# 4549

### LOCUS OF CONTROL, QUALITY AND OUTCOMES OF CARE AMONG MANAGED CARE PATIENTS WITH DIABETES IN HAWAI'I

## A DISSERTATION SUBMITTED TO THE GRADUATE DIVISION OF THE UNIVERSITY OF HAWAI'I IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

IN

SOCIOLOGY

December 2004

By Beth E. Waitzfelder

Dissertation Committee:

Eldon Wegner, Chairperson Albert Robillard Libby Ruch D. William Wood J. David Curb

©Copyright 2004 by Beth E. Waitzfelder

#### ACKNOWLEDGEMENTS

Gratefully acknowledgement goes to Dr. J. David Curb for his encouragement to undertake this graduate program, and the educational support provided by the Pacific Health Research Institute. I also wish to thank all of my committee members, particularly Dr. Eldon Wegner, for lending their knowledge, advice and insights to this dissertation research.

My sincere appreciation also goes to my family, friends and co-workers for their continued support throughout this process and for helping me to achieve this goal.

This dissertation research was conducted as part of the Translating Research Into Action (TRIAD) Study. The project described was supported by cooperative agreement U48/CCU916382 from CDC/NIDDK. Its contents are solely the responsibility of the author and do not necessarily represent the official views of CDC/NIDDK.

#### ABSTRACT

Locus of control (LOC) is a psychological concept with particular sociological relevance. Theoretical and empirical evidence support LOC as a mechanism mediating social, economic and cultural disparities. Current information on LOC and health is limited by measurement issues and small samples. The objectives of this study were to: 1) assess the factorial structure of a diabetes-specific LOC (DLOC) instrument; 2) describe socioeconomic and racial/ethnic differences in DLOC; and 3) measure the relationship of DLOC to quality of care, self care behaviors and intermediate outcomes.

This study was conducted as part of the Translating Research Into Action (TRIAD) Study, a multi-center study of the quality of care for people with diabetes enrolled in managed care health plans at six sites in the United States. The sample for this dissertation study included 1106 Hawai'i participants who completed the 18 item DLOC instrument. Factor analysis was used to identify domains of DLOC. Scales were developed to measure these domains and subsequently used in multivariate analysis.

Two significant domains of DLOC were identified in this study, internal and chance. Differences among study subgroups defined by age, gender, educational achievement, income and race/ethnicity were identified. The quality of care received was not related to internal DLOC. Patients with a high chance DLOC orientation were more likely to receive some services, possibly resulting from poorer health status. A high internal DLOC was significantly associated with not smoking, daily self-monitoring of blood sugar and spending more time

exercising. Individuals with a high chance DLOC orientation were significantly more likely to smoke, spend more time shopping and preparing food and caring for their feet. They were also less likely to monitor blood sugar. Neither internal nor chance DLOC was associated with physiological outcomes of diabetes. Internal DLOC was associated with fewer comorbidities, diabetes symptoms, better mental health and physical functioning summary scores. Chance DLOC was associated with more comorbidities, diabetes symptoms and lower physical functioning.

The association of socioeconomic position and DLOC lends further evidence to support LOC as a social, as well as a psychological phenomenon, and as one mechanism leading to disparities in health.

ABSTRACT	V
LIST OF TABLES	ix
LIST OF FIGURES	xi
LIST OF ABBREVIATIONS	xii
CHAPTER 1: Introduction	1
CHAPTER 2: The Burden of Diabetes	5
CHAPTER 3: Disparities in Health	8
Socioeconomic Status and Health The Effects of Race, Ethnicity and Culture on Health and Health Care	8 .11
CHAPTER 4: Quality of Care	. 17
Quality of Care as a Measure of Organizational Effectiveness Quality of Care for Diabetes	.18 .22
CHAPTER 5: Locus of Control	.26
Concepts and Definitions Measurement of LOC Socioeconomic Position and LOC Age, Gender and LOC Race, Ethnicity and Culture and LOC Health and LOC Diabetes and LOC Diabetes Anowledge and LOC Diabetes Knowledge and LOC Perceived Risk Associated with Diabetes and Related Complications LOC and Health Care LOC and Adherence to Treatment Recommendations LOC and Psychological and Physiological Outcomes and Comorbidities. Health LOC, Quality and Outcomes of Care for Diabetes	.26 .28 .32 .35 .43 .43 .43 .43 .43 .44 .49 .53 .55 .57
CHAPTER 6: Research Questions and Hypotheses	.60

# TABLE OF CONTENTS

Patients in Hawai'i with Dispatas
DLOC and Quality of Care63
DLOC and Self-Care
DLOC, Intermediate Outcomes and Comorbidities
CHAPTER 7: Methods
Procedures
Study Sample73
Sample Bias74
Independent Variables74
Dependent Variables
Covariates
Analytic Procedures
Statistical Methods
CHAPTER 8: RESULTS
Factorial Structure of Peyrot and Rubin's DLOC Instrument
Socioeconomic Position and DLOC
Race/Ethnicity and DLOC107
Quality of Care for Diabetes and DLOC113
Self-care Behaviors and DLOC117
Intermediate Outcomes, Comorbidities and DLOC119
CHAPTER 9: CONCLUSIONS AND DISCUSSION
Study Limitations
Concepts and Measurement
DLOC – The Comparison of Groups
DLOC and Self-care Behaviors
Process Quality of Care Indicators and DLOC133
DLOC and Diabetes-Related Comorbidity and Outcomes
Directions for Future Research136
Appendix A – Exemption Approval Letter from University of Hawai'i
Committee on Human Subjects138
Appendix B – TRIAD STUDY Baseline Patient Survey140
Appendix C – TRIAD STUDY Medical Record Review Form
Literature Cited

LIST OF TAB	LES
-------------	-----

Table Page
7.1: Sample Characteristics74
7.2: Recoded Race/Ethnicity Variable78
7.3: Crosstabulation of Race/Ethnicity with Asian Category Variables79
7.4: Component Correlation Matrix – Oblique Rotation
7.5: Rotated Component Matrix – Orthogonal Rotation
7.6: Total Variance Explained86
7.7: Two and Three Factor Solutions: Item Loading and Internal Consistency89
8.1: Comparison of DLOC Factorial Structure Reported by Peyrot and Rubin to Hawai'i TRIAD Study Sample Results
8.2: Responses to DLOC Items
8.3: Mean Internal and Chance DLOC Scores by Age and Gender101
8.4: Mean Internal and Chance DLOC Scores by Education and Gender102
8.5: Mean Internal and Chance DLOC Scores by Income and Gender
8.6: Percentage by DLOC Type, Gender, Age, Education and Income
8.7: Adjusted and Unadjusted Mean Internal DLOC Scores by Race/Ethnicity107
8.8: Mean Chance DLOC Scores by Race/Ethnicity
8.9: Percentage of Cases for Racial/Ethnic Groups by DLOC Type
8.10: Percentage of Respondents That Received Each Process Quality of Care Indicators

Table		<u>age</u>
8.11:	Self-care Behaviors and DLOC	. 117
8.12:	Intermediate Outcomes and DLOC	.122

ŕ

# LIST OF FIGURES

Figure	<u>Page</u>
7.1: Scree Plot of Full Factor Orthogonal Model	87
8.1: Adjusted Mean Internal DLOC by Race/Ethnicity with 95% Confidence Intervals	108
8.2: Adjusted Mean Chance DLOC by Race/Ethnicity with 95% Confidence Intervals	110
8.3: Percentage of Type A (Hi Internal/Lo Chance) and Type D (Lo Internal/Hi Chance) by Race Ethnicity	112

## LIST OF ABBREVIATIONS

CASRO – Council of American Survey Research Organizations

- CHS Committee on Human Subjects
- DLOC Diabetes-related LOC
- HEDIS Health Employer Data Information System
- IRB Institutional Review Board

LOC – LOC

- NCQA National Committee on Quality Assurance
- TRIAD Translating Research Into Action (TRIAD) Study

#### **CHAPTER 1: INTRODUCTION**

Diabetes is among the most prevalent and costly diseases in the United States, both in terms of economic costs and diminished quality of life. Despite strong evidence that diabetes can be prevented by changes in lifestyle, and that the incidence of major complications, such as renal failure, amputation and blindness, can be reduced by known efficacious treatment, the prevalence of diabetes continues to rise and major complications continue to occur at high rates. It has also been well documented through epidemiological evidence that diabetes disproportionately affects minority populations and the poor. In the United States, reducing disparities in health has become a national priority and has had a substantial impact on improving access to health care for all Americans. At the same time, escalating health care costs have forced the issue of accountability in health care leading to increased scrutiny of health care system performance with regard to quality of care.

Despite efforts to improve access and quality of care, there is substantial evidence that quality of care for diabetes remains less than optimal and disparities continue to exist with regard to intermediate and long-term outcomes of the disease. These findings indicate the presence of mediating factors that may result in differences in quality and outcomes of care for some diseases, including diabetes, among populations that have access to health care. Theoretical perspectives and empirical evidence suggest that one mediating factor, health related LOC (LOC), might be important in understanding why some

people with diabetes receive poorer quality of care and experience worse outcomes of the disease than others.

The objectives of this dissertation study are to:

- describe the association of diabetes-related LOC (DLOC) with age, gender, race/ethnicity and socioeconomic status among patients receiving care under managed health care systems in Hawai'i;
- assess the utility of DLOC in explaining differences in quality of diabetes health care; and
- assess the utility of DLOC in explaining differences in intermediate outcomes of diabetes.

This study will make a number of important contributions to the understanding of chronic illness among minority populations and factors contributing to the quality and outcomes of diabetes health care. An exhaustive search of the medical, sociological and psychological literature revealed only a few published studies addressing LOC among Asian populations and none could be found that specifically studied Asian American populations with diabetes. In addition, not a single research study was found examining LOC, either in a general sense or with regard to health, among Pacific Islanders.

This study would also illuminate the relationship of patient characteristics as predictors of quality of care for diabetes. While the quality of care for diabetes has shown steady improvement over the past decade, there remains a group of individuals with diabetes and access to health care that for unknown reasons, continue to receive sub-optimal quality of care. The concept of quality of care is

almost invariably measured as if it was purely the function of health care organizations. The patient's role in health care is, however, interactional and quality of care is likely to be affected by patient characteristics, attitudes and behaviors. Diabetes related LOC (DLOC), specifically high internal DLOC, may enhance the role of patients as consumers of health care, resulting in the receipt of higher quality of care than other individuals who perceive the DLOC for their disease as external to themselves, or as a matter of chance.

Although the quality of care for diabetes has continued to improve, clinical outcomes for the disease have not improved at the same pace. The apparent explanation for this phenomenon has been noncompliance of patients with recommended treatment and lifestyle changes. This study may shed light on a possible underlying cause of patients' inability or unwillingness to fully comply with treatment recommendations.

Lastly, the results of published reports of the structure and correlates of DLOC are inconsistent and inconclusive. This study will constitute the largest study of DLOC in the United States and include a greater degree of population diversity in terms of race/ethnicity and socioeconomic status than other previously published studies. In addition, the wealth of data collected in the larger study of which this DLOC component is a part, will enable more comprehensive assessment of the relationships of DLOC with processes and outcomes of care than other published reports.

Data for this DLOC study were collected as part of the Translating Research Into Action (TRIAD) study, a five-year, multi-center study of patients with

diabetes receiving care in managed care systems, funded in 1998 by the Centers for Disease Control and Prevention (CDC) and the National Institute of Digestive Disorders and Kidney Disease (NIDDK). The primary objective of the TRIAD Study is to assess the importance of managed health care organizational and systems factors in the quality of care for diabetes. Study sites include California, Indiana, Michigan, New Jersey, Texas and Hawai'i. The Pacific Health Research Institute is conducting the study in Hawai'i and the author is a Co-Investigator and Project Coordinator on the study. In total, the study includes approximately 11,000 patients nationally with more than 2,500 study participants in Hawai'i. A parallel study was also conducted by the Veterans Administration at sites corresponding to five of the six TRIAD study sites. The TRIAD II Study, including the Hawai'i site, has recently been funded to continue this project for an additional five years.

This dissertation is organized in nine chapters. Following this introduction, Chapter 2 describes the burden of diabetes nationally and in Hawai'i. Chapter 3 discusses disparities in health with regard to socioeconomic status, race/ethnicity and culture. Chapter 4 presents an overview of theoretical and empirical perspectives on quality of health care in general and specifically for diabetes. Chapter 5 is a comprehensive literature review of LOC. Chapter 6 describes the specific research questions and hypotheses of this dissertation. Research methods are presented in Chapter 7, study results in Chapter 8 and study conclusions and discussion comprise Chapter 9.

#### **CHAPTER 2: THE BURDEN OF DIABETES**

An estimated 16 million people in the United States have diabetes mellitus and nearly 800,000 people develop the disease each year (CDC 1997). Economic studies have found that persons with diabetes account for 15% of all United States health care expenditures and that the total annual costs attributable to diabetes are estimated to be \$98 billion (Rubin, Altman and Mendelson 1997; American Diabetes Association 1998). Nearly 190,000 deaths each year are attributable to diabetes and it is the leading cause of new cases of blindness among working-age adults, end-stage renal disease and non-traumatic amputation (CDC 1997). People with diabetes have 2 to 4 times the risk of people without diabetes for cardiovascular disease and are also at increased risk for neuropathy, complications of pregnancy and dental disease (CDC 1997; The Carter Center of Emory University 1985; Vinicor 1994; Wingard and Barrett-Conner 1995). Diabetes also has a major impact upon the quality of life experienced by people with the disease and their ability to function at normal levels of activity (Harris 1995).

Among a population of 1.24 million in the State of Hawai'i (United States Census Bureau website), the number of individuals with diabetes has been estimated to be almost 60,000 (Hawai'i Department of Health 2002). A significant factor in the prevalence of diabetes in Hawai'i is the population composition. National epidemiological studies have demonstrated that minority (non-white) ethnic populations are disproportionately affected by diabetes (Carter Center of Emory University 1985). Minority ethnic groups comprise close to 70%

of Hawai'i's population, and a number of studies have examined diabetes prevalence among racial and ethnic groups in Hawai'i (State of Hawai'i 1993). Prevalence rates per 1,000 persons reported by the Hawai'i Health Survey in 2001 show the highest rates among Japanese (75.9 per 1,000) and Chinese (54.0 per 1,000) residents (Hawai'i Department of Health 2002). Although these rates indicate that the prevalence of diabetes is higher in other ethnic groups than in Hawaiians/Part Hawaiians, they are based primarily on self-report survey data and are not age adjusted. In addition, anecdotal reports suggest that differences in socioeconomic status, access and utilization of health care could contribute to higher measurements of prevalence rates as a result of a higher degree of engagement with health care systems. An older study reports age adjusted rates among populations on O'ahu for 1958-59 per 1,000 people as 21.8 for Filipinos, 20.1 for Japanese, 19.7 for Koreans, 14.6 for Chinese and 7.3 for Caucasians (Sloan 1963, in Fujimoto 1995:665). A more recent study reported that the age adjusted prevalence diabetes among Hawaiian men was 3.0% compared to 1.4% for Caucasian men, and 3.1% for Hawaiian women, compared to 1.5% for Caucasian women for the time period 1980-86 (Johnson 1989, in Fujimoto 1995:675). In terms of outcomes, the mortality rate due to diabetes among Hawaiians/Part Hawaiians is reportedly 222% (two-hundred twenty-two percent) higher than for all United States races combined (Blaisdell 1993).

Another important factor in Hawai'i is the increased prevalence of diabetes associated with age. The population age composition of Hawai'i residents is

proportionately older than elsewhere in the United States, and with a 52% increase in the number of Hawai'i residents 60 years of age and older from 1980-1990, the number of people with diabetes in Hawai'i is expected to increase (International Center for Health Promotion and Disease Prevention Research 1994). Based on data from the Hawai'i Diabetes Data Network (HDDN), the rates for individuals ages 44 years and under is 8.7 per 1,000 compared to 73.8 per 1,000 for individuals ages 45-64 years, 144.6 per 1,000 for individuals ages 65-74 years and 144.1 for those 75 years and older (HDDN 1997). Comparative United States prevalence rates for these age groups are 6.8 for those ages 44 years and under, 54.1 for ages 45-64 years, 96.0 for ages 65-74 and 82.6 for ages 75 and older (CDC 1993). Recent data from the Honolulu Heart Program also indicate a high prevalence of diabetes among older populations in Hawai'i, finding that 36% of elderly (70-93 year old) Japanese men have diabetes by World Health Organization (WHO) criteria and another 32% more have impaired glucose tolerance (Rodriguez et al. 1996).

#### **CHAPTER 3: DISPARITIES IN HEALTH**

Disparities in health are the result of unequal distribution of particular diseases among population groups as well as differences in access, quality of care and outcomes of diseases among those that suffer from them. Genetic factors, socioeconomic factors and cultural factors contribute to these disparities. Unraveling the complex inter-relationships of socioeconomic status, race, ethnicity and culture, and genetics poses a formidable challenge for research.

#### **Socioeconomic Status and Health**

The simple explanation for disparities in health is to attribute the phenomenon to inequalities in health care. However, as Marmot and Wilkinson contend, disparities in health have much deeper social roots and create problems with which the health care system must contend (1999:3). The theoretical causes for health disparities are sociological, psychological and biological in nature. The most compelling argument for the social causation of health disparities is evidence that such disparities exist throughout the entire social hierarchy and are not confined to the poorest members of society. The Whitehall study in particular, provided evidence of differences in rates of mortality and serious health conditions such as coronary heart disease and stroke, even among managerial levels of British workers (Marmot, Shipley and Rose 1984). Although differences in health can be related to occupational hazards of the

physical work environment, findings from the Whitehall and other studies indicate increased health risk attributable to social environments as well.

Characteristics of the social environment can affect health in positive and negative ways. The mechanisms of the negative affect upon health associated lower social status are theorized to be psychological in nature. Among the most frequently identified psychological states associated with diminished health in this regard are stress and diminished sense of control (Brunner and Marmot 1999:17). There are numerous indirect effects of lower social status upon health as well, such as lack of social support, transportation problems, stressful residential environments, including limited access to parks and other areas for physical activity, and availability of fresh fruits and vegetables.

Link and Phelan (2000) propose a "fundamental cause" explanation for social disparities in health. Although the authors do not make reference to Bourdieu, they suggest that, "...those who command the most resources are best able to avoid the risks and take advantage of the protective factors, resulting in the emergence of an SES gradient in these factors" (2000:39). Similarly they contend that the sense of control experienced by those at the upper levels of the social hierarchy provides a sense of dominance and well-being, protective of health, and inversely related to the stress associated with the lack of control perceived by those at lower levels of the hierarchy.

From a biological standpoint, the stress associated with occupying lower levels of the social hierarchy and the associated sense of lack of control, is thought to lead to chronic anxiety, insecurity, low self-esteem and social isolation,

which in turn is thought to undermine mental and physical health (Brunner and Marmot 1999).

Socioeconomic status also affects access to health care. Even among relatively affluent societies with sophisticated health care systems, socioeconomic factors create barriers to obtaining adequate health care and achieving the best possible outcomes of care. For the uninsured, seeking health care is often postponed until symptoms are unbearable and prescribed medicines may be unaffordable, resulting in avoidable adverse outcomes of illness. In 1997 it was reported that an estimated 43 million Americans were uninsured (Lohr 1997). More recent estimates from the United States 2000 Census suggest that this number is increasing. Simply having insurance however, does not completely solve the problem. Depending on market conditions, physicians may be unwilling to accept the lower reimbursement rates offered by Medicaid and Medicare. Public hospitals, traditionally the haven of the poor for health care, are closing throughout the United States at an alarming rate, due to financial insolvency. Medicines may still be unaffordable, particularly for the chronically ill and the elderly. In the case of diabetes, the majority of patients take some form of medication on a daily basis for their entire lives. Out of pocket costs for oral and injectable medications and necessary blood sugar testing supplies may be substantial, even for those with health insurance.

#### The Effects of Race, Ethnicity and Culture on Health and Health Care

The meaning of racial and ethnic groupings and the inclusion of such categories in social research is increasingly being scrutinized and challenged. It has been correctly observed that these distinctions are often based more on social affiliations such as language, religion, territory and history than biological differences (Smaje 2000:115). In many instances, the result of racism and discriminatory practices has rendered the inclusion of race as variable as little more than a proxy measure for socioeconomic status. This is not to suggest that race and ethnicity have no place in social research, it does however call for a theoretical basis for the inclusion of these variables in any particular study.

Kleinman in particular has drawn attention to the historicity and culturespecific nature of biomedical constructs (1977, in Zola 1983). As suggested by Zola, early studies of ethnic differences in illness rates identified working conditions, living arrangements and poverty as contributing causes of differential illness rates, but at that same time, indicted those with cultural differences for their failure to assimilate which would theoretically enable them to rise out of poverty (1983:232). According to Chrisman and Kleinman, people whose ethnic identity is an important part of their daily lives will act in accordance with the traditional beliefs and practices of their ethnic heritage (1980, in Zola 1983:228). This pertains to the characterization of physical signs and sensations as illness as well as to the acceptability of treatment options. Zola has identified two important ways in which culture influences the conceptualization of illness (1983:88). The first is the prevalence of the condition among the social group.

He cites many examples in which the high prevalence of a given condition within a particular social group results in the consideration of the condition as normal and the absence of the condition as aberrant. Although the condition may not be considered good, it is accepted as natural and inevitable. The perceived fatalistic attitude towards diabetes among Native American and Pacific Islander populations may be related to the high prevalence of diabetes among these populations.

The second way in which culture influences the conceptualization of illness suggested by Zola is relationship of the physical sign or symptom to the value structure of that particular culture (1983:89). Common physical conditions such as tiredness, menstruation and obesity may or may not be considered problematic within various cultural contexts. With particular relevance to diabetes, the relationship of obesity to body image among different ethnic groups has been has been investigated in a number of studies with findings that suggest that obesity has more of a negative impact upon body image among Caucasians and Asians than for other ethnic groups.

Importantly, Zola cautions against the tendency to stereotype characteristics of various ethnic groups since many factors such as relative acculturation, within group differences as well as individual differences can affect the relative importance of traditional cultural values for any particular individual. In addition, he cautions against the exploitation of cultural awareness for use as a tool to redirect patients away from their chosen lifestyle practices towards those that may be more consistent with other (e.g. medical) value systems.

Emphasizing the dyadic nature of both minority culture within a larger majority culture, and of the individual patient and the health care system, Zola advocates the importance of awareness and appreciation and cautions against the identification of cultural differences as a mechanism for blaming the patient for medical conditions (1983:236).

In the case of diabetes, it is clear that there are also genetic factors that predispose certain racial/ethnic groups to having the disease. Type I diabetes, characterized by early age of onset and thought to be an auto-immune disorder causing the destruction of the cells that produce insulin, is most prevalent among Caucasians. For the time period 1985-89 the prevalence of Type I diabetes was estimated to be 20 per 100,000 population for Caucasian men, compared to 17 for non-Caucasian men, and 15 for Caucasian women, compared to 14 for non-Caucasian women (Dokheel 1993, in LaPorte, Matsushima and Chang 1995:44). Type II diabetes, characterized by increasing prevalence with age and resulting in diminished insulin production and/or insulin resistance, is more prevalent among non-whites. For 1993, the percentage of the White population with diagnosed diabetes was 9.79 among individuals age 65, compared to 16.21 for Blacks in the same age group (Kenny, Aubert and Geiss 1995:65). Although lifestyle factors, particularly diet and exercise, play an important role in the development and outcome of Type II diabetes, genetic factors have been identified in association with this form of diabetes as well. Rates of diabetes among Pacific Islanders and Native Americans are among the highest in the world. As stated earlier, rates for Hawaiians are more than double those of

Caucasians, and among some Native American tribes, the prevalence of diabetes has been estimated to be nearly 40% (Gohdes 1995). It has been hypothesized that among populations that were exposed to periods of famine, the ability to store energy with maximum efficiency (the "thrifty" gene) resulted in a survival advantage (Neel 1962 in Fujimoto 1995:676). However, this genetic factor is also thought to contribute to excess obesity under circumstances when food is abundant. This is particularly important today as modern American society is being increasingly characterized as obesogenic. The interaction of genetic and environmental factors is illustrated in a study of Samoans, finding that the rate of diabetes among those living in urban areas was more than double that of those living in rural areas with more traditional lifestyles with regard to food and physical activity (Zimmet 1981, in Fujimoto 1995).

Among insured populations, important differences in health care quality, utilization and outcomes have been identified. For example, screening rates for cancer have been found to be lower among minority group patients (Lee 2000; Powe 1994, 1996). Poorer prognosis, increased mortality and decreased 5-year survival rates for several gynecological cancers have been reported for African American women in comparison to Caucasian women (Haynes 1996). With direct relevance for diabetes, results of the Medical Outcomes Study published in 1996 report that elderly and poor and chronically ill patients had worse physical outcomes of care in managed care systems than in a more traditional fee-forservice system (Ware et al. 1996). These findings suggest that there is an interaction between patient characteristics and the characteristics of health care

systems that can result in inequality of health care services and outcomes of care. Recent results from the TRIAD Study did not reveal significant differences in the processes of care that constitute measures of quality (Brown et al. 2003). This report did, however, identify some significant differences in health outcomes among racial/ethnic groups included in the study.

Factors associated with age and cultural differences have also been found to be associated with sub-optimal health care and outcomes. Incomplete knowledge about health and available health care resources can have a direct impact on lifestyle choices and help-seeking behavior. For example, failure to recognize early signs of disease and having inaccurate ideas about causes can delay treatment with adverse results (Lee 2000). It has been reported that elderly patients in particular do not seek information as a coping mechanism for illness. Fear and distrust of the health care system by patients, especially if an individual has had previous negative experiences, is also an obstacle to care (Haynes 1996). Embarrassment, denial, level of acculturation and the cultural acceptability of treatment may also act as impediments to health.

Although access to health care is a necessary condition in reducing disparities in health, access alone is insufficient. The relationships among socioeconomic factors, health and health care are complex, and from a practical standpoint, much remains to be learned about the precise mechanisms by which health and health care are affected by socioeconomic status. In addition, these mechanisms are likely to vary and interact among population groups of different age and cultural backgrounds and within the context of specific diseases and

health care systems. A better understanding of the socioeconomic and cultural barriers to health and health care is critical to the task of reducing disparities, both in terms of public policy and in order to tailor interventions to improve health outcomes for a particular population or condition.

#### CHAPTER 4: QUALITY OF CARE

Clinical quality of care can be thought of as one aspect of the organizational performance of health care systems. Ironically, the prominence of health care quality as a public issue today is directly attributable to efforts to contain the alarming escalation of health care costs over the past two or three decades. While it was generally agreed upon that the escalation of health care spending could not continue unchecked, neither the American public nor health care providers were willing to compromise what they perceived to be the best health care in the world in order to cut costs. Efforts to achieve the highest value in health care services, or the balance between highest quality and lowest cost, have driven health care reform since the 1970's.

These efforts have forced the definition and objective measurement of clinical quality as an indicator of organizational performance and the performance of individual health care providers. The advent of "managed" care represents a step in the evolutionary process of the organization of health care delivery designed to meet the dual objectives of maximizing quality and minimizing cost.

Although initially regarded with much fear and speculation that managed care was sacrificing both quantity and quality of care in the interest of reducing costs, or "stinting", there is no evidence that the overall performance of managed care organizations is substantially better or worse than other organizational forms (Miller and Luft 1997; Greenfield et al. 1995). In fact, all health care delivery today is managed to some degree, and there is as much organizational diversity

among managed care organizations as there is between it and other organizational forms.

#### **Quality of Care as a Measure of Organizational Effectiveness**

The imperative to be accountable and competitive in the health care marketplace has required that the continuous, comprehensive and systematic measurement of quality of care be a central function for all health care organizations. Measures, or indicators, of clinical care quality are generally condition or disease specific, and fall into two general categories, process measures and outcomes measures. Theoretically the selected process measures are directly related to outcomes, although temporally they may be quite far apart. For example, annual eye exams to check for early signs of retinopathy are a process measure for diabetes. However, it may take many years before this condition develops.

Because these quality indicators are disease specific, clinical experts in conjunction with disease specific organizations/entities develop most quality measures. In the case of diabetes, clinical quality indicators, or standards of care, have been produced by the American Diabetes Association and are updated on a regular basis (1998a). Disease specific indicators have been compiled for the most common conditions affecting various age groups and are utilized in the single, most widely used quality measures for managed care organizations, the Health Employer Data Information System (HEDIS) measures (McGlynn 1996; Olden and Mims 2002). Developed by the National Committee

on Quality Assurance (NCQA), these measures were designed primarily to enable employers to compare the performance of managed care plans, and with cost considerations, choose plans to offer to employees.

