management success. As found in this study, much patient education relies predominantly on heuristic processing through which patients have a rather passive role, mostly listening to health care professionals telling them about their illness (Skinner et al 2003:76). In such instances, health care professionals are seen as experts who should be listened to and whose advice should be followed (Skinner et al 2003:76). However, the information provided is usually generic and usually easily rationalized as not relevant to the individual (Skinner et al 2003:76). This may be especially true

where cultural beliefs and behaviors for such factors as diet and exercise may not be considerations in the development of curricula and presentations for educational sessions. The present study found that education sessions are primarily provided as lectures. Other studies suggest that these sessions need to involve fewer lectures and more practical, interactive exercises that focus on developing skills (Krichbaum, Aarestad, and Buethe 2003:653).

Additionally, including family as support was found to be important to the women of the current study. Similarly, family discussions about health and diabetes as well as family attendance of educational sessions were indicated as methods of family involvement in diabetes prevention (Taylor et al 2004:5). A family's active support for dietary changes, exercise, and monitoring of blood glucose concentrations and the positive relationships among extended family members may buffer African American women from negative consequences of stress (McBride Murray et al 2003:169). The women, educators and programs included in the present study indicated stress management as an important behavior in the self-management regimen for glucose control.

As the women in this study utilized religion/spirituality to assist with managing diabetes, Abrums' (2000) research on the life experiences and belief systems of a small group of African American women from a storefront church in Seattle, Washington, found that the women believed that the "Spirit" healed the individual, prayer acts as therapy at the individual level, and that the women's theories about the body, healing, and prayer enabled them to deal with illness; prayer was

the most effective way to influence healing.

Snow's (1993) work recognizes the important symbolism of blood in African American life. She believes that "blood as the shimmering red symbol of life itself," is of immense importance in African American traditional medicine (Snow 1993:97). However, in the present study traditional medicine was not reported by any of the women as being utilized in their self-management regimen. Research does suggest though the relevance for clinicians to be aware of the possible hidden symbolism in any lay conceptualization of blood (Helman 1990:26). While this awareness is deemed important, the purpose of the present study did not include physician's perceptions of the lay conceptualization of blood as revealed by the women in this study. However, because of contrasting ideas about blood and its functions between physicians and African American patients in clinical settings, Snow (1993) reports that misunderstandings do occur in the interaction between the two. In the present study, for the women to understand the functions of blood glucose and its relationship to self-management, it was necessary for physicians to report the results of the hemoglobin A1c (HbA1c) blood glucose test. This is a test that measures the average level of glucose in the blood during the previous three months, and is an important indicator of how well diabetes is being controlled. Ideal glycemic control is <7.0% (Norris et al 2002:39). Sixteen women (80%) reported receiving HbA1c tests over the previous year however all of them reported not knowing the result of the test. Three women (15%) did not remember if they had received the test over the past

year and one woman (5%) did not respond to the query on having the test.

Snow (1993) suggests that the prescriptive and proscriptive measures whose aim is keeping the blood just right require constant attention when the goal is to maintain a balance between factors impinging on the state of the blood and their presumed effect. Rock (2003) adds that research and interventions focused on the sweetness of blood would benefit from rethinking intersections between diabetes, duress, and distress. The present study suggests the need for improved health communication between the women and their primary care physician regarding blood glucose test results and the meaning of the test in relation to glycemic control.

Similar to the present study, McBride Murray et al (2003) characterized diabetes self-management as adherence to prescribed dietary, exercise, foot care, and glucose monitoring practices through setting goals, forming plans to meet those goals, and persisting in working toward those goals. Cox et al (2004) found in their type 2 diabetes self-management research on the characteristics of low-income African American and Caucasian adults, that factors such as perceived knowledge, meal plan adherence, diabetes control, and attitudes toward diabetes were highly correlated, and thus interdependent.

Lastly, the results from this study are similar to those in the Anderson et al (1995) study on how Euro-Canadians and Chinese-Canadian women living with diabetes experienced and managed their illness. The findings revealed that management of diabetes is a complex construct, comprised of several

components, each being influenced by a number of factors (Anderson et al 1995:181).

### Contributions to Theory

This research contributes to and supports conceptual frameworks such as the Health Belief Model and the Theory of Reasoned Action because both posit a relationship between health beliefs and health behaviors that can be applicable to chronic diseases such as diabetes, its self-management, and its treatment. This research also contributes to the relevance of the cultural construction and explanatory models of health and illness for understanding that health and illness are personally and socially adaptive responses (Kleinman 1980:74), individuals explain events in their lives and try to make sense of the world around them (Glanz, Lewis, and Rimer 1990:35), and that explanations provided by individuals are sets of beliefs or understandings that specify for an illness episode its causes, time, and mode of onset of symptoms, patho-physiology, course of sickness, and treatment (Rubel and Hass 1996:121). These health beliefs are important to consider because they can either facilitate or become substantial barriers to implementing policies and programs (Kleinman and Petryna 2001:6).

From a cultural construction of health and illness perspective, the women in this study constructed the onset of their diabetes (e.g. excessive thirst, excessive urination, itchy skin, being overweight, vaginal infections, blurry vision, no symptoms, etc), and sought to provide explanations for the perceived causes of

their condition (being overweight/obese, family history or not knowing). Likewise, some women recalled the year of diagnosis, the initial recommendations they received from their primary care physician (lose weight, change the diet, exercise, blood glucose monitoring, take medications, etc), and the behavioral change in the form of action they initiated to address and adapt to their diagnosis (e.g. reduction of high carbohydrate foods, eating smaller portions, increase in exercise/physical activity).

As reasoned behavior, individuals will take action to ward off, to screen for, or control an ill-health condition if four conditions exist (Strecher and Rosenstock 1997:44). First, individuals take action if they regard themselves as susceptible to the condition. Second, individuals take action if they believe that a condition has potentially serious consequences. Third, action is undertaken if the course of action available to an individual would be beneficial in reducing either their susceptibility to or severity of the condition, and lastly, if the individual believes that the anticipated barriers to or costs of taking the action are outweighed by its benefits.

The conceptual underpinnings of the Health Belief Model applied to this study revealed that the women had a belief of susceptibility to diabetes because of their overweight or obese status at time of diagnosis, and/or because of their susceptibility due to family history (genetics). From the interviews and questionnaire data, the women also revealed a belief of the serious nature of diabetes—"it is a serious disease;" "it is a disease that can not be cured, but can

be controlled;" it is "a disease where your body does not produce enough insulin;" and "a chronic condition; a killer." Similarly, the women revealed a belief about the outcome of carrying out the recommended behaviors. They believed that to do so would assist them with glucose control, and thus the prevention and/or elimination of complications. From these beliefs about diabetes and beliefs toward the prescribed behaviors, the women made evaluations of the outcomes (prevention and/or elimination of complications or onset of complications), and then initiated or intended to initiate action to carry out the prescribed behaviors (nutritional changes, exercise, blood glucose monitoring, medications, etc). Their beliefs, outcome evaluations, and actions were also based on knowledge and education gained from their primary care physician, nurse educator, nutritionist and/or diabetes educator, along with personal experience.

The insight from this study based on the conceptual framework of the Cultural Construction of Health used in the design, data collection and analysis provided a basis for understanding of how the women conceptualized and understood diabetes, its diagnosis and the initial and on-going response to prescribed treatment behaviors. The findings from this research demonstrated that an individual's beliefs about illness influence her or his health behavior (Schoenberg, Amey and Coward 1998:2113), and that health behaviors affect treatment outcomes. The insights gained are important for addressing several outcomes. First, it provides opportunities for examining belief systems and their

affect upon the diabetic self-care regimen. What an individual believes about her/his condition may in the short or long run affect treatment outcomes.

Second, understanding behavioral intention and action initiated or not initiated for self-management (e.g. modifiable behaviors such as dietary changes and exercise) is important for planning culturally appropriate diabetes education interventions. Likewise, insights gained are valuable for addressing socio-cultural barriers to the delivery of health care treatment services.

## Contributions to Applied Anthropology

Identifying and engaging major social problems of the day is a concern of anthropology (McDonald 2002:2), the study of humankind (Bailey 2000:4), in all places and throughout time (Haviland 2002:6). Medical anthropology focuses on disease, illness, medical problems, and theories of illness in different cultural and ethnic groups from a biopsychosociocultural perspective; a perspective for recognizing the biological, psychological, social, and cultural factors that are connected with each individual as they relate to health or illness (Bailey 2000:4). Such an approach is holistic, and therefore, anthropological in perspective (Bailey 2000:4).

The applied anthropologist uses the knowledge, skills, and perspective of the discipline to help solve human problems and facilitate change (Chambers 1985:8). The human problem this research addressed is the diabetes-related problems of African American women with the disease, and factors contributing to their increased diabetes-related morbidity and mortality. Such factors have been cited as the high rates of obesity, and diabetes-related complications (Auslander et al 2002:809; Bailey 2000:73; Liberman, Probart, and Schoenberg 2003:79) in this population for whom there is little research (Livingston 1994:105; Schoenberg 2001:448). Thus, a first contribution of this research is to the sparse applied anthropology literature on African American women with diabetes mellitus. For example, this research has generated knowledge on the role beliefs

play in how some African American women with diabetes may understand and respond to diabetes, its symptoms and treatment recommendations. It has indicated that biopsychosocio-cultural factors may affect diabetes self-management (e.g. family history of diabetes, stress, family support, dietary and exercise patterns). Additionally, this research has contributed to the applied anthropology literature the knowledge that some African American women with diabetes may experience barriers that impede the delivery of diabetes education (lack of physician referral, and lack of healthcare insurance, may experience barriers that impede effective patient self-management (health care policies that allow for costs to cover diabetic testing supplies but not medications), but may have and/or need support systems that facilitate self-management (education classes, family, friends, and religion/spirituality). Such knowledge is beneficial for designing and implementation of interventions. Likewise, the knowledge is applicable for the development of recommendations that address the inclusion of family, friend support systems for diabetic African American women, cultural sensitivity and awareness of behavioral practices such as nutritional changes that impact family systems, health care policy change for the coverage of diabetes medications, improved accessibility, affordability and design of diabetes education and improved patient-provider health communication (interaction between patients and physicians, diabetes educators and patients, health care providers such as nurses, pharmacists, psychologists, and patients) for African American women with the disease.

A second contribution is to the value of using qualitative, anthropological methods such as in-depth interviewing, direct and participant observation and thematic analysis as research tools to explicate and inform quantitative questionnaire data such as used in this study. The use of these anthropological methods provided for a richer contextualization and understanding of the diabetes self-management experiences of the participants in this study.