The organizational importance of quality measurement is evidenced by the fact that HEDIS measures are also used as the basis for the accreditation of managed care organizations by the NCQA. The majority of published studies examining quality of care among health care organizations, for various conditions and for various patient groups, use HEDIS measures as quality indicators. An important result of the development of these measures and their use in accreditation, is that it forced managed care organizations to collect information about quality in order to be competitive. Prior to this, differences in the amount and types of data collected by health care organizations made the standardized comparison of organizational performance difficult, if not impossible.

Another set of widely used measures is the Consumer Assessment of Health Plans (CAHPS) measures (Agency for Health Care Policy and Research 1999). These measures are primarily focused on customer service issues such as the ability to get an appointment as soon as desired, being treated with respect, etc., rather than on the assessment of clinical care. The CAHPS measures do include items measuring satisfaction with some aspects of the clinical encounter as well, e.g. perceiving that the doctor listened to the patient and spent enough time with them. Although these measures do address some important aspects of quality of care, they are actually more indicative of

organizational performance with regard to customer service, rather than measures of clinical care quality.

With regard to diabetes, there have been substantial efforts to develop standardized and clinically valid measures of quality of care. The Diabetes Quality Improvement Project (DQIP) involved the collaboration of Centers for Medicare and Medicaid Services, the National Committee for Quality Assurance (NCQA) and the American Diabetes Association in the development of a set of comprehensive performance measures for diabetes (Saadine et al. 2002, Fleming et al. 2001). These DQIP measures were then incorporated into HEDIS, the American Diabetes Association Provider Recognition Program, the American Medical Association Diabetes Measures Group, and the VA performance monitoring program (Kerr et al. 2004).

The development of standardized outcomes measures actually preceded the development of HEDIS and CAHPS measures. The Short Form 36 (Stewart, Hays and Ware 1988) and later shorter versions, provided a series of valid and reliable measures across several domains of quality of life, including physical functioning, general health, emotional well being, role functioning and other areas. These outcome measures are the most widely used generic instruments in published studies of health care quality and organizational performance.

While the measurement of clinical quality as an indicator of organizational performance has undoubtedly led to improvements in both the quality and costs of care, some troubling issues still remain. In many instances, performance in the area of processes of care has not been found to be consistently related to

clinical outcomes, particularly for diabetes (Brook et al. 1990; Renders et al. 2001; Petitti et al. 2000; Norris, Engelgau and Narayan 2001). Although most measures of quality are based on clinical evidence, they also serve the purposes of accountability and as a basis of comparison "shopping" by purchasers. Process measures generally fail to capture other important clinical information that is relevant to outcomes. For example, knowing that blood pressure is monitored and the proportion of patients with controlled blood pressure is important. However, knowing the proportion of patients that were appropriately treated with medication may be more relevant to clinical outcomes.

With rare exceptions, the concept of health care quality is measured as if it was a "pure" function of organizational performance, not unlike the quality of a bolt produced by a steel plant. The intrinsically interactional process of health care, particularly the influence that individual patients may have on the quality of care they receive, is generally disregarded in quality measurement, especially with regard to process measures of quality. Although some gross adjustments are made in measurement in terms of age and gender, patients are generally treated as identical and passive objects upon which the health care system acts. This phenomenon has been recognized by organizational theorists, as Scott (1992) suggests, outcomes are never pure indicators of organizational performance "...since they reflect not only the care and accuracy with which work activities are carried out but also the current state of the technology and the characteristics of the organization's input and output environments " (1992:353). Scott identifies this issue of the relationship between organizational performance

and outcomes as particularly characteristic of health care and cites Mann and Yett (1968) who suggest that it makes no more sense to consider health as an output of health care organizations than to consider beauty as an output of beauty salons (1992:353).

It seems obvious that a young, highly educated, assertive urban resident may make demands upon health care providers that other patients might not, for example, an elderly Asian patient in a rural area, and as a result, experience differences in the care they receive. Differences in care may also result from more passive patient behaviors, such as not filling prescriptions, not going to the lab for additional tests, or not keeping appointments. Clearly, patient characteristics, life circumstances and behaviors may play a role in determining the quality of the health care they receive and the health that they experience. Patient perceived LOC is one factor that may affect how patients view their role in health and health care and in turn, affect the quality of care they receive.

#### Quality of Care for Diabetes

Optimal care and outcomes for diabetes relies upon vigilant self-care by patients in regulating their levels of blood sugar through compliance with medication regimes, self-monitoring of blood sugar, proper diet and exercise. Optimal care also relies upon proper medical treatment to monitor carefully the disease and to detect, treat and minimize the progression of complications. While health care providers can educate, encourage and support patients' ability to manage their own diabetes, their ability to influence the behavior of patients is limited. Health care providers do have somewhat greater control, however, over the quality of medical care received by patients. Consequently, disease management programs typically include interventions directed towards patients, but focus primarily on improving the quality of care provided to patients.

Effective medical treatment of diabetes has been well-established. Improving glycemic control (levels of blood sugar) has been demonstrated to reduce the risk of microvascular complications by 30% for non-insulin dependent diabetics (85% of diabetics) and 70% for insulin dependent diabetics (The Diabetes Control and Complications Trial Research Group 1993; The UK Prospective Diabetes Study Group 1998a). Improved blood pressure control can reduce diabetes-related complications by 24% and total mortality by one-third (The UK Prospective Diabetes Study Group 1998a). Lipid (cholesterol) management can reduce coronary events by 55% and total mortality by 43% (Pyorala et al. 1997). Early detection and treatment of retinopathy can reduce the risk of severe vision loss by 60-70% (Early Treatment of Diabetic Retinopathy Study Research Group 1991). From an economic perspective, several diabetes interventions have been demonstrated to be cost effective, including glycemic control (The Diabetes Control and Complications Trial Research Group 1996), blood pressure control (The UK Prospective Diabetes Study Group 1998), lipid management (Schwartz et al. 1997) and early detection and treatment of retinopathy and nephropathy (Javitt et al. 1994; Kiberd and Jindal 1995; Siegel et al. 1992). Diabetes education has also been demonstrated to be cost effective,

potentially improving self-care behavior, metabolic control, and patient knowledge (Brown 1990).

The results of clinical trials and the consensus of clinical experts in diabetes have provided evidence to support standardized guidelines for the optimal medical treatment of patients with diabetes. The American Diabetes Association, a number of states, including Hawai'i, and various other diabetes-related organizations, have developed specific guidelines for the care of diabetes (American Diabetes Association 1998; Hawai'i State Department of Health 1998). Features common to all of these guidelines include at least one of each of the following on an annual basis: outpatient visit; hemoglobin A1c (HbA1C) laboratory test (this is a measure of glycemic control); eye exam; lipid level (laboratory test for cholesterol levels, related to cardiovascular risk); urinalysis (to assess kidney function); and foot exam (to check for peripheral nerve damage via sensitivity test and any resulting injuries or infections that may be slow to heal as a result of vascular damage).

Despite known effective treatments and widely agreed upon standards of quality of care for diabetes, there is substantial evidence that many patients do not receive optimal care. Studies have shown that up to 60% of diabetic patients do not receive annual HbA1c testing, up to 75% have no documented foot exam, more than half are not referred for an annual eye exam, and less than half receive annual lipid and urinalysis testing (Beckels et al. 1998; Brechner et al. 1993; CDC 1997a Engelgau et al. 1998; Hiss 1996; Jacques et al. 1991; Kenny et al. 1993; Marshall et al. 1996; Peters et al. 1996; Simon et al. 1999; Weiner et

al. 1995). Recent data from the HDDN indicate that the quality of diabetes care in Hawai'i, as elsewhere in the United States, falls considerably below optimal standards of care in terms of annual eye exams, HbA1c testing, lipid level testing and urinalysis (HDDN 1999). In fact, Wagner et al. (2001) report that fewer than half of United States patients with hypertension, depression, diabetes, and asthma are receiving appropriate treatment.

The previous chapters have outlined the import issues with regard to quality of care for diabetes. The next chapter describes the concept of LOC (LOC) and illuminates the role of LOC in health, health care and specifically within the context of diabetes.
#### Chapter 5: Locus of Control

#### **Concepts and Definitions**

LOC is a psychological concept, defined in a simple sense by Lefcourt (1982:33) as "...a generalized expectancy for internal as opposed to external control of reinforcements". Initial interest in the concept stemmed from its potential to shed light on the mechanisms that cause and perpetuate social inequality, and more recently for its role in explaining differences in health behaviors and outcomes. Julian Rotter (1966) introduced the concept of LOC within the larger psychological framework of social learning theory. Although life for everyone is comprised of autonomous actions as well as circumstances and events which an individual has no control over, LOC refers to the perception of an individual of the degree to which his life is controlled by himself or by forces outside of himself. Whereas prior social learning theory emphasized motives in predicting behavior, Rotter's unique contribution was the additional consideration of *expectancy* of reinforcement in the understanding of behavior (Lefcourt 1982:33). At the heart of this idea is the causal attribution of outcomes by individuals to their own actions. According to this formulation of social learning theory, behavioral reproduction relies not only upon learning the connection between cause and effect or action and reward, but also that the effect is contingent upon, or under the personal control of, the individual's actions.

LOC was initially conceptualized as unidimensional, with individuals having a central tendency to perceive control over life trajectory as either internal or external. Some of the characteristics that have been associated with an

internal LOC orientation include autonomy, goal orientation, seeking and utilizing information and opportunities, self-efficacy, future orientation, persistence despite failure, and the attribution of success to one's own efforts. Some of the characteristics that have been associated with external LOC orientation include fatalism, conformity, submission to authority, acceptance of dependence on others, dogmatism, believing in fate, luck and chance and others as important determinants of life events, present oriented, ceasing efforts in the face of failure or avoiding failure, and uncertainty about causes of success.

Subsequent thinking and research have refined the concept as multidimensional, moving away from the notion that individuals could be classified as internal or external, but instead recognizing that LOC may be a general tendency of individuals but could vary in terms of different aspects of individual's life. For example, an individual may feel a strong sense of internal control over occupational success but acknowledge a greater role for chance and luck in their personal relationships. In addition, perceived LOC can shift over the life course in response to experiences and events. Major unanticipated positive and negative events such as winning the lottery, triumph over adversity, the loss of a job or being diagnosed with a terminal condition can substantially alter one's perception of sense of control over life. It is important to acknowledge that Rotter was interested in the application of this concept within the realm of clinical psychotherapy. The ability to intentionally modify an individual's perception of control is critical to the success of psychotherapy and is relevant in many other fields as well, including education, rehabilitation of criminals, and health care.

Although LOC is conceptualized as an individual psychological characteristic, the historical context in which it emerged and the early research applications of this concept provide evidence of the utility of the concept in the understanding of social phenomena. Using some of Lefcourt's (1982) examples, the aftermath of the Nuremberg trials left the world shocked by the apparently total relinguishment of morality and human compassion by the Nazis in their treatment of Jews and other designated undesirables during World War II. Publicized events that took place during the Vietnam War raised similar issues. The central focus of the Calley trial was whether the soldiers responsible for the destruction of a Vietnamese village were acting as individuals or purely under the direction of superior officers and/or sanctioned wartime policies. While it was difficult enough to conceive of reasoning human beings committing such atrocities in the context of war, the experiments of Stanley Milgram (1963) made it abundantly clear how readily "average" people would abandon their own personal values and morality in the face of authority and participate in harmful behavior toward others.

#### Measurement of LOC

According to Rotter's original work in the area of social learning theory, expectations for internal and external control of reinforcement of behavior are learned through social interaction and experience and represented opposite ends of a single continuum. This broad psychological conceptualization of LOC corresponds to the sociological concepts of agency and structure as external

LOC was originally conceived of as control by social systems. In 1973, Levenson contended that external LOC was multidimensional, distinguishing between beliefs in external control by social structure or powerful others, and beliefs in chance or luck as playing an important role in one's life trajectory. Similarly, it was increasingly recognized that individuals could not be simply categorized in terms of LOC beliefs and were likely to have different control expectancies for different areas of their lives.

Many psychologists during this time acknowledged a general tendency to view success and failure in different ways, with success attributed to internal control and failure more subject to external forces, was acknowledged by many psychologists during this time period. As the complexity of LOC perceptions was increasingly recognized, psychologists advocated the development of more specific measures to address critical aspects of particular areas of life experience. The psychometric properties of many LOC instruments were extensively analyzed, prompting Lefcourt to caution that the appeal of the analytic process can overshadow the more compelling pursuit of seeking the ramifications of control (1982:187).

Although initial interest in LOC was primarily focused on the contribution the concept could make in understanding social stratification, the largest area of research application of the concept has been in the area of health. Wallston and colleagues are primarily credited with the development of LOC instruments for application in health research (Wallston et al. 1976, 1981). Beginning with a unidimensional framework similar to Rotter's, Wallston et al. initially developed

the Health LOC (HLC) scale (1976). In collaboration with others, Wallston et al. subsequently developed a multidimensional instrument to measure health related LOC, the MHLC (Wallston, Wallston and DeVellis 1978), utilizing a three dimensional approach incorporating the distinctions in external LOC domains proposed earlier by Levenson. The MHLC was essentially a generic measure of health LOC and did not distinguish between chronic and acute illness. Recognizing the difficulties experienced by individuals with chronic illness in interpreting some of the items, e.g., "If I do the right things, I can stay healthy", Wallston et al. (1994) developed Form C of the MHLOC which could be easily modified for use with specific medical conditions, while retaining essentially the same items and wording of the MHLC. Factor analysis of results of this new instrument resulted in the reduction of items from 24 to 18, and a four factor subscale structure, with the distinction within external control ( "Powerful Others") between medical professionals and others (e.g. family and friends).

Prior to the publication of Form C of the MHLC, other investigators also modified the original MHLC for use with specific medical conditions such as diabetes, cancer and heart disease (Wallston, Stein and Smith 1994:536). Among these was a diabetes specific instrument developed by Ferraro et al. (1987). After testing, this instrument contained 18 items and three subscales were identified (Internal, Chance and Powerful Others). This instrument was reported to be internally consistent, reliable and to demonstrate content, criterion and construct validity (1987:769). A potential limitation of this instrument acknowledged by the authors was that its predictive ability of actual control

behaviors by people with diabetes was not measured. In addition, the instrument was constructed at a 10<sup>th</sup> grade reading level, which made it inappropriate for use with some populations. Drawing on the work of attributional style theorists and LOC research, Bradley et al. (1990) used scenarios to investigate perceptions of control for positive and negative outcomes among people with tablet treated diabetes. Through factor analysis, the authors identified three perceived control scales (Personal, Medical and Situational). They assessed the correlations between scores on these scales and metabolic control, weight, depression, anxiety, well-being and treatment satisfaction. The authors conclude that personal control (but not medical control) was associated with better glucose control, psychological well-being and satisfaction with treatment.

Peyrot and Rubin (1994) developed a diabetes specific LOC instrument, similar to Ferraro's, except they intentionally designed it for appropriate use with older children, adolescents and adults. The final instrument (DLOC) consisted of six items in each of three DLOC domains (internal, powerful other and chance) and was used with a sample of 164 patients with diabetes. The authors acknowledge their interest in the paradoxical finding of an association of internality and negative diabetes outcomes reported in some studies. Based on their factor analysis, they found the structure of DLOC to be more complex than the original three factor conceptualization (1994:996). They not only identified the same dual externality attribution theorized by Wallston et al., but also identified two dimensions of internal DLOC – autonomy and self-blame. Correlations of diabetes DLOC scales and glycemic control, aspects of self-

management, diabetes specific competence and emotional well being were assessed. The authors concluded that the five factor structure of this instrument had better explanatory power in terms of health outcomes than earlier three and four factor models (1994:994). This instrument was subsequently used in a study of approximately 300 low-literacy, economically deprived African Americans with Type 2 diabetes (Hayes et al. 2000). The instrument was administered orally and response categories were slightly re-worded (e.g. "very much agree" instead of "strongly agree"). The authors report that the structure and correlates of the DLOC were more similar than different in their study population in comparison to the largely Caucasian, more highly educated population studied by Peyrot and Rubin (Hayes et al. 2000:121). A significant negative relationship was also found between belief in chance and glycemic control.

## **Socioeconomic Position and LOC**

Perhaps most salient to contemporary issues during the 1960's, at the time that interest in LOC was growing, was the increased recognition of social and racial inequality. LOC was thought to offer some insights about the formation and reproduction of social class. It was theorized that racial and ethnic minorities, and those of lower socioeconomic status, did not relate their social situation to their own actions in the same way that white, upper class individuals did. Interpreted alternately as the desire by those in upper classes to claim responsibility for their success and the desire by those in lower classes to

absolve themselves of failure, numerous studies focused racial and class differences in internal and external LOC during this time period. A study by Battle and Rotter (1963) found that lower class black children displayed more frequent scores indicating externality than either middle class black children or lower class white children. The Coleman report (1966) found that a child's belief that academic outcomes were determinable by his own efforts was the best predictor of achievement in school. Stephen and Delys (1973) provided further evidence of the gradient in the relationship between socioeconomic status finding that among lower class children, those from homes below the poverty line were more external than those above the poverty line. Lefcourt summarizes this early research by stating, "...*members of the lower socioeconomic class never exceed the more fortunate middle and upper class persons in statements of internality"* (1982:29).

The theoretical explanation for these findings was that environmental deprivation and social denigration encountered by the poor and disenfranchised minorities result in a sense of fatalism and futility. Furthermore, it was theorized, that individuals in this situation cannot reasonably be expected to blame themselves for their life circumstances. An external LOC orientation, therefore, is hypothesized as a coping mechanism. This external orientation theoretically affects subsequent achievement and attenuates potential to break out of lower socioeconomic position. For example, Lefcourt (1982:82) reports that "…*slum dwelling blacks that find the schools to be remote, repressive, middle-class institutions, usually score at least one standard deviation below white averages* 

on tests of intelligence and achievement." According to Lefcourt, the conclusion of many of these studies was that helplessness and a perceived inability to affect one's fate was a natural response to socioeconomic deprivation and denigration (1982:25). Implicit in this theoretical approach is that internality is contingent upon success.

Sociological theory and more recent research support the linkage of socioeconomic position and perceived LOC. LOC appears to be both a product of social stratification and a mechanism in its reproduction. An internal LOC orientation was found in many early studies to be an important factor in academic achievement and differences among students from varying economic and racial backgrounds were apparent, even among grade school children. While there are a few exceptions, educational achievement is an essential component of the social capital described by Bourdieu (Joppke 1986) and is requirement for the occupation of middle and upper tiers of the social structure. The presence of this characteristic in childhood among the poor and disenfranchised minorities particularly reduces the likelihood of later success. While individuals may retain a sense of agency, as did the working class British boys studied by Willis (1977), it is with the conscious or unconscious resignation to the hopelessness of attaining a higher social and economic position. The attribution of low socioeconomic position to circumstances beyond one's control may be a realistic and understandable coping mechanism, particularly for children, but at the same time it may diminish the perceived possibility for achievement.

Support for the theoretical proposition that LOC attribution is a coping mechanism associated with social class is provided by a 1981 study by Husaini and Neff. The study focused on the relationship between life events, social class, LOC and depression. The authors found that the total number of reported life events, as well as the total number of undesirable, unexpected, or unpreventable events, was actually higher for middle and upper class individuals, and that LOC (internality) was positively associated with social class. Depressive symptomatology was not found to be simply a function of life events, however, leading the authors to conclude that LOC, as a coping style, influenced the degree of psychological impairment resulting from life events. Lefkowitz, Tesiny and Gordon (1980) similarly found that externality was associated with depression among children and that the joint effects of low family income and externality produced the highest depressions scores. Landau (1995) in a study of Israeli widows, did not find this interaction effect and concluded that both LOC and socioeconomic status were independently related to depression and life satisfaction, and that LOC reflects more than socioeconomic resources.

# Age, Gender and LOC

Lefcourt (1982) suggests that perceived competency may increase with maturity and that perceived contingency (the relative attribution of control over outcomes to self) may decline with maturity. Frazier (2002) describes internal LOC as a dynamic personality disposition enabling older adults to manage the challenges of aging. While many studies have focused on LOC at a given point

in time among particular age groups (e.g. elderly, adolescents), few studies have compared LOC across age groups or studied changes in LOC within a given population longitudinally. Blanchard and Fields (1988) suggest that age moderates the relationship between LOC and coping styles, finding that an internal LOC orientation among a younger population was associated with coping styles of escape/avoidance, hostile reactions and self-blame, whereas internal LOC was negatively associated with these particular coping styles among an older population. An interesting study by Rhee and Gatz (1993) revealed that self-ratings of internality were higher among older individuals than college students. However, college students rated older people as being more external than older people rated themselves, and conversely, older people rated college students as being more internal than self-ratings by college students. Molinari and Niederehe (1985) found that older people tended to be more external (chance orientation) and that higher self-ratings of internality and lower selfratings of powerful others (external) LOC were associated with lowered rates of depression among the elderly but not among younger populations.

In general, women are thought to have a greater powerful other (external) LOC orientation than men. Results of an early study on school achievement reported by Lefcourt suggest that self-attribution was important for achievement among boys but that only the personal value placed upon intellectual attainment was related to achievement among girls (1982:85). Sadowski et al. (1983) report that for men and women, a higher internal LOC was associated with higher self esteem and ego strength. In a more recent study, Kuther (1998) identified

differences between men and women in terms of gender role orientation but no mean differences among men and women. With regard to health, Furnam and Kirkcaldy (1997) report that men relied more on provider control for their health than women, and that women were more diet conscious and had greater beliefs in the role of psychological factors in the etiology of illness. Hale (1985) reported an association of LOC orientation and psychopathology among older females but not among males. Finally, an Australian study about weight reported that men tended to avoid self attribution for excess weight but claimed success for being trim, whereas results for women revealed an opposite pattern (Scott 1997).

# **Race, Ethnicity and Culture and LOC**

As described previously, much of the research that has been done in the area of LOC, particularly in the early years, has been focused on social inequality. For this reason, it is very difficult to isolate the effects of race, ethnicity and culture of published reports, from the broader social context in which they were conducted. In a social commentary of 1944, Arnold Rose describes the sense of futility of African Americans, "*Thus both the lack of a strong cultural tradition and the caste-fostered trait of cynical bitterness combine to make the Negro less inhibited in a way which may be dangerous to his fellows. They also make him more lazy, less punctual, less careful, and generally less efficient as a functional member of society.*" (Rose 1944:302 in Lefcourt 1982:84). While this description is dated, it clearly illustrates the confusion of class and culture, and the ease with which the effects of social structure can be

ascribed to cultural characteristics (or the lack culture!) of a given group. These same derogatory adjectives have since been used to describe other disenfranchised minority groups. It may be that the persistent finding that minority groups tend to be more external LOC orientation and more fatalistic in general, has very little to do with culture and is primarily an effect of socioeconomic position. In addition to social position, evidence that age and gender are differentially associated with LOC necessitates consideration in the assessment of culture and LOC. Cultural sensitivity and appropriateness in the conduct of research can also affect findings and need to be considered. For example, in a study of racial differences in the preference for immediate versus delayed gratification (thought to be important in achievement), Strickland (1972) found that the race of the experimenter was more important than LOC orientation in predicting the selection of delayed versus immediate rewards among black children. Similarly, many studies of cultural differences in LOC are based upon populations of immigrants and may reflect the experience of immigration as well as true cultural differences.

There is some evidence that ethnicity and culture may have an independent effect upon LOC orientation. Among the earliest studies was Boor's (1976) international study of suicide. Based on the postulated relationship of external LOC and depression, Boor found that among ten countries, those with the highest internal LOC scores (New Zealand and Israel) had the lowest suicide rates and those with the highest external LOC scores (Japan and Sweden) had the highest suicide rates (in Lefcourt 1982:119). The finding that suicides, and

higher external LOC scores, more frequently occurred in Sweden and Japan than in Australia, New Zealand and the United States was attributed to cultural differences in paternalism and the importance of autonomy versus fitting in (Boor 1974, in Lefcourt 1982).

In a study of nine Western European countries, Jensen (1990) found that country of residence was more predictive of LOC than age, gender or social class. Bachiocco, Credico and Tiengo (2002) in an Italian study of pain LOC orientation reported a significant effect of ethnocultural area and education on internality. Westbrook (1984) compared beliefs about personal responsibility for health in Sweden and Australia, finding that Swedes had significantly stronger beliefs about personal responsibility. Studying the relationship between collectivism and individualism as cultural manifestations, Santiago and Tarantino (2002) found that contrary to their expectations, the Puerto Rican sample scored lower in external LOC than did the United States sample. In a study of health LOC in Florida, Smiley et al. (2000) found that differences among Hispanic and non-Hispanic women remained after controlling for age and education; however, these differences decreased with acculturation.

Several recent studies comparing African Americans and Caucasians provide insights that contrast those of earlier reports. Tashakkori and Thompson (1991), found that Black adolescents rated themselves more positively than Whites in self-esteem and specific self beliefs (e.g. social attractiveness) and had slightly greater expectations about future academic success, although they perceived greater external control pertaining to personal efficacy. Tabb (1990)

failed to find any significant difference in LOC between black and white elderly individuals.

Asian populations have been studied in cultural contrast to Western populations, and the American cultural value of individualism in particular, as they are thought to be more collectivist in nature, and consequently more external in LOC. Wrightson and Wardle (1997) studied LOC among Caucasian, South Asian and Afro-Caribbean mothers. Not only were the health-related scores of South Asian women higher than the other two groups for external LOC (chance and powerful others) as might be expected, they were also higher for internal LOC. These differences remained after controlling for health status and occupation.

A number of studies have focused on LOC among populations in Hong Kong. Hamid and Chan (1998) report that LOC was related to psychological and occupational distress among Chinese professionals, although women scored higher on externality and reported more physical symptoms. Siu et al. (2001) also studied managerial stress in Hong Kong and found that age was positively related to well-being, with older managers reporting fewer sources of stress, better coping and a more internal LOC. Holroyd, Molassiotis and Taylor-Pilliae (2001) studied Filipino domestic workers in Hong Kong and reported that although the level of health related behaviors was generally high, two-thirds of the subjects saw reinforcement for health behaviors as either a matter of chance or being influenced by powerful others.

Liu et al. (2000) studied adolescents in mainland China finding that behavioral problems were related to high external LOC, life events and high stress. Sun and Stewart (2000) studied psychological adjustment to cancer in China and reported that even in a collective culture where supernatural beliefs are widespread, internal LOC related positively and "chance" beliefs related negatively to psychological adjustment to cancer.

Few studies could be found that examined LOC among Japanese populations. Tsukamoto (1999) reported an association between health LOC and anxiety and depression among cancer patients. Horie (1991) addressed a methodological issue with regard to health LOC and Japanese populations in Japan, finding a somewhat different subscale structure that includes the supernatural as part of external LOC, and developed a Japanese LOC scale.

As with Horie's (1991) identification of the supernatural as an important domain of external LOC among Japanese populations, other cultural differences in domain attribution within the broader context of external LOC have also been identified. The importance of religious faith and belief in the role of God in controlling health outcomes, particularly among African Americans, has been increasingly recognized (Wallston et al. 1999, Welton et al. 1996, Bekhuis et al. 1995, Holt et al. 2003, Swinney 2002).

Some researchers have also suggested that national health policy can influence perceived health LOC, again emphasizing the importance of environmental context in understanding national and cultural differences in LOC. Stein, Smith and Wallston (1984) suggest that availability, cost and status of

health care professionals can affect health care utilization and LOC beliefs. They specifically point to a de-emphasis on self-reliance for health in the United States, leading to increased health care utilization, despite a culture that tends to value individuality and self-reliance in general. Westbrook, Nordholm and Mcgee (1984) studied the reactions of health care providers in Sweden and Australia to the same series of patient case histories and transcribed interviews. They found that Swedes had stronger beliefs regarding personal responsibility for health and that Australians were more likely to perceive the patients as dependent, depressed and poorly adjusted.

Despite an exhaustive literature search, with the exception of a few studies that included Australian and New Zealand populations, no published reports could be found that specifically focused on or included Pacific Islander populations.

With out a doubt there are differences in LOC orientation associated with cultural difference and socioeconomic strata and it may be difficult to distinguish these relationships for a particular group or individual. However, whether differences in perceived LOC are truly cultural or more the result of socioeconomic factors associated with particular racial and ethnic groups, theoretical arguments and empirical evidence suggest that LOC beliefs of parents are reproduced in children. Lefcourt, in his review of the psychological literature, suggests that both a nurturing and approving environment, as well as the opportunity for active interaction with social and physical environment (i.e. not overly protective, the "push" from the nest), are critical to the formation of an

internal LOC (1982:139). Cousins, Powell and Olvera-Ezzell (1993) studied Mexican-American mothers' interactions with their children and found that mothers with more external health LOC beliefs were less likely to use socialization techniques associated with internalization. Interestingly, the authors report that acculturation was negatively related to internalization techniques, with less traditional mothers using more directive strategies. Familial stability, which may be related to culture as well as socioeconomic position, is also suggested to be important as Lefcourt (1982:138) reports that major trauma during childhood, such as the break up of the family, has been found to be associated with the development of an external LOC orientation.

# Health and LOC

As described previously, sense of control, and the lack thereof, has been identified as a potentially important factor in health status and as a contributor to health disparities. LOC, or the attribution of control, to oneself (internal), to others (external) or to chance, or fate has been extensively studied in the psychology and sociology literature. This theoretical framework has been extended and applied to general health, health behaviors and specific medical conditions.

LOC is a particularly important concept with regard to chronic conditions such as low back pain, asthma, diabetes and other long term debilitating illnesses, which require patients to cope with and manage symptoms on a frequent, if not daily basis, and for a long period of time. Receiving the diagnosis

of a chronic health condition can be considered, to use Lefcourt's (1982) terminology, a "massive dose of fate". To the extent that health status and outcomes are dependent upon patient actions, in addition to the actions of health care providers, LOC may play an important contributing role in explaining health disparities among individuals and patient groups. Furthermore, patient LOC beliefs may play a mediating role in the relationships of patients and health care providers, resulting in differential processes and outcomes of care.

Health-related fatalism, or the sense that neither the patient himself nor important others, including health care providers, has any control over one's health status or outcomes, is an extreme dimension of LOC. Fatalism is particularly relevant to chronic conditions due to the duration of the disease, the coping mechanisms used to live with the condition and the importance of active patient participation in care. There is some evidence that fatalism is culturally related. Fatalism has been specifically been demonstrated to be an important barrier to positive health outcomes for cancer among African Americans (Philips 1999; Hoffman-Goetz 1999; Haynes 1996; Powe 1996) Hispanic populations (Laws and Mayo 1998; Chavez et al. 1997; Carpenter and Colwell 1995) Native Americans (Kaur 1996) and Korean Americans (Lee 2000). Fatalism with regard to diabetes has been shown to be an important factor in the treatment of diabetes among Hispanic populations particularly (Quatromoni et al. 1994; Schwab, Meyer and Merrell 1994), and among non-western populations in general (Larsen 2000).

A critical issue with LOC theory is the degree to which LOC orientation is associated with actual behavior. Health LOC has been studied as a factor in health related behaviors, such as exercise, dietary patterns and smoking among various patient groups (gender, age, sociodemographic and racial/ethnic) and for a variety of medical conditions and diseases. In a general sense, internal LOC has been associated with seeking information or knowledge, and in order to utilize it to meet individual objectives (Lefcourt 1982:61). An early study by Seeman and Evans (1962) found that among patients with tuberculosis, those with an internal LOC had more knowledge about their condition than those with an external LOC. Aruffo et al. (1993) found the same result regarding AIDS knowledge among a community health center population. Among the most important studies of LOC and health behavior is the 2001 study by Steptoe and Wardle that included a large sample of young adults from 18 countries. Analysis of the results for 10 health related behaviors (e.g. exercise, smoking, healthy diet, alcohol consumption and seatbelt use) revealed that the odds of engaging in healthy behavior were more than 40% greater for five health behaviors among individuals with the highest internal LOC orientation. High chance LOC scores were associated with a more than 20% reduction in the likelihood of six healthy behaviors. Importantly, health value, thought by some investigators to mediate the relationship of LOC and health behaviors, did not change the observed relationships.

With regard to exercise, Norman et al. (1997) found a weak but significant correlation of LOC dimensions with exercise in a sample of 13,000 adults, and

again, did not find evidence in support of the moderating effect of health value. Gregg et al. (1996) report that controlling for age and body mass index, an internal LOC was significantly associated with a higher level of physical activity among Pima Indian men and women without diabetes, but not among those with diabetes.

Although there have been many studies regarding LOC and smoking behavior, the results of these studies are mixed and contradictory. In a sample of over 11,000, Bennett et al. (1997) found that smokers had higher scores in all three domains of LOC (internal, chance and powerful others) in comparison to those who had never smoked. Among adolescents, Booth-Butterfield, Anderson and Booth-Butterfield (2000) report that tobacco users scored higher on chance and lower on internality than non-tobacco users. Burgess and Hamblett (1994) and Molloy et al. (1997) found no significant differences in LOC among smokers, non-smokers and ex-smokers.

With regard to health care, Nagata (1998,1999) found that both nurse practitioners and medical students underestimated patients' self reported internal LOC.

### **Diabetes and LOC**

There is perhaps no illness or condition in which control issues are more important than diabetes. The importance of taking daily medication as prescribed, maintaining a proper diet, regular exercise, and self-monitoring of blood glucose in achieving positive outcomes and avoiding serious complications has been clearly established. While adequate medical care remains a critical determinant of health status for people with diabetes, without the active participation of patients in their own care, positive outcomes are impossible to achieve.

LOC has been studied extensively within the context of diabetes and is thought to play an important role in patients' experience of this and other chronic medical conditions, including: seeking knowledge about the disease; perceived risks; adherence to recommended treatment; interaction with health care systems and providers; and psychological and physiological outcomes and comorbidities. Examples of amenability of LOC to change as a result of targeted intervention strategies are provided throughout this discussion. The results of published reports studying the association of LOC with each of these areas within the context of diabetes are described below. Overall, findings can be described as inconsistent and inconclusive. Contributing to these inconsistent findings are the use of multiple LOC measures, different approaches to the construction and analyses of subscales, important differences in populations studied, and in many cases, small sample sizes. For the purposes of this review of the literature, evidence presented is limited to studies of adults.

#### Diabetes Knowledge and LOC

One of the characteristics thought to differentiate those with an internal LOC from those with an external orientation is the active seeking, processing and utilization of information in order to support goal oriented behavior. Lefcourt

(1982:61-65) suggests that individuals with an internal LOC orientation have a clearer sense of their own purposes and values and are more likely to seek information, recognize its relevance for goal attainment and utilize the information in decision making. Knowledge is recognized as a critical tool in assisting people with diabetes to actively manage their own condition. Lowry and DuCette (1976), Pawar, Walford and Singh (1999), Reynaert et al. (1995) and Peyrot and McMurry (1985) identified associations between LOC and knowledge levels related to diabetes. Peyrot and Rubin report that diabetes knowledge was not related to internal LOC overall, but separating internal LOC into the domains of autonomy and self-blame, the authors found that diabetes knowledge was negatively associated with self-blame and chance LOC (1994:997). Diabetes knowledge, however, was not consistently related to better patient management or outcomes of the disease as indicated by frequency of self-monitoring of blood glucose and metabolic control.

# Perceived Risk Associated with Diabetes and Related Complications

On a theoretical basis, increased knowledge about diabetes is thought to result in greater appreciation of the risks associated with the disease and consequently, behavioral modification to reduce these risks. In a recent household study comparing healthy African Americans to those with hypertension and diabetes, Plescia and Groblewski (2004) found that older patients and those with chronic disease also tended to have an external LOC orientation. Frijling et al. (2004) measured perceived risk in a large sample of

patients with diabetes or hypertension (N=1194) using the Framingham risk model. The authors found that respondents tended to overestimate their cardiovascular disease risk, overall by more than 20%. More accurate perceptions of risk were found to be associated with male gender, higher scores for internal LOC, lower scores for physician LOC and higher self-rated health status.

The inconsistencies in findings with regard to LOC studies are illustrated on the topic of smoking among people with diabetes. Spangler et al. (2001) report that smoking was associated with higher powerful others (external) LOC in their study of Type 1 diabetes. In contrast, Stenstrom and Anderson (2000) report that smokers showed a lesser belief than non-smokers in powerful others such as physicians and diabetes nurses with regard to diabetes control in their Swedish study of people with Type 1 diabetes.

In a study of first degree relatives of individuals with Type 1 diabetes in Belgium, Hendrieckx et al. (2002) report that prior to testing, stated intention to modify lifestyle if found to be at increased risk for diabetes, was related to higher personal control scores.

### LOC and Health Care

It is important to first acknowledge that getting people with diabetes to assume responsibility for their condition is currently the foremost objective of health care for people with diabetes. While the terminology and thinking about how to achieve this goal may have shifted away from the power-laden concepts of compliance and treatment adherence to more supportive orientations of patient empowerment, the centrality of the importance of patients taking care of their own condition remains. Anderson and Funnell (2000) describe the goal of diabetes treatment as empowering patients to "...actualize their personal responsibility for their diabetes self-management". Langewitz et al. (1997) state, "To be the master of their disease and not its slave is the ultimate goal of many patients with diabetes". Achieving the optimal balance of shared responsibility between patients and their health care providers to result in the best possible outcomes is a major challenge faced by individuals with diabetes, health care providers and health care systems.

A direct relationship between LOC and health care utilization patterns of people with diabetes has been identified by a number of investigators. A recent study by Spikmans et al. (2003) in the Netherlands studied a broad range of predictors of missed appointments with dietitians by people with diabetes and found that only health LOC and obligation to attend were significantly predictors of attendance. In a study of 998 low-income elderly African Americans (some with diabetes), Bazargan, Bazargan and Baker (1998) concluded that hospital and emergency department use were not the result of nondiscretionary behavior as previously thought, finding that LOC had a significant impact upon emergency department use, hospital admissions and office based physician visits. A second report from the same study (Bazargan, Baker and Bazargan 1998a) reported that LOC, and other factors, were related to the receipt of eye examinations. Butler, Secundy and Romberg (1994) report significant correlations between activities of

daily living, self-esteem, depression, LOC and social support systems and health care utilization patterns among hypertensive and diabetic elderly African Americans. Reporting on a culturally sensitive educational program for Latinos with diabetes, Philis-Tsimikas et al. (2001) found that program participants had higher levels of internal LOC, improved diabetes knowledge, were more satisfied with treatment and importantly, received a higher quality of care in terms of standards for diabetes care (e.g. eye exams, specific lab tests, foot exams, etc.) in comparison to matched controls.

A number of studies have compared patient and health care providers' perceptions of control. White, Tata and Burns (1996) found little congruence among doctor and patient pairs about responsibility for controlling diabetes in their study of 90 Type 1 diabetics, and that patients who viewed physicians as in control of good outcomes fared worse in terms of physiological measures. A 1991 study by Petty, Sensky and Mahler in the UK found more positive concordance of belief in control of health by others among patients with diabetes and their physicians. Another UK study by Gillespie and Bradley (1988) also found incongruence of perceived control between patients with poorly controlled diabetes and their physicians, and demonstrated that experimental manipulation of the clinical encounter to directly address and negotiate causal attribution could successfully reduce this incongruence. Auerbach et al. (2002) studied the relationship of the patient and provider control appraisals to metabolic control and found that better metabolic control was associated with patients' desire for

control and physicians' perception of this desire, highlighting the importance of transactional fit between patient and provider expectancies.

The interpersonal dynamics of the clinical encounter have also been examined for the effects on the balance of power and control in diabetes care. Paterson (2001) describes the "*myth of empowerment in chronic illness*" in a study of patients with a long history of diabetes, claiming that health care practitioners contradict their stated goals of empowerment by discounting patients' experiential knowledge of the disease and failing to provide the resources necessary to make informed decisions. Similarly, Gillibrand and Flynn (2001), in their UK study report patient descriptions of "forced" externalizaton of diabetes control to health care professionals.

There is substantial evidence that patients with diabetes differ in their desire for control as well as contextual differences in manner in which patients and health care providers approach diabetes. Hunt, Arar and Larme (1998) interviewed patients with diabetes and practitioners who cared for them, concluding there were critical differences in many key areas. The authors suggest that practitioners tend to presume that failed treatment is indicative of patients' lack of cooperation. Interviews with patients, however, revealed that they understood and were committed to self-care but lacked full access to behavioral options due to poverty and limited social power. A number of other studies provide evidence that patients do not necessarily desire control. In a study of older adults, Robinson-Whelen and Storandt (1992) found that patients with diabetes reported greater belief in powerful others LOC and less desire for

behavioral involvement in the health care process than did non-diabetic patients. Albeit an older study, Ruzicki (1984) found that the majority of patients (64%) of all LOC groups preferred a prescriptive as opposed to a participatory approach to health care.

The general conclusion of these studies is that the fit between patient and health care provider expectations for control are important for good outcomes. With the current health care emphasis on the importance of the patient's role in controlling diabetes outcomes, it may be that patients with an internal LOC are more likely to conform to providers' expectations. The studies described above, however, provide encouraging evidence that changes in clinical approach, as well as interventions intended to alter patients' control orientation, can improve the concordance between patient and provider expectations.

#### LOC and Adherence to Treatment Recommendations

The underlying assumption of much of the research on LOC and treatment adherence, or compliance, is that patients with an internal LOC orientation will recognize the value of health care goals, seek and incorporate information to achieve those goals and adapt their behavior in a manner consistent with desired outcomes. Research evidence provides only limited support for this theory. A meta-analysis of the correlates of diabetes patients' compliance with prescribed medications identified both internal and external motivations as correlates of compliance (Nagasawa et al. 1990). Tillotson and Smith (1996) report a modest but significant relationship between internal LOC and adherence to a weight

control regimen by people with diabetes. As described previously, smoking among people with diabetes has been associated with both internal and external LOC orientations. Peyrot and Rubin (1994), separating internal LOC into the domains of autonomy and self-blame found a significant negative association between self-blame and the frequency of self monitoring of blood glucose, and that exercise was negatively associated with chance LOC (1994:997). Kneckt, Syrjala and Knuuttila (1999) report a weak association between DLOC and adherence to self-care regimen among people with diabetes in Finland. In a study of Pima Indians, Gregg et al. (1996) identified a relationship between internal LOC and physical activity among non-diabetics, but not among people with diabetes. Schlenk and Hart (1984) report a statistically significant relationship between compliance and social support, powerful others LOC and internal LOC in a study of thirty patients with insulin dependent diabetes. Similarly, Alogna (1980) found that compliant diabetic patients tended to exhibit more of an internal LOC than non-compliant patients. deWeert et al. (1990) report that positive attitude was most important with regard to self-care and that knowledge and low orientation on the powerful other LOC were prerequisites for positive attitude.

The results of these studies raise some important questions about the relationship of LOC to treatment adherence. It could be that powerful other LOC, particularly specific to health care providers, may result in a stronger inclination among patients to comply with their doctor's recommendations. Individuals with more of an internal LOC orientation may adhere to treatment recommendations if

they share the value of the outcome and assess the risks of noncompliance in a manner similar to the health care providers. However, if an individual has an internal LOC orientation and does not assess the value or the associated risks in the same manner as their provider, they may feel more comfortable acting in opposition than someone with a powerful other LOC orientation.

#### LOC, Psychological and Physiological Outcomes and Comorbidities

Among the most important indicators of present and future health status and outcomes for individuals with diabetes is measurement of metabolic control. The Diabetes Control and Complications Trial (1993) clearly established that "tight" control of blood sugars is critically important in the prevention of diabetes-related complications such as kidney failure, neuropathy and loss of vision. Approximately twenty studies included the assessment of LOC with regard to metabolic control. Overall the results can best be described as contradictory and inconclusive.

Positive associations between glycosylated hemoglobin (HbA1c), an indicator of metabolic control, were found by Philis-Tsimikas and Walker (2001) in their evaluation of a culturally sensitive diabetes education and treatment program upon 556 patients. Significant increases in internal LOC and decreases in HbA1c, total cholesterol and blood pressure measures were found among program participants one year following the program, in comparison to a control group of patients not enrolled in the program. Peyrot and Rubin (1994) found no association of HbA1c and LOC, but they did find negative association of internal

LOC and a positive association of chance LOC with high blood glucose (1994:997). Surgenor et al. (2000), in their New Zealand study of psychological sense of control and metabolic control among women with diabetes, conclude that optimal metabolic control is significantly associated with overall sense of control and that poor metabolic control was associated with loss of psychological control. Hayes et al. (2000) utilized a diabetes specific measure of LOC in their study of urban African Americans, finding that belief in chance was significantly related to glycemic control and in change in glycemic control over time. Perhaps the strongest evidence for the importance of LOC and glycemic control comes from Reynaert et al. (1995), reporting that among individuals with Type 1 diabetes, those with an internal LOC exhibited better metabolic control, even with a lower level of knowledge and less frequent self monitoring of blood glucose. The authors do note, however, that this effect was less pronounced among those with extremely high scores for internal LOC. Konen, Summerson and Dignan (1993) report an association of acceptable HbA1c levels with low chance LOC. Schwartz et al. (1991) report the association of external LOC with poorer control both in short term follow up and as a predictor of long term control.

In terms of negative findings, Pawar, Walford and Singh (1999) found that patients in a specialized multiple insulin injection trial had poorer metabolic control, despite being more knowledgeable and self-directed. This result may be related to treatment factors as well as LOC perceptions, however. Wallhagan and Lacson (1999), using their own diabetes control perception scale, found no association with HbA1c. Kneckt, Syrjala and Knuuttila (1999) also found no

association of LOC with HbA1c. White, Tata and Burns (1996) report that high powerful other (health professionals) LOC was associated with worse metabolic control. O'Connor, Crabtree and Abourizh (1992) determined that LOC was not a significant predictor of improved HbA1c. Eaton et al. (1992) report no broad strong association of any psychosocial factors, including LOC, with blood sugar levels, although they concede that relationships may exist for some population subgroups. Similarly, Meize-Grochowski (1990) reported little relationship of LOC with HbA1c. Finally, White et al. (1986) reported a negative and significant association between internal LOC and initial and follow up measures of HbA1c.

Published reports provide some evidence of the association of external LOC orientation with other co-morbidities among people with diabetes, particularly depression and high levels of perceived stress. Evidence of this association is reported in studies by Pouwer et al. (2003), Spangler et al. (2001), Butler, Secundy and Romberg (1995), Bell, Summerson and Konen (1995) and Peyrot and Rubin (1994). Machenback et al. (2001) report that controlling for disease severity, an external LOC orientation was among the factors associated with decreased physical functioning and disability among people with diabetes.

#### Health LOC and Quality and Outcomes of Care for Diabetes

An exhaustive search of the literature revealed no studies that have specifically studied LOC as a predictor of quality of care for diabetes. This information would have direct practical relevance in two respects. First, there is some evidence that intervention efforts designed for patients with specific LOC profiles (i.e. internal vs. external) can be effective (Cromwell et al. 1977) and that LOC is modifiable through intervention efforts (Moffatt and Pless 1983; Kennedy et al. 1999). The design of interventions around issues of LOC, either intended to change the orientation of patients or to increase the concordance of patient and physician expectations in the context of the clinical encounter, offers the potential to reduce disparities in health.

In another regard, illuminating the relationship between LOC and quality of care would add an important dimension to the assessment of health care system performance. While it is understood that patients need to cooperate with health care providers to achieve high quality care, as described previously, the relative degree to which patients facilitate or present obstacles to the delivery of high quality care is almost never considered in organizational quality measurement. This is potentially an important consideration in the comparison of performance among population subgroups served by a particular health care organization and in the comparison of performance among multiple organizations. In the case of diabetes, quality of care depends upon patients making and keeping appointments for eye exams and lab tests and seeing their health care provider on a regular basis. While health care organizations can encourage and facilitate these services, it is up to the patient to insure that they get these consultations done. In addition, knowledge about diabetes and active participation in care can increase the awareness patients have about the kinds of services they should have, such as blood pressure checks and foot exams. Patients acting as more competent agents in their own care or as more informed consumers, are more

likely to receive higher quality care. Differences in patient populations, particularly if LOC is associated with specific socioeconomic, racial, ethnic and cultural characteristics, may explain a significant proportion of variation in the quality of care provided to different groups by one health care organization and in differences observed in the performance among multiple organizations. In addition, diabetes related LOC may also be an important factor in explaining the apparent gap between process measures of quality and outcomes of care.

# **CHAPTER 6: RESEARCH QUESTIONS AND HYPOTHESES**

As described in the preceding chapters, LOC is a psychological concept that describes an individual's belief system or attributional style regarding the source of control over their life's events or trajectory. There are, however, socioeconomic and cultural correlates of LOC. It has been theorized that LOC is both the result of and a contributing factor to social stratification. Although it has been studied primarily as a psychological phenomenon, the relationship of LOC to social disparities and stratification makes LOC an area of sociological interest as well.

While an individual is likely to have a general overall tendency toward a LOC orientation, there may differences in the sense of control that an individual has over various aspects their life. LOC instruments designed to measure specific areas of perceived control, such as health or specific health conditions, are thought to be better predictors of behaviors and outcomes related to that condition than more global measures.

Diabetes-related LOC (DLOC) specifically focuses on the beliefs an individual has about the source of control over diabetes symptoms, glycemic control and disease outcomes. An *internal* DLOC orientation, characterized by the belief that one has personal control over their diabetes, is thought to be associated with better glycemic control and diabetes outcomes. An *external* DLOC orientation, sometimes referred to as a "*Powerful Others*" orientation, is characterized by the belief that other people play an important role in diabetes control and outcomes. External DLOC is thought to be related to treatment

adherence, and consequently to enhance diabetes control and outcomes. A *chance* DLOC orientation, characterized by the belief in chance, fate and/or luck as determining diabetes control and outcomes, is thought to be associated with poor glycemic control and outcomes. The evidence to support these theoretical associations, as described in the preceding literature review, is inconclusive as a result of differences in methodological approaches and sample characteristics, as well as problems associated with small sample sizes.

The central research questions and hypotheses of this dissertation address five main areas: the factorial structure of Peyrot and Rubin's (1994) diabetes-related LOC (DLOC) instrument; a description of DLOC orientation of a large sample of people with diabetes in Hawai'i; and the relationship of patients' DLOC orientation with quality of care; self-care; intermediate physiological outcomes and comorbidities.

#### **Factorial Structure of Peyrot and Rubin's DLOC Instrument**

The DLOC instrument developed by Peyrot and Rubin (1994) is reported to have a unique five-domain structure. In addition to four DLOC domains (Internal, Chance, and Powerful Others [comprised of two subdomains – *Powerful Others - Health Professionals* and *Powerful Others – Non-health professionals*]) included in earlier measures, Peyrot and Rubin's instrument reportedly results in a new subdomain within the larger domain of internal DLOC. They describe internal DLOC as comprised of two subdomains – autonomy and self-blame. The authors present evidence of the enhanced utility of this
instrument, and the five-domain structure, in the prediction of diabetes-related self-care and outcomes. In addition, the instrument features more simplified wording of survey items in comparison to previously developed DLOC instruments, enabling the use of this instrument with populations of older children and adolescents as well as adults, and in populations with relatively lower literacy levels. The authors report a fairly robust factorial structure and positive predictive ability for important aspects of diabetes self-care. A subsequent study in an African American population with relatively low literacy levels (Hayes et al. 2000), confirmed that the structure and correlates of the instrument were similar to those found by Peyrot and Rubin.

Although the results of these two published reports are encouraging regarding the utility of this instrument, both reports are based on fairly small samples of patients (Peyrot and Rubin, N=165, Hayes et al., N=300). In addition, while these two populations collectively represent some diversity with regard to race/ethnicity and literacy levels, evaluation of the structure and correlates of this measure in a larger population with greater diversity in terms of race/ethnicity, socioeconomic status and diabetes duration and severity, will provide evidence to inform decisions about future uses of this measure. This study will specifically address the following question:

1. Is the five-domain structure of the DLOC instrument reported by Peyrot and Rubin supported by results based on a large, diverse sample of patients with diabetes in Hawai'i?

#### **DLOC Orientation among Managed Care Patients in Hawai'i with Diabetes**

There is evidence that general LOC orientation (not diabetes specific) varies by gender, age, socioeconomic status and race/ethnicity. There is a paucity of information about LOC among Asian Americans and no published reports could be found regarding LOC and Pacific Islanders. Potential demographic differences in diabetes-related LOC (DLOC) among these groups remains virtually unexplored. This study will:

 Describe DLOC orientation patterns in terms of each of these demographic variables among individuals in Hawai'i with diabetes receiving care in managed care settings.

# **DLOC and Quality of Care**

Certainly, managed care organizational structure and diabetes-specific care management strategies may have a substantial impact on the quality of care delivered. Measuring the impact of these organizational and care management characteristics is the primary objective of the TRIAD Study, with the parallel VA TRIAD Study. With ten participating managed health care plans and more than fifty medical groups, the TRIAD Study has the capacity to isolate the effects of organizational characteristics and strategies by studying them in a fairly large sample of health care organizations. Patient characteristics may also be associated with differences in quality of care. The association of broad patient characteristics, such as Medicaid/Medicare status and race/ethnicity, and quality of care has been studied for a variety of specific medical conditions, including

diabetes. As health care organizations have increasingly focused on quality and access to care, differences across these broad patient characteristics appear to be declining. For example, in a recent paper focussing on Latinos in the TRIAD Study, no significant differences in quality of care among the racial/ethnic groups included (English and Spanish speaking Latinos and Caucasians) in the approximately 4,500 diabetes patients in the study of a subsample of TRIAD participants (Brown et al. 2003).

However, some patients still receive sub-optimal quality of care and there continue to be differences among patient groups in outcomes of care, despite receiving equivalent quality of care. The mechanisms underlying these differences in quality and outcomes of care are poorly understood. DLOC may be an important factor contributing to these differences. Evidence suggests that an internal DLOC orientation is associated with more condition specific knowledge, more effective use of knowledge to meet objectives, and goal directed action. Therefore, it is hypothesized that patients with an internal DLOC orientation will be more knowledgeable about their condition, diabetes self-care, their health plan benefits, standards of quality of care for diabetes, and better able to advocate on their own behalf for quality of care from their physicians and their health plans. The specific hypotheses to be tested in this study are:

3. A high internal DLOC orientation will be associated with better quality of care as measured by seven specific measures of quality of care for diabetes (for example, annual eye exam, foot exam, etc.) and a composite measure of

these seven measures, controlling for age, gender, education level, race/ethnicity and health plan effects.

4. The association of internal DLOC with quality of care will be stronger for measures of quality that require more active participation by patients, specifically eye examinations and lab tests (HbA1c, cholesterol level testing and urinalysis).

#### **DLOC and Self-care**

The relationship of DLOC orientation and actual behavior has not been well established. The use of different DLOC measures with different populations and the measurement of different self-care behaviors have resulted in inconsistent and inconclusive evidence. Theoretically, an internal DLOC orientation would result in more active participation in self-care and adherence to health provider recommendations in the interest of minimizing the risks of diabetes-related complications, in comparison to those with other DLOC orientations. There is some evidence, however, that those with an extreme internal DLOC orientation may actually be less compliant with health care provider recommendations (Reynaert et al. 1995). It has been suggested that these individuals may be more comfortable acting in opposition to others and may fail to adhere to optimal self-care behavior, as a result of rationalizing their own behavior or viewing their behavior as a calculated risk. This study will test the following hypotheses:

- 5. A high internal DLOC orientation will be associated with more frequent selfmonitoring of blood glucose, lower body mass index (BMI), lower rates of smoking, and more time spent on self-care activities than other DLOC orientations, particularly chance DLOC orientation.
- 6. The positive association of high internal DLOC with self-care behaviors will not be as strong among individuals with extremely high (top 25%) internal DLOC.

#### **DLOC, Intermediate Outcomes and Comorbidities**

As DLOC is hypothesized to contribute to both quality of care and selfcare for diabetes, it may also contribute to differences in outcomes for diabetes. Although the most serious negative outcomes for diabetes, such as cardiovascular disease, end stage renal failure, amputation and blindness, take many years to develop and are beyond the present scope of the TRIAD Study to measure, there are some intermediate outcomes that can be assessed. High HbA1C, blood pressure and high cholesterol levels are well-established risk factors for more serious cardiovascular disease, particularly among people with diabetes. In addition to these measures, differences in diabetes-related symptoms, the number of comorbid conditions present, mental health and physical functioning will also be assessed. This study will specifically test the following hypotheses in this area:

- 7. Individuals with a high chance DLOC orientation will have higher glycosylated hemoglobin, blood pressure, cholesterol levels, more diabetes symptoms, and poorer mental health and physical functioning than those with a high internal DLOC orientation.
- 8. The association of higher glycosylated hemoglobin, blood pressure and cholesterol levels will remain after controlling for differences in quality of care received.