#### Contribution to Public Health

Public health is a broad social enterprise that seeks to extend the benefits of current knowledge in ways that will have the maximum impact on the health status of a population by identifying problems that call for collective action to protect, promote, and improve health, primarily through preventive strategies (Turnock 2001:11). Turnock informs us that this prevention is characterized by actions that are taken to reduce the possibility that something will happen or in hopes of minimizing the damage that may occur if it does happen. In the case of this research, prevention is focused on reducing and/or eliminating the high rates of diabetes-related morbidity and mortality in African American women with the disease through understanding beliefs and behavioral factors that affect their self-management. As such, this research makes a contribution to public health knowledge of diabetes self-management treatment behaviors and beliefs of African American women with diabetes mellitus, and of diabetes educators and self-management programs providing services to these women. An awareness of the self-care behaviors that are initiated (e.g. dietary changes,

exercise/physical activity, medication use) and to what degree, and barriers to implementation of the behaviors, can assist in clinical prevention, preventive interventions that target individuals, and community prevention that targets populations (Turnock 2001:251). Identified barriers included disability affecting exercise, financial cost of class attendance with or without insurance, lack of exercise partner, dietary changes requiring smaller portion sizes, inclusion of more fresh fruits and vegetables, limitation of high carbohydrate foods, and cost of medications. Based upon the findings from the present study, clinical prevention should focus on reduction of diabetes related complications such as amputations, blindness, hypertension, heart disease, and kidney failure. Community health promotion would address culturally appropriate diabetes education, risk reduction, and prevention to include an awareness of proper nutrition, and exercise/physical activity.

A second contribution of this research to public health is an awareness of the need for developing and delivering culturally competent health education for diabetes self-management geared to African American women with the disease. Health education itself is education about health, and cultural competency is a concept designed to optimize the service and treatment received by racial and ethnic minorities with the health care system (Gilbert and Sawyer 2000:3). This study reveals the difficulties the women face in making the prescribed nutritional and exercise modifications. Culturally aware and sensitive educators must consider appropriate methods of presentation of information such as nutrition and

exercise to optimize the effectiveness of a diabetes health education program for women with diabetes, their families and the community in which they live. With all things being equal, there is a consensus that the preferable presenter/teacher be someone of similar culture to the audience to ensure educator sensitivity and participants' trust (Gilbert and Sawyer 2000:253). Such awareness is shared by African American diabetes educators in this study. Beckles and Thompson-Reed (2001) believe that it is important for the health care system to consider custom-designed prevention and control programs tailored for women and based on local and regional attitudes about health care, differing cultural health beliefs, and available social supports.

Third, this research demonstrated that anthropologists as behavioral scientist offer significant contributions as interdisciplinary team members for public health research focusing on and policy addressing major chronic disease issues such as diabetes. Likewise, anthropological methods such as in-depth interviewing, direct and participant observation, as used in this study, offers to public health the value of qualitative anthropological methods for in-depth understanding and expansion of quantitative survey/questionnaire data and methods; data and method that while good at enumerating problems, is less well able to explain them (Carroll et al 2003:356).

#### Limitations

1. This research design did not include access to private participant medical records for determining blood glucose levels as an indicator of clinical

diabetes control measured by HbA1c levels. As such, data analysis correlating diabetes self-management behaviors and glucose control was not possible for this study. Instead, diabetes control was indicated by participant self-report interview and questionnaire data based upon the performance of self-care behaviors.

2. This study included seven primary members of the diabetes self-management health care educator team; nurse educators, nutritionists, physicians and exercise physiologist/specialist. Due to the small sample size, the findings from the educators should be used only as a frame of reference for the role of diabetes educators, and not representative of all educators providing diabetes self-management education.
3. This study included twenty-five (25) African American women as the primary research population. Though sufficient for this study, the small sample size is not meant to generalize to all African American women with diabetes. As such, the study can only provide specific insight into and recommendations for this one culture of diabetic women.
4. The questionnaire used for this study was developed from interview data with the African American women included in this study, and from questions from the Center's for Disease Control and Prevention' Behavior Risk Factor Surveillance Survey. The instrument was pre-tested on a similar subject population of women and men with diabetes mellitus.

However, the instrument should be further tested for reliability and validity.

5. Non-random sampling in the form of snowball and convenience sampling was initiated to recruit participants. The potential for bias in participant responses is a possibility where one friend or family member recruited another to participate in this study and shared information with each regarding the interview and questionnaire process. Therefore, information may have a response bias due to the influence of friends and/or family.
6. An eighty percent return (20 of the 25 women) was received on the Self-Management Questionnaire. The questionnaire was self-administered by all of the women except for one that was researcher administered. Some questions on some questionnaires were incomplete. Researcher assisted administration may have facilitated the completion of these items. Additionally, diabetic retinopathy was a factor for three women who did not return the self-addressed survey.
7. Although a majority of the women had received some type of diabetes education since diagnosis (e.g. most reported having received education from their physician), few women were continuing to participate in diabetes self-management education classes at the time of the study. As such, a perspective on the benefits received from present self-management education was not available from the majority of the women.

## Implications and Recommendations

Recommendations highlight the need for improvement in the provision of patient education, physician-patient interaction, and elimination of structural barriers affecting access to care, and stronger community and family support systems.

1. Accessible community-based self-management programs covered by insurance should be funded and offered by private health care providers and public health programs. Funding should include community-based organizations, service clubs, faith-based institutions and health care programs with access to the targeted community.
2. Public Health efforts should target interventions that increase family support for re-enforcing treatment behaviors of diabetic individuals. A proactive approach of family members can assist in preventing diabetic complications.
3. Health care providers and the health care system should increase the amount of free blood glucose testing supplies needed monthly based on recommendations for daily testing.
4. Insurance and health care providers should fund diabetes case management specialists for on-going outreach to and follow-up with diabetic women.
5. The medical profession should ensure physician continuing education credits for diabetes self-management. This training would include

guidelines on referring patients to self-management classes. Additionally, the education should include cultural competency training.

6. Private and public health care insurers should revise policies to reflect coverage for the cost of diabetic medications.
7. The recommendation is offered for diabetes educators to include culturally-sensitive meal planning as part of educational instruction. For example, the inclusion of culturally-sensitive dietary modifications that take into account the history of African American women and their diets.
8. Private and public insurance providers should include coverage for home health exercise specialists for diabetic patients. Costs for the specialists should be covered by health insurance, and/or provided at minimal cost to the patient.
9. The medical profession would benefit from medical education to improve physician-patient communication regarding the discussion of diabetic blood glucose test results and the meaning of those results as they relate to self-management, e.g. HbA1c tests.
10. The involvement of women's auxiliary groups and committees within faith-based institutions is an avenue for women with diabetes to discuss and provide support systems (e.g. diabetes prayer group) for diabetes self-management. Recommendation is made for the development and

funding support of these groups within the faith-based environment.

11. Public and privately funded and provided self-management education programs should expand education sessions to include “family education day or night.” This is to encourage family involvement in educational, treatment, intervention and support efforts.
12. Economic and political determinants of self-management should be considered for health care policy change—change that will provide accessibility and affordability of health care treatment regardless of socio-economic status.
13. The diabetes self-management team and self-management education programs should include peer educators as members of diabetes education, prevention and outreach efforts.
14. Where similarities of diabetes beliefs and behaviors are identified, it is recommended that educators, programs and health care service providers remain mindful of intra-cultural variations and modify as appropriate education, prevention and health care service intervention approaches and strategies.
15. The survey used in this study was designed from data provided in the in-depth interviews with the women, educators and from participant observations. The approach of designing an instrument from participant interviews and observations provided value for the tool as culturally relative to the research population. In this study, such an approach was

valuable for assessing and understanding beliefs and behaviors that were specifically germane to the women. The approach has applicability and usefulness for the culturally aware and appropriate development, design and delivery of health education and health care services targeted toward little researched and underserved ethnic and racial minority populations.

16. Health care providers and diabetes educators should develop, in conjunction with the patient and patient's support systems, and community resources, individualized, on-going self-management treatment plan. Such plans are proactive intervention tools that can be used by the patient, patient's family or other significant support system and healthcare providers to intercede before interruptions may occur in the treatment cycle.

### Future Research

The following recommendations are made for future research:

1. Future research may benefit from the inclusion of a larger sample size of educators who work directly with African American individuals with type 2 diabetes. Such research may offer broader perspectives on diabetes education, and self-management issues for African American women.
2. Future studies could benefit from research with African American diabetes educators. Recommendations from these individuals may

provide a cross-cultural and culture specific ecological context to and perspective on diabetes education within African American communities.

3. Research on a younger population (45 and under) of African American women with diabetes mellitus and their self-management behaviors may assist families, physicians, and other health care providers with early intervention to prevent later diabetes complications.
4. The incidence of diabetes mellitus is on the increase for African American adolescents. Research exploring factors associated with the increase of genetic factors of mothers with diabetes and their children diagnosed with type 2 diabetes may be beneficial for health promotion and disease prevention.
5. Research with families that have two or more individuals diagnosed with diabetes mellitus, and a comparison of the self-management behaviors used, and support mechanisms influencing treatment behaviors may offer insight for treatment planning and lay education intervention.
6. Research that explores the perceptions of African Americans with diabetes mellitus on the lack of attendance by African Americans at diabetes self-management education classes may provide insights into effective outreach strategies.
7. Research on faith-based initiatives and faith communities providing

diabetes self-management education provides an opportunity to design evaluation studies of program effectiveness.

8. Research on genetic testing and diabetes in minority populations to support public health and biomedicine health education, prevention, and intervention efforts .

## REFERENCES CITED

- Abrums, Mary  
2000 Jesus will fix it after awhile: Meanings and health. *Social Science and Medicine* 50(1): 89-105.
- Acosta-Patiño, J. L., E. Jiménez-Balderas, M. A. Juárez-Oropeza, and J. C. Díaz-Zagoya.  
2001 Hypoglycemic action of *Cucurbita ficifolia* on Type 2 diabetic patients with moderately high blood glucose levels. *Journal of Ethnopharmacology* 77(1): 99-101.
- Anderson, B.J.  
2003 Diabetes self-care: lessons from research on the family and broader contexts. *Current Diabetes Report* 3(2): 134-140.
- Anderson, J.M., S. Wiggins, R. Rajwani, A. Holbrook, C. Blue, and M. Ng  
1995 Living with a chronic illness: Chinese-Canadian and Euro-Canadian women with diabetes—exploring factors that influence management.
- Angel, Ronald and Peggy Thoits  
1987 The impact of culture on the cognitive structure of illness. *Culture, Medicine and Psychiatry* 11(4):465-493.
- Angrosino, Michael V.  
1987 *A health practitioner's guide to the social and behavioral sciences.* Dover, MA: Auburn House.  
  
2001 *Talking about cultural diversity in your church.* Lanham, MD: AltaMira Press.
- Auslander, Wendy, Debra Haire-Joshu, Cheryl Houston, James Herbert Williams, and Hope Krebill  
2000 The short-term impact of a health promotion program for low-income African American women. *Research on Social Work Practice* 10(1): 78-97.
- Auslander, Wendy, Debra Haire-Joshu, Cheryl Houston, Chaie-Won Rhee, James Herbert Williams  
2002 A controlled evaluation of staging dietary patterns to reduce the risk of Diabetes in African American women. *Diabetes Care* 25(5): 809-814.