#### **CHAPTER 7: METHODS**

# **Procedures**

Data for this DLOC study were collected as part of the TRIAD Study, a five-year, multi-center study of patients with diabetes receiving health care in managed care systems, funded in 1998 by the Centers for Disease Control and Prevention (CDC) and the National Institute of Digestive Disorders and Kidney Disease (NIDDK). The primary aim of the TRIAD Study was to assess the importance of managed health care organizational and systems factors in the quality of care for diabetes. The goal of the study was to identify potentially modifiable structural factors or procedures in managed care organizations to inform later intervention efforts to enhance the quality of diabetes care. The methodology of the overall TRIAD Study has been reported previously (The TRIAD Study Group 2002). Study sites included California, Indiana, Michigan, New Jersey, Texas and Hawai'i. Each study site joined with, or were themselves part of, managed care health plans. In Hawai'i, the two largest health plans in the State, with a collective membership of approximately 90% of the non-military residents of Hawai'i, partnered with the Pacific Health Research Institute (PHRI) to conduct the study. The TRIAD Study was conducted by the VA at geographic sites corresponding to TRIAD Study sites, with the exception of Hawaii, due to IRB issues. The author was a Co-Investigator and Project Coordinator on the study.

Partnering health plans used a uniform criteria developed by TRIAD investigators to identify patients with diabetes from insurance claims data,

diabetes registries and other available administrative data. The criteria resulted in the inclusion of both Type I (insulin dependent, generally onset in youth) and Type II (generally adult onset, may be treated with insulin but also with tablets or diet and exercise alone). Due to the clinical difficulty of accurately assigning diabetes type, and the many clinical subtypes, no attempt was made in this study to classify patients according to diabetes type. The criteria included inpatient and outpatient diagnosis codes, pharmaceutical orders for insulin or oral diabetes medications, diabetes-related laboratory tests (HbA1C and fructosamine tests) and lab results if available.

Investigators from the six study sites collaboratively developed the protocol and study instruments for the TRIAD Study. The target study enrollment goal was 1500 patients per site.

Eligibility criteria for the study were:

1. Age 18 or older

- 2. At least 18 months of continuous enrollment at the time of the study in a managed care health plan.
- 3. Acknowledgement of physician diagnosis of diabetes.

Study exclusion criteria included the following:

- 1. Participant denies having diabetes.
- 2. Participant is not enrolled in a study health plan at the time of the study.
- 3. Participant does not use the health plan for the majority of diabetes care.

- 4. Participant not enrolled continuously for 18 months prior to the study.
- 5. Participant is currently pregnant.
- 6. Participant is less than 18 years old.
- 7. Participant is not living in the community (e.g. lives in a nursing home).
- Participant cannot give informed consent (too ill, cognitively impaired, or cannot speak English or Spanish).

The study protocol, data collection instruments and all study materials (e.g. brochures, scripts, letters, newsletters, etc.) were reviewed and approved by the Institutional Review Boards of each study site and the CDC obtained a Certificate of Confidentiality for the study. A separate file of Hawai'i site data, including variables of interest for this dissertation study without TRIAD Study IDs or patient identifiers was created for purposes of this dissertation. An application for IRB exemption for this dissertation was reviewed and approved by the University of Hawai'i Committee on Human Subjects (CHS) (attached as Appendix A).

In collaboration with partnering health plans, potential study participants were sent a letter describing the study and inviting them to participate. The letter contained consent requirements in accordance with federal regulations regarding participation in research, including the explicit definition of study participation as voluntary and that the decision to participate or not, would in no way affect the medical benefits or treatment to which the potential participant was otherwise entitled to. The letter also included a reply card with a stamped, self-addressed

envelope for patients to indicate to study personnel their interest in participation. decision to decline participation or to inform study personnel that they had been incorrectly identified as having diabetes. If interested in participation, patients were asked to indicate their preference for a written survey or telephone interview, and to provide current contact information. This contact letter also informed patients that if they did not respond, they would be called for an interview, again reiterating the voluntary nature of participation. The entire patient survey instrument contained approximately 150 items and took about 45 minutes to conduct over the telephone (attached as Appendix B). The computer assisted telephone interviews (CATIs) were performed by a Hawai'i based survey research company, under the direction of Hawai'i study personnel and the CATI company conducting the telephone interviews for the other TRIAD Study sites. The protocol called for 15 attempts to contact patients by phone, staggering attempts across daytime and evening hours and during weekdays and weekends. Patients who did not want to complete the interview over the phone were offered the option of completing a mailed written survey. Patients who indicated they wanted to complete a written survey on the initial reply card, those who chose this option when contacted by phone, or could never be reached by phone, were mailed written surveys. Three attempts were made to obtain completed written surveys, the third attempt was via courier delivery on O'ahu and priority mail service on neighbor islands.

The Hawai'i site identified approximately 40,000 potentially eligible patients for the study. Approximately 8,600 of these patients were randomly

selected for recruitment into the study. Of these, 2,771 completed the baseline survey (64% written and 36% CATI). This represents a CASRO (Council of American Survey Research Organizations) response rate of 69%. The CASRO rate apportions dispositions with unknown eligibility status to dispositions representing eligible respondents in the same proportions as exists among all cases with known eligibility, and has been endorsed by the Council of American Survey Research Organizations (Frankel 1983). For the Hawai'i TRIAD sample, of the 8,607 patients in the initial sample, 2,771 completed a survey, 3,238 others were found to be ineligible, 37 of those with confirmed eligibility refused to participate and for 2,561 cases, eligibility could not be confirmed. The formula for calculating the CASRO rate is as follows: completes/ known eligibles + [unknown eligibles x known eligibles/ (known eligibles + known ineligibles)].

The study design called for the administration of a baseline patient survey with a follow-up survey conducted 18 months later. At the end of both the baseline and follow-up patient surveys, participants were asked for their consent to review their outpatient medical records and for the name of the physician who treated them for their diabetes. All medical records abstractors were centrally trained to ensure consistency in the performance of medical records reviews for the TRIAD Study. Nurses were hired in Hawai'i to perform these reviews in clinics and doctors' offices throughout the State. With patient consent, a total of 1829 (66% of baseline participants) chart reviews were completed (Chart Review data collection instrument attached as Appendix C).

Surveys of health plan and medical group directors were conducted to coincide with the baseline patient surveys to gather general information about the plans and medical groups and to specifically catalogue the mechanisms in place to manage diabetes care. Representative from each of the two partnering health plans served as Co-Investigators on the Hawai'i TRIAD Study team.

The baseline patient survey was conducted in Hawai'i between 9/9/2000 and 1/30/2002. Each site had the opportunity to add site-specific questions to the survey. This author added Peyrot and Rubin's (1994) 18-item DLOC measure to the baseline written patient questionnaire on 12/29/2000. These DLOC items were used by the Hawai'i site only.

All study data was processed and aggregated by analysts at the CDC. Each site then received a copy of their own dataset, including all additional variables constructed and/or recoded by CDC analysts.

# Study Sample

The study population for this DLOC study is defined as the subset of Hawai'i TRIAD Study participants who completed all or part of the 18-item DLOC measure. A total of 1,446 participants completed all or some of the items, 1,106 completed all 18 items. As shown in Table 7.1, respondents who completed the DLOC instrument were similar to those who did not, although the distribution between the health plans is somewhat different in comparison to the total Hawai'i sample. This is the result of the timing of implementation of the DLOC measure since sample was fielded in waves consisting of patients from each health plan

and several waves of sample from Health Plan A had already been fielded prior to the introduction of the DLOC measure.

	Total Hawai'i Sample		DLOC Sample		Non-DLOC Sample	
	N	N % N %		N	%	
Females	1409	50.8	718	49.7	691	52.2
Caucasian	357	12.9	183	12.7	174	13.2
Health Plan A	1293	46.7	570	39.4	723	54.6
Health Plan B	1478	53.3	876	60.6	602	45.5
Mean Age	57.1		57.3		56.9	
Duration of DM	11	.3	11.1		11.5	

#### Table 7.1: Sample Characteristics

#### Sample Bias

Based on the eligibility criteria, the study sample is limited to insured health plan members and those who have engaged in health care. In addition, patient's whose diabetes is better controlled may have been more likely to participate in the study. Finally, patients had to be literate in English (Spanish versions were not used in Hawai'i) in order to participate. These factors may have introduced bias into the study and results may not be generalizable to individuals without health insurance or those who are not receiving health care services, patients whose diabetes is poorly controlled, or those who are not minimally literate in the English language.

# Independent Variables

*Diabetes-related LOC* - DLOC was measured using Peyrot and Rubin's (1994) diabetes-specific instrument. The 18 items of this instrument correspond to items

QH2a- QH2r on the patient survey. As described previously, the instrument is derived from Wallston's Multidimensional Health LOC scales (MHLC) (1978). The instrument includes the 18 items listed below and is designed to be used as a specific measure of LOC for diabetes. All items are scored from 1 to 6 (strongly disagree, disagree, mildly disagree, mildly agree, agree, strongly agree) and none of the items require reverse scoring (Peyrot and Rubin 1994:995). The notations after each item indicate which of the five DLOC domains and subdomains the authors claim the items measure: (I-A internal-autonomy, I-B internal – self blame, C chance, P-HP powerful others-health care providers, and P-NM power others-non medical).

1. I can avoid complications. (I-A)

2. When my sugar is high it's because of something I've done. (I-B)

3. Good health is a matter of good fortune. (C)

4. Regular doctor's visits avoid problems. (P-HP)

- 5. What I do is the main influence on my health. (I-A)
- 6. If it's meant to be I will avoid complications. (C)
- 7. I should call my doctor whenever I feel bad. (P-HP)
- 8. My blood sugars will be what they will be. (I-A)
- 9. Blood sugars are controlled by accident. (C)
- 10.1 can only do what my doctor tells me. (P-HP)
- 11.1 never know why I am out of control. (C)
- 12. Health professionals keep me healthy. (P-HP)
- 13. My family is a big help in controlling my diabetes. (P-NM)

14. When my blood sugar is high it's because I've made a mistake. (I-B)

15. Good control is a matter of luck. (C)

16. Complications are the result of carelessness. (I-B)

17.1 am responsible for my health. (I-A)

18. Other people have a big responsibility for my diabetes. (P-NM)

The MHLC originally had three subscales (internal LOC, external LOC and chance LOC). Wallston later split the original measure of external LOC into two distinct factors – health professionals and other (powerful) people, such as family members (1994). Based on their own observations, Peyrot and Rubin identified a fifth domain which represents a splitting of internal DLOC into autonomy and self-blame. According to the authors, items scores can be summed as measures of specific domains of DLOC (Internal-autonomy [I-A] items 1, 5 and 17; Internal-self-blame [I-B] items 2, 14 and 16; Chance [C] items 3, 6, 8, 9, 11 and 15; Powerful Others- Health Professionals [P-HP] items 4, 7, 10, and 12; and Powerful Others-Non-Medical [P-NM] items 13 and 18).

The sample for this dissertation study was substantially larger and more diverse than that of Peyrot and Rubin or the study by Hayes et al. (2000) that used the same instrument. In addition, almost 10 years had passed since Peyrot and Rubin's study and the systematic efforts by managed care health plans to improve the quality and outcomes of diabetes could have altered patients' perceptions of diabetes-related LOC. For these reasons, factor analysis of the responses to the 18-item instrument was performed to derive measures of internal, chance and external DLOC domains, based on the study population.

This procedure was also used to explore the hypothesized subdomains within internal DLOC and powerful others DLOC. Factor analysis procedures and the resulting measures of DLOC domains are described later in the section on Analytic Procedures.

Patient Demographic Factors - Patient demographic information was collected on the patient survey (Appendix B). The specific items included in this dissertation include: gender (Q9); age at interview (from date of birth) (Q8); highest grade of school completed (Q95); annual household income (Q94); and race/ethnicity (Q96-97). The race/ethnicity items instructed respondents to check all categories that applied. In order to classify participants in a manner more relevant to Hawai'i's population, discrete categories and combinations of self-reported race/ethnicity by Hawai'i study participants were collapsed into seven major categories for purposes of analysis as shown in Table 7.2. The methodology employed in combining these categories assigned individuals that listed more than one racial/ethnic group to 'Hawaiian/Part Hawaiian', if this category was checked, regardless of whatever other group(s) were checked, to 'Asian', if this category was checked, regardless of any other group checked unless it was Hawaiian, and to 'Hispanic', regardless of any other group checked unless it was Hawaiian.

	Haw'n/	Cau-	His-	Asian	Other	Unk	TOTAL
	Pt	casian	panic		Pac Isi	/Ref	
	Haw'n						
Caucasian	0	183	0	0	0	0	183
Hawaiian	7	0	0	0	0	0	7
Other Pacific	0	0	0	0	10	0	10
Islander							
Asian only	0	0	0	668	0	0	668
Other	0	0	0	0	0	10	10
Unk/refused	0	0	0	0	0	182	182
Asian + <u>&gt;</u> 2 other	0	0	0	70	0	0	70
groups							
Hawaiian + <u>&gt;</u> 2	3	0	0	0	0	0	3
other groups							
Other + > 2 other	0	0	0	0	0	9	9
groups							
Pacific Islander + >	0	0	0	0	9	0	9
2 other groups							
Caucasian + <u>&gt;</u> 2	0	27	0	0	0	0	27
other groups							
Hawaiian Asian	70	0	0	0	0	0	70
Caucasian							
Asian Caucasian	0	0	0	27	0	0	27
Hawaiian Asian	126	0	0	0	0	0	126
Hawaiian Caucasian	6	0	0	0	0	0	6
Hispanic Only	0	0	37	0	0	0	37
TOTAL	212	210	37	765	19	201	1444

#### Table 7.2: Recoded Race/Ethnicity Variable

For the analysis of Hawai'i data, a second variable was created to code groups within the larger category of "Asian". For this variable anyone who indicated they were Asian and specified a subgroup (i.e. Japanese) was counted in that subgroup, regardless of any other group they may have checked. The correspondence of these two variables is shown in Table 7.3. For this reason, individuals may be included in more than one category in some results tables, but are included only once in analytic procedures.

		Race/Et	Total				
		Hawaiian/ Part Hawaiian	Hawaiian/ Other Part Pacific Hawaiian Asian Islander				
Asian category	Chinese	92	91	1	184		
	Filipino	48	236	4	288		
	Japanese	45	400	4	449		
	Korean	11	27	0	38		
Total		196	754	9	959		

 Table 7.3:
 Crosstabulation of Race/Ethnicity with Asian Category Variables

#### **Dependent Variables**

*Quality of Care* - Quality of care for TRIAD Study was measured in terms of seven specific care processes and as a composite score. These measures were agreed upon by TRIAD Study investigators to insure uniformity in study analyses. These standards of care are the DQIP measures (described on page 21) and are recommended by the American Diabetes Association and published on an annual basis. They are also used by the National Committee on Quality Assurance in their assessment of managed care organizational performance in the area of diabetes (HEDIS measures). The seven indicators include:

- 1. Annual eye exam
- 2. Annual HbA1c lab test
- 3. Annual lipid profile
- 4. Annual foot examination
- 5. Annual proteinuria screening (urine test)
- 6. Annual flu vaccination
- 7. Advised to take aspirin

Evidence of advice to take aspirin and flu vaccination were obtained from the patient survey (Q22, Q23). Evidence of eye exams and foot exams were derived first from the medical record review (Q26, Q25) and if this was absent, from the patient survey (Q19, Q20). Evidence of the HbA1c test, lipid profile and proteinuria screening were obtained from the medical record review form (Q16, Q17, Q21-23). Dates recorded for each of these items were compared to the patient's survey completion date to ascertain whether the particular test or exam was performed in the 12 month period prior to the survey.

*Self-Care Measures* – Nine measures of diabetes-related self-care were included in the analysis. Body mass index (BMI) was calculated from the self-reported height from the patient survey (Q10) and last recorded weight from the chart review (Q12a), or if this was absent, from the patient survey (Q11). Selfmonitoring of blood glucose (SMBG) was obtained from three items on the patient survey, the first a simple yes or no question (Q15), and if yes, the number of days per week tested (Q16) and number of times per day (Q17). A fourth, dichotomous variable was constructed to indicate daily self-monitoring of blood glucose (Yes or No). This variable counted patients who reported they did not monitor at home and those who reported monitoring less than seven days per week in Q16, as 'no'. The amount of time spent (minutes per day) caring for feet, exercising and shopping for and cooking special foods attributed by patients to diabetes self-care was obtained from the patient survey (Q90a, b, and c).

Intermediate Outcomes and Comorbidities of Diabetes – The most serious adverse outcomes of diabetes, heart attack and stroke, end stage renal failure, blindness and amputation, occur relatively infrequently and typically take many years to develop. Given the sample size and duration of the TRIAD Study, these outcomes can most reliably assessed later in the study (it has been funded for an additional five years). There are, however, well-established precursors to these events/conditions, or intermediate outcomes that can be assessed with this study design. These include blood pressure, HbA1C and total cholesterol, all obtained from the medical record review (Q14a,b, Q16b, Q17a).

Diabetes symptoms, indicative of poor glycemic control, neuropathy (peripheral nerve damage) and vascular complications, are measured via the Testa score (Testa and Simonson 1998). The ten items comprising this score are obtained from the patient survey (Q34a-j).

Self-reported health status is measured using a single item from the SF-12 (Ware, Korsinski and Keller 1996), obtained from Q37 of the patient survey.

Comorbidities often associated with diabetes, including the number of other medical conditions present, mental health score and physical functioning are also measured. The presence of comorbid medical conditions is measured with the Charleson Index using items 12a. – 12.I from the medical record review form (Charleson et al. 1986).

The mental health summary score and physical functioning scores are derived from SF-12 items on the patient survey.

#### Covariates

*Health Plan* - The primary objective of the TRIAD Study is to measure the effects of managed care organizational structure and processes upon the quality and outcomes of diabetes care. A number of papers reporting these findings have been published and are in progress. As an example, a recent TRIAD publication by Kerr et al. compared the quality of diabetes care provided by the VA to that provided by commercial managed care plans, concluding that specific organizational and care management strategies, similar to those used by commercial managed care plans, put in place as part of a major reorganization of the VA system, resulted in better quality and outcomes of care for diabetes in comparison to commercial managed care plans in the TRIAD Study.

While there are some potentially important differences between the two health plans included in the Hawai'i sample, the effects of these organizational differences are better assessed using the entire TRIAD sample which includes approximately 12,000 patients, ten health plans and considerably more diversity in patient population. In addition, what may appear to be health plan effects in the Hawai'i analysis may actually represent differences in the membership of the two health plans, which in turn may reflect self-selection by patients. Importantly, both Hawai'i health plans have comprehensive diabetes care management programs in place. For these reasons, the effects of the two health plans upon processes and outcomes of care in this dissertation study will be controlled for, by treating the dichotomous variable 'health plan' as a covariate in analyses.

*Duration* - The effects of diabetes tend to worsen with duration. Duration (Q7) will be treated as a covariate in some analyses.

*Treatment* – Treatment modality is indicative of diabetes severity for patients with Type II diabetes (an estimated 80-90% of study participants). This information is obtained from item Q12 on the patient survey (*diet and exercise only, oral medications, insulin, insulin plus oral medications*).

*Birthplace* – Birthplace (United States or not) is used as a very crude measure of acculturation and is included as a covariate in some analytic models. This is the only item in this dissertation analysis that is obtained from the follow-up patient survey.

#### **Analytic Procedures**

#### Factor Analysis

Principal components analysis was performed on Peyrot and Rubin's 18item DLOC measure using SPSS 12.0 and data from the 1,106 survey respondents who completed all of the 18 items. This sample size, with more than 1,000 cases is considered more than adequate to perform such analyses (Comrey and Lee 1992). Orthogonal (SPSS Varimax procedure) and oblique (SPSS Direct Oblimin procedure) rotations were performed, since it was unclear whether the domains of DLOC would be correlated. Both rotation methods resulted in the identification of five factors with eigenvalues greater than one and accounted for 55.2% of the variance in the model. Tabachnick and Fidell (2001:622) suggest that the decision to use an orthogonal versus oblique rotation should be driven by the observed correlations among the factors derived from the oblique rotation. They recommend using an orthogonal rotation if any of the correlations among the factors are .32 or higher. As shown in the Component Correlation Matrix using an oblique rotation (Table 7.4), none of the correlations among the factors derived from the oblique rotation exceed .32, which supports the use of an orthogonal rotation.

Та	ble	€7.	4: (	Component	Correl	ation I	Matrix	– Oblique	Rotation
----	-----	-----	------	-----------	--------	---------	--------	-----------	----------

Component	1	2	3	4	5
1	1.00	09	24	.05	.02
2	09	1.00	22	.23	13
3	26	22	1.00	17	.08
4	.05	.23	17	1.00	04
5	.02	13	.08	04	1.00

Extraction Method: Principal Component Analysis. Rotation Method: Oblimin with Kaiser Normalization.

The factor loadings for each of the 18 items in the five-factor model are shown in Table 7.5 . These figures represent the correlation of each variable with each factor. Loading values greater than .71 are considered excellent, .63 - very good, .55 - good and .45 – fair (Comrey and Lee 1992, in Tabachnick and Fidell 2001:625). Variables with loading values at or above .5 are in bold face Table 7.5.

	Component					
	1	2	3	4	5	
Good control is a matter of luck	.76	02	.06	01	.17	
Blood sugars are controlled by accident	.76	08	06	04	.12	
My blood sugars will be what they will be	.70	05	.20	.03	03	
I never know why I'm out of control	.57	22	.10	.16	06	
Good health is a matter of good fortune	.51	.19	.44	05	06	
l can avoid complications	06	.78	07	03	.11	
What I do is the main influence of my health	12	.69	.18	.18	13	
It's something I have done when my sugar is high	04	.64	10	.36	.12	
Regular doctor's visits avoid problems	07	.63	.33	.09	.12	
I should call my doctor whenever I feel bad	.04	.07	.70	.086	.15	
If it's meant to be I will avoid complications	.28	.37	.57	02	04	
I can only do what my doctor tells me	.38	12	.54	.17	.12	
Health professionals keep me healthy	06	.06	.52	.15	.54	
When my blood sugar is high it's because l've made a mistake	.05	.11	.02	.79	.20	
Complications are the result of carelessness	.11	.17	.12	.73	03	
My family is a big help in controlling my diabetes	02	.13	.31	.09	.68	
Other people have a big responsibility for my diabetes	.42	02	15	02	.61	

# Table 7.5: Rotated Component Matrix – Orthogonal Rotation

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.

Rotation converged in 35 iterations.

The next decision was to determine the number of factors to be retained for analysis. There are several methods for making this determination. The decision inevitably involves the tradeoff of attempting to develop a model that adequately fits the data but is as parsimonious as possible. One commonly used method is to select factors with eigenvalues greater than 1. Eigenvalues represent the variance that each standardized variable (factor) contributes to the principal components model. Factors with an eigenvalue of less than 1 are generally not considered important in terms of contributing to the model (Tabachnick and Fidell 2001:620). However, as Gorsuch suggests, the goal is to extract non-trivial factors and factors with eigenvalues of 1 or greater still may be trivial in terms of the theoretical model (1982:164). The eigenvalues and variance explained by each of the five factors in the orthogonal model are presented in Table 7.6 below. Factors 3, 4 and 5 each account for less than 7% of the variance in the model.

		Initial Eigenvalu	les	Extraction Sums of Squared Loadings			
Component	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	
1	3.53	19.62	19.62	3.53	19.62	19.62	
2	3.01	16.74	36.36	3.01	16.74	36.36	
3	1.22	6.79	43.15	1.22	6.79	43.15	
4	1.16	6.43	49.57	1.16	6.43	49.57	
5	1.01	5.59	55.16	1.01	5.59	55.16	

Extraction Method: Principal Component Analysis.

Another method to determine the number of factors to be retained in the model is the scree test (Cattell 1966). The scree test involves plotting the

eigenvalues in ascending order and identifying the point at which the slope drawn through these point changes. Factors to the left of this point, those explaining the most variance in the model, are retained, and those to the right are dropped. The scree plot for the full factor orthogonal model is shown below in Figure 7.1. While in some cases the point at which the slope of the line changes may be difficult to interpret, in this case it is clear. The scree test indicates that there are only two meaningful factors in the dataset.

In addition, as shown in Table 7.5, only two variables load on factor 4 and three on 5. Interpretation of factors with only one or two variables is considered hazardous, adding further support to the decision to use fewer factors in the model (Tabachnick and Fidell 2001:622).



#### Figure 7.1: Scree Plot of Full Factor Orthogonal Model

As a result of these findings, models forcing two and three factor solutions were further explored. Interpretation of the factors was based on Peyrot and Rubin's (1994) work and face validity. The three factor model produced factors corresponding to internal DLOC, chance DLOC and powerful others (external) DLOC. The two-factor model produced factors that corresponded to internal DLOC and chance DLOC. Since the intended use of these factors was as independent variables in subsequent analyses, the scaling properties of each factor was an important consideration. The variable loadings (using a threshold of .5 or better) and internal consistency of each factor, derived from factor analysis forcing two and three factor solutions, are shown in Table 7.7. Cronbach's alpha, a measure of internal consistency, was higher for the internal and chance LOC factors using the two-factor model than the three-factor model (.71 vs. .70 for internal DLOC, and .74 vs. .71 for chance DLOC). The powerful other (external) DLOC factor, produced in the three factor solution, had an internal consistency of .54. According to DeVellis (2003:95), alphas between .70 and .80 are considered respectable for research scales, those less than .60 are considered unacceptable. While this low alpha for the powerful other DLOC factor may be the result of having only three variables that loaded on this factor, it diminishes the ability to use this factor to construct a scale for powerful other DLOC. Therefore, scales were only constructed for internal and chance DLOC.

Internal LOC	2 Factor	3 Factor
	Solution	Solution
Regular doctor's visits avoid problems	.69	.57
What I do is the main influence of my health	.66	.68
It's something I have done when my sugar is high	.61	.72
I can avoid complications	.56	.61
I am responsible for my health	.54	.53
When my blood sugar is high it is because I made a		52
Complications are the result of carelessness		.56
Alpha	.71	.71
Chance LOC	2 Factor	3 Factor
Good control is a matter of luck	.74	.76
My blood sugars will be what they will be	.69	.71
Blood sugars are controlled by accident	.69	.75
I can only do what my doctor tells me	.59	
I never know why I'm out of control	.58	.62
Good health is a matter of good fortune	.56	
Alpha	./4	./1
Powerful Others LOC		3 Factor
Health professionals keep me healthy		.72
My family is a big help in controlling my diabetes		.61
I should call my doctor whenever I feel bad		.67
·		
Alpha		.54

Table7.7:	Two and Three Factor Solutions: Item Loading and Internal Consistency

# Scale Construction

Two scales were constructed for the purposes of these analyses, one for internal DLOC and one for chance DLOC. Variables that loaded on each of these two factors at a level of .5 or higher in the forced two factor orthogonal solution comprised each of these scales. Prior to constructing these scales, the two-factor model was run using an oblique rotation. The variables loading on the internal and chance DLOC factors were the same for both the orthogonal and oblique two factor solutions. Use of the two-factor solution added one additional variable to the internal DLOC scale (*I am responsible for my health*), and one additional variable to the chance DLOC scale (*I can only do what my doctor tells me*) in comparison to the three-factor solution. The internal consistency of the two scales was measured with and without these two additional items, revealing that the alpha value for the internal DLOC would be the same, and the alpha value for chance DLOC would be slightly lower with the three-factor solution.

The internal DLOC scale constructed for these analyses consisted of a simple sum of the values (1=strongly disagree, 2=disagree, 3=mildly disagree, 4=mildly agree, 5=agree and 6=strongly agree) for the following five items:

- Regular doctor's visits avoid problems
- What I do is the main influence of my health
- It's something I have done when my sugar is high
- I can avoid complications
- I am responsible for my health

Scores on this scale ranged from 5-30. The mean score on this scale in the study sample was 25.4, with a standard deviation of 3.4. The study sample distribution is skewed in the direction of high internal DLOC on this scale.

A second scale was constructed for chance DLOC including the following six items:

- Good control is a matter of luck
- My blood sugars will be what they will be

- Blood sugars are controlled by accident
- I can only do what my doctor tells me
- I never know why I'm out of control
- Good health is a matter of good fortune

Scores on this scale ranged from 6-36. The mean score on this scale in the study sample was 15.8, with a standard deviation of 5.6.

The correlation between these two scales was -.07. This correlation was statistically significant (p=.01), influenced to some extent by a large sample size. The absolute value of the correlation is very close to zero, however, indicating a weak correlation.

# DLOC Type

Previous work in the area of DLOC has utilized a method of characterizing patients in terms of their scores on multiple dimensions of DLOC (Wallston, Wallston and DeVellis 1978; Bradley et al. 1990). Theoretically, patients with a high internal DLOC and a low chance DLOC would have better metabolic control and better outcomes than patients with low internal DLOC and high chance DLOC. A similar approach was taken for this analysis by dividing each scale of the study sample median resulting in a dichotomous variable for each scale – high and low, with approximately the same number of cases in each group. These two dichotomous variables were then crosstabulated to result in four

DLOC types:

Type A = Hi internal DLOC, Lo chance DLOC (n=325, 27.9%)

Type B = Hi internal DLOC, Hi chance DLOC (n=218, 18.7%)

Type C = Lo internal DLOC, Lo chance DLOC (n=310, 26.6%)

Type D = Lo internal DLOC, Hi chance DLOC (n=312, 26.8%)

Types B and C are difficult to interpret as they indicate the endorsement of both chance and internal loci of control (Type B) or neither (Type C). These two Types may also be the result of response bias. Types A and D are the most interesting for theoretical reasons and are used in study analyses.