- Babbie, Earl  
1992 The practice of social science research, 6<sup>th</sup> Edition. Belmont, CA: Wadsworth.
- Bailey, Eric J.  
2000 Medical anthropology and African American health. Westport, CT: Bergin and Garvey.
- Bandura, Albert  
2004 Health promotion by social cognitive means. Health Education and Behavior 31(2):143-164.
- Beckles, GLA, PE Thompson-Reid, eds.  
2001 Diabetes and women's health across the life stages: A public health perspective. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Diabetes Translation.
- Berg, Bruce Lawrence  
2001 Qualitative research methods for the social sciences, 4<sup>th</sup> Edition. Boston: Allyn and Bacon.
- Bernard, Russell H.  
1994 Interviewing: Unstructured and semi-structured. *In* Research Methods in Anthropology: Qualitative and Quantitative Approaches, 2nd Edition, Russell Bernard ed., p. 203-239. Thousand Oaks, CA: Sage Publications.
- Bharati, Agehananda  
1971 Anthropological approaches to the study of religion: Ritual and belief systems. Biennial Review of Anthropology 7:230-282.
- BlackHealthCare.com  
2002 Diabetes in African Americans. Electronic document.  
<http://www.blackhealthcare.com/BHC/Diabetes/Description.asp>
- Bodenheimer, Thomas, Kate Lorig, Halsted Holman, and Kevin Grumbach  
2002 Patient self-management of chronic disease in primary care. JAMA 288:2469-2475.
- Bradley, Candice  
1997 Doing fieldwork with diabetes. Cultural Anthropology Methods 9(2): 1-7.

- Brashears, Freda  
 2000 The black church response to the mental health needs of the elderly. *In* Health Care In the Black Community: Empowerment, Knowledge, Skills and Collectivism, Sadye L. Logan, Edith M. Freeman, eds. p.199-214. Binghamton, NY: Haworth Press.
- Brown, Sharon A., Alexandra A. Garcia, Kamiar Kouzekanani, and Craig L. Hanis  
 2002 Culturally competent diabetes self-management education for Mexican Americans. *Diabetes Care* 25(2): 259-268.
- Brownson, Ross C., Patrick L. Remington and James R. Davis, eds.  
 1998 Chronic disease epidemiology and control, 2<sup>nd</sup> ed. D.C.: American Public Health Association.
- Bruce, Sharon  
 2000 Prevalence and determinants of diabetes among the Metis of Western Canada. *American Journal of Human Biology* 12: 542-551.
- Burrus, Barri B., Leandris C. Liburd, and Angela Burroughs.  
 1998 Maximizing participation by Black Americans in population-based diabetes research: the Project DIRECT pilot experience. *Journal of Community Health* 23(1): 15-27.
- Carrese, Joseph A., and Patricia A. Marshall  
 2000 Teaching anthropology in the medical curriculum. *The American Journal of the Medical Sciences* 319(5):297-305).
- Carroll, C., E. Naylor, P. Marsden, and T. Dornan  
 2003 How do people with type 2 diabetes perceive and respond to cardiovascular risk? *Diabetic Medicine* 20: 355-360.
- Carson-Henderson, Linda  
 2002 Cultural construction of diabetes mellitus among Oklahoma Choctaw Elders and Choctaw Nation health care providers: an examination of Concordance between models and implications for care-seeking and compliance. Ph.D. dissertation, University of South Florida.
- Carter, Janette S., Jacqueline A. Pugh, and Ana Monterrosa  
 1996 Non-insulin-dependent diabetes mellitus in minorities in the United States. *Annals of Internal Medicine* 125: 221-232.
- Centers for Disease Control and Prevention  
 National Diabetes Fact Sheet.  
<http://www.cdc.gov/diabetes/pub/estimates.htm#prev4>

- Chambers, Erve  
1985 *Applied Anthropology: A practical guide*. Prospect Heights, IL: Waveland.
- Charmaz, Kathy  
2000 Experiencing chronic illness. *In Handbook of Social Studies in Health and Medicine*, Gary L. Albrecht, Ray Fitzpatrick, and Susan C. Scrimshaw, eds. p. 277-292. Thousand Oaks, CA: Sage Publications.
- Chen, Lincoln C., Arthur Kleinman and Norma C. Ware  
1992 *Advancing health in developing countries: the role of social research*. New York: Auburn House.
- Chin, Marshall H., Steven B. Auerbach, and Sandy Cook  
2000 Quality of diabetes care in community health centers. *Journal of Public Health* 90(3): 431-434.
- Chrisman, Noel J. and Thomas M. Johnson  
1996 Clinically applied anthropology. *In Medical Anthropology: Contemporary theory and method*, Carolyn F. Sargeant and Thomas M. Johnson, eds., p. 89-109. Westport, CN: Praeger.
- Clarke, Janice, Albert Crawford, and David B. Nash  
2002 Evaluation of a comprehensive diabetes disease management program: Progress in the struggle for sustained behavior change. *Disease Management* 5(2):77-86.
- Cooper, Richard S., Charles N. Rotimi, Jay S. Kaufman, Eme E. Owoaje, Henry Fraser, Terrence Forrester, Rainford Wilks, Lisa K. Riste, and J. Kennedy Cruickshank  
1997 Prevalence of NIDDM among populations of the African Diaspora. *Diabetes Care* 20(3): 343-348.
- Corin, Ellen  
1995 The cultural frame: Context and meaning in the construction of health. *In Society and Health*, Amick, Benjamin C., Sol Levine, Alvin R. Tarlov and Diana Chapman Walsh, eds. p. 272-304. New York, NY: Oxford University Press.
- Cox, Ruby H., John Paul Carpenter, Franklin A. Bruce, Kathleen P. Poole, and Clark K. Gaylord  
2004 Characteristics of low-income African American and Caucasian adults that are important in self-management of type 2 diabetes. *Journal of Community Health* 29(2): 155-170.

- Creswell, John W.  
1998 *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage Publications.
- Davidson, Jaime A,  
1991 Diabetes care in minority groups: Overcoming barriers to meet these patients' special needs. *Postgraduate Medicine* 90(2): 153-168.
- Department of Health and Human Services, Office of Minority Health,  
<http://www.hhs.omh.gov>
- Department of Health and Human Services, National Institutes of Health,  
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).  
<http://www.niddk.nih.gov>
- Department of Health and Human Services, National Women's Health  
Information Center, Diabetes and African American women.  
2000 [http://www.4woman.gov/faq/afrocam\\_american.htm](http://www.4woman.gov/faq/afrocam_american.htm)
- Department of Health and Human Services  
2003 *The Initiative to Eliminate Racial and Ethnic Disparities in Health*.  
<http://raceandhealth.hhs.gov>
- Dye, Cheryl J., Vivian Haley-Sitlin and Deborah Willoughby  
2003 Insights from older adults with type 2 diabetes: Making dietary and exercise changes. *Diabetes Educator* 29(1):116-128.
- Elders, M. Jocelyn, and Frederick G. Murphy  
2001 Diabetes. *In Health Issues in the Black Community*, 2<sup>nd</sup> ed., Ronald Braithwaite, and Sandra E. Taylor, ed., p.226-241. San Francisco, CA: Jossey Bass.
- Ellison, Christopher G.  
1998 Religion, health, and well-being among African Americans. *African American Research Perspectives* 4(1): 7.  
<http://rcgd.isr.umich.edu/prba/perspectives>
- Ellison, Geraldine C. and Kathleen M. Rayman  
1998 Exemplars' experience of self-managing Type 2 diabetes. *The Diabetes Educator* 24(3): 325-330.
- Ember, Carol, and Melvin Ember  
1988 *Cultural Anthropology*. Englewood Cliffs, NJ: Prentice Hall.

- Ervin, Alexander, M.  
2000 Applied anthropology: tools and perspectives for contemporary practice. Needham Heights: Allyn & Bacon.
- Ferzacca, Steve  
2000 "Actually, I don't feel that bad;" Managing diabetes and the clinical encounter. *Medical Anthropology Quarterly* 14(1): 1-18.
- Fitzerald, JT, W.K. Davis, C.M. Connell, G.E. Hess, M.M. Fennell, R.G. Hiss  
1996 Development and validation of the diabetes care profile. *Evaluation & The Health Profession* 19:208-230.
- Fitzgerald, James T., Larry D. Gruppen, Robert M. Anderson, Martha M. Funnell, Scott J. Jacober, George Grunberger, and Linda C. Aman  
2000 The influence of treatment modality and ethnicity on attitudes in type 2 diabetes. *Diabetes Care* 23(3):313-318.
- Florida Policy Exchange Center on Aging, Healthy People 2010-Diabetes-Conference Edition.  
<http://www.fpeca.usf.edu/Data%20Center/Resources/Health/Volume1/05Diabetes.htm> www.fpeca.usf.edu.
- Funnell, Martha M., and Robert M. Anderson  
2002 Working toward the next generation of diabetes self-management education. *American Journal of Preventive Medicine* 22(4S): 3-5.
- Furnham, Adrian  
1994 Explaining health and illness: Lay perceptions on current and future health, the causes of illness, and the nature of recovery. *Social Science and Medicine* 39(5):715:725.
- Garro, Linda C.  
1995 Individual or societal responsibility? Explanations of diabetes in an Anishinaabe (Ojibway) community. *Social Science and Medicine*, 40(1): 37-46.
- Gilbert, Glen G., and Robin G. Sawyer  
2000 Health education: Creating strategies for school and community health (2<sup>nd</sup> ed). Sudbury, MA: Jones and Bartlett.
- Glanz, Karen, Frances Marcus Lewis, and Barbara K Rimer  
1990 Models of individual health behavior. *In Health Behavior and Health Education: Theory, Research, and Practice*. Karen Glanz, Frances M. Lewis, and Barbara K. Rimer eds. Pp. 33-62. San Francisco San Francisco: Jossey-Bass.

- Glasgow, R.E., S.E. Hampton, L.A. Strycker, and L. Ruggiero  
1997 Personal-model beliefs and socio-environmental barriers related to diabetes self-management. *Diabetes Care* 20(4):556-61.
- Goodall TA, and WK Halford  
1991 Self-management of diabetes mellitus: a critical review. *Health Psychology* 10(1):1-8.
- Green, L.W., and M.W. Kreuter  
1999 *Health promotion planning: An educational and ecological approach* 3<sup>rd</sup> ed. California: Mayfield.
- Grieco, Elizabeth M., Rachael C. Cassidy  
2001 Overview of race and Hispanic origin 2000 (Report No. C2KBR/01-1). Washington, DC: U.S. Department of Commerce, Economics and Statistics Administration, U.S. Census Bureau.
- Hahn, Robert A.  
1995 *Sickness and healing: An anthropological perspective*. New Haven, CN: Yale University Press.
- 1999 *Anthropology and Public Health: Bridging differences in culture and society*. New York, NY: Oxford University Press.
- Hamburg, David A., Glen R. Elliott and Delores L. Parron, eds.  
1982 *Health and behavior: frontiers of research in the biobehavioral sciences*. Washington, D.C. :National Academy Press.
- Haire-Joshu, Debra, Ross C. Brownson, Ken Schechtman, Marilyn S. Nanney, Cheryl Houston, and Wendy Auslander  
2001 A community research partnership to improve the diet of African Americans. *American Journal of Health Behavior* 25(2): 140-146.
- Harris, MI  
1991 Epidemiological correlates of NIDDM in Hispanics, whites and blacks in the U.S. population. *Diabetes Care* 14(7):639-648.
- Hays, L.M., and D.O. Clark  
1999 Correlates of physical activity in a sample of older adults with type 2 diabetes. *Diabetes Care* 22(5): 706-712
- Hegele, Robert A., Matthew R. Ban, Christine V. Carrington, and D. Dan Ramdath.  
2001 Allele frequencies for candidate genes in atherosclerosis and diabetes among Trinidadian neonates. *Human Biology* 73(4): 525-531.

- Helman, Cecil  
1990 Culture, health and illness: An introduction for health professionals.  
Boston, MA: Wright.
- Hills-Briggs, F.  
2003 Problem solving in diabetes self-management: A model of chronic illness self-management behavior. *Annals of Behavioral Medicine* 25(3):182-93.
- Hosey, G., S. Gordon, and A. Levine  
1998 Type 2 diabetes in people of color. *Nurse Practitioner Forum* 9(2): 108-114.
- Hunt, Linda M., Miguel A. Valenzuela and Jacqueline A. Pugh  
1998 Por que me toco a mi? Mexican American diabetes patients causal stories and their relationship to treatment behaviors. *Social Science and Medicine* 46(8): 959-969.
- Hunt, Linda M., Jacqueline A. Pugh, and Miguel A. Valenzuela  
1998 How patients adapt diabetes self-care recommendations in everyday life. *Journal of Family Practice* 46(3):207-215).
- Jewler, D.  
1991 Blacks and diabetes. *Diabetes Forecast* 44(2), 49-52.
- Jet Magazine  
1996 Diabetes association launches campaign to heighten Blacks' awareness of disease. *Jet Magazine*, March 89(15):36.
- Jouad, H., M. Haloui, H. Rhiouani, J. El Hilaly, and M. Eddouks  
2001 Ethnobotanical survey of medicinal plants used for the treatment of diabetes, cardiac and renal diseases in the north centre region of Morocco (Fez-Boulemane). *Journal of Ethnopharmacology* 77( 2-3):175-182.
- Keyserling, Thomas C., Carmen D. Samuel-Hodge, Alice S. Ammerman, Barbara E. Ainsworth, Carlos F. Henriquez-Roldan, Tom A. Elasy, Anne H. Skelly, Larry F. Johnston, Shrikant Bangdiwala, and I. Bangdiwala  
2002 A randomized trial of an intervention to improve self-care behaviors of African American women with Type-2 diabetes. *Diabetes Care* 25(9): 1576-1583.
- Kimble, Deborah L.  
2000 The relationship of self-care behaviors, diabetes specific locus of control, and glycemic control in adults with diabetes. M.A. thesis, University of South Florida.

- Kleinman, Arthur  
 1980 Patients and healers in the context of culture. Berkeley: University of California Press.
- Kleinman, Arthur and Adriana Petryna  
 2001 Health, anthropological aspects. Electronic document.  
<http://opr.princeton.edu/seminars/Petryna.s01.pdf>
- Koley, Shyamal, and Prabodh K. Shrivastava  
 1997 Distribution of the ABO and LH blood types among three religious groups in patients with diabetes mellitus. *Journal of the Anthropological Survey of India* 46(1): 103-110.
- Krichbaum K., V. Aarestad, and M. Buethe  
 2003 Exploring the connection between self-efficacy and effective diabetes self-management. *Diabetes Educator* 29(4):653-62).
- Lang, Gretchen Chesley  
 1989 "Making sense" about diabetes: Dakota narratives of illness. *Medical Anthropology* 11: 305-327.
- LeCompte, Margaret D., and Jean J. Schensul  
 1999 Designing and conducting ethnographic research. Walnut Creek, CA: Altamira Press.
- Lee, Young-Mi., Harriet Kim, Eun-Kyung Hong, Boo-Hyon Kang, Sung-Jin Kim.  
 2000 Water extract of 1:1 mixture of Phellodendron cortex and Aralia cortex has inhibitory effects on oxidative stress in kidney of diabetic rats. *Journal of Ethnopharmacology* 73(3): 429-436.
- Leedy, Paul D., and Jeanne Ellis Ormond  
 2001 Practical research planning and design, (7<sup>th</sup> ed). Upper Saddle River, NJ: Prentice Hall.
- Leonetti, Donna L., Wilfred Y. Fujimoto, and Patricia W. Wahl  
 1989 Early-life background and the development of non-insulin dependent diabetes mellitus. *American Journal of Physical Anthropology* 79: 345-355.
- Li, Xiu, and Shang P. Deng  
 1995 Some aspects of diabetes care in Chengdu. *Social Science and Medicine* 41(8): 1185-1190.

- Liberman, Leslie Sue  
2004 Diabetes mellitus and medical anthropology. *In* Encyclopedia of Medical Anthropology, Carol R. Ember and Melvin Ember eds. Pp. 335-353. New York, NY: Kluwer Academic/Plenum.
- Liberman, Leslie Sue, Claudia K. Probart, and Nancy Schoenberg  
1999 Barriers to weight reduction among African American women with type 2 diabetes. *Women's Health and Research: Health Education on Special Populations*. Paper presented at the 2<sup>nd</sup> Annual International Festival of Women Composers, University of Florida, Gainesville, Florida
- 2003 Body image among older, rural, African American women with type 2 diabetes. *Collegium Anthropologicum* 27(1): 79-86.
- Liburd, Leandris C.  
2003 Food, identity, and African American women with type 2 diabetes: An anthropological perspective. *Diabetes Spectrum* 16(i3): 160-165).
- Lindenbaum, Shirley and Margaret Lock  
1993 Knowledge, power and practice: The anthropology of medicine and everyday life. Berkeley: University of California Press.
- Livingston, Ivor Lensworth  
1994 Handbook of Black American health: The mosaic of conditions, issues, policies, and prospects. Westport, CT: Greenwood Press.
- Livneh, Hanoch and Richard F. Anthonak  
1997 Psychosocial adaptation to chronic illness and disability. Gaithersburg, MD: Aspen Publishers.
- Lorig, KR, D.S. Sobel, P.L. Ritter, D. Laurent, and M. Hobbs  
2001 Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice* 4(6):256-62.
- Lorig, Kate, and Halsted Holman  
2000 Self-management education: context, definition and outcomes and Mechanisms. Paper presented at the first Chronic Disease Self-Management Conference, Australia, August, n.d.
- Marshall, Patricia A.  
1991 Research ethics in applied medical anthropology. *In* Training Manual in Applied Medical Anthropology, Carole E. Hill ed., p. 213-235. Washington, DC: American Anthropological Association.

- Marshall, Catherine and Gretchen B. Rossman  
 1994 *Designing Qualitative Research*, 2<sup>nd</sup> ed. Thousand Oaks, CA: SAGE Publications.
- Mathews, Holly F., Donald R. Lannin and James P. Mitchell  
 1994 Coming to terms with advanced breast cancer: Black women's narratives from eastern North Carolina. *Social Science and Medicine* 38(6):789-800.
- Mattis, Jacqueline  
 1997 Spirituality and religiosity in the lives of Black women. *African American Research Perspectives* 3(2): 1-6.
- McBride Murry, Velma, Michelle D. Owens, Gene H. Brody, Angela R. Black, Amanda S. Willert, and Anita C. Brown  
 2003 Factors and processes associated with physical and psychological health of African-American mothers with type 2 diabetes: A heuristic model. *Diabetes Spectrum* 16(i3):166-171.
- McDermott, Robyn  
 1998 Ethics, epidemiology and the thrifty gene: biological determinism as a health hazard. *Social Science and Medicine* 47(9): 1189-1195.
- McDonald, James H.  
 2002 *The applied anthropology reader*. Boston, MA: Allyn and Bacon.
- McElroy, Ann, and Mary Ann Jezewski  
 2000 Cultural Variation in the experience of health and illness. *In Handbook of Social Studies in Health and Medicine*, Gary L. Albrecht, Ray Fitzpatrick, and Susan Scrimshaw eds., p. 191-209. Thousand Oaks, CA: Sage Publications.
- Mensing, Carole R., and Susan L. Norris  
 2003 Group education in diabetes: Effectiveness and implementation. *Diabetes Spectrum* 16: 96-103.
- Mensing, Carole, Jackie Boucher, Marjorie Cypress, Katie Weinger, Kathryn Mulcahy, Patricia Barta, Gwen Hosey, Wendy Kopher, Andrea Lasichak, Betty Lamb, Mavourneed Mangan, Jan Norman, Jon Tanja, Linda Yauk, Kimberlydawn Wisdom, and Cynthia Adams  
 2000 National standards for diabetes self-management education. *Diabetes Care* 23(5): 682-689.
- Miewald, C.E.  
 1997 Is awareness enough? The contribution of self-care in a chronic disease clinic. *Human Organization*, 56(3): 353-363.

Morsy, Soheir A.

1996 Political economy in medical anthropology. *In Medical Anthropology: Contemporary theory and method*, Carolyn F. Sargeant and Thomas M. Johnson, eds., p. 21-40. Westport, CN: Praeger.

Mull, J. Dennis

1993 Cross-cultural communication in the physician's office. *Western Journal of Medicine* 159(5): 609-613.

National Chronic Care Consortium

1999 Self-efficacy/self-health care among older adults: A literature review. Report for the Minnesota Senior Health Options of the Minnesota Department of Human Services, September.

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK),  
National

Institutes of Health. Diabetes in African Americans. NIH Publication No. 01-3266, August 1998.

<http://www.niddk.nih.gov/health/diabetes/pubs/afam/afam.htm>

National Women's Health Information Center

2000 Diabetes and African American Women.

[http://www.4woman.gov/faq/afrocam\\_american.htm](http://www.4woman.gov/faq/afrocam_american.htm)

Navas, M. Angeles, Christian Vaisse, Stephanie Boger, Markus Heimesaat,  
Louis A. Kollee, and Markus Stoffel

2000 The human HNF-3 genes: cloning, partial sequence and mutation screening in patients with impaired glucose homeostasis. *Human Heredity* 50(6):370-381.

Nelson, Karin M., Gayle Reiber, and Edward J. Boyko

2002 Diet and exercise among adults with Type 2 diabetes: Findings from the Third National Health and Nutrition Examination Survey (NHANES III). *Diabetes Care* 25(10): 1722-1728.

Neuman, Lawrence W.

2000 Social research methods: Qualitative and quantitative approaches, 3<sup>rd</sup> ed. Boston: Allyn and Bacon.

Norris, Susan L., Phyllis J. Nichols, Carl J. Caspersen, Russell E. Glasgow,  
Michael M. Engelgau, Leonard Jack, Jr, Susan R. Snyder, Vilma G. Carande-  
Kulis, George Isham, Sanford Garfield, Peter Briss, David McCulloch, and Task  
Force on Community Preventive Services

2002 Increasing diabetes self-management education in community settings. *American Journal of Preventive Medicine* 22(4S): 39-66.