# Internal and Chance DLOC Quartiles

A categorical variable was also constructed for each scale that divided individuals into quartiles and is used in some analyses.

# **Statistical Methods**

In addition to the factor analyses described earlier, a number of statistical methods were employed to address the main research questions and hypotheses in each of the five areas of investigation. In describing the study sample in terms of DLOC, simple crosstabulations were used with the chi square statistic. Differences in mean internal and chance DLOC scores were measured using T-tests and confidence intervals. Mean scores were adjusted for covariates by using general linear models to predict adjusted scores. Analyses of process quality of care indicators initially used two by two tables and the chi

square statistic to measure significance of association. ANOVA was used to measure the significance of differences among groups of respondents. Binary logistic regression models were constructed for each process quality of care indicator to measure the relative importance of internal and chance DLOC with other covariates in the model. A similar model was constructed for the sum of the seven indicators using a general linear regression model. The association of DLOC with outcomes and comorbidities was assessed using simple correlations.

# Missing Data

Values for missing data were not imputed for any of the variables used in these analyses. Cases that were missing data on any of the variables used in a particular analytic procedure were excluded. This also applies to cases that were missing data on variables used to create the internal and chance DLOC scales.

#### **CHAPTER 8: RESULTS**

Study results are organized in sections to correspond to the five areas of investigation described in Chapter 6. The eight specific research questions and hypotheses outlined in Chapter 6 are addressed within these sections. Results are briefly summarized at the end of each of the five sections.

#### **Factorial Structure of Peyrot and Rubin's DLOC Instrument**

Study Question 1: Is the five-domain structure of the DLOC instrument reported by Peyrot and Rubin supported by results based on a large, diverse population of patients with diabetes in Hawai'i?

Table 8.1 presents a comparison of the factorial structure of the 18-item DLOC measure reported by Peyrot and Rubin to the structure found in the sample of Hawai'i TRIAD Study participants in terms of the three primary domains of DLOC - internal, chance and powerful others. Although the scales for internal and chance DLOC were developed using the two-factor model, this table reflects the results of the three-factor orthogonal model to facilitate comparison.

All of the six items reported by Peyrot and Rubin to measure internal DLOC also clustered together to form a single distinct factor in this study sample. A notable difference is that one item, *Regular doctor's visits avoid problems*, reported by Peyrot and Rubin as a measure of powerful others DLOC, also loaded on this internal DLOC factor. In fact, in the two-factor model, this item had the highest loading value of all items in the factor.

Of the six items reported to measure chance DLOC, five items also loaded

on this factor in the study sample. The sixth item, If it's meant to be I will avoid

complications, loaded on the powerful others DLOC factor in this study sample,

but at a subthreshold level (.48).

# Table 8.1:Comparison of DLOC Factorial Structure Reported by Peyrot and Rubin to<br/>Hawai'i TRIAD Study Sample Results

(Factor loadings at below threshold level (.5) are indicated in parentheses).

	Hawai'i TRIAD Study Sample				
Peyrot and Rubin DLOC Structure	Internal	Chance	Powerful Others		
Internal					
I can avoid complications	X				
What I do is the main influence on my health	X				
I am responsible for my health	X				
When my sugar is high it's because of something I've done	X				
When my blood sugar is high it's because I've made a mistake	X				
Complications are the result of carelessness	X				
Chance					
Good health is a matter of good		v			
fortune		^			
If it's meant to be I will avoid complications			(X) .48		
My blood sugars will be what they will be		x			
Blood sugars are controlled by accident		X			
I never know why I am out of control		Х			
Good control is a matter of luck		Х			
Powerful Others					
Regular doctors visits avoid problems	X	· · · · · · · · · · · · · · · · · · ·			
I should call my doctor whenever I feel bad			X		
I can only do what my doctor tells me		(X) .46	(X) .48		
Health professionals keep me healthy			X		
My family is a big help in controlling my diabetes			X		
Other people have a big responsibility for my diabetes		(X) .44			

Of the six items reported to measure powerful others DLOC, only three loaded on this factor in the study sample, with a fourth at a subthreshold level. Two of the six items, *I can only do what my doctor tells me*, and *Other people have a big responsibility for my diabetes*, loaded on the chance DLOC factor in this study, and only at subthreshold levels.

Overall, in terms of the three main domains of DLOC, 13 of the 18 items factored in a manner consistent with that reported by Peyrot and Rubin. All six of the internal DLOC items, and five of the chance DLOC items (including the one just below the loading threshold) performed as Peyrot and Rubin suggested they would. The measures of powerful others DLOC did not perform as well. Only three of the items clearly clustered together on this factor. Although the item, *I can only do what my doctor tells me*, nearly reached the loading threshold on this factor, it also nearly reached the loading threshold on the chance DLOC factor, indicating it is not clearly a measure of either factor. The item, *Other people have a big responsibility for my diabetes*, loaded on the chance DLOC factor, but at a subthreshold level.

Perhaps the most interesting difference is in the item, *Regular doctor's visits avoid problems*. This was reported by Peyrot and Rubin as a measure of powerful others DLOC but performed as a measure of internal DLOC in this sample. This suggests that respondents interpreted this item as having more to do with their efforts to visit the doctor than the importance of doctors in avoiding diabetes-related problems.

Alpha reliabilities for each of the three scales hypothesized by Peyrot and Rubin are not reported individually but as a range between .65 to .75 (1994:996). Alpha reliabilities for each of the three factors in this study (including only items that loaded at a level of .5 or higher) are .71 for internal DLOC, .71 for chance DLOC and .54 for powerful others DLOC.

Peyrot and Rubin reported that powerful others DLOC was actually comprised of two factors with eigenvalues greater than one. They describe these two factors as powerful others - health care professionals and powerful others non-medical others. Similarly they reported that internal DLOC separated into two factors after an educational intervention and re-measurement of the same subjects. They describe these two factors as measures of autonomy and selfblame, and provide some evidence that the associations of these two factors with diabetes outcomes are different. As described previously, the initial factor analysis with this study sample did result in a five-factor solution. Two of the three items hypothesized by Peyrot and Rubin as measures of internal DLOC autonomy, clustered together on the same factor in the five factor model (I can avoid complications and What I do is the main influence on my health), although in this study, the factor also included the items It's something I've done when my blood sugar is high and Regular doctor's visits avoid problems. Two of three items hypothesized as measures of internal DLOC - self blame, When my blood sugar is high it's because I've made a mistake and Complications are the result of carelessness, do load on a single factor with no other items. It appears that the distinction between autonomy and self-blame may be supported by the data
but there are differences in the items that measure each of these components in comparison to those reported by Peyrot and Rubin.

The separate components of powerful others – health professionals and powerful others – non-medical were not supported in this study. As described previously, the item *Regular doctor's visits avoid problems*, was correlated with measures of internal DLOC. The items, *I can only do what my doctor tells me* and *I should call my doctor whenever I feel bad*, loaded on the factor with *If it's meant to be I will avoid complications*. Similarly, the two hypothesized *powerful others – non-medical* items, *My family is a big help in controlling my diabetes* and *Other people have a big responsibility for my diabetes*, loaded on a separate factor with the item, *Health professionals keep me healthy*. In general, the hypothesized powerful others DLOC items were not correlated in the manner suggested by Peyrot and Rubin and the clear distinction between powerful others DLOC – health professionals and powerful others DLOC –non-medical, is not supported by the data collected for this study sample.

Results for this sample indicate that the items theorized by Peyrot and Rubin to measure internal and chance DLOC, for the most part, also constituted coherent internal and chance factors in the Hawai'i TRIAD sample. The items theorized to measure powerful others DLOC did not correlate with factors as predicted, nor did the theorized subdomain items within internal DLOC and powerful others DLOC.

# **Socioeconomic Position and DLOC**

Study Question 2: Describe DLOC orientation patterns in terms of demographic variables among individuals in Hawai'i with diabetes receiving care in managed care settings.

The mean, standard deviation and percent agreement (collapsing responses of *mildly agree*, *agree* and *strongly agree*) and percent disagreement (collapsing responses of *mildly disagree*, *disagree* and *strongly disagree*) for each of the 18 items in the DLOC measure are presented in Table 8.2. All items have a possible value range from 1 (strongly disagree) to 6 (strongly agree).

	N	Mean	S.D.	%	%
				Disagree	Agree
What I do is the main influence of my health	1394	5.2	0.8	3.0	97.0
I can avoid complications	1354	4.8	1.2	11.2	88.8
Regular doctor's visits avoid problems	1407	5.0	1.1	8.7	91.3
It's something I have done when my sugar					
is high	1393	4.9	1.1	8.5	91.5
I am responsible for my health	1410	5.4	0.8	2.2	97.8
When my blood sugar is high it is because I					
made a mistake	1388	4.4	1.4	23.3	76.7
Good control is a matter of luck	1391	2.0	1.3	84.8	15.2
Blood sugars are controlled by accident	1371	1.9	1.0	93.4	6.6
My blood sugars will be what they will be	1357	2.6	1.5	74.6	25.4
I never know why I'm out of control	1322	2.5	1.3	79.7	20.3
Good health is a matter of good fortune	1392	3.6	1.8	48.0	52.0
I can only do what my doctor tells me	1376	3.0	1.6	55.1	44.9
If it's meant to be I will avoid complications	1364	4.4	1.6	24.6	75.4
I should call my doctor whenever I feel bad	1400	4.2	1.5	30.4	69.6
Health professionals keep me healthy	1389	4.6	1.2	16.4	83.6
My family is a big help in controlling my					
diabetes	1371	4.2	1.5	28.0	72.0
Complications are the result of					
carelessness	1396	4.5	1.4	22.1	77.9
Other people have a big responsibility for my diabetes	1402	2.1	1.2	86.8	13.2

#### Table 8.2: Responses to DLOC Items

Overall, these results show that respondents had a strong sense of responsibility for their health. Over 95% of respondents agreed the statement, *I am responsible for my health*, and other indicative items such as *What I do is the main influence on my health*. Results indicate that respondents were fairly knowledgeable about diabetes as well, acknowledging that blood sugar is controlled by what they do and not by accident.

There are, however, indications that some respondents did not feel they had control over their condition or diabetes-related outcomes. Twenty percent agreed with the statement, *I never know why I'm out of control*, 25% agreed that *My blood sugars will be what they will be*, and 15% agreed that good control is a matter of luck. Fourteen percent agreed that they could only do what their doctor told them.

Table 8.3 presents the mean internal DLOC and chance DLOC scores by gender and age. Overall, there was no significant relationship between gender and internal DLOC or chance DLOC, although scores for women in this sample were slightly higher for both scales in comparison to scores for men. Overall, there were no significant differences among the three age groups in terms of internal DLOC, or among these age groups for men and women. The trend for internal DLOC is opposite for men and women, with older men having higher scores than younger men, and older women having lower scores than younger women. Given that this is a cross sectional study, it is not possible to determine whether these trends are the result of the aging process or more related to

generational effects and the past experiences of women and men who are currently age 65 or older.

With regard to chance DLOC, there was a significant association with age (p<.05) and this is due to significant differences among women of different age groups (p<.01). Among 18-44 and 45-64 year olds, scores on chance DLOC are comparable for men and women. Scores for men in the 65+ age group are higher than for younger men, but not significantly higher. Among older women, however, scores for chance DLOC are significantly higher than for younger groups (p<.01).

		N	Internal	Chance
1		I-DLOC/C-DLOC	DLOC	DLOC
Males	Age Group			
	18-44	89/86	24.8	15.6
	45-64	405/394	25.4	15.4
	65+	167/159	25.7	15.8
	Total Males	687/639	25.3	15.6
			p=.082	p=.860
Females	Age Group			
	18-44	133/128	25.4	15.4
	45-64	347/317	25.8	15.7
	65+	154/137	25.1	17.4
	Total Females	634/582	25.5	16.0
			p=.155	p=.006
Total	18-44	218/214	25.2	15.5
	45-64	752/711	25.5	15.6
	65+	321/295	25.4	16.6
			p=.489	p=.031
	All Ages	1291/1221	25.4	15.8

 Table 8.3:
 Mean Internal and Chance DLOC Scores by Age and Gender

Table 8.4 presents results for internal and chance DLOC by education and gender. Overall the association of internal DLOC and education is not

significant, nor are there significant relationships for men and women separately. In contrast, education is significantly associated with chance DLOC overall (p<.001) and for men and women separately (p<.001 for both). Chance DLOC scores are highest among those with the least education and decrease with each higher category of educational attainment. This trend is evident for both men and women. Again, since this is a cross sectional study, it cannot be determined whether education alters internal or chance DLOC. It may be that broad beliefs about LOC in general, likely to be correlated with DLOC, affect educational attainment.

		N I DI OCIO DI OC	Internal	Chance
		I-DLOC/C-DLOC	DLOC	DLOC
Males	Education			
	Level			
	Some HS or			
	less	73/69	24.8	18.6
	HS Grad	213/208	_ 25.3	16.4
	Some College	188/184	25.4	15.2
	>=4yr College	183/178	25.4	14.1
	Total Males		25.3	15.7
			p=.528	p=.000
Females	Education			- Participation
	Level			
	Some HS or	86/81	24.9	19.6
	less			
	HS Grad	207/193	25.5	16.2
	Some College	240/214	25.5	15.1
	>=4yr College	101/94	26.1	14.8
	Total Females		25.5	16.0
			p=.114	p=.000
Total				
	Some HS or	159/150	24.8	19.1
	less			
	HS Grad	420/401	25.4	16.3
	Some College	428/398	25.4	15.1
	>=4yr College	284/272	25.7	14.3
			p=.102	p=.000

 Table 8.4:
 Mean Internal and Chance DLOC Scores by Education and Gender

The association of income with internal and chance DLOC presented in Table 8.5 shows a trend similar to that for education and both domains of DLOC (internal and chance) are significantly associated with income (p<.01 for internal DLOC and p<.001 for chance DLOC). Internal DLOC scores increase and chance DLOC decrease as income increases. The association of internal DLOC and income is significant for men (p<.05) but not for women. The association of chance DLOC and income is significant (p<.001) for both men and women.

		N	Internal	Chance
			DLUC	DLOC
Males	Income Level			
	<pre><than \$15k<="" pre=""></than></pre>	91/89	24.7	18.3
	\$15K - \$40K	219/212	25.0	16.2
	\$40K - \$75K	192/187	25.4	15.3
	>than \$75K	155/151	25.9	13.7
	Total Males	657/639	25.3	15.7
			p=.014	p=.000
Females	Income Level			
	<than \$15k<="" td=""><td>144/141</td><td>25.1</td><td>18.3</td></than>	144/141	25.1	18.3
	\$15K - \$40K	259/237	25.5	16.3
	\$40K - \$75K	123/108	25.8	14.1
	>than \$75K	108/96	26.0	14.4
	Total Females	634/582	25.5	16.0
			p=.229	p=.000
Total	<than \$15k<="" td=""><td>235/230</td><td>24.9</td><td>18.3</td></than>	235/230	24.9	18.3
	\$15K - \$40K	478/449	25.3	16.2
	\$40K - \$75K	315/295	25.5	14.9
	>than \$75K	263/247	25.9	14.0
			p=.007	p=.000

 Table 8.5:
 Mean Internal and Chance DLOC Scores by Income and Gender

Using the variable DLOC type, constructed from the scales for internal and chance DLOC, the proportions of respondents categorized as "Type A" (high

internal DLOC and low chance DLOC) and as "Type D" (low internal DLOC and high chance DLOC) for gender, age, education and income groups are compared in Table 8.6. These two groups can be thought of as 'pure' internal (Type A) and 'pure' chance (Type D). The proportions for men and women are similar although a higher proportion of women in this sample were classified as Type A and a higher proportion of men were classified as Type D.

		% TYPE A (Hi internal/ Lo chance	% TYPE D (Lo internal/ Hi chance
Gender	······································		· · · ·
	M	25.2%	29.1%
	<u> </u>	154	178
	F	30.9%	24.2%
	n	325	134
Age			
	18-44	33.3%	24.6%
	<u> </u>	69	51
	45-64	28.5%	25.6%
	n	193	173
	65+	22.4%	31.3%
	<u> </u>	63	88
Education			
	Some HS or	13.9%	47.4%
	less	19	65
	<u>n</u>		
	HS grad	25.2%	27.6%
	n	95	104
	Some college	31.9%	24.1%
	n	123	93
	>=4yr college	33.2%	18.9%
	<u> </u>	88	50
Income			
	< than \$15K	18.5%	40.8%
	n	39	86
	\$15K - \$40K	25.8%	28.4%
	<u>n</u>	110	21
	\$40K - \$75K	31.5%	22.7%
	n	90	65
	>\$75K	35.5%	16.5%
ł	n	86	40

 Table 8.6:
 Percentage by DLOC Type, Gender, Age, Education and Income

A third of respondents aged 18-44 years fell into the Type A group and almost a third of the seniors in the study fell into the Type D group. Only 13.9% of those who did not graduate from high school were classified as Type A, compared to 33.2% of college graduates. Almost half of those who did not graduate from high school fell into the Type D group, compared to less than 20% of the college graduates. Similarly, less than 20% of those earning less than \$15,000 per year were classified as Type A, compared to more than a third of those earning more than \$75,000 per year. More than 40% of those earning \$15,000 or less were classified as Type D, compared to 16.5% of those earning more than \$75,000 per year.

#### Summary of Results

*Internal DLOC* – Overall, internal DLOC among this study population was high, as measured using Peyrot and Rubin's instrument and scales derived from factor analysis. On a scale ranging from 5-30, the mean score for this population was 25.4, with a standard deviation of 3.4.

*Chance DLOC* – There was more variation in chance DLOC scores in the study population than in internal DLOC scores. On a scale ranging from 6-36, the mean score was 15.8, with a standard deviation of 5.6.

*Gender* – There were no statistically significant differences between men and women in overall internal or chance DLOC scores. A larger proportion of women

than men in the study were categorized in the "pure" internal group and a larger proportion of men were categorized in the "pure" chance group. There were, however, differences in chance DLOC between older men and women, with older women having higher chance DLOC scores than younger women and older men.

*Age* – Internal DLOC was approximately the same across age groups. Chance DLOC increased only slightly across age groups for men but was significantly higher for older women. Chance DLOC was consequently significantly higher for all respondents aged 65 years and older than for younger groups.

*Education* – There were no significant differences in internal DLOC among categories of educational attainment for men, women or the total sample. Chance DLOC scores, in contrast, were lower for each increasing category of educational attainment for men and women, and for the total study sample. Nearly half of respondents who did not graduate from high school were classified in the 'pure' chance group, compared to less than 20% of those who graduated from college. Similarly, less than 15% of respondents who did not graduate from high school of those who graduate from high school were classified in the 'pure' internal group compared to a third of those who graduated from college.

Income – Income was significantly associated with internal and chance DLOC for men and with chance DLOC for women. Internal DLOC scores go up and chance DLOC scores go down with each higher income bracket. Both domains

of DLOC were significantly associated with income for the total study sample. More than 40% of those earning less than \$15,000 annually fell into the 'pure' chance group compared to 16.5% of those earning more than \$75,000 annually.

#### Race/Ethnicity and DLOC

As described in the methods section, special race/ethnicity variables were constructed for the Hawai'i study population in order to present study results in a manner most relevant to Hawai'i's population (See Table s 7.2 and 7.3). This classification scheme does result in counting some individuals in more than one category in some tables, however statistics are based on unduplicated counts. Mean scores for internal and chance DLOC are presented in Table 8.7. A univariate generalized linear model was used to calculate adjusted means separately for internal DLOC and chance DLOC with the following variables included in the model as covariates: gender, age at interview (as a continuous variable), education (4 categories) and birthplace (United States – yes or no). Table 8.7: Adjusted and Unadjusted Mean Internal DLOC Scores by Race/Ethnicity

	N*	Unadjusted Internal DLOC	Adjusted Internal DLOC**	95% C.I. Lower	95% C.I. Upper
Asian	561/496	25.6	25.7	25.4	26.0
Japanese	398/314	25.6	25.5	25.1	25.9
Filipino	244/157	25.5	26.0	25.4	26.5
Chinese	165/131	25.6	25.7	25.2	26.3
Korean	37/25	25.1	24.6	23.4	25.9
Caucasian	203/142	25.4	25.4	24.8	25.9
Hawaiian/Pt Hawaiian	197/146	25.5	25.6	25.1	26.2
Hispanic	33/22	22.8	22.0	20.7	23.4
Other Pac Isl	16/7	24.9	24.7	22.5	27.4
Other/Unknown	179/115	25.2			

\* N (unadjusted/adjusted)

\*\*Scores adjusted for gender, age, education and birthplace.

In general, the scores for internal DLOC did not differ appreciably among these racial and ethnic groups after adjusting for differences in gender, age, education and birthplace. Based on the confidence intervals, there is only one significant difference – Hispanics have lower internal DLOC scores in comparison to other groups except Other Pacific Islanders and Koreans. These results are illustrated in Figure 8.1. It should be cautioned, however, that the Hispanic and Other Pacific Islander groups were relatively small and therefore scores may not be as stable as those for other groups.





While there are only small differences between these groups, they can be rank ordered in terms of internal DLOC as follows:

1.	Filipino		26.0
2.	Chinese		25.7
3.	Asian	25.7	
4.	Hawaiian/Part Hawaiian	25.6	
5.	Japanese		25.5
6.	Caucasian	25.4	
7.	Other Pacific Islander		24.7
8.	Korean		24.6
9.	Hispanic		22.0

Table 8.8 presents the adjusted and unadjusted mean scores for chance DLOC by race/ethnicity. As with internal DLOC, after controlling for gender, age, education and place of birth, there are no significant differences among these groups. These results are displayed graphically in Figure 8.2. It should be noted that the difference between Hawaiians and Other Pacific Islanders is most likely a result of the inclusion of Part Hawaiians and the lower chance DLOC scores found for groups that may also be represented among Part Hawaiians (e.g. Caucasians and Japanese).

	N*	Unadjusted	Adjusted	95% C.I.	95% C.I.
		Chance DLOC	Chance DLOC*	Lower	Upper
Asian	635/479	16.2	15.9	14.7	16.5
Japanese	379/302	15.1	15.6	15.0	16.2
Filipino	233/152	17.2	16.1	15.2	17.0
Chinese	151/120	16.3	16.0	15.1	16.9
Korean	34/23	16.6	16.5	14.4	18.5
Caucasian	187/131	14.0	14.5	13.6	15.4
Hawaiian/Pt Haw'n	176/131	15.6	15.8	14.7	16.5
Hispanic	34/22	15.2	14.9	12.8	17.1
Other Pacific Islander	16/7	20.4	18.4	14.6	22.2
Other/Unk	171/119	16.2	16.2	15.3	17.2

	Table 8.8:	Mean Chance	<b>DLOC Scores by</b>	Race/Ethnicity
--	------------	-------------	-----------------------	----------------

N (unadjusted/adjusted)

\*\*Scores adjusted for gender, age, education and birthplace.



Figure 8.2: Adjusted Mean Chance DLOC by Race/Ethnicity with 95% Confidence Intervals

Although differences between racial/ethnic groups in chance DLOC scores are

small and statistically insignificant, groups can be rank ordered based on these

scores as follows:

1.	Other Pacific Islander	18.4
2.	Korean	16.5
3.	Filipino	16.1
4.	Chinese	16.0
5.	Asian	15.9
6.	Hawaiian/Pt. Hawaiian	15.8
7.	Japanese	15.6
8.	Hispanic	14.9
9.	Caucasian	14.5

Controlling for covariates such as age, gender, education and birthplace,

as was done in comparing DLOC scores among racial and ethnic groups, is

important when trying to answer the academic question of whether differences are due to cultural factors or socioeconomic factors. In actuality, however, socioeconomic factors are correlated with racial and ethnic groups. To describe patterns of DLOC among study participants of different racial and ethnic groups, the proportion of patients was measured in terms of DLOC type. As shown in Table 8.9, different patterns emerged for various racial and ethnic groups. Sixty percent of Other Pacific Islander (a very small group), 43% of Hispanic, 38% of Korean and 35% of Chinese respondents were categorized as Type D (high chance, low internal DLOC). Thirty-two percent of Caucasian, 31% of Hawaiian/Part Hawaiian and 30% of Japanese respondents were categorized as Type A (high internal, low chance DLOC). Figure 8.3 presents graphically the proportion of Type A and Type D respondents in each racial/ethnic group.

	N	Туре А	Type D
	Type A/	(Hi Internal/	(Lo Internal/
	Type D	Lo Chance)	Hi Chance)
Asian	314/597	26.5%	26.1%
Japanese	187/359	30.4%	21.7%
Filipino	112/217	24.9%	26.7%
Chinese	90/148	25.7%	35.1%
Korean	21/34	23.5%	38.2%
Caucasian	96/183	32.2%	20.2%
Hawaiian	102/173	31.2%	27.7%
Hispanic	17/32	9.4%	43.8%
Other Pacific			
Islander	13/15	26.7	60.0%
Other/Unknown	94/163	28.8%	28.8%
Total	636/1163	27.9%	26.7%

Table 8.9: Percentage of Cases for Racial/Ethnic Groups by DLOC Type





# Figure 8.3: Percentage of Type A (Hi Internal/Lo Chance) and Type D (Lo Internal/Hi Chance) by Race Ethnicity

# **Summary of Results**

In terms of race/ethnicity, only minor differences remain after controlling for gender, age, education and birthplace. This finding suggests that differences in DLOC are more the result of socioeconomic differences rather than cultural differences. Although they constitute a very small group, Hispanics in this study have a unique pattern of DLOC with significantly lower internal DLOC and relatively low chance DLOC.

#### Quality of Care for Diabetes and DLOC

Hypotheses:

- 3. A high internal DLOC orientation will be associated with better quality of care as measured by seven specific measures of quality of care for diabetes and a composite measure of these seven measures, controlling for age, gender, education level, race/ethnicity and health plan effects.
- 4. The association of internal DLOC with quality of care will be stronger for measures of quality that require more active participation by patients, specifically eye examinations and lab tests (HbA1c, cholesterol level testing and urinalysis).

Overall, the quality of care received by the respondents of this study was quite good. Table 8.10 presents the percentages of respondents who received each of the seven process quality of care indicators. Of the seven services, over 80% received five or more.

To examine the relationship between internal and chance DLOC and quality of care as measured by these seven indicators, a series of two by two tables were initially generated, crosstabulating the dichotomous internal and chance DLOC variables (high and low) with the seven variables indicating whether or not the service was received by the patient. Based on the chi square statistic, only two significant associations were identified. Patients with high chance DLOC scores were more likely to get a foot exam than patients with low chance DLOC scores (88.5% vs. 82.7%, p=.020). Patients with low internal DLOC scores were more likely to get a proteinuria assessment than patients with high internal DLOC scores (87.1% vs. 80.4%, p=.011). Of the seven services, the mean number received by those in the high internal DLOC group was 5.5, compared to 5.6 for the low internal DLOC group. On the average, individuals in the high chance DLOC received 5.6 services, compared to 5.5 for the low chance DLOC group.

Table 8.10:	Percentage of Respondents That Received Each P	rocess Quality of Care
Indicators		

Process of Care		%
	N	Received
Eye Exam	925	81.8%
Foot Exam	925	84.9%
HbA1c Measured	925	89.4%
Lipids Measured	925	80.5%
Proteinuria	925	94.09/
Assessed		04.0 %
Advice to take	925	61 1%
Aspirin		01.176
Flu Vaccination	911	72.3%

Because these dichotomous measures of DLOC may have been too crude to capture finer differences in DLOC, mean internal and chance DLOC scores were compared for groups who did and did not receive each of the seven services. The significance of differences between each of these 14 pairs of means (internal and chance DLOC for each of the seven services) was measured using ANOVA. Once again, only two significant associations were identified. The mean chance DLOC score for those who received a foot exam was 15.9, compared to 14.7 for those who did not (p=.038). Similarly, the mean internal DLOC score for those who received a proteinuria assessment was 25.4, compared to 26.3 for those who did not (p=.005).

In an attempt to measure the independent effects of internal and chance DLOC, binomial logistic regression models were run for each of the seven processes of care quality indicators with the following variables included in the models: internal DLOC, chance DLOC, health plan, sex, age, duration of diabetes, income, education, treatment and race/ethnicity. Internal and chance DLOC, duration and age were entered into the model as continuous variables, the rest were included as categorical variables. Internal DLOC continued to have a significant independent effect upon proteinuria assessment (p=.023), with the likelihood of receiving this test decreasing as internal DLOC scores increased. There were significant effects for health plan and treatment (diet only vs. oral medications, insulin and insulin with oral medications) upon predicted receipt of proteinuria assessment. Predicted receipt of proteinuria increased as treatment intensity increased. Neither internal nor chance were significant independent predictors of receiving any of the other six services in these models.