- Olefsky, Jerrold M.  
2001 Prospects for research in diabetes mellitus. *Journal of the American Medical Association* 285(5): 628-632.
- Olson, Brooke  
1999 Applying medical anthropology: Developing diabetes education and prevention programs in American Indian cultures. *American Indian Culture and Research Journal* 23(3): 185-203.
- Owens, Michelle D.  
2003 Diabetes and women's health: Preface. *Diabetes Spectrum* 16(i3): 146-148.
- Peacock, James L.  
2001 *The anthropological lens: Harsh light, soft focus*. New York, NY: Cambridge.
- Perrin, Karen M. and Robert J. McDermott  
1997 The spiritual dimension of health: A review. *American Journal of Health Studies* 13(2): 90-99.
- Pierce, Mary, and David Armstrong  
1996 Afro-Caribbean lay beliefs about diabetes: an exploratory study. *In Researching Cultural Differences in Health*, David Kelleher and Sheila M. Hillier eds. P. 91-102. London: Routledge.
- Prochaska, James O., Colleen A. Redding, and Kerry Evers  
1997 The Transtheoretical Model and Stages of Change. *In Health Behavior and Health Education: Theory, Research and Practice*. Karen Glanz, Frances M. Lewis, and Barbara K. Rimer eds. Pp. 60-84. San Francisco San Francisco: Josey-Bass.
- Redding, Colleen A., Joseph S. Rossi, Susan R. Rossi, Wayne F. Velicer, and James O. Prochaska  
2000 Health behavior models. *The International Electronic Journal of Health Education* 3(Special Edition): 180-193.
- Ritenbaugh, Cheryl, and Carol-Sue Goodby  
1989 Beyond the thrifty gene: metabolic implications of prehistoric migration into the new world. *Medical Anthropology* 11:227-236.
- Rock, Melanie  
2003 Sweet blood and social suffering: Rethinking cause-effect relationships in diabetes, distress, and duress. *Medical Anthropology* 22:131-174.

- Robbins, Jessica M., Viola Vaccarino, and Heping Zhang  
2001 Socioeconomic status and type 2 diabetes in African American and non-Hispanic white women and men: Evidence from the Third National Health and Nutrition Examination Survey. *American Journal of Public Health* 91(1):76-83.
- Romeo, June Hart  
2000 Comprehensive versus holistic care: Case studies of chronic disease. *Journal of Holistic Nursing* 18(4): 352-361.
- Rosenstock, IM  
1985 Understanding and enhancing patient compliance with diabetic regimens. *Diabetes Care* 8(6):610-6.
- Rubel, Arthur J., and Michael R. Hass  
1996 Ethnomedicine. *In Medical anthropology: Contemporary theory and method*, Carolyn F. Sargent, and Thomas M. Johnson, eds. p. 113-130. Westport, CT: Praeger.
- Rundle, Anne Knights, Maria Carvalho and Mary Robinson  
1999 Honoring patient preferences: A guide to complying with multi-cultural patient requirements. San Francisco, CA: Jossey Bass Publishers.
- Sabu, M. C., and Ramadasan Kuttan  
2002 Anti-diabetic activity of medicinal plants and its relationship with their antioxidant property. *Journal of Ethnopharmacology* 81(2): 155-160.
- Schechter, Clyde B., and Elizabeth A. Walker  
2002 Improving adherence to diabetes self-management recommendations. *Diabetes Spectrum* 15(3): 170-175.
- Schensul, Stephen L., Jean J. Schensul and Margaret D. LeCompte  
1999 Essential ethnographic methods: Observations interviews, and questionnaires. New York: Rowman and Littlefield.
- Schoenberg, Nancy E., Cheryl H. Amey and Raymond T. Coward  
1998 Stories of meaning: Lay perspectives on the origin and management of non-insulin dependent diabetes mellitus among older women in the United States. *Social Science and Medicine* 47(12): 2113-2125.
- Schoenberg, Nancy E., and Suzanne C. Drungle  
2001 Barriers to non-insulin dependent diabetes mellitus (NIDDM) self-care practices among older women. *Journal of Aging and Health* 13(4): 443-466.

- Singh, Devendra and Valerie C. Rosen  
2001 Effects of maternal body morphology, morning sickness, gestational diabetes and hypertension on fluctuating asymmetry in young women. *Evolution and Human Behavior* 22(6): 373-384.
- Skelly, Anne Herrstrom  
1992 Psychosocial determinants of self-care practices and glycemic control in Black women with type II diabetes mellitus. Ph.D. dissertation, State University of New York at Buffalo.
- Skinner, Chas T., Sue Cradock, Francesca Arundel and Williams Graham  
2003 Four theories and a philosophy: self-management education for individuals newly diagnosed with type 2 diabetes. *Diabetes Spectrum* 16(2):75(5).
- Snow, Loudell F.  
1993 *Walkin' over medicine*. Boulder, CO: Westview Press.
- Spector, Rachel E.  
2000 *Cultural diversity in health and illness*, 5<sup>th</sup> ed. Upper Saddle River, NJ: Prentice Hall.
- Spikmans, F.J.M., J. Burg, M.M.B. Doven, H.M. Druizenga, G.H. Hofsteenge, and M.A.E. van Bokhorst-van der Schueren  
2003 Why do diabetic patients not attend appointments with their dietitians? *Journal of Human Nutritional Dietetics* 16: 151-158.
- Steffen, Vibeke  
1997 Life stories and shared experience. *Social Science and Medicine* 45(1): 99-111.
- Stretcher, V.J. and I.M. Rosenstock  
1997 The Health Belief Model. *In Health Behavior and Health Education: Theory, Research, and Practice*, Karen Glanz, Frances Marcus Lewis and Barbara K. Rimer, eds. p.41-59. San Francisco, CA: Josey-Bass.
- Task Force on Community Preventive Services  
2002 Recommendations for healthcare system and self-management education interventions to reduce morbidity and mortality from diabetes. *American Journal of Preventive Medicine* 22(4S): 10-14.

- Taylor, Christopher, Kathryn S. Keim, Alicia Sparrer, Jean Van Delinder and Stephany Parker  
2004 Social and cultural barriers to diabetes prevention in Oklahoma American Indian women. *Preventing Chronic Disease* [serial online] Public Health Research, Practice and Policy 1(2):1-10,  
[http://www.cdc.gov/pcd/issues/2004/apr/03\\_0017.htm](http://www.cdc.gov/pcd/issues/2004/apr/03_0017.htm)
- Taylor, Sandra E.  
2001 The health status of black women. *In* *Health Issues in the Black Community*, 2<sup>nd</sup> ed., Ronald Braithwaite, and Sandra E. Taylor, eds., p.44-61. San Francisco, CA: Jossey Bass.
- Thompson, Samantha J., and Sandra M. Gifford  
2000 Trying to keep a balance: the meaning of health and diabetes in an urban Aboriginal community. *Social Science and Medicine* 51(10): 1457-1472.
- Thompson, Sanna J., Wendy F. Auslander, and Neil H. White  
2001 Influence of family structure on health among youths with diabetes. *Health and Social Work* 26(1): 7-14.
- Tripp-Reimer, Toni, Eunice Choi, Lisa Skemp, and Janet C. Enslein.  
2001 Cultural barriers to care: inverting the problem. *Diabetes Spectrum* 14(ii).
- Trotter II, Robert T., and Jean J. Schensul  
1998 Methods in applied anthropology. *In* *Handbook of methods in cultural anthropology*, H. Russell Bernard, ed. p. 691-735 Walnut Creek, CA: AltaMira Press.
- Tull, Eugene S., and Jeffrey M. Roseman  
1995 Diabetes in African Americans. Chapter 31 in *Diabetes in America*, 2<sup>nd</sup> Edition (NIH Publication No. 95-1468). Bethesda, MD: National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health.
- Turnock, Bernard J.  
2001 *Public Health, what it is and how it works*, 2<sup>nd</sup> ed. Gaithersburg, MD: Aspen.
- Tylor, Sir Edward Burnett  
2000 The science of culture. *In* *Anthropological theory: an introductory history*, 2<sup>nd</sup> edition. R. Jon McGee and Richard Warms, eds. p. 27-41. Mountain View, CA: Mayfield.

- Urdaneta, Maria Luisa, and Rodney Krehbiel  
1989 Anthropological perspectives on diabetes mellitus type II. *Medical Anthropology* 11: 221-225.
- Uusitupa, Matti  
2002 Lifestyles matter in the prevention of Type 2 diabetes. *Diabetes Care* 25(9): 1650-1651.
- Weller, Susan C., Roberta D. Baer, Lee M. Pachter, Robert T. Trotter, Glazer Mark, Javier E. Garcia de Alba Garcia, and Robert E. Klein  
1999 Latino beliefs about diabetes. *Diabetes Care* 22(5): 722-728.
- Weiner, Diane  
1999 Ethnogenetics: Interpreting ideas about diabetes and inheritance. *American Indian Culture and Research Journal* 23(3): 155-184.
- Weiss, Kenneth M., Jan S. Ulbrecht, Peter R. Cavanagh, and Anne V. Buchanan  
1989 Diabetes mellitus in American Indians: characteristics, origins and preventive health care implications. *Medical Anthropology* 2: 283-304.
- Weidman, Dennis  
1989 Adiposity or longevity: Which factor accounts for the increase in type II diabetes when populations acculturate to an industrial technology? *Medical Anthropology* 2: 237-253.
- Wiedman, Dennis  
2002 Anthropological contributions to diabetes research and interventions. Electronic article.  
<http://www.foi.edu/~wiedmand/medanthro/diabetesanthropubs.htm>
- Wikblad, K.F.  
1991 Patient perspectives of diabetes care and education. *Journal of Advanced Nursing* 16(7): 837-844.
- Wimberly, Anne E. Streaty  
2001 The role of the black faith communities in fostering health. In *Health Issues in the Black Community*, 2<sup>nd</sup> ed., Ronald L. Braithwaite, Sandra E. Taylor eds, p.129-150. San Francisco, CA: Jossey-Bass.
- Zgibor, Janice C., and David Simmons  
2002 Barriers to blood glucose monitoring in a multiethnic community. *Diabetes Care* 25: 1772-1777.

Zgibor, Janice C., and Thomas J. Songer  
2001 External barriers to diabetes care: addressing personal and health  
systems issues. *Diabetes Spectrum* 14: 23-28.

# Appendices

## Appendix A

### Recruitment Letter—Women

Dear:

#### **My Reason for Writing You:**

I am interested in learning about the many different ways that African American women with diabetes manage their condition. As such, I am requesting your assistance. I would like to interview you about the things you do to manage your diabetes. For example, some women watch what, when, and how much they eat. Others exercise by walking, or dancing, or attending exercise/fitness classes. Some women take medications, include prayer, and/or attend support groups. Several women attend diabetes self-management education classes. I'd like to know what do you do?

#### **Why Should You Be Interviewed?**

Your participation in the study I am conducting will help provide information that may help other African American women with diabetes to better manage their diabetes. Also, your contribution can provide valuable information to help providers serve you better.

Some of these providers include diabetes health educators, nutritionists, physicians, health promoters, policy makers, and community agencies that provide services to you. Diabetes is a very serious condition affecting African American women. Your experiences are important in helping to address health education, intervention, promotion and medical service needs for African American women trying to manage diabetes.