Three variables emerged as important predictors of receiving these services. Health plan, treatment and age were significant predictors of receiving a foot exam, eye exam, an HbA1c test and advice to take aspirin, with older patients and those with more intensive diabetes treatment more likely to receive

these services. Those with higher income and males were significantly more likely to receive advice to take aspirin. Other Pacific Islanders were more likely to receive flu shots. Health plan and older age were the only significant predictors of having lipids measured.

A generalized linear model was generated to measure the effects of these ten variables upon the number of services (out of seven) received. In this model, neither internal nor chance DLOC were significant. Health plan, higher income, older age and treatment intensity were all significant predictors of receiving more services. The two study hypotheses were not confirmed. Internal LOC was not associated with better quality of care. In fact, the trend was in the opposite direction.

## Summary of Results

Low internal DLOC was associated with an increased likelihood of proteinuria assessment and high chance DLOC was associated with getting a foot exam. High internal DLOC was not associated with receiving any of the seven individual processes of care or with more of the seven processes measured. Health plan, income, age and treatment were found to be positive predictors of receiving individual processes of care and a higher proportion of the seven measured.

### Self-care Behaviors and DLOC

Hypotheses:

- 5. A high internal DLOC orientation will be associated with more frequent selfmonitoring of blood glucose, lower body mass index (BMI), lower rates of smoking, and more time spent on self-care activities than other DLOC orientations, particularly chance DLOC orientation.
- 6. The positive association of high DLOC with self-care behaviors will not be as strong among individuals with extremely high (top 25%) internal DLOC.

To assess the relationship of internal and chance DLOC and self-care behaviors, simple correlations were measured for each of the two scales with each self-care variable. The results are summarized in Table 8.11.

	Table 8.11:	Self-care	<b>Behaviors</b>	and DLOC
--	-------------	-----------	------------------	----------

	Internal DLOC		Chance DLOC			
	n	Correla- tion Coeffi- cient	P*	n	Correla- tion Coeffi- cient	P*
Body Mass Index (BMI)	1291	.02	NS	1221	07	.010
Smoking in Past Year	1264	07	.013	1196	.07	.018
Self Monitoring of Blood Glucose (SMBG)						
Y/N	1252	.02	NS	1189	05	NS
Times per week	846	.06	NS	808	09	.010
Daily	1208	.06	.032	1146	09	.004
Times per day	862	04	NS	820	05	NS
Extra Minutes per day						
Exercise	1173	.08	.010	1117	01	NS
Shopping, preparing food	1099	.06	NS	1055	.11	.000
Caring for feet	1158	04	NS	1099	.10	.001

\* 2 tailed significance

Internal DLOC was significantly associated with three self-care behaviors, smoking in the past year (negative association), self-monitoring of blood glucose (SMBG) on a daily basis (positive association) and the number of extra minutes spent per day exercising, due to diabetes (positive association). Interestingly, Chance DLOC was negatively associated with body mass index (BMI). Chance DLOC was positively associated with smoking in the past year, and also with extra minutes spent per day shopping for and preparing food and foot care, as a result of diabetes. Chance DLOC was negatively associated with SMBG on a daily basis and the number of times monitored per week.

To more closely examine trends, internal and chance DLOC were divided into quartiles and some significant trends were identified. With regard to internal DLOC, 30.3% of the highest quartile monitored blood glucose at home compared to 21.6% of those in the lowest quartile. Twenty-nine percent in the highest quartile monitored blood glucose on a daily basis, compared to 24.6% of the lowest quartile. On the average, those in the lowest quartile monitored their blood glucose 4.9 times per week, compared to 5.4 times for the highest quartile. Those in the lowest quartile spend less additional time on exercise and shopping for and preparing food as a result of their diabetes in comparison to those in the highest quartile (27.8 vs. 35.6 minutes per day for exercise and 20.7 vs. 27.3 minutes per day for food shopping and preparation).

With regard to chance DLOC, 33.1% of the lowest quartile monitored blood glucose at home compared to 21.2% of the highest quartile. Thirty-seven percent of those in the lowest quartile monitored on a daily basis, compared to 19.8% of those in the highest quartile. On the average, those in the lowest quartile monitored 5.3 days per week, compared to 4.8 days per week among those in the highest quartile. Respondents in the highest chance quartile spent significantly more time caring for their feet (8.1 vs. 4.9 minutes per day) and in food shopping and preparation (28.6 vs. 18.9 minutes per day) in comparison to those in the lowest chance quartile.

### Summary of Results

Internal DLOC was positively and significantly associated with daily selfmonitoring of blood glucose, and additional minutes spent per day on exercise. There was a significant negative association of internal DLOC with smoking. Chance DLOC was positively and significantly associated with smoking, shopping for and preparing food and foot care and negatively associated with self-monitoring of blood glucose. Surprisingly, chance DLOC was negatively associated with BMI. The relationship of internal DLOC with positive self-care behaviors was stronger among those with the highest scores. Similarly the relationship of chance DLOC with negative health behaviors was strongest among those with the highest chance scores.

#### Intermediate Outcomes, Comorbidities and DLOC

Hypotheses:

7. Individuals with a high chance DLOC orientation will have higher glycosylated hemoglobin, blood pressure, cholesterol levels, more diabetes symptoms,

and poorer mental health and physical functioning than those with a high internal DLOC orientation.

 The association of higher glycosylated hemoglobin, blood pressure and cholesterol levels will remain after controlling for differences in quality of care received.

The association of internal and chance DLOC with intermediate outcomes and comorbidities associated with diabetes are summarized in Table 8.12. Neither internal nor chance DLOC were significantly correlated with HbA1c, diastolic or systolic blood pressure or total cholesterol. However, internal DLOC was negatively associated with increased comorbidities (Charleson Index), more self-reported diabetes symptoms (Testa score), and positively associated with lower (better) scores on the mental health summary score (MCS) and higher (better) physical functioning summary score (PCS) of the SF-12. Chance DLOC was positively associated with increased co-morbidities, more self-reported diabetes symptoms, better mental health and lower physical functioning scores, although the association with mental health scores did not reach significance.

	Internal DLOC			Chance DLOC		
	n	Correla- tion Coeffi- cient	P*	n	Correla- tion Coeffi- cient	P*
HbA1c	862	06	NS	730	.03	NS
Blood Pressure						
Systolic	813	03	NS	769	07	NS
Diastolic	660	01	NS	625	.03	NS
Total Cholesterol	684	.00	NS	574	.01	NS
LDL	797	.02	NS	797	.06	NS
Charleson Index	827	11	.002	784	.07	.049
Testa Score	1000	19	.000	952	.14	.000
MCS Score	1291	14	.000	1221	02	NS
PCS Score	1291	.16	.000	1221	14	.000

#### Table 8.12: Intermediate Outcomes and DLOC

\* 2 tailed significance

These results seem to indicate that in terms of objective, diabetes-related physiological measures, there are no differences associated with internal or chance DLOC. However, there are indications that those with lower internal DLOC and those with higher chance DLOC both objectively and subjectively experience a greater burden of illness. Although the likelihood of comorbid conditions and physical disability increases with age and duration of diabetes, as reported previously, internal DLOC is not independently associated with age, and diabetes duration is not independently correlated with either internal or chance DLOC. In addition, treatment modality, an indication of diabetes severity, does not differ appreciably between the low and high groups for internal and chance DLOC (22.8% vs. 21.3% on insulin or insulin plus oral meds for internal DLOC

and 24.1% vs. 20.5% for chance DLOC). Yet, self-reported health status was worse for the high chance DLOC group (21.7% excellent or very good) than the high internal DLOC group (29.3% excellent or very good).

### Summary of Results

Neither internal nor chance DLOC were related to intermediate physiological outcomes of diabetes. Internal DLOC was related to fewer comorbid medical conditions, fewer diabetes symptoms, better mental health and physical functioning scores. Chance DLOC was associated with more comorbid medical conditions and diabetes symptoms, as well as poorer physical functioning.

# **CHAPTER 9: CONCLUSIONS AND DISCUSSION**

Six main conclusions can be drawn from this study:

- Peyrot and Rubin's instrument performed well for the measurement of internal and chance DLOC, but less well for external DLOC and hypothesized subdomains.
- 2. DLOC is related to socioeconomic position.
- There was no evidence of strong cultural effects upon DLOC, after controlling for the effects of socioeconomic position.
- 4. The quality of care received by people with a high chance DLOC was as good or better than that received by those with a high internal DLOC.
- 5. Internal DLOC is positively related to self-care behaviors and chance DLOC is negatively related to self-care behaviors.
- 6. DLOC is not related to physiological measures of diabetes-related outcomes but high chance DLOC orientation is related to a greater burden of illness including diabetes symptoms, comorbid conditions, mental health and physical functioning.

More detailed discussion of these conclusions follow in for each of the five areas of investigation, along with a description of study limitations and possible directions for future research.

# **Study Limitations**

Prior to the discussion of study conclusions, there are some study limitations that warrant notation. As discussed in the Methods section, there are factors related to eligibility for the TRIAD Study that result in sample bias. This study represents an insured population, engaged in health care (all had to have received services in the eighteen months prior to the study), and is likely to include patients who are healthier and those with better controlled diabetes, than that of the entire population in Hawai'i with diabetes. For these reasons, this study may not adequately reflect the barriers to optimal diabetes care and outcomes for patients at highest risk due to severity of illness and/or lack of insurance. It is likely, however, that the barriers faced by these individuals would be similar to those faced by some study participants with economic hardships and poorly controlled diabetes, but magnified as a result of increased health and socioeconomic stressors.

Another limitation results from the cross sectional design of the study. While significant relationships were identified between DLOC and patient characteristics, self-care behaviors and diabetes related outcomes and comorbidities, the causal direction of these associations cannot be definitively demonstrated with a cross sectional design. Even with the eighteen-month follow-up and planned re-survey of the cohort in the future, it is not possible to conclusively demonstrate causal direction for many observed relationships.

Another issue related to cross sectional design is that DLOC was only measured once. Without repeated measurement it is difficult to determine the stability of DLOC over time, or whether measurements are more indicative of transient states. Based on the results of this study, DLOC measures may be

included in planned future follow-up surveys of the entire TRIAD cohort (all six sites).

Diabetes knowledge *per se* was never measured directly in this study. Although this was a candidate domain for inclusion in the patient survey, it was dropped due to the length of the survey and competing priorities for other measures. This is an important factor because it is thought to be an important tool used by those with high internal DLOC in achieving better care and outcomes. Study data do, however, provide some indirect indicators of diabetes knowledge among respondents.

An additional area that cannot be adequately assessed with the current TRIAD data is treatment adherence, particularly with prescribed medication. The chart review and patient survey provide information about medications prescribed, but there is little information about what the patient actually took or the degree to which they followed instructions about taking medications. This is an important issue, particularly with regard to seniors and changes in Medicare prescription benefits. The collection of more detailed information about medication adherence and barriers to adherence is planned for future follow-up of the existing TRIAD cohort, and possibly a new cohort of patients. There are some indicators of treatment adherence in the current data, including smoking status, BMI, self-monitoring of blood glucose, and time spent on exercise and foot care.

#### **Concepts and Measurement**

As described previously, Peyrot and Rubin's DLOC instrument performed well in the measurement of internal and chance DLOC. This is a very positive result considering ten years have passed since they published this instrument, the substantially larger population it was tested on in Hawai'i (1400 patients vs. 169), and the significant differences in racial and ethnic composition between the two study samples. It bears reiteration, however, that there are somewhat subjective decisions involved in factor analysis, and there is no single "correct" solution. Others may have interpreted the data in slightly different ways.

It is not surprising that the instrument performed least well in the area of external DLOC. To some extent this is reflective of a larger issue with the concept of LOC in general. Rotter's initial work in the measurement of LOC essentially focused the relative sense of perceived individual control. Using this instrument, an investigator could draw conclusions about whether an individual felt they had control over their life, or not. With the intent of more specifically articulating the sources of control, if it was not within one's self, LOC measurement became multidimensional. These multiple dimensions, however, are all in external LOC. Rotter's original concept is still present, in the measurement of internal LOC. This shift to multidimensional measurement has had some benefits but has caused some problems as well. First of all, the notion of control or direct causation of events may be irrelevant for some people. If an individual does not feel they have control over events or circumstances, they may also have no idea about who else or what else does have control. In this study,

for example, almost 27% of respondents scored low for both internal and chance DLOC. While it is possible that this may be a response set, given the substantial size of this group, it is more likely that these respondents could not identify a specific source of control or that the idea of control was irrelevant to them. While adding additional domains of external LOC may be helpful in some cases (i.e., questions regarding spirituality), the increasing measurement of additional domains of external LOC may contribute very little if it is already known that an individual does not feel they have control.

An additional problem resulting from multidimensional measurement is the issue of trying to combine scores from different domains to form a coherent picture of individuals or groups. Scores on separate domain scales tend to be uncorrelated. For the internal and chance scales in this study the correlation coefficient was -.07, although statistically significant (p=012), the absolute value of this coefficient was very close to zero. This characteristic warrants against the combination of the two scales into a single scale. Individuals with high internal and low chance scores could look similar to individuals with low internal and high chance scores. The method of classifying patients into types, as done by Wallston and Wallston (1982) and Bradley et al. (1990), and for this study, is somewhat helpful but may be too crude to measure fine distinctions, and result in some useless categories. In the meantime, it is difficult to interpret whether high internality is similar to low externality or if low internality is related to high chance. Although intuitively it would seem that these relationships must exist, the data do not always bear this out. This situation makes the comparison of findings among

different studies using multidimensional measures very difficult. Perhaps the best approach would be a unidimensional, condition-specific instrument.

#### **DLOC – The Comparison of Groups**

Although LOC has been studied as a psychological construct for more than fifty years, this study, and numerous others before it, provide evidence that LOC is a sociological, as well as a psychological phenomenon. As described in the literature review section, initial interest in LOC was driven by efforts to understand the mechanisms of social inequality. Theorists in the area of socioeconomic status and health in particular, point to the stress and diminished sense control associated with poor social environments as a primary mechanism of disparities in health (Brunner and Marmot 1999). Link and Phelan propose a "fundamental cause" explanation, suggesting that the sense of control experienced by those at the upper levels of the social hierarchy provides a sense of dominance and well being (Link and Phelan 2000). While perceived LOC may be measured as an individual phenomenon, it is considerably influenced by the social environment.

With regard to gender, some previous studies have found that women tend to be more external in LOC orientation than men. This study did not identify significant difference in internal or chance DLOC between men and women. One possible factor is that much of diabetes control involves knowledge about food and diet and women may be more knowledgeable in this area, as indicated in other studies (Furnam and Kircaldy 1997; Hale 1985). For men, both internal

and chance DLOC scores were similar across age groups. For women, chance DLOC was significantly higher among those over age 65 in comparison to younger groups. As a cross sectional study, it is not possible to determine whether this is an effect of the aging process or instead reflects differences among generations of women.

Mean scores for internal DLOC are generally high and increase with each level of educational attainment for men and women, but they do not change significantly. Scores for chance DLOC decrease with each level of educational attainment and these changes are significant. It is important to bear in mind that the average age of respondents is 57 and the average duration of diabetes is 11 years. For most respondents, educational attainment took place long before the diagnosis of diabetes. While it cannot be stated with absolute certainty since this is a cross sectional study, these findings suggest that general control orientation is related to educational attainment and that this same control orientation carries over to diabetes specific LOC later in life. For example, strong beliefs in fate or luck are likely to reduce the likelihood of educational attainment. Later on, these same beliefs in fate may be reflected in the sense of control one perceives they have over their diabetes. This is also an example of how the correspondence between domains of DLOC can be counterintuitive. One would expect that internal DLOC would show significant increases with educational attainment (as chance DLOC shows significant decreases), but this is not the case, at least in this study.

The relationship of income to DLOC does display this pattern of both increases in internal DLOC and decreases in chance DLOC with each increasing level of income. This finding, again, points to the social context of DLOC, perhaps more so than education, since income coincides with having diabetes and education is likely to have taken place years before. Both education and income play a role, however, with nearly half of those with less than a high school education and more than 40% of those earning less than \$15,000 annually having both high chance and low internal DLOC scores (DLOC Type D). Recalling Link and Phelan's (2000) fundamental cause theory, these factors would increase the likelihood of getting diabetes in the first place and diminish ability to manage it once diagnosed. Lower socioeconomic position would decrease the resources available to prevent and manage diabetes. Limited access to information, supermarkets with fresh fruit and vegetables and recreational facilities are all associated with living in poor neighborhoods and related to the prevention and successful management of diabetes.

In an attempt to measure the separate effects of race/ethnicity and socioeconomic status in this study, DLOC scores for racial/ethnic groups were compared, adjusting for age, gender, education and place of birth (United States or not). Controlling for these covariates, only one significant difference among these groups was identified - Hispanics in the study had lower internal DLOC scores than other groups except Other Pacific Islanders and Koreans. These findings suggest that differences among these groups are more related to socioeconomic differences than cultural differences. The finding for Hispanics is

interesting but with such a small sample, it may not be a reliable finding. In addition, it may not be representative of Hispanics in other locations in which they occupy a larger segment of the population.

These findings represent a statistical approach to an academic question, however, among actual patients, race/ethnicity and socioeconomic position are correlated. In the interest of translational research and developing interventions to improve outcomes for diabetes, it is important to recognize socioeconomic barriers as well as potential cultural barriers. Zola cautions against the exploitation of culture in the design of culturally specific interventions as a tool to redirect patients away from their chosen lifestyle practices towards those that may be more consistent with other value systems (e.g. medical) (1983:236). Similarly, the coincidence of lower socioeconomic conditions among minority patients could lead providers to focus on cultural barriers when in fact, the barriers are more socioeconomic in nature. Among the respondents in this study, 35% of the Hispanics and 42% of the Other Pacific Islanders had less than a high school education and earned less than \$15,000 annually, compared to 12% and 15% of Caucasians respectively.

The LOC construct in general, and the diabetes-specific version, can also imply a moral judgement that internal control is good and belief in fate is bad, and that those who endorse the former are in some way superior to those who endorse the latter. Without diminishing the importance of patient vigilance in caring for their own diabetes, the value of self-sufficiency and self-determination are not universally shared. These are particularly western values, reflected in

study results with Caucasians having lower chance DLOC scores than any other group. Taken to an extreme, total avoidance of risk may not be a desirable or even practical option. To quote Myers (in Zola),

"A physician constructed composite picture of an individual with a low risk of atherosclerosis would be:

"...an effeminate municipal worker or embalmer completely lacking in physical or mental alertness and without drive, ambition, or competitive spirit; who has never attempted to meet a deadline of any kind; a man with poor appetite, subsisting on fruits and vegetables laced with corn and whale oil, detesting tobacco, spurning ownership of radio, television, or motorcar, with full head of hair but scrawny and unathletic appearance, yet constantly straining his puny muscles by exercise. Low in income, blood pressure, blood sugar, uric acid and cholesterol, he has been taking nicotinic acid, pyridoxine, and long term anti-coagulant therapy ever since his prophylactic castration" (Meyers 1968:215-216 in Zola 1983:267).

Similarly, chance is part of life and cannot be totally controlled. Calvin Coolidge, former American president, offered the following insight regarding chance and risk:

"When you see ten troubles rolling down the road, if you don't do anything, nine of them will roll into a ditch before they get to you."

#### **DLOC and Self-Care Behaviors**

An area of controversy in LOC research is whether people's perceptions of control actually relate to observable behavior. The results of this study suggest that they do. Internal DLOC was positively and significantly associated with daily self-monitoring of blood glucose, and additional minutes spent per day on exercise. There was a significant negative association of internal DLOC with smoking. Chance DLOC was positively and significantly associated with smoking, shopping for and preparing food and foot care (although this could be indicative of diabetes complications) and negatively associated with selfmonitoring of blood glucose. Results in this area also showed larger effect sizes with increasing scores. These results confirm the findings of Steptoe and Wardle (2001) with regard to general LOC, Booth-Butterfield, Anderson and Booth-Butterfield (2001) with regard to smoking, and Peyrot and Rubin (1994) regarding self-monitoring of blood glucose.

### **Process Quality of Care Indicators and DLOC**

It was hypothesized that patients in the study with high internal DLOC would receive more of the seven services that constitute standards for diabetes care, and that these patients would also receive services that required additional patient action (i.e. eye exams and lab tests) at a higher rate than patients with low internal DLOC or high chance DLOC. Neither of these hypotheses were confirmed. The only significant differences were in foot exams and the assessment of proteinuria, and patients with high chance scores received these
services more often than other groups. One possible explanation suggested by these results is that health care providers generally attempt to adhere to standards of care, since overall quality by these measures was good, but they also respond to the needs of individual patients. For example, it may not be necessary for a 45 year-old diet controlled person with diabetes to have a foot exam at every visit. Since patients with high chance DLOC scores were likely to be older, and also had more diabetes symptoms and comorbid conditions, it is possible they received more intensive treatment. It would appear that forces impinging on health care providers and organizations from other sources, e.g. clinicians' desire to provide high quality care and pressures upon the organization to meet accreditation standards, have more of an impact on physician behavior than individual patient characteristics.

### **DLOC and Diabetes-related Comorbidity and Outcomes**

Although contrary to study hypotheses, DLOC was not found to be related to any of the three hallmark intermediate physiological outcomes for diabetes, HbA1c, blood pressure and total cholesterol. Internal DLOC was related to fewer comorbid medical conditions, fewer diabetes symptoms, better mental health and physical functioning scores. Chance DLOC was associated with more comorbid medical conditions and diabetes symptoms, as well as poorer physical functioning. One possible explanation for these findings is that the physiological outcomes can be treated with medication, whereas the number of comorbidities, diabetes symptoms, mental health and physical functioning are not as effectively

134

treatable with medication. As with the finding for process measures of quality, it may be that clinicians are able to identify patients with uncontrolled HbA1C, blood pressure and cholesterol levels, and adjust medication regimens accordingly. Although not readily feasible with the current data, it would be important to look at medication use as a factor mediating the relationship of internal and chance DLOC with these physiological outcomes before drawing any firm conclusions about these relationships.

The results show that by objective and subjective measures, patients with high chance DLOC have a greater burden of illness than patients with high internal DLOC. This finding highlights an important question with regard to DLOC as contributor to outcomes for diabetes vs. an outcome of diabetes experience. There seems to be ample evidence that DLOC is related to a general sense of control, present prior to the diagnosis of diabetes. There is no clear pattern of association between duration of diabetes and DLOC, but it would seem reasonable to assume that patients learn through their experience, the degree to which they can manage the condition. Socioeconomic barriers and associated low sense of control may contribute to a host of other physical and psychological problems, in addition to diabetes. The experience of trying to manage diabetes and other medical conditions with other social stressors may reduce an individual's sense of control or exacerbate an already poor sense of control. It seems likely that LOC in general, and DLOC specifically, acts in two ways - the first is a general sense of control that an individual has, based on

135

previous life experience, at the time of diagnosis. The second is the moderating effect resulting from experience managing diabetes.

### **Directions for Future Research**

Future studies of DLOC would benefit from more work in the area of measurement. While including multiple domains of external DLOC is helpful to a degree, it also substantially complicated the integration of domain measurements and hampers the comparison of results from different studies. A single measure, or a method of combining measures of multiple domains into a single measure, would greatly facilitate future research.

While this study focussed on patient DLOC, health care takes place within a patient/physician diad. There have been a number of attempts to enhance patient internal DLOC, or to empower patients, to care for their diabetes, with mixed results. Another potential approach would be to assist patients with limited internal DLOC by providing support groups. In addition, while there is some evidence that clinicians adapt their treatment to the DLOC style and needs of patients, it may be of benefit to assist physicians with a method to more readily assess patient preferences with regard to diabetes control. Health services research has repeatedly demonstrated that patients differ in their desire for control over treatment. The goal to have all patients become the primary managers of their diabetes, or going further, their diabetes care, as Wagner et al. suggest (2001:66), may not be the most effective approach for all patients, or even a realistic goal. Several studies in the United Kingdom have tested

136

interventions to manipulate the clinical encounter based on the control preference of patients. Such interventions appear to have promise and should be more extensively tested in the United States.

Optimal care for diabetes requires patients and healthcare providers to work together as a team. While considerable efforts have been made to alter the role of patients in diabetes care, the opportunity for providers to adjust their role to meet the needs and preferences of patients also offers the potential to improve diabetes care and reduce disparities in health.



### Appendix A: Exemption Approval Letter from University of Hawai'i CHS

#### UNIVERSITY OF HAWAI'I

**Committee on Human Studies** 

#### MEMORANDUM

January 6, 2004

Beth Waitzfelder Principal Investigator Department of Sociology

William H. Dendle Executive Secretary

FROM:

TO:

SUBJECT:

CHS #12767- "Locus of Control, Quality and Outcomes of Care Among Managed Care Patient with Diabetes in Hawaii"

Your project identified above was reviewed and has been determined to be exempt from Department of Health and Human Services (DHHS) regulations, 45 CFR Part 46. Specifically, the authority for this exemption is section 46.101(b)(6). Your certificate of exemption (Optional Form 310) is enclosed. This certificate is your record of CHS review of this study and will be effective as of the date shown on the certificate

An exempt status signifies that you will not be required to subinit renewal applications for full Committee review as long as that portion of your project involving human subjects remains unchanged. If, during the course of your project, you intend to make changes which may significantly affect the human subjects involved, you should contact this office for guidance prior to implementing these changes.

Any unanticipated problems related to your use of human subjects in this project must be promptly reported to the CHS through this office. This is required so that the CHS can institute or update protective measures for human subjects as may be necessary. In addition, under the University's Assurance with the U.S. Department of Health and Human Services, the University must report certain situations to the federal government. Examples of these reportable situations include deaths, injuries, adverse reactions or unforeseen risks to human subjects. These reports must be made regardless of the source funding or exempt status of your project.

University policy requires you to maintain as an essential part of your project records, any documents pertaining to the use of humans as subjects in your research. This includes any information or materials conveyed to, and received from, the subjects, as well as any executed consent forms, data and analysis results. These records must be maintained for at least three years after project completion or termination. If this is a funded project, you should be aware that these records are subject to inspection and review by authorized representatives of the University, State and Federal governments.

<u>Please notify this office when your project is completed.</u> We may ask that you provide information regarding your experiences with human subjects and with the CHS review process. Upon notification, we will close our files pertaining to your project. Any subsequent reactivation of the project will require a new CHS application.

Please do not hesitate to contact me if you have any questions or require assistance. I will be happy to assist you in any way I can.

Thank you for your cooperation and efforts throughout this review process. I wish you success in this endeavor.

Enclosure

2540 Maile Way, Spalding 252, Honolulu, Hawai'i 96822-2303 Telephone: (808) 539-3955/(808) 956-5007, Facsimile: (808) 539-3954, Web site: www.hawaii.edu/irb An Equal Opportunity/Affirmative Action Institution

	OMB No. 0990-0263 Approved for use through 07/31/2005
Protection of Huma Assurance Identification/IRB Certificat (Common Ru	n Subjects tion/Declaration of Exemption le)
Policy: Research activities involving human subjects may not be conducted or supported by the Institution Departments and Agencies adopting the Common Rule (56FR28003, June 18, 1991) unless the should stativities are exempt from or approved in accordance with the Common Rule. See section 101(b) otherwise of the Common Rule for exemptions. Institutions submitting applications or proposals for support must submit cartification of appropriate Institutional Review Board (IRB) review and approval to the Department or Agency in accordance with the Common Rule.	ns must have an assurance of compliance that applies to the research to be conducted and ubmit certification of IRB review and approval with each application or proposal unless e advised by the Department or Agency.
1. Request Type       2. Type of Mechanism         [] ORIGINAL       [] GRANT       [] CONTRACT       [] FELLOWSHIP         [] CONTINUATION       [] COOPERATIVE AGREEMENT         [X] EXEMPTION       [] OTHER:	<ol> <li>Name of Federal Department or Agency and, if known, Application or Proposal Identification No.</li> </ol>
4. Title of Application or Activity	5. Name of Principal Investigator, Program Director, Fellow, or Other
with Diabetes in Hawaii"	Beth Waitzfelder
6. Assurance Status of this Project (Respond to one of the following)	
[X] This Assurance, on file with Department of Health and Human Services, covers the Assurance Identification No. <u>F-3526</u> , the expiration date <u>October 15, 2005</u>	nis activity: IRB Registration No. <u>IORG0000169</u>
[] This Assurance, on file with (agency/dept)         Assurance No, the expiration date	Registration/Identification No, covers this activity.
[] No assurance has been filed for this institution. This institution declares that it will approval upon request.	provide an Assurance and Certification of IR8 review and
[X] Exemption Status: Human subjects are involved, but this activity qualifies for exer	nption under Section 101(b), paragraph <u>6</u> .