#### **What about Your Privacy?**

Your privacy is important to me. I will make every effort to ensure that your name, and the information you share with me are kept confidential. Your interview may be held at a location where you are most comfortable. If you would like to talk to me by phone, by e-mail, or write me a letter about how you manage your diabetes, all of these ways are also are welcomed.

#### **How to Be Interviewed?**

If you have questions, and/or would like to be interviewed for this study, please contact me at the information above. Thank your for your help.

Sincerely Yours,  
Bridgett Rahim-Williams, Ph.D. Candidate, M.P.H., M.A.

## Appendix B

### Recruitment Letter—Churches and Community

#### **A REQUEST FOR YOUR HELP**

Diabetes is a very serious health concern affecting African American women. What women do to manage diabetes plays an important role in reducing the complications of diabetes. A study is being conducted to learn what African American women with Type 2 diabetes are doing to manage diabetes. The importance of this study is in:

- (1) The information it can give to other African American women with Type 2 diabetes to help them to better manage their diabetes
- (2) The knowledge it can provide to help medical providers better serve African American women with diabetes.
- (3) The information it can provide for family members who may be at risk for developing diabetes, and
- (4) The insight it can give to family members caring for and supporting a loved one with diabetes.

If you are, or someone whom you know is an African American woman with Type 2 diabetes, your help is needed. A few moments of your time can play a special part in understanding how diabetes is managed. Please contact Bridgett at (727) 642-6860, or [brahimwi@tampabay.rr.com](mailto:brahimwi@tampabay.rr.com)

Thank you for your support.

**PARTICIPANT'S PROFILE**

*“African American Women with Type 2 Diabetes: Understanding Self-Management”*

1. Age: \_\_\_\_\_ Height: \_\_\_\_\_ Weight: \_\_\_\_\_
  
2. Marital Status: (check one)  
 Married                       Widow                       Never Married  
 Divorced                       Separated                       Other \_\_\_\_\_
  
3. Occupation: \_\_\_\_\_
  
4. Education: (check highest level completed)  
 High school graduate     2 year college     Tech/Vocational school  
 4 year college               Graduate school  
 Other \_\_\_\_\_
  
5. City of Residence: (check one)  
 St. Petersburg     Pinellas Park     Kenneth City  
 Gulfport     Largo     Clearwater     Other \_\_\_\_\_
  
6. Annual Income level:  
 \$100,000 and over     \$75,000-50,000     \$49,999-40,000  
 \$39,999-30,000     \$29,999-20,000     \$19,999-10,000  
 Other \_\_\_\_\_
  
7. Religion:  Baptist     Methodist     Presbyterian     Muslim     Catholic  
 Seventh Day Adventist     Jehovah's Witness     Non-denominational  
 Other \_\_\_\_\_
  
8. How long have you been diagnosed with diabetes? \_\_\_\_\_
  
9. Do you attend diabetes education classes?     Yes               No
  
10. If yes, where do you attend classes? \_\_\_\_\_
  
11. How often do you attend classes?     1-2x per week     1-2x per month  
 Other \_\_\_\_\_

12. If you do not presently attend classes, have you ever attended?

Yes  No

How often? \_\_\_\_\_ Where? \_\_\_\_\_

Appendix D

Profile Code

Diabetes Self-Management Educator

Self-Profile

1. How long have you provided diabetes education? \_\_\_\_\_ -  
\_\_\_\_\_

2. Location of your classes (check all that apply):

Clinic-based (community)  Hospital (no diabetes clinic)  Clinic-based hospital

University-based clinic  Community-based Facility (no clinic)  Other \_\_\_\_\_

3. When and for how long are your classes held?  
\_\_\_\_\_  
\_\_\_\_\_

4. Profession (Check all that apply):

Certified Diabetes Self-Management Educator

Nurse  LPN

Dietician  Nutritionist

Other \_\_\_\_\_

Other \_\_\_\_\_

5. Education:

BA/BS  MA/MS  MPH  MBA  AA/AS  Ph.D.

M.D.  Other \_\_\_\_\_

6. Other Certifications/Licenses/Education/Training (not listed above):  
\_\_\_\_\_  
\_\_\_\_\_

7. Gender:  Female  Male

8. Ethnicity/Race:  African American  White  Hispanic  Asian

Other \_\_\_\_\_

## Appendix E

### **Informed Consent—Women Participants**

Social and Behavioral Sciences  
University of South Florida

#### Information for People Who Take Part in Research Studies

---

Researchers at the University of South Florida (USF) study many topics. For example: We want learn more about diabetes self-management. To do this, we need the help of people who agree to take part in a research study.

Title of research study: African American women with Type 2 diabetes:  
Understanding Self-management.

Person in charge of study: F. Bridgett Rahim-Williams

Where the study will be done: All counties in Florida

Who is paying for it: F. Bridgett Rahim-Williams

#### *Should you take part in this study?*

This form tells you about this research study. You can decide if you want to take part in it. You do not have to take part. Reading this form can help you decide.

Before you decide:

- Read this form.
- Talk about this study with the person in charge of the study or the person explaining the study. You can have someone with you when you talk about the study.
- Find out what the study is about.

You can ask questions:

- You may have questions this form does not answer. If you do, ask the person in charge of the study or study staff as you go along.
- You don't have to guess at things you don't understand. Ask the people doing the study to explain things in a way you can understand.

After you read this form, you can:

- Take your time to think about it.
- Have a friend or family member read it.
- Talk it over with someone you trust.

It's up to you. If you choose to be in the study, then you can sign the form. If you do not want to take part in this study, do not sign the form.

*Why is this research being done?*

The purpose of this study is to find out what do African American women with diabetes do to manage their condition. The study will involve personal interviews, a self-profile, a questionnaire, and observations of diabetes self-management education classes, exercise/fitness classes, and other activities involving management of diabetes.

*Why are you being asked to take part?*

We are asking you to take part in this study because you are a woman with diabetes. We would like to know what you do to self-manage your condition.

*How long will you be asked to stay in the study?*

You will be asked to spend about four months in this study. During this time, you will be interviewed, complete your profile information, and complete a survey/questionnaire. I will also observe the diabetes self-management education classes, and activities in which you may be involved. The four months will allow us to talk with you more than once to better understand your self-management practices.

*How often will you need to come for study visits?*

A study visit is one you have with the person in charge of the study or study staff. You will need to come for one to two (1-2) study visits in all.

Interviews and observations will begin in November 2003. We anticipate administering the questionnaire in January 2004.

Most study visits will take about 1-2 hours. Some may be longer.

At each visit, I will interview you to find out what you do to manage your diabetes. I will tape-record the interviews, and I will also make written notes to assist me in remembering the important information you share. Questions will focus on the things you may do such as exercise, eating habits, medications you take, self-management classes you attend, doctor visits, etc.

*How many other people will take part?*

About twenty-five (25) African American women with diabetes will take part in this study. The study will also include five to seven (5-7) diabetes self-management educators.

*What other choices do you have if you decide not to take part?*

This is a one-time study. If you decide not to take part in this study, that is okay. Your participation is completely voluntary.

If you decide to take part in this *How do you get started?* study, you will need to sign this consent form.

*What will happen during this study?*

During this study, you will be interviewed two (2) times, and asked to share information about the things you do to manage your diabetes. Along with interviews, you will be asked to provide brief information about yourself, like your age, and marital status, education, etc. I will also ask you to answer a few questions on a survey. The survey provides more information about the things you do to your diabetes. Additionally, I will observe and participate in exercise/fitness classes, nutrition classes, self-management education classes, blood glucose screenings, health fairs, and other activities in which you may attend. These activities will also help me to learn about how you manage diabetes.

Here is what you will need to do during this study:

*There is nothing special you are required to do to be a part of this study. Your signed consent form allows us to talk to you, to administer the self-profile and questionnaire, and to include you in this study.*

*Will you be paid for taking part in this study?*

There is no payment for the time you volunteer in this study.

*What will it cost you to take part in this study?*

It will not cost you anything to take part in the study.

*What are the potential benefits if you take part in this study?*

*Your information can be valuable in the planning, and delivery of diabetes services, and education for African American women with diabetes.*

*What are the risks if you take part in this study?*

There are no known risks to those who take part in this study. However, at times you might find it emotionally difficult to talk about your condition. If this should occur, you may stop the interview at any time. You are under no obligation to continue and nothing adverse will happen to you for not continuing to participate in this study.

*What will we do to keep your study records private?*

Federal law requires us to keep your study records private. All information in this study is kept in a locked file cabinet in my home. When information is transported by car, the information is kept secured in the vehicle. Data will only be stored in the car during transport.

However, certain people may need to see your study records. By law, anyone who looks at your records must keep them confidential. The only people who will be allowed to see these records are:

- People who make sure that we are doing the study in the right way. They also make sure that we protect your rights and safety:
  - The USF Institutional Review Board (IRB), and its staff and others acting on behalf of USF.
  - The United States Department of Health and Human Services (DHHS)

We may publish what we find out from this study. If we do, we will not use your name or anything else that would let people know who you are.

*What happens if you decide not to take part in this study?*

Nothing will happen to you if you decide not to be a part of this study. You should only take part in this study if you would like to help us better understand what African American women like yourself do to manage diabetes.

If you decide not to take part:

- You will not lose any rights you normally have.
- You will still get the same services you would normally have.

What if you join the study and then later decide you want to stop?

If you decide to stop taking part in the study, this is okay. You are under no obligation to continue in the study if you choose not to.

Are there reasons we might take you out of the study later on?

Even if you want to stay in the study, there may be reasons we will need to take you out of it. For example, you may be taken out of this study:

- If we find out it is not safe for you to stay in the study. For example, your health may get worse.

*You can get the answers to your questions.*

If you have any questions about this study, call Bridgett Rahim-Williams at (727) 642-6860.

If you have questions about your rights as a person who is taking part in a study, call USF Research Compliance at (813) 974-5638.

Consent to Take Part in this Research Study (Your participation is voluntary).

I freely give my consent to take part in this study. I understand that this is research. I have received a copy of this consent form.

\_\_\_\_\_  
Signature  
of Person taking part in study

\_\_\_\_\_  
Printed Name  
of Person taking part in study

\_\_\_\_\_  
Date

*Statement of Person Obtaining Informed Consent*

I have carefully explained to the person taking part in the study what he or she can expect.

The person who is giving consent to take part in this study

- Understands the language that is used.
- Reads well enough to understand this form. Or is able to hear and understand when the form is read to him or her.
- Does not have any problems that could make it hard to understand what it means to take part in this study.
- Is not taking drugs that make it hard to understand what is being explained.

To the best of my knowledge, when this person signs this form, he or she understands:

- What the study is about.
- What needs to be done.
- What the potential benefits might be.
- What the known risks might be.
- That taking part in the study is voluntary.

\_\_\_\_\_  
Signature of Investigator  
or authorized research  
investigator designated by  
the Principal Investigator

\_\_\_\_\_  
Printed Name of Investigator

\_\_\_\_\_  
Date

## Appendix E.1

### **Informed Consent—Diabetes Health Educator**

Social and Behavioral Sciences  
University of South Florida

---

#### Information for People Who Take Part in Research Studies

Researchers at the University of South Florida (USF) study many topics. For example: We want learn more about diabetes self-management. To do this, we need the help of people who agree to take part in a research study.