7. Certification of IRB Review (Respond to one of the following IF you have an Assurance on file)

[] This activity has been reviewed and approved by the IRB in accordance with the Common Rule and any other governing regulations.

- by: [] Full IRB Review on (date of IRB meeting) \_\_\_\_\_ or [] Expedited Review on (date)
  - [] If less than one year approval, provide expiration date \_

[] This activity contains multiple projects, some of which have not been reviewed. The IRB has granted approval on condition that all projects covered by the Common Rule will be reviewed and approved before they are initiated and that appropriate further certification will be submitted.

8. Comments

	· · · · · · · · · · · · · · · · · · ·	CHS #12767		
<ol> <li>The official signing below certifier correct and that, as required, future closure and certification will be prov</li> </ol>	s that the information provided above is reviews will be performed until study vided.	10. Name and Address of Institution		
11. Phone No. (with area code) (808) 956-5007		Office of the Chancellor		
12. Fax No. (with area code)	(808) 539-3954	2444 Dole Street, Bachman Hall Honolulu, HI 96822		
13. Email:				
· · · · · · · · · · · · · · · · · · ·	dendle@hawaii.edu			
14. Name of Official	· · · · · · · · · · · · · · · · · · ·	15. Title		
William H. Dendle		Compliance Officer		
16. Signature			17. Date	
NO X	vol		January 2, 2004	
Authorized for local Reproduction			Sponsored by HHS	

Public reporting burden for this collection of information is estimated to average less than an hour per response. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: OS Reports Clearance Officer, Room 503 200 Independence Avenue, SW., Washington, DC 20201. Do not return the completed form to this address.

### **Appendix B: TRIAD Baseline Patient Survey**



The HEALTH PLAN and the Pacific Health Research Institute are participating with the Centers for Disease Control in a national study to improve the quality of health care being delivered to persons with diabetes. As part of that project, survey information is being collected from members of HEALTH PLAN to learn more about their health and the type of care they receive. We realize that there are quite a few questions, but the information is very important. It will be used to help design new methods to improve diabetes health care delivery. This questionnaire will be given to you twice: now and again in about two years. *You can decide to fill out the questionnaire yourself or call us to complete the questionnaire over the phone.* 

There are no right or wrong answers. We are interested in <u>your</u> experiences, so please answer each question honestly. All of your answers are confidential. When you complete the survey, please return it in the enclosed self-addressed stamped envelope.

- There are few risks related to taking part in this study. Some of the questions may cause you to feel uncomfortable. You are free to skip any questions that make you uncomfortable and to stop at any time. Taking part in the study will not affect the health services or benefits you get from your health plan. You are not giving up any legal rights or benefits to which you are entitled by taking part in this study.
- The information you give us will be kept private. All data collected will be coded so that your name does not appear on the data files used for analyses. Only the principal investigator and members of his staff will be able to link data to individual names. You will not be named in any reports on this study.

Please return your completed questionnaire and signed consent – if you agree – in the enclosed stamped and addressed envelope as soon as you finish it. If you have any questions, please call 585-6181 from Oahu, or call our toll-free number 1-877-503-7911 from the neighbor islands, Monday through Friday between 9:00 a.m. and 5:00 p.m. After we get your questionnaire, we will send you a phone card with 60 minutes of free calling time to thank you for taking the time to complete the questionnaire. While taking part is voluntary, your cooperation is VERY important for the success of our study.

### THANK YOU



### Directions

Read each question carefully and place a check in the box that most closely reflects your experience. Depending on your answers, you might be asked to skip some of the questions on this survey.

- Are you currently a member of HEALTH PLAN?
   <sup>1</sup> Yes
   <sup>2</sup> No (If no, this survey is complete. Please return in the envelope provided.)
- 2. Is HEALTH PLAN the primary source for your health care?
  1 Yes
  2 No (If no, this survey is complete. Please return in the envelope provided.)
- 3. Has a doctor or other health professional *ever* told you that you had diabetes, also known as sugar diabetes or high blood sugar?
  1□ Yes
  2□ No (If no, this survey is complete. Please return in the envelope provided.)
- 4. <u>IF YOU ARE FEMALE</u>: If you have ever been pregnant, did you have diabetes only while you were pregnant?
  1□ Yes (*If yes, this survey is complete. Please return in the envelope provided.*)
  2□ Unsure (*If unsure, this survey is complete. Please return in the envelope provided.*)
  3□ No
- 5. <u>IF YOU ARE FEMALE:</u> Are you currently pregnant?
   1□ Yes (*If yes, this survey is complete. Please return in the envelope provided.*)
   2□ Unsure (*If unsure, this survey is complete. Please return in the envelope provided.*)
   3□ No
- Do you currently have diabetes?
  1□ Yes
  2□ No (If no, this survey is complete. Please return in the envelope provided.)

	TRIAD
	Not for use, in whole or in part, without permission from the aut
7.	About how old were you when you were first told you had diabetes?
8.	What is your birth date? (mo/day/yr)/
9	What is your gender?
•••	□ Male
	$_2\square$ Female
10.	How tall are you without your shoes? feet inches
11	How much do you weigh without clothes?
	now much do you weigh without clothes: pounds
12.	How do you currently manage or control your diabetes?
	CHECK ALL THAT APPLY
	$\Box$ Diet &/or exercise only
	<sup>2</sup> <sup>□</sup> Oral medications
	$_{3}\square$ Insulin injection
	₄□ Insulin pump
	$\square$ Other (place list)

# 14. For the next set of items, please indicate if your current doctor or other health care provider (such as a diabetes educator or nurse) in your doctor's office explained to you, showed you or gave you information about the following:

		Yes	No	Unsure	
		1	2	3	
A.	How to care for your feet?				
Β.	What to do for symptoms of low blood sugar?				
C.	How to exercise appropriately?				
D.	What is a good number for your blood sugar?				
E.	How to adjust your diabetes medications in response to blood sugar values on sick days?				

TRIAD

Not for use, in whole or in part, without permission from the author.

- 15. Do you test your blood sugar levels at home?
  1□ Yes
  2□ No (If no, skip to question 19.)
- 16. How many **days a week** do you test your blood sugar?  $\Box 1 \quad \Box 2 \quad \Box 3 \quad \Box 4 \quad \Box 5 \quad \Box 6 \quad \Box 7$
- 17. When you test your blood sugar, how many times per day do you usually test?□1 □2 □3 □4 or more
- 18. During the past year, how often did your doctor or some other health care professional review your home blood or urine sugar test results?
  - <sup>1</sup> Every visit
  - $_2\square$  Most of the visits
  - $_{3}\Box$  At least one of the visits
  - $_4\square$  None of the visits
  - $_{5}\square$  Not sure
- 19. When was the last time you had an eye exam in which your pupils were dilated (drops in your eyes that make you temporarily sensitive to bright light)?
  - $_1\square$  During the past 12 months
  - $_2\square$  More than a year but less than 2 years
  - $_{3}\Box$  More than 2 years
  - ₄□ Never
  - ₅□ Not sure
- 20. During the past year, how often did your doctor or some other health care professional examine your feet with your socks off?
  - <sup>1</sup> Every visit
  - $_2\square$  Most of the visits
  - $_{3}\square$  At least one of the visits
  - $_4\square$  None of the visits
  - $_5\square$  Not sure



- 21. When was the last time a doctor or other health professional tested the feeling in your feet or legs by touching them with a monofilament (which looks like a short piece of fishing line)?
  - $_{1}\square$  During the past 12 months
  - $_2\square$  More than a year but less than 2 years
  - $_{3}\square$  More than 2 years
  - $_4\square$  Never
  - $_{5}\square$  Not sure
- 22. Has your doctor or some other health care professional told you to take aspirin regularly to lower your risk of developing heart disease or stroke?
  - $_1\square$  Yes
  - $_2\square$  No
  - <sub>3</sub> Unsure
- 23. Did you get a flu shot during the past 12 months?
  - $_1\square$  Yes
  - $_{2}\square$  No (If no, skip to question 24.)
- 23a.  $\rightarrow$  *If Yes*, did you get your flu shot through your health plan?
  - $_1\square$  Yes
  - $_2\square$  No
  - <sub>3</sub> Unsure
- 24. In the past year, have you smoked cigarettes every day, some days, or not at all?  $\Box Every day$ 
  - <sup>2</sup>□ Some days <sup>3</sup>□ Not at all (If not at all, skip to question 28.)
- 25. Were you advised by a doctor or other health care provider to quit?
  1□ Yes
  2□ No (If no, skip to question 28.)
- 26. Were you referred to a smoking cessation program by a doctor or other health care provider? 1□ Yes 2□ No



27. Were medications recommended or prescribed by a doctor or other health care provider to help you quit smoking?

 $_1 \square$  Yes  $_2 \square$  No

28. During the past 12 months, *have you received any of the following types of diabetes-related information* from your doctor's office or health care plan:

	Yes 1	<u>No</u> 2	Unsure 3
Diabetes materials (e.g. pamphlets or newsletters, audiotapes or videotapes)			
Reminders about upcoming appointments			
Reminders that diabetes-related services or tests are due			
A copy of diabetes-related laboratory results after or between visits			
Information about diabetes education (such as support groups or one-on-one counseling, advice services, or Internet sites)	_	0	•
	Diabetes materials (e.g. pamphlets or newsletters, audiotapes or videotapes) Reminders about upcoming appointments Reminders that diabetes-related services or tests are due A copy of diabetes-related laboratory results after or between visits Information about diabetes education (such as support groups or one-on-one counseling, advice services, or Internet sites)	Yes         1         Diabetes materials (e.g. pamphlets or         newsletters, audiotapes or videotapes)         Reminders about upcoming appointments         Reminders that diabetes-related services or tests are due         A copy of diabetes-related laboratory results after or between         visits         Information about diabetes education (such as         support groups or one-on-one counseling, advice         services, or Internet sites)	Yes 1No 2Diabetes materials (e.g. pamphlets or newsletters, audiotapes or videotapes)□Reminders about upcoming appointments□Reminders that diabetes-related services or tests are due□A copy of diabetes-related laboratory results after or between visits□Information about diabetes education (such as support groups or one-on-one counseling, advice services, or Internet sites)□

29. During the past 12 months, *have you used* any of the following diabetes-related services or attended any of the following diabetes-related programs:

		<u>Yes</u> 1	<u>No</u> 2	Unsure 3
A.	A diabetes support group			
B.	One-on-one or group diabetes education			
C.	A diabetes-related Internet site			
D.	A personal diabetes health record (also sometimes called a "passport") to remind you and your health care provider about your diabetes-related care		•	

30. Have you ever been told by a doctor or someone in your doctor's office that you have high cholesterol or triglycerides or elevated lipids (fatty substance in the blood)?
 1□ Yes
 2□ No



11

- 31. Have you ever been told by a doctor or someone in your doctor's office that you have had a heart attack, a "coronary" or a myocardial infarction?
   1□ Yes
  - $_2\square$  No
- 32. Have you ever been told by a doctor or someone in your doctor's office that you have had a stroke, cerebrovascular accident, blood clot or bleeding in the brain, or a transient ischemic attack or "mini-stroke"?

 $_1\square$  Yes

 $_2$  No

### 33. Have you ever had any of the following procedures:

	Tes	NO	Unsure
	1	2	3
A. Surgery to bypass or unclog arteries to your heart			
B. Angioplasty or a balloon to unclog arteries to your			
heart or leg			
C. A toe, foot, or leg amputation			
1 YAYY 1			

→ If Yes, what was amputated?

<sup>1</sup> One or more toes, but neither foot

<sup>2</sup> One foot (or leg), but not both feet <sup>3</sup> Both feet (or legs)

### 34. During the PAST 4 WEEKS have you experienced the following:

	1.36.4	All of the Time 1	Most of the Time t 2	Some of he Time th 3	Little of he Time t 4	None of he Time 5
A.	Dry mouth?					
B.	Having to get up at night to urinate?					
C.	Frequent urination?					
D.	Excessive thirst?					
E.	Blurred or double vision?		0			
F.	Decreased ability to feel hot of cold with your hands or feet?	r D	0	D	D	

	Not for use, in t	whole or in p	part, without	t permission	from the a	author.
		All of the Time 1	Most of the Time ( 2	Some of the Time the 3	Little of he Time 4	None of the Time 5
(Sł	KIP G-J AND 35 IF YOU HAVE H	AD BOTH	FEET AMP	PUTATED.)	10 (S. 1.) 10 (S. 1.)	
G.	Numbness or loss of feeling in your feet?					
H.	Tingling or burning sensation in your feet?					
I.	Sores or wounds on your feet that did not heal?				+	
J.	Dry or cracked feet?		0			

35. Do you or someone in your home check your feet for sores every day?
 1□ Yes
 2□ No

36. Has your doctor or other health care professional talked with you about whether you experienced any decrease in sexual interest or performance?
 1□ Yes
 2□ No

### The next question asks about your health in general.

37. In general, would you say your health is:

1 Excellent
2 Very good
3 Good
4 Fair
5 Poor

TRIAD

The next set of questions ask for your views on your health. First, please consider activities that you might do during a *typical day*. Does your health now limit you in these activities? If so, how much?

- 38. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.
  - $_1\square$  Yes, limited a lot
  - $_2\square$  Yes, limited a little
  - $_{3}\Box$  No, not limited at all



- 39. Climbing several flights of stairs.
  - $_1\square$  Yes, limited a lot
  - <sup>2</sup><sup>D</sup> Yes, limited a little
  - $_{3}\square$  No, not limited at all

During the *past 4 weeks*, have you had any of the following problems with your work or other regular daily activities as a result of your <u>physical</u> health?

40. Accomplished less than you would like as a result of your physical health?

 $_1 \square$  Yes  $_2 \square$  No

41. Were limited in the kind of work or other regular daily activities?
 1□ Yes
 2□ No

During the *past 4 weeks*, have you had any of the following problems with your work or other regular daily activities *as a result of any <u>emotional</u> problems*, such as feeling depressed or anxious?

42. Accomplished less than you would like?

 $_1 \square$  Yes  $_2 \square$  No

- 43. Didn't do work or other activities as carefully as usual?
   1□ Yes
   2□ No
- 44. During the past four weeks, how much did pain interfere with your normal work, including both work outside the home and housework? Would you say it interfered:
  - $\square$  Not at all
  - $_2\Box$  A little bit,
  - <sup>3</sup> Moderately,
  - $_4\square$  Quite a bit, or
  - ₅□ Extremely

TRIAD

Not for use, in whole or in part, without permission from the author.

The next questions are about how you feel and how things have been with you *during the* past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

45. How much of the time during the past 4 weeks:

		All of the Time	Most of the Time of	A Good bit the Time th	Some of the Time th	Little of e Time the	None of Time
	144 (ATR)	1	2	3	4	5	0
A.	Have you felt calm and peaceful					0	
Β.	Did you have a lot	of					
	energy						
C.	Have you felt downhearted						
	and blue						
D.	Has your physical visiting with friend	health or en ls and relati	notional prob ves <i>during th</i>	lems interfere e past 4 week.	ed with you s?	r social activ	vities like

All of the Time

 $_2\square$  Most of the Time

 $_{3}\Box$  Some of the Time

 $_{4}\Box$  A little of the Time

 $_{5}\Box$  None of the time

The next questions are about the type of health care professionals you see and the quality of the medical services you receive from your health plan.

46. <u>A personal doctor or nurse</u> is the health provider who knows you best. This can be a general doctor, a specialist doctor, a nurse practitioner, or a physician assistant. When you joined your health plan or at any time since then, did you get a *new* personal doctor or nurse?
 1□ Yes

 $_2\square$  No (If no, go to question 48.)

47. With the choices your health plan gave you, how much of a problem, if any, was it to get a personal doctor or nurse you are happy with?

 $\square$  A big problem

 $_2\square$  A small problem

<sup>3</sup> Not a problem

<sup>4</sup>□ I didn't get a new personal doctor or nurse



- 48. Do you have one person you think of as your personal doctor or nurse?  $_{1}\Box$  Yes
- → If yes, what is his/her name?
  2□ No (If no, skip to question 52.)

### 49. Is this person:

- $_1\square$  A family practice physician
- <sup>2</sup>□ An internal medicine physician
- $_{3}\square$  An endocrinologist or diabetes specialist
- $_4\square$  Another type of physician
- $_5\square$  A nurse or physician's assistant
- <sub>6</sub>D Unsure
- 50. Is this person part of your health plan?
  - $_{1}\square$  Yes  $_{2}\square$  No
- 51. Is this the person that you go to for most of the care related to your diabetes?
  1□ Yes (If yes, skip to question 54.)
  2□ No
- 52. Would you say the person that you go to for your diabetes care is a:
  - $_1\square$  A family practice physician
  - $_2\square$  An internal medicine doctor
  - $_{3}\square$  An endocrinologist or diabetes specialist
  - $_4\Box$  Another type of physician
  - $_{5}\square$  A nurse or physician's assistant
  - <sub>6</sub>□ Unsure
- 53. Is this person part of your health plan?
  - $\Box$  Yes
  - $_2\square$  No



The next few questions are about doctors that you may have seen for special health needs like surgeons, heart doctors, allergy doctors, skin doctors, and others who specialize in one area of health care. In answering these questions, do not include visits to your dentist.

54. In the last 12 months, did you or a doctor think you needed to see a specialist? □ Yes

 $_2\square$  No (If no, go to question 56.)

55. In the last 12 months, how much of a problem, if any, was it to get a referral to a specialist that you needed to see?

 $_1\square$  A big problem

 $_2\square$  A small problem

 $_{3}\square$  Not a problem at all

- $_4\square$  I didn't need to see a specialist in the last 12 months
- 56. In the last 12 months, did you see a specialist?
  1□ Yes
  2□ No (If no, go to question 58.)
- 57. Was the specialist you saw most often the same doctor as your personal doctor?
   1□ Yes
   2□ No
  - $_{3}\Box$  I don't have a personal doctor or I didn't see a specialist in the last 12 months
- 58. In the last 12 months, did you make any appointments with a doctor or other health provider for regular or routine health care?
  1□ Yes
  2□ No (If no, go to question 60.)
- 59. In the last 12 months, how often did you get an appointment for *regular or routine* health care *as soon* as you wanted?

 $_1\square$  Never

 $_2\square$  Sometimes

 $_{3}\Box$  Usually

₄□ Always

 $_{5}\Box$  I didn't need an appointment for regular or routine care in the last 12 months



60. In the last 12 months, did you have an *illness or injury* that needed care right away from a doctor's office, clinic or emergency room?

 $_1\square$  Yes

 $_2\square$  No (If no, go to question 62.)

61. In the last 12 months, when you needed care right away for an *illness or injury*, how often did you get care as soon as you wanted?

 $_1\square$  Never

<sub>2</sub> Sometimes

<sup>3</sup>□ Usually

₄□ Always

 $_{5}\Box$  I didn't need care right away for an illness or injury in the last 12 months

62. In the last 12 months, how many times did you go to an emergency room to get care for yourself?

 $_1\square$  None

<sup>2</sup><sup>D</sup> Yes (Write in number of times.)

63. In the last 12 months (not counting the times you went to an emergency room), how many times did you go to a doctor's office or clinic to get care for yourself?1□ 0 None

1 L	0 NOILC		
$_2\square$	1	5	4

₃□ 2	₀□ 5-9
------	--------

 $_{4}\Box$  3  $_{7}\Box$  10 or more

64. In the last 12 months how much of a problem, if any, was it to get the care you or your doctor believed necessary?

 $_1\Box$  A big problem

 $_{2}\Box$  A small problem

 $_{3}\Box$  Not a problem at all

 $_4\square$  I had no visits in the last 12 months

65. In the last 12 months, how much of a problem, if any, were delays in health care while you waited for approval from your health plan?

 $_1\square$  A big problem

 $_2\Box$  A small problem

 $_{3}\square$  Not a problem at all

 $_4\square$  I had no visits in the last 12 months



- 66. In the last 12 months, how often did office staff at a doctor's office or clinic treat you with courtesy and respect?
  - $\Box$  Never
  - $_2\square$  Sometimes
  - ₃□ Usually
  - ₄□ Always
  - $_5\square$  I had no visits in the last 12 months
- 67. In the last 12 months, how often was office staff at a doctor's office or clinic as helpful as you thought they should be?
  - $_1\square$  Never
  - 2□ Sometimes
  - ₃□ Usually
  - ₄□ Always
  - $_5\square$  I had no visits in the last 12 months
- 68. In the last 12 months, how often did doctors or other health providers listen carefully to you?  $_{1}\square$  Never
  - <sub>2</sub> Sometimes
  - $_{3}\square$  Usually
  - $_4\square$  Always
  - $_{5}\square$  I had no visits in the last 12 months
- 69. In the last 12 months, how often did doctors or other health providers explain things in a way you could understand?
  - $_1\square$  Never
  - $_2\square$  Sometimes
  - 3□ Usually
  - $_4\square$  Always
  - $_{5}\square$  I had no visits in the last 12 months
- 70. In the last 12 months, how often did doctors or other health providers show respect for what you had to say?
  - $_1\square$  Never
  - $_2\square$  Sometimes
  - ₃□ Usually
  - ₄□ Always
  - $_{5}\Box$  I had no visits in the last 12 months



- 71. In the last 12 months, how often did doctors or other health providers spend enough time with you?
  - $\square$  Never
  - $_2\square$  Sometimes
  - $_3\square$  Usually
  - ₄□ Always
  - $_5\square$  I had no visits in the last 12 months
- 72. Over the past twelve months, how would you rate the quality of care you received for your diabetes?
  - $_1\square$  Excellent
  - $_2\square$  Very good
  - $_3\square$  Good
  - ₄□ Fair
  - ₅□ Poor

### The next questions ask about your experiences with your health plan.

- 73. In the last 12 months, did you call your health plan's customer service to get information or help?
  - $_1 \square$  Yes

 $_2\square$  No (If no, skip to question 75.)

74. 74. In the last 12 months, how much of a problem, if any, was it to get the help you needed when

you called your health plan's customer service?

 $_1\square$  A big problem

- $_2\square$  A small problem
- <sup>3</sup>□ Not a problem
- $_4\Box$  I didn't call my health plan's customer service in the last 12 months
- 75. Paperwork means things like getting your ID card, having your records changed, processing forms, or other paperwork related to getting care. In the last 12 months, did you have any experiences with paperwork for your health plan?
   1□ Yes

 $_{2}\square$  No (If no, skip to question H1a.)



- 76. In the last 12 months, how much of a problem, if any, did you have with paperwork for your health plan?
  - $\square$  A big problem
  - $_2\square$  A small problem
  - $_{3}\square$  Not a problem
  - $_4\Box$  I didn't have any experience with paperwork for my health plan in the last 12 months
- H1a. In the past 12 months, how often did you have a hard time speaking or understanding a doctor or other health provider because you spoke a different language?
  - <sup>1</sup> Never (*If never, skip to question 77.*)
  - $_2\square$  Sometimes

 $_{3}\Box$  Usually

 $_4\Box$  Always

- $_{5}\Box$  I had no visits in the last 12 months
- H1b. An interpreter is someone who repeats what one person says in a language used by another person. In the past 12 months, did you need an interpreter to help you *speak to a doctor or other health provider?*

<sup>1</sup> No (If no, skip to question 77.) <sup>2</sup> Yes

- H1c. In the past 12 months, when you needed an interpreter to help you speak to a doctor or other health provider, how often did you get one?
  - <sup>1</sup> Never (*If never, skip to question 77.*)
  - <sub>2</sub> Sometimes

<sub>3</sub>□ Usually

- <sub>4</sub> Always
- $_{5}\square$  I had no visits in the last 12 months
- H1d. Has your health plan, medical group, or a health care professional provided you with educational materials and food plans that show an appreciation of your culture and language?
  - <sub>2</sub>D Yes

# The next questions focus on how you would describe your health *today*. Please check the box that comes closest to your health *today*.

- 77. How about your mobility? Would you say:
  - $_1\square$  I have no problems in walking
  - $_2\square$  I have some problems in walking about
  - $_{3}\square$  I am confined to bed



- 78. How about self-care? Would you say:
  - $_1\square$  I have no problems with self-care
  - $_2\square$  I have some problems washing or dressing myself
  - $_{3}\square$  I am unable to wash or dress myself
- 79. How about your usual activities (such as your job, study, housework, family, or leisure activities). Would you say:
  - $_{1}\square$  I have no problems with performing my usual activities
  - $_2\square$  I have some problems with performing my usual activities
  - $_{3}\square$  I am unable to perform my usual activities
- 80. How about pain or discomfort? Would you say that today:
  - $_1\square$  I have no pain or discomfort
  - $_2\square$  I have moderate pain or discomfort
  - $_{3}\square$  I have extreme pain or discomfort
- 81. How about anxiety or depression? Would you say that today:
  - $_1\square$  I am not anxious or depressed
  - $_2\square$  I am moderately anxious or depressed
  - $_{3}\Box$  I am extremely anxious or depressed

### The next questions are about the costs of your healthcare.

- 82. Some people have more than one type of insurance. Do you have any of the following types of health insurance? Check all that apply.
  - $_{1}\square$  No, I do not have any other type of health insurance
  - $_2\square$  Other private health insurance
  - <sup>3</sup>□ Medicare
  - <sup>₄</sup>□ Supplemental Medicare
  - 5<sup>□</sup> Medicaid/QUEST
  - <sub>6</sub>□ Veterans Administration (VA)
  - <sup>7</sup><sup>D</sup> Other (*please write in*)\_\_\_\_\_
  - <sub>8</sub>D Unsure



83. Does HEALTH PLAN pay for most of your health care needs?  $\Box$  Yes

 $_{2}\square$  No  $\rightarrow$  If No, what is the main reason that you do not use HEALTH PLAN to pay for most of your

health care needs?

### CHECK UP TO THREE ITEMS

 $_{1}\square$  I am covered by other health insurance (e.g., through a spouse or relative)

 $_2\square$  I moved

- $_{3}\Box$  My out of pocket costs were too high
- $_4\square$  My doctor is not in the plan
- $_5\square$  My doctor left the plan
- $_{6}\square$  I did not like the way plan doctors treated me as a person

 $_7\square$  I was unhappy with the medical care I received

- $_{8}\Box$  It was too hard to get permission to see a specialist
- $_{9}\square$  It was too hard to get permission for tests or treatment

 $_{10}$  D My health changed

- $_{11}\square$  I did not like the way the plan handled problems/complaints
- $_{12}\square$  I did not like the way the plan handled claims and paperwork
- $_{13}\square$  I was unhappy with the prescription benefits/coverage

 $_{14}\square$  I was unhappy with the medical benefits/coverage

 $_{15}\square$  Other (Specify:

84. Do you have to pay a co-payment, or a fixed dollar amount that you pay every time you see your regular doctor?

₁□ Yes

- ➔ If yes, how much? (enter amount)\$\_\_\_\_\_ 2□ No
- 85. Do you have to pay a co-payment, or fixed dollar amount every time you see a specialist?
   1□ Yes
- ➔ If yes, how much? (enter amount)\$\_\_\_\_\_
  2□ No

86. Do you have to pay a co-payment, or fixed dollar amount every time you buy a prescription

medication?

 $_{1}\square$  Yes  $_{2}\square$  No



87. Do you have a deductible or an amount that you must pay first, before outpatient health care is a covered benefit?

<sup>1</sup> Yes

- ➔ If yes, how much? (enter amount)\$\_\_\_\_\_ 2□ No
- 88. Please check the box that best describes if your insurance plan pays for all, some or none of the following equipment or supplies related to your diabetes care. If you pay a small co-pay, choose "Insurance Pays Some."

		<b>Insurance</b> Pays All 1	Insurance Pays Some 2	Insurance Pays None 3	Unsure 4	Not Applicable 5	
Α.	Glucose monitors						
Β.	Glucose strips						
C.	Insulin syringes						
D.	Insulin pens						

89. Please check the box that best describes if your insurance plan pays for all, some or none of the following services related to your diabetes care. If you pay a small co-pay, choose "Insurance Pays Some."

		Insurance Pays All	<b>Insurance</b> Pays Some	<b>Insurance</b> Pays None	Unsure	Not Applicable	
		1	2	3	4	5	
Α.	Eye exams						
Β.	Nutrition counseling						
C.	Diabetes education						
D.	Foot doctor/ podiatrist	t 🗖					
E.	Smoking cessation						
F.	Psychiatrist or other mental health professional						

90. Think about the extra time <u>you yourself</u> spend taking care of your diabetes-related health problems (Related problems might include high blood pressure, high cholesterol, or heart and circulation problems). If you spend <u>no</u> extra time, please indicate "0" minutes.