Title of research study: African American women with Type 2 diabetes:  
Understanding Self-management

Person in charge of study: F. Bridgett Rahim-Williams

Where the study will be done: All counties in Florida.

Who is paying for it: F. Bridgett Rahim-Williams

#### *Should you take part in this study?*

This form tells you about this research study. You can decide if you want to take part in it. You do not have to take part. Reading this form can help you decide.

Before you decide:

- Read this form.
- Talk about this study with the person in charge of the study or the person explaining the study. You can have someone with you when you talk about the study.
- Find out what the study is about.

You can ask questions:

- You may have questions this form does not answer. If you do, ask the person in charge of the study or study staff as you go along.
- You don't have to guess at things you don't understand. Ask the people doing the study to explain things in a way you can understand.

After you read this form, you can:

- Take your time to think about it.
- Have a friend or family member read it.
- Talk it over with someone you trust.

It's up to you. If you choose to be in the study, then you can sign the form. If you do not want to take part in this study, do not sign the form.

*Why is this research being done?*

African American women are adversely affected by diabetes. Health educators can help us better understand strategies for diabetes self-management education designed to reach African American women with diabetes.

The purpose of this study is to find out what do African American women with diabetes do to manage their condition. The study will involve personal interviews, a self-profile of the women, a questionnaire for the women with diabetes, and observations of diabetes self-management education classes, exercise/fitness and nutrition classes, and other activities involving self-management of diabetes.

*Why are you being asked to take part?*

We are asking you to take part in this study because you are a diabetes self-management educator and/or diabetes health educator. We would like to know the issues in, and barriers to diabetes self-management education for African American women with diabetes. Likewise, we would like to know what do you do to address the self-management needs of these women.

*How long will you be asked to stay in the study?*

You will be asked to spend about four months in this study. The four months will allow us to talk with you more than once, and to observe the diabetes self-management classes you teach.

*How often will you need to come for study visits?*

A study visit is one you have with the person in charge of the study. I will ask you to participate in one to two (1-2) study visits in all. The meetings will be to conduct the interviews. At other times, I will observe the weekly and/or monthly education classes you teach.

Interviews and observations will begin in November 2003.

Most study visits will take about 1-2 hours. Some may be longer.

At each visit, I will interview you to find out what you do in teaching diabetes self-management classes where African American women with diabetes are present. The interview will be tape-recorded and written notes will also be made to assist in remembering the important information you share.

*How many other people will take part?*

Approximately five to seven (5-7) diabetes health educators, and about twenty-five (25) African American women with diabetes will take part in this study.

*What other choices do you have if you decide not to take part?*

This is a one-time study. If you decide not to take part in this study, that is okay. Your participation is completely voluntary.

*How do you get started?*

If you decide to take part in this study, you will need to sign this consent form.

*What will happen during this study?*

During this study, you will be interviewed two (2) times, and asked to share information about the things you do to teach diabetes self-management education with a special interest in African American women with diabetes. Along with interviews, you will be asked to provide brief information about yourself, like your years of education, professional associations, and experience; a self-profile. Additionally, I will observe and participate in exercise/fitness classes, nutrition classes, self-management education classes, blood glucose screenings, health fairs, and other activities in which you may attend. These activities will also help me to learn about diabetes self-management.

Here is what you will need to do during this study

*There is nothing special you are required to do to be a part of this study. Your signed consent form allows us to talk to you, to administer the self-profile, and to include you in this study.*

*Will you be paid for taking part in this study?*

There is no payment for the time you volunteer in this study.

***What will it cost you to take part in this study?***

It will not cost you anything to take part in the study.

*What are the potential benefits if you take part in this study?*

Your information can be valuable in the planning, and delivery of diabetes education classes for African American women with diabetes. Additionally, your information can be instrumental in developing recommendations for health educators who provide this service.

*What are the risks if you take part in this study?*

There are no known risks to those who take part in this study. However, at times you might find it emotionally difficult to talk about issues related to diabetes, and persons with diabetes. If this should occur, you may stop the interview at any time. You are under no obligation to continue and nothing adverse will happen to you for not continuing to participate in this study.

*What will we do to keep your study records private?*

Federal law requires us to keep your study records private.

All information in this study is kept in a locked file cabinet in my home. When information is transported by car, the information is kept secured in the vehicle. The data will only be stored in the car during transport.

However, certain people may need to see your study records. By law, anyone who looks at your records must keep them confidential. The only people who will be allowed to see these records are:

- People who make sure that we are doing the study in the right way. They also make sure that we protect your rights and safety:
  - The USF Institutional Review Board (IRB), and its staff and others acting on behalf of USF.
  - The United States Department of Health and Human Services (DHHS)

We may publish what we find out from this study. If we do, we will not use your name or anything else that would let people know who you are.

*What happens if you decide not to take part in this study?*

Nothing will happen to you if you decide not to be a part of this study. You should only take part in this study if you would like to help us better understand strategies for diabetes self-management education designed to reach African American women with diabetes.

If you decide not to take part:

- You will not lose any rights you normally have.
- You will still get the same services you would normally have.

What if you join the study and then later decide you want to stop?

If you decide to stop taking part in the study, this is okay. You are under no obligation to continue in the study if you choose not to.

Are there reasons we might take you out of the study later on?

Even if you want to stay in the study, there may be reasons we will need to take you out of it. For example, you may be taken out of this study:

- If you become ill, and are not able to continue in the study.

*You can get the answers to your questions.*

If you have any questions about this study, call Bridgett Rahim-Williams at (727) 642-6860. If you have questions about your rights as a person who is taking part in a study, call USF Research Compliance at (813) 974-5638.

Consent to Take Part in this Research Study (Your participation is voluntary).

I freely give my consent to take part in this study. I understand that this is research. I have received a copy of this consent form.

\_\_\_\_\_  
Signature  
of Person taking part in study

\_\_\_\_\_  
Printed Name  
of Person taking part in study

\_\_\_\_\_  
Date

*Statement of Person Obtaining Informed Consent*

I have carefully explained to the person taking part in the study what he or she can expect.

The person who is giving consent to take part in this study

- Understands the language that is used.
- Reads well enough to understand this form. Or is able to hear and understand when the form is read to him or her.
- Does not have any problems that could make it hard to understand what it means to take part in this study.
- Is not taking drugs that make it hard to understand what is being explained.

To the best of my knowledge, when this person signs this form, he or she understands:

- What the study is about.
- What needs to be done.
- What the potential benefits might be.
- What the known risks might be.
- That taking part in the study is voluntary.

\_\_\_\_\_  
Signature of Investigator  
or authorized research  
investigator designated by  
the Principal Investigator

\_\_\_\_\_  
Printed Name of Investigator

\_\_\_\_\_  
Date

Appendix F

**Please Do Not Include Your Name**

Date \_\_\_\_\_

**Self-Management Survey/Questionnaire**

**African American Women with Type 2 Diabetes: Understanding Self-Management**

**Marital status:** ? Married ? Divorced ? Widowed ? Separated ? Never Married

**Age:** ? 20-29 ? 30-39 ? 40-49 ? 50-59 ? 60-69 ? 70-79 ? 80+

**Race/Ethnicity:** ? Black/African American ? Caucasian ? Hispanic  
? Asian/Pacific Islander ? Native American  
? Other (Please list) \_\_\_\_\_

1. In general, diabetes is **managed** through (check all that apply):
- ? Exercise/Physical Activity
  - ? Diet/Nutrition changes
  - ? Testing/monitoring
  - ? Family Support
  - ? Doctor visits
  - ? Keeping a log of glucose readings
  - ? Diabetes Education Classes
  - ? Other (please list) \_\_\_\_\_
  - ? Medication (insulin/pills, etc)
  - ? Meal Planning
  - ? Religion/Spirituality
  - ? Support of Friends
  - ? Keeping a food log
  - ? Losing weight if overweight
  - ? Meditation
2. In the past, I have received diabetes self-management **education** from (check all that apply).
- ? Physician
  - ? Nutritionist/Dietician
  - ? Family member with diabetes
  - ? Friend without diabetes
  - ? Reading brochures, books, pamphlets
  - ? Have not received education
  - ? Other (please list) \_\_\_\_\_.
  - ? Nurse
  - ? Friend with diabetes
  - ? Exercise Physiologist
  - ? Family member without diabetes

3. Diabetes management classes I **presently** attend are held at (check all that apply):
- Community center
  - Hospital
  - Community-based Clinic
  - Church
  - Hospital-based clinic
  - University clinic
  - Do not presently attend classes
  - Other (please list) \_\_\_\_\_
4. Diabetes management classes I **previously attended** were held at (check all that apply):
- Community center
  - Hospital
  - Community-based Clinic
  - University clinic
  - Hospital-based clinic
  - Church
  - Did not attend any classes
  - Other (please list) \_\_\_\_\_
5. Diabetes self-management **classes** have helped me to manage diabetes.
- Yes
  - No
  - Does not apply (Did not attend classes)
6. My physician **referred** me to diabetes self-management classes.
- Yes
  - No
  - Don't remember
7. My physician **referred** me to a nutritionist/dietician for diabetes self-management information.
- Yes
  - No
  - Don't remember
8. Things I do to **manage** diabetes (check all that apply):
- Exercise/Physical Activity
  - Medication (insulin/pills, etc)
  - Diet/Nutrition changes
  - Meal Planning
  - Testing/self-monitoring
  - Religion/Spirituality
  - Family Support
  - Support of Friends
  - Doctor visits
  - Diabetes Education Classes
  - Keeping a food log
  - Lose weight
  - Meditate
  - Check my feet
  - Keep a log of blood glucose readings
  - Reduce Stress
  - Other (please list) \_\_\_\_\_.
9. Things that make it **easy** for me to manage diabetes are (check all that apply):
- Exercise/Physical Activity
  - Meal Planning
  - Changing eating habits
  - Taking medications (pills, insulin, etc)
  - Talking with my physician
  - Talking with a family member with diabetes
  - Talking with my friend(s) with diabetes
  - Talking with a friend who does not have diabetes
  - Talking with a family member who does not have diabetes

- ? My religion/spirituality/God
- ? Having Insurance coverage
- ? Going to diabetes classes
- ? Testing/self-monitoring
- ? Losing weight
- ? Taking herbal medicines
- ? Eliminating Stress
- ? Other (please list) \_\_\_\_\_

10. I have attended diabetes self-management education **classes**:

- ? 1-2 times
- ? 3-4 times
- ? 5-6 times
- ? 7-10 times
- ? 11 times or more
- ? Have never attended

11. Things that make it **difficult** for me to manage diabetes are (Check all that apply):

- ? Cost of medications (pills, insulin, etc)
- ? Daily testing/monitoring
- ? Injecting insulin
- ? Changing eating habits
- ? Stress
- ? Giving up foods I like
- ? Close neighborhood place to exercise
- ? Safe neighborhood place to exercise
- ? Amount of Insurance co-payment
- ? Cost of supplies (test strips, monitor, lancets, syringes)
- ? Other Health problems (please list) \_\_\_\_\_
- ? Other (please list) \_\_\_\_\_
- ? Cost of insurance
- ? Lack of insurance
- ? Cost of foods
- ? Losing weight
- ? Not enough insurance coverage
- ? Exercising/Physical Activity
- ? Talking with my physician
- ? Don't know about classes

12. **Exercise/physical activity** that I do now to manage my diabetes are (check all that apply).

- ? Walk outside
- ? Jog/run
- ? Use stationery bike inside
- ? Aerobics
- ? Dance
- ? Tennis
- ? Attend YMCA/YWCA
- ? Other (Please list) \_\_\_\_\_
- ? Use treadmill
- ? Work in Garden
- ? Ride bicycle outside
- ? Use stair stepper
- ? Yoga
- ? Lift weights
- ? Swim
- ? Do not exercise at present
- ? water aerobics

13. Types of **support** I need for managing diabetes are (check all that apply):

- ? Talking with Pastor/Minister
- ? Telephone support line
- ? Family support
- ? Friend support
- ? Assistance with paying for medicines

- ? Assistance with access to testing supplies (monitor, syringes, strips, lancets)
- ? Walking/exercise partners
- ? Assistance with cost of insurance
- ? Self-management instruction offered in-home
- ? Support group
- ? Transportation to doctor visits
- ? Help with losing weight
- ? A patient advocate to attend doctor visits with me
- ? Changing my eating habits (fewer carbohydrates, smaller meals more times a day, eating more fruits and vegetables, etc).

14. I presently **weigh** more than my doctor says I should weigh (over weight).

? Yes ? No      Height \_\_\_\_\_      Weight \_\_\_\_\_

15. I **check** my blood sugar/glucose.

? Once per day                      ? Twice per day                      ? Do not check  
 ? Three times per day              ? More than three times per day

16. I have been **diagnosed** with diabetes for

? 3-6 months	? 7-11 months
? 1-2 years	? 3-5 years
? 6-10 years	? 11-15 years
? 16-20 years	? 21-25 years
? 26-30 years	? More than 30 years

17. In the **past 30 days**, I have **exercised**/been involved in **physical activity** (walking, jogging, gardening, raking/mowing the yard, bicycling, aerobics, swimming, etc)

? Once in the past 30 days  
 ? Two-Three times in the past 30 days  
 ? Four-six times in the past 30 days  
 ? Seven-ten times in the past 30 days  
 ? More than 10 times in the past 30 days  
 ? Have not exercised/been involved in any physical activity in the past 30 days.

Please list the **Type** of activity you have done \_\_\_\_\_.

18. The number of servings of grains, beans, and starchy vegetables that I eat each day are:

? 1-2      ? 3-4      ? 5-6      ? 7 or more      ? I do not keep count.

19. I take **pills** to manage diabetes.

? Once per day                      ? Twice per day  
 ? Three times per day              ? I do not take pills

20. I take **insulin** to manage diabetes.
- ? Once per day
  - ? Three times a day
  - ? I do not take insulin
  - ? Twice a day
  - ? More than three times per day
21. A test that measures the average level of blood sugar over the past three months is called a “hemoglobin **A one C**” (HbA1C) test. About how many times over the past year has a doctor, nurse, or other health professional given you the “A one C” blood test?
- ? Once
  - ? Three times
  - ? More than four times
  - ? Twice
  - ? Four times
  - ? Don't know
22. I engage in physical activity/exercise for at least 20 minutes each time
- ? Once a week
  - ? 2-3 times per week
  - ? Do not exercise each week
  - ? 3-4 times per week
  - ? 5 or more times per week
23. The number of servings of **fruits** that I eat each day are:
- ? 1-2
  - ? 3-4
  - ? 5 or more
  - ? I do not keep count.
24. The number of servings of **vegetables** that I eat each day are:
- ? 1-2
  - ? 3-4
  - ? 5 or more
  - ? I don't keep count
25. When diabetes is discussed in my **family**, we talk about (check all that apply).
- ? How I am feeling
  - ? What to eat or not to eat
  - ? Cost of medications
  - ? Doctor visits
  - ? Exercising/physical activity
  - ? Losing weight/dieting
  - ? Family members who have
  - ? Family members who had diabetes
  - ? Getting family members tested
  - ? Monitoring blood sugar/glucose
  - ? Testing supplies needed
  - ? Taking medications
  - ? Other (please list) \_\_\_\_\_
26. Diabetes runs in my family (other members have, or if deceased, had diabetes/**hereditary**).
- ? Yes
  - ? No
  - ? Don't know of anyone else in family with diabetes or who had diabetes.





Appendix G  
INTERVIEW GUIDE  
The Women

1. What is diabetes?
2. What do you do to manage your condition?
3. What makes it easy for you to manage your condition?
3. What makes it difficult to manage diabetes?
4. What do you do to stay healthy?
5. What type of support do you have for managing your condition?
6. What type of support do you need?
7. What recommendations have you been given for managing your condition?
8. What is important for managing diabetes?
10. Have you ever been offered or had an HbA1c test?
11. When were you diagnosed, and how did you come to know that you had diabetes?

## Appendix G.1

### INTERVIEW GUIDE

#### Diabetes Self-Management Health Educators

1. What is diabetes?
2. How is diabetes managed?
3. What behaviors are prescribed for managing diabetes?
4. What makes it easy to manage diabetes?
5. What makes it difficult to manage diabetes?
6. What type of support is needed for managing diabetes?
7. What are the benefits of self-management education?
9. What are the barriers to diabetes self-management for African American women?
10. Why do you think more African Americans are not represented in diabetes self-management classes?
11. Why do you think the prevalence of diabetes is so high in African Americans?
12. What type of education is needed to assist African Americans with managing diabetes?

Appendix H

USF IRB Approval



APPENDIX H

November 18, 2003

F. Bridgett Rahim-Williams, MA  
PO Box 3286  
St. Petersburg, FL 33731

Dear Ms. Rahim-Williams:

Your new protocol (IRB #101936) entitled, "African American Women with Type-2 Diabetes: Understanding Self-Management" including the informed consent forms (Health Educators & Diabetic Participants) has been reviewed under expedited review categories number six and seven (6,7). Having made any required revisions, the approval period for your protocol is shown on the stamp below. This information shall be presented to the Institutional Review Board-02 at its next convened meeting on December 12, 2003.

You should take special note of the following:

- Approval is for up to a twelve-month period, after date of initial review. A Research Progress Report to request renewed approval must be submitted to this office **by the submission deadline in the eleventh month of this approval period**. A final report must be submitted if the study was never initiated, or you or the sponsor closed the study.
- Any changes in the above referenced study may not be initiated without IRB approval except in the event of a life-threatening situation where there has not been sufficient time to obtain IRB approval.
- All changes in the protocol must be reported to the IRB.
- If there are any adverse events, the Chairperson of the IRB must be notified immediately in writing.

*Please note: Based on the new HIPAA Privacy Rule, if you are generating, collecting, using, or disclosing private health information about subjects, they cannot be enrolled into your research study without signing an appropriately approved Authorization Form. Please forward a copy of the approved authorization form from the site's privacy officer for the file*

If you have any questions regarding this matter, please do not hesitate to call Christy Stephens at (813) 974-3216 or myself at (813) 974-9343.

Sincerely,

Paul G. Stiles, J.D., Ph.D.  
Chairperson, IRB-02

PGS: cas

pc: Dr. Angrosino

<b>IRB Approval</b>	
FWA 00001669	
IRB Number:	101936
From	11/13/03
Thru	11/11/04

OFFICE OF RESEARCH • DIVISION OF RESEARCH COMPLIANCE  
INSTITUTIONAL REVIEW BOARDS, FWA No. 00001669  
University of South Florida • 12901 Bruce B. Downs Blvd., MDC235 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX (813) 974-5618

Appendix I

WEIGHT STATUS OF STUDY PARTICIPANTS

BODY MASS INDICATORS (BMI) CUTPOINTS FOR ADULTS

Source: Centers for Disease Control and Prevention, United States Department of Health and Human Services

Underweight	BMI less than 18.5
Overweight	BMI of 25.0 -29.9
Obese	BMI of 30.0 or more

WEIGHT STATUS OF WOMEN

N=25

PERCENTAGE

Overweight	12	48%
Obese	12	48%
Normal	1	4%

COMPOSITE OF WEIGHT STATUS OF WOMEN BY AGE

AGE	OVERWEIGHT	OBESE	NORMAL	TOTAL
40-49	1	1	0	2
50-59	4	2	1	7
60-69	3	6	0	9
70-79	3	3	0	6
80-89	1	0	0	1

Appendix I

WEIGHT STATUS OF STUDY PARTICIPANTS

OVERWEIGHT and OBESE STATUS

PERCENTAGE OF OVERWEIGHT STATUS BY AGE			N=12
AGE	OVERWEIGHT	PERCENTAGE	
40-49	1	8.33%	
50-59	4	33.33%	
60-69	3	25%	
70-79	3	25%	
80-89	1	8.33%	

PERCENTAGE OF OBESE WEIGHT STATUS BY AGE

N=12

AGE	OBESE	%
40-49	1	8%
50-59	2	17%
60-69	6	50%
70-79	3	25%
80-89	0	0

Appendix J

**DIABETES JEOPARDY**

<b>SELF-MONITORING</b>	<b>HEALTH</b>	<b>NUTRITION</b>	<b>SUPPORT</b>	<b>Points Color Code</b>
100	100	100	100	Yellow
200	200	200	200	Blue
300	300	300	300	Green
Daily Double	Daily Double	Daily Double	Daily Double	Red

**Self-Monitoring (Glucose):**

- When
- How Often
- Meaning of results
- Action to take
- Other

**Health:**

- Exercise/Physical Activity
- Medications (insulin, pills, none, over-the-counter, etc)
- Physician Visits
- Personal Care (checking feet, etc)
- Stress
- Weight Loss/monitoring
- Mental Health (depression)
- Other

**Nutrition:**

- Meal Planning (several small meals a day, healthy snacks)
- Food Choices > Label Reading
- Serving sizes

**Support:**

- Diabetes Team Make-up (Patient, Health Educator, Physician, Nurse, Dietician/Nutritionist, Exercise Physiologist, Counselor, etc)
- Family > Support Groups > Peers/Friends > Church

## About the Author

F. Bridgett Rahim (Newkirk) Williams received a Bachelor's Degree in English from Spelman College in Atlanta, Georgia in 1975. She received a Master's Degree in Communication from the University of South Florida in 1995, and a Master's Degree in Public Health Education from the University of South Florida in 2003. Ms. Rahim-Williams is a public health professional with over 15 years of experience in minority health program management; social and community services; evaluation of program services; contract negotiation and management; technical assistance to community based organizations; community outreach and education; and health education and prevention. She has also taught anthropology courses at the University of South Florida-St. Petersburg campus.

Ms. Rahim-Williams' public health career has included positions as Medical Health Care Program Analyst/Coordinator, Health Education Program Manager, Program Director, Health Services Manager, Operations Manager, Health Services Manager, Project Coordinator, Contract Manager, Program Specialist, Health Educator, Disease Intervention Specialist, and Operations and Management Consultant.