-		
	Not for use, in whole or in part, without	permission from the author.
On	a typical day, how many EXTRA minutes do you spend: A. Caring for your feet? minutes	
	B. Exercising? minutes	
	C. Shopping for and cooking special foods?	minutes
91.	In a typical week, how many hours do <b>other people</b> (spouse helping you with the following activities to take care of your conditions: A. Transportation: hours	e, family, or friends) spend r diabetes-related health
	B Getting or using medications injections or supplies:	hours
	C. Foot care: hours	10013
92.	In a typical week, how many days do you work for pay? (note: if you do not work for pay, skip to question H2a.)	days
93.	During the past four weeks, because of your diabetes or relations were you not able to work? days	ted health problems, how many

The following statements have to do with attitudes about health and diabetes. Please indicate whether you agree or disagree with each statement.

	Strong	ly	Mildly	Mildly	y	Strongly
	Disagree 1	Disagree 2	Disagree 3	Agree 4	Agree 5	Agree 6
H2a. I can avoid complications.						
H2b. When my sugar is high it's because of something I've done.	0			•		
H2c. Good health is a matter of good fortune.						
H2d. Regular doctor's visits avoid problems.						
H2e. What I do is the main influence on my health.			0			
H2f. If it's meant to be I will avoid complications.		0	•	0		



	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
	1	2	3	4	5	6
H2g. I should call my doctor whenever I feel bad.			0			
H2h. My blood sugars will be what they will be.						
H2i. Blood sugars are controlled by accident.						
H2j. I can only do what my doctor tells me.						
H2k. I never know why I'm out of control.						
H21. Health professionals keep me healthy.						
H2m. My family is a big help in controlling my diabetes.			0			
H2n. When my blood sugar is high it's because I've made a mistake.						
H2o. Good control is a matter of luck.						
H2p. Complications are the result of carelessness.						
H2q. I am responsible for my health.						٥
H2r. Other people have a big responsibility for my diabetes.						



- 94. Which income category below best describes your total annual household income before taxes?
  - $_1\square$  Less than \$5,000
  - $_2\square$  \$5,000 to under \$7,500
  - $_{3}\square$  \$7,500 to under \$10,000
  - ₄□ \$10,000 to under \$12,500
  - $_{5}\square$  \$12,500 to under \$15,000
  - $_{6}\square$  \$15,000 to under \$20,000
  - 7□ \$20,000 to under \$25,000
  - <sup>8</sup>□ \$25,000 to under \$30,000
  - <sup>9</sup>□ \$30,000 to under \$35,000
  - 10 \$35,000 to under \$40,000
  - 11□ \$40,000 to under \$75,000
  - $12\square$  \$75,000 to under \$100,000
  - $_{13}$  \$100,000 and above
- 95. What is the highest grade of school that you completed?
  - $_1\square$  8<sup>th</sup> grade or less
  - $_2\square$  Some high school, but did not graduate
  - $_{3}\square$  High school graduate or GED
  - $_4\square$  Some college or 2-year college degree
  - $_5\square$  4-year college graduate
  - $_6\square$  More than 4-year college degree
- 96. Are you of Hispanic or Latino origin?
  - $_1\square$  Yes
  - 2□ No
- → If yes, is that:
  - <sup>3</sup><sup>D</sup> Cuban, Puerto Rican, other Caribbean: specify:\_\_\_\_\_
  - <sup>4</sup> Mexican American, or Chicano/a: specify:\_\_\_\_\_
  - <sup>5</sup> Other Central or South American: specify:\_\_\_\_\_
  - <sup>6</sup> Other Hispanic/Latino specify:

	Not for use, in whole or in part, without permission from the author.
97.	What is your race? <i>Please select all that apply</i> .
	$_{1}\square$ American Indian or Alaska Native
	$_{2}\square$ Asian – Is that: $_{3}\square$ Chinese
	4□ Filipino
	₅□ Japanese
	6 Korean
	$_7\square$ Asian (or East) Indian
	<sup>8</sup> Native Hawaiian
	Pacific Islander
	Black or African American
	$11 \square$ White
	) Other (specify: $($ )

The second part of the study looks at your medical record for the past 18 months. We want to see if the kind of tests and measures you identified in the questionnaire are really being done and recorded. This will help us understand how well your health care plan serves your diabetes health care needs.

1. To look at your medical record we need your permission. May we have your consent to review your medical record for the past 18 months? Please check one box only.

Yes □ No □ Date: \_\_/\_\_/\_\_\_

Your signature: \_\_\_\_\_

2. We said that we would try to call you again in about 2 years. In case you move or change your phone number, can you please give us the name and phone number of a person who is likely to know where you are?

Relationship: _	 	 
Address:	 	 

Thank you for completing this survey!

### Appendix C: TRIAD STUDY Medical Record Review Form

# TRIAD MEDICAL CHART REVIEW INSTRUMENT

### VERSION 5.1

<b>Please refer to the TRIAD</b> <b>for detailed information re</b> Study Subject ID Number:	Medical Char egarding use of	t Abstraction In this instrument	structions t
Date of TRIAD Patient Sur	vey Interview:	/	/
	·	(month) (day)	(4 digit year)
Review Period End Date:		/	/
		(month) (day)	(4 digit year)
18-Month Review Period St	tart Date:	/	_/
		(month) (day)	(4 digit year)
3-Year Review Interval Star	rt Date:		
		(month) (day)	(4 digit year)
Date of Medical Chart Abst	raction:	${(maxth)}$	
Reviewer's ID Number:		(month) (day)	(4 digit year)
PATIENT DEMOGRA	APHICS		
1. Patient's Date of Birth:		(month) (day)	(4 digit year)
2. Patient's Gender:	Male	<b>1</b>	
	Female	$\square_2$	

### **PATIENT MEDICAL HISTORY**

For the Patient Medical History Section (items 3-12), abstractors should consider medical documentation covering an entire 3-year interval. Based on these medical records, check 'Yes' or 'No' to indicate if the patient has a record of EVER having the listed condition, treatment, or risk factor. Refer to page 1 for start and end dates of the 3-year interval.

3. History of Cardiovascular Risk Factor or Vascular Disease: (answer all items)

a. Hypertension (HTN)	🗖 1 No	🗖 2 Yes
b. Hyperlipidemia/Hypercholesterolemia	🗖 1 No	2 Yes

c. Cigarette Smoking	🗖 1 No	2 Yes
d. Transient ischemic attack (TIA)	🗖 1 No	2 Yes
e. Cerebral vascular accident (CVA)	1 No	2 Yes
f. Angina	🖬 1 No	2 Yes
g. Myocardial Infarction (MI)	🖬 1 No	2 Yes
h. Congestive heart failure	1 No	2 Yes
i. Other coronary heart disease (CHD) or Coronary Artery Disease (CAD)	🖵 1 No	2 Yes
j. Peripheral Vascular Disease (PVD) /	🖬 1 No	2 Yes
PVOD / Claudication 4. History of Vascular Treatment: <i>(answer all items)</i>		
a. Carotid endarterectomy	🔲 1 No	2 Yes
b. Coronary angioplasty	1 No	2 Yes
c. Coronary bypass (CABG)	🖬 1 No	2 Yes
d. Peripheral vascular angioplasty or bypass	🖵 1 No	2 Yes
5. History of End-Stage Renal Disease (ESRD):	🗖 1 No	2 Yes
If No, go to Q.6		
a. History of Dialysis	🔲 1 No	2 Yes
b. History of Kidney Transplant	🗖 1 No	2 Yes
6. History of Microalbuminuria:	🗖 1 No	2 Yes
7. History of Diabetic Nephropathy:	🖬 1 No	2 Yes
8. History of Diabetic Peripheral Neuropathy:	🗖 1 No	2 Yes

9. History of complete Amputation of both Feet:	🖵 1 No	2 Yes
10. History of Retinal Laser Treatment:	🖵 1 No	2 Yes
11. History of Diabetic Retinopathy:	<b>1</b> 1 No	2 Yes

## PATIENT MEDICAL HISTORY continued

12. History of Comorbid Conditions: (check one box for each item in the list below):

a. Dementia	🔲 1 No	2 Yes
b. Chronic Pulmonary Disease	🔲 1 No	2 Yes
c. Connective Tissue Disease	🖵 1 No	2 Yes
d. Ulcer Disease	🔲 1 No	2 Yes
e. Mild Liver Disease	🖵 1 No	2 Yes
f. Hemiplegia	🖵 1 No	2 Yes
g. Non-metastatic solid cancer (5 yrs.)	1 No	2 Yes
h. Leukemia	<b>1</b> 1 No	2 Yes
i. Lymphoma	<b>1</b> 1 No	2 Yes
j. Moderate or Severe Liver Disease	<b>1</b> No	2 Yes
k. Metastatic solid cancer	🔲 1 No	2 Yes
1. AIDS	<b>1</b> No	2 Yes
	🔲 3 Not Abs	stracted

For Item 12 l., check the "Not Abstracted" box only if review of AIDS status has not received local IRB approval. Otherwise, check either "No" or "Yes" for this item.

### **MEDICAL DATA DURING 18 MONTH REVIEW PERIOD**

For Items 13-28 all tests and other events considered MUST have occurred during the 18month period. Refer to page 1 for start and end dates of the 18-month review period.

13. Did the patient have Outpatient Visits to a PCP, Nurse Practitioner, Endocrinologist, or Diabetologist during the review period? (exclude telephone encounters and visits to other specialists, ER visits, urgent care visits, and visits for lab tests, infusions, flu or allergy injections)

## 🗋 1 No 🗖 2 Yes

### If No, go to Q.16

a. Total number of outpatient visits to PCP, NP, Endocrinologist or Diabetologist:

b. Total number of visits recorded in #13a. for which a record of the visit was not available for review:

14. Was Weight recorded at a visit included in #13a?

 $\square$  1 No  $\square$  2 Yes

If No, go to Q.15

a. Most recent recorded Weight \_\_\_\_\_ **kg** or **lbs**. (IMPORTANT: circle unit of measure )

15. Was a blood pressure reading taken at any visit included in item #13a?

1 No 2 Yes

If No, go to Q.16

a. Number of such visits during which a b.p. reading was taken:

l One

2 Two

**3** Three

4 Four

**5** Five

Given the second second

b. Value of most recent systolic pressure:

c. Value of most recent diastolic pressure: \_\_\_\_\_ \_\_\_\_ Date: \_\_\_\_/\_\_\_/\_\_\_\_

16. Was a glycosylated hemoglobin, HbA1c, or Fructosamine test performed during the review period?

 $\square$  1 No  $\square$  2 Yes

If No, go to Q.17

a. Total number of g. hemoglobin, HbA1c, and Fructosamine tests:

b. Value of <u>first</u> g. hemoglobin or HbA1c test: : \_\_\_\_\_\_ Upper limit of normal range for first assay: \_\_\_\_\_\_% *Note: exclude Fructosamine tests in 16b.* Date: \_\_\_/\_\_/\_\_\_\_

c. Value of most recent g. hemoglobin or HbA1c test: \_\_\_\_\_\_% Upper limit of normal range for most recent assay: \_\_\_\_\_% *Note: exclude Fructosamine tests in 16c.* Date: ///

### **MEDICAL DATA DURING 18-MONTH REVIEW PERIOD continued**

17. Was Total Cholesterol measured during the review period?	🖵 1 No	2 Yes		
	If No, go to	o Q.18		
a. Most recent Total Cholesterol measured:				
18. Were Triglycerides measured during the review period?	<b>1</b> No	2 Yes		
	If No, go to	o Q.19		
a. Most recent Triglycerides value:				
19. Was high-density lipid (HDL) measured during the review period?				
	🗋 1 No	2 Yes		
	If No, go to	o Q.20		
a. Most recent HDL value: Date://				
20. Was low-density lipid (LDL) measured during the review period?				

 $\square$  1 No  $\square$  2 Yes

Not for use, in whole or in part, without permission from the auti				
a. Most recent LDL value: Date: / /		1 <i>j</i> 110, go to <u>g</u> .21		
21. Was Serum Creatinine measured during the revie	w period?	$\square$ 1 No $\square$ 2 Yes		
a. Most recent Serum Creatinine value: Date://		IJ NO, g0 10 Q.22		
22. Was a dipstick Urinalysis performed during the r	eview period?	$\square$ 1 No $\square$ 2 Yes		
a. Most recent Urine Protein value:		1 1,0, go to <u>2</u> .20		
		0 mg/dl or Negative		
		15 mg/dl or Trace		
	3	30 mg/dl or "1+"		
	4	100 mg/dl or "2+"		
	5 5	500 mg/dl or "3+"		
	Date:	//		
23. Were any of the following Microalbuminuria or quantitative urine protein tests				
performed during the review period?	l No	2 Yes		
<ul> <li>Urine Microalbumin/Creatinine ratio</li> <li>Urine Protein/Creatinine ratio</li> <li>Urine Microalbumin (without Creatinine)</li> <li>Quantitative Urine Protein (without Creatinine)</li> <li>Micral Test</li> </ul>	If No, go to <b>(</b>	<u>Q</u> .24		
a. If Yes, Which tests listed above were performed during the 18-month review period? (check all that apply)				
a1. Urine Microalbumin/Creatinine ratio	🔲 1 No	2 Yes		
a2. Urine Protein/Creatinine ratio	🗖 1 No	2 Yes		
a3. Urine Microalbumin	<b>1</b> 1 No	2 Yes		
168				
Not for use, in whole or in part, without permission from the author  $\square$  1 No  $\square$  2 Yes a<sub>4</sub>. Quantitative Urine Protein  $\square_{1 \text{ No}}$  $\square$  2 Yes as. Micral Test b. For the test checked YES appearing first in the list, indicate the most recent value, unit of measure and date: For example: if a 1 and as are checked YES, record the a 1 result. Unit: numerator denominator Date: / / c. If a Micral test is the *only* test checked above, indicate the most recent Micral result: 1 Negative 2 20 mg/l 3 50 mg/l 4 100 mg/l **U** 9 UTD 24. Was an EKG test performed during the review period?  $\square$  2 Yes  $\square$  1 No If No, go to Q.25 a. Date of the most recent EKG: Date: 25. Was a Foot Exam performed during the review period? 1 No 2 Yes Include foot exams by any provider in any setting. If No, go to Q.26 a. Date of most recent Foot Exam: Date: \_\_\_/\_\_/\_\_\_\_ b. Total number of Foot Exams performed: □ 1 One 2 Two □ 3 Three 4 Four □ 5 Five □ 6 Six or more

Not for use, in whole or in part, without permission from the author c. Specify the Foot Exams performed during the review period (*check all that apply*) c1. Visual inspection of the feet (lesions, dry skin, callus, deformity, infection, nail changes, ulcers

	and/or amputation):	🔲 1 No	2 Yes				
	c1aResult of the most recent exam:	1 Normal	2 Abnormal 9 UTD				
	c2. 10 gram Monofilament test:	1 No	2 Yes				
	c2aResult of the most recent exam:	🔲 ı Normal	2 Abnormal 9 UTD				
	c3. Sensory examination other than monofilament (temperature, pin, vibration, and/or soft touch):						
		1 No	2 Yes				
	c3aResult of the most recent exam:	1 Normal	2 Abnormal 9 UTD				
	c4. Vascular examination (pulses):	<b>1</b> No	2 Yes				
	$c_{4a}$ Result of the most recent Exam:	1 Normal	2 Abnormal 9 UTD				
	cs. Unable to Determine type of Ex	able to Determine type of Exam					
	csaResult of the Exam:	1 Normal	2 Abnormal 🖵 9 UTD				
26. Was a Dilated Eye Exam performed during the review period?							
		🔲 1 No	2 Yes				
		If No, go to g	Q.26d.				
<ul> <li>a. Date of most recent dilated eye exam: Date://</li> <li>b. Total number of dilated eye exams performed:</li> <li>c. Who performed the dilated eye exam(s) during the review period?</li> <li>(check all that apply)</li> </ul>							
cı. Oph	thalmologist	🖬 1 No	2 Yes				
c2. Opt	ometrist	🗖 1 No	2 Yes				

Not for use, in whole or in part, without permission from the author

c3. PCP	🗖 1 No	2 Yes				
c4. UTD	🗖 1 No	2 Yes				
d. Were retinal photos submitted to an eye care						
professional during the review period?	🖵 1 No	2 Yes				
27. What is the Retinopathy status: (indicate the highest level noted; check only one)						
a. None		<b>1</b>				
b. Diabetic Retinopathy noted, level not sp	ecified	<b>2</b>				
c. Non-proliferative Diabetic Retinopathy or Background Diabetic Retinopathy (BDI	(NPDR) R)	3				
d. Macular Edema (ME or CSME)		4				
e. Proliferative Diabetic Retinopathy (PDR or PDR with HRC)		5				
f. UTD- no record of retinopathy status	9					

## **CURRENT MEDICATIONS**

28. Were any of the medications listed on pages 9-11 prescribed or taken during the review period with no indication that they were stopped or discontinued prior to the end of the review period?

2 Yes

If Yes, indicate these current medications by recording the number of each in the spaces provided below.

Note: Medications are listed alphabetically. Trade names are capitalized and generics are in lower case. Generic equivalents to trade name medications are shown within brackets.

171

 · · · · · · · · · · · · · · · · · · ·				
	END OF DATA ENTRY			

## LITERATURE CITED

1999. *CAHPS 2.0 Survey and Reporting Kit.* Rockville, MD: Agency for Health Care Policy and Research.

Alogna, M. 1980. "Perception of Severity of Disease and Health LOC in Compliant and Noncompliant Diabetic Patients." *Diabetes Care* 3:533-4.

American Diabetes Association. 1998. "Clinical Practice Recommendations." *Diabetes Care* 21 Suppl 1.

American Diabetes Association. 1998. "Economic Consequences of Diabetes Mellitus in the United States in 1997." *Diabetes Care* 21(2):296-309.

Anderson, R. M. and M. M. Funnell. 2000. "Compliance and Adherence are Dysfunctional Concepts in Diabetes Care." *Diabetes Educator* 26:597-604.

Aruffo, J. F., J. H. Coverdale, V. N. Pavlik, and C. Vallbona. 1993. "AIDS Knowledge in Minorities: Significance of LOC." *American Journal of Preventive Medicine* 9:15-20.

Auerbach, Stephen M. and Phillip O. Pegg. 2002. "Appraisal of Desire for Control Over Healthcare: Structure, Stability, and Relation to Health LOC and to the "Big Five" Personality Traits." *Journal of Health Psychology* 7[4]:393-408.

Bachiocco, V., C. Credico, and M. Tiengo. 2002. "The Pain LOC Orientation in a Healthy Sample of the Italian Population: Sociodemographic Modulating Factors." *Journal of Cultural Diversity* 9:55-62.

Battle, E., J. B. Rotter. 1963. "Children's Feelings of Personal Control as Related to Social Class and Ethnic Groups." *Journal of Personality* 31:482-90.

Bazargan, M., S. Bazargan, and R. S. Baker. 1998. "Emergency Department Utilization, Hospital Admissions, and Physician Visits Among Elderly African American Persons." *Gerontologist* 38:25-36.

Bazargan, M., R. S. Baker, and S. Bazargan. 1998a. "Correlates of Recency of Eye Examination Among Elderly African-Americans." *Ophthalmic Epidemiology* 5 :91-100.

Beckles G. L., M. M. Engelgau, K. M. Narayan, W. H. Herman, R. E. Aubert, and D. F. Williamson. 1998. "Population-based Assessment of the Level of Care Among Adults with Diabetes in the U.S." *Diabetes Care* 21(9):1432-8.

Bekhuis, Tanja, Harold Cook, Kathleen Holt, Jane Scott-Lennox, and et al. "Ethnicity, Church Affiliation and Beliefs About the Causal Agents of Health: a Comparative Study Employing a Multivariate Analysis of Covariance." 1995. *Health Education Research* Special Issue: Measurement in Health Education Research Mar; 10(1):73-82; ISSN: 0268-1153.

Bell, R. A., J. H. Summerson, and J. C. Konen. 1995. "Racial Differences in Psychosocial Variables Among adults with Non-insulin-Dependent Diabetes Mellitus." *Behavioral Medicine* 21:69-73.

Bennett, P., P. Norman, L. Moore, S. Murphy, and C. Tudor-Smith. 1997. "Health LOC and Value for Health in Smokers and Nonsmokers." *Health Psychol*ogy 16:179-82.

Blaisell, R. K. 1993. "Health Status of Kanaka Maoli (Indigenous Hawaiians)." *Asian American and Pacific Islander Journal of Health* Autumn 1(2):116-60.

Blanchard-Fields, F. and J. C. Irion. 1988. "The Relation Between LOC and Coping in Two Contexts: Age as a Moderator Variable." *Psychology and Aging* 3:197-203.

Boor, M. 1976. "Relationship of Internal-External Control and National Suicide Rates." *The Journal of Social Psychology* 100:143-4.

Booth-Butterfield, M., R. H. Anderson, and S. Booth-Butterfield. 2000. "Adolescents' Use of Tobacco, Health LOC, and Self-monitoring." *Health Communication* 12:137-48.

Bradley, C., K. S. Lewis, A. M. Jennings, and J. D. Ward. 1990. "Scales to Measure Perceived Control Developed Specifically for People with Tablet-treated Diabetes." *Diabetic Medicine* 7:685-94.

Brechner, R. J., C. C. Cowie, L. J. Howie, W. H. Herman, J. C. Will, and M. I. Harris. 1993. "Ophthalmic Examination Among Adults with Diagnosed Diabetes Mellitus." *Journal of the American Medical Association* 270(14):1714-8.

Brook, R. H., C. J. Kamberg, K. N. Lohr, G. A. Goldberg, E. B. Keeler, and J. P. Newhouse. 1990. "Quality of Ambulatory Care. Epidemiology and Comparison by Insurance Status and Income." *Medical Care* 28(5):392-433.

Brown, S. A. 1990. "Studies of Educational Interventions and Outcomes in Diabetic Adults: a Meta-analysis Revisited." *Patient Education and Counseling* 16(3):189-215.

Brown, A. F., R. B. Gerzoff, A. J. Karter, E. Gregg, M. Safford, B. Waitzfelder, G.
L. Beckles, R. Brusuelas, and C. M. Mangione. 2003. "Health Behaviors and
Quality of Care Among Latinos with Diabetes in Managed Care." *American Journal of Public Health* 93:1694-8.

Brunner, E. and M. Marmot. 1999. "Social Organization, Stress and Health." Pp.
17-41 in *Social Determinants of Health*, edited by M. Marmot and R. G.
Wilkinson. New York, NY: Oxford University Press.

Burgess, C. and M. L. Hamblett. 1994. "Application of the Rotter Scale of Internal-External LOC to Determine Differences Between Smokers, Non-smokers and Ex-smokers in Their General LOC." *Journal of Advanced Nursing* 19:699-704.

Butler, F. R., M. G. Secundy, and E. E. Romberg. 1994. "Health Care Utilization Patterns of Hypertensive and Diabetic African American Elderly." *Journal of Cultural Diversity* 1:74-8.

Carpenter, V. and B. Colwell. 1995. "Cancer Knowledge, Self-efficacy, and Cancer Screening Behaviors Among Mexican-American Women." *Journal of Cancer Education* Winter;10(4):217-22.

Cattell, R. B. 1966. "The Scree Test for the Number of Factors." *Multivariate Behavioral Research* 1:245-76.

CDC. <u>Diabetes Surveillance 1993</u>. Atlanta: Public Health Service, 1993.

CDC. <u>Diabetes Surveillance 1997</u>. Atlanta: Public Health Service, 1997.

CDC. Diabetes-specific preventive-care practices among adults in a managed care population-Colorado, Behavioral Risk Factor Surveillance System, 1995. *MMWR* 1997a; 46:1018-23.

Charleson, M. E., F. Sax, C. R. MacKenzie, S. Fields, R. L. Braham, and R. G. Douglas. 1986. "Assessing Illness Severity: Does Clinical Judgement Work?" 39:439-52.

Chavez, L. R., F. A. Hubbel, S. I. Mishra, and R. B. Valdez. 1997. "The influence of Fatalism on Self-reported Use of Papanicolaou Smears." *American Journal of Preventive Medicine* Nov-Dec;13(6);418-24.

Chrisman, N. J., and A. Kleinman. 1980. "Health Beliefs and Practices Among American Ethnic Groups". In *Harvard Encyclopedia of American Ethnic Groups*, edited by S. Thernstrom. Cambridge:Belknap Press.

Coleman, J. S., E. Q. Campbell, C. J. Hobson, J. McPartland, A. M. Mood, F. D. Weinfeld, and R. L. York. 1966. "Equality of Educational Opportunity." Washington D.C.:United States Government Printing Office.

Comrey, A. L., and H. B. Lee. 1992. *A First Course in Factor Analysis*. Second Edition. Hillsdale, New Jersey: Lawrence Erlbaum Associaties, Publishers. Cousins, Jennifer H., Thomas G. Power, and Norma Olvera-Ezzell. 1993.

"Mexican-American Mothers' Socialization Strategies: Effects of Education, Acculturation, and Health LOC." *Journal of Experimental Child Psychology*. Special Issue: Social context, social behavior, and socialization 55[2], 258-76.

Cromwell, R. L., E. C. Butterfield, F. M. Brayfield, and J. J. Curry. 1977. *Acute Myocardial Infarction: Reaction and Recovery*. St. Louis: C.V. Mosby, 1977.

Devellis, Robert F. 2003. *Scale Development:Theory and Applications.* Second Edition, Thousand Oaks, California: Sage Publications, Inc.

de Weerdt, I., A. P. Visser, G. Kok, and E. A. van der Veen. 1990. "Determinants of Active Self-care Behavior of Insulin Treated Patients with Diabetes: Implications for Diabetes Education." *Social Science and Medicine* 30(5):605-15.

Dokheel, T. M. for the Pittsburg Diabetes Epidemiology Research Group. 1993. "An Epidemic of Childhood Diabetes in the United States? Evidence from Allegheny County, PA." *Diabetes Care* 16:1606-11.

Early Treatment of Diabetic Retinopathy Study Research Group. Early photocoagulation for diabetic retinopathy: ETDRS report number 9. *Ophthalomology* 1991; 98(suppl):767-85.

Eaton, William W, M. Mengel, L. Mengel, D. Larson, et al. 1992. "Psychosocial and Psychopathologic Influences on Management and Control of Insulin-Dependent Diabetes." *International Journal of Psychiatry in Medicine* 22(2):105-17. Engelgau, M. M., L. S. Geiss, D. L. Manninen, C. E. Orians, E. H. Wagner, N. M. Friedman, J. S. Hurley, K. M. Trinkaus, D. Shatin, and K. A. Van Vorst. 1998. "Use of Services by Diabetes Patients in Managed Care Organizations. Development of a diabetes surveillance system. CDC Diabetes in Managed Care Work Group." *Diabetes Care* 21(12):2062-8.

Ferraro, Laurie A., James H. Price, Sharon M. Desmond, and Stephen M. Roberts. 1987. "Development of a Diabetes LOC Scale." *Psychological Reports* 61[3],763-70.

Fleming, B. B., S. Greenfield, M. M. Engelgau, L. M. Pogash, S. B. Clauser, M.
A. Parrot. 2001. "The Diabetes Quality Improvement Project: Moving Science into Health Policy to Gain an Edge on the Diabetes Epidemic." *Diabetes Care* 24:1815-20.

Frankel, I. 1983. *The Report of the CASRO Task Force on Response Rates.* In Wiseman F. ed. Improving Data Quality in a Sample Survey. Cambridge, MA:Marketing Science Institute; 1-11.

Frazier, Leslie D. 2002. Perceptions of Control Over Health: Implications for Sense of Self in Healthy and III Older Adults. Hauppauge, N.Y., U.S.:Nova Science Publishers, Inc.

Frijling, B. D., C. M. Lobo, I. M. Keus, K. M. Jenks, R. P. Akkermans, M. E. Hulscher, A. Prins, J. C. van der Wouden, and R. P. Grol. 2004. "Perceptions of Cardiovascular Risk Among Patients with Hypertension or Diabetes." *Patient Education and Counseling* 52:47-53.

Fujimoto, W. Y. 1995. "Diabetes in Asian and Pacific Islander Americans." Pp. 661-82 in *Diabetes in America*, Second Edition. National Institutes of Health and National Institute of Diabetes and Digestive and Kidney Diseases. NIH Publication No. 95-1468.

Gillespie, C. R. and C. Bradley. 1988. "Causal Attributions of Doctor and Patients in a Diabetes Clinic." *British Journal of Clinical Psychology* 27( Pt 1):67-76.

Gillibrand, W. and M. Flynn. 2001. "Forced Externalization of Control in People with Diabetes: a Qualitative Exploratory Study." *Journal of Advanced Nursing* 34:501-10.

Gohdes, Dorothy. 1995. "Diabetes in North American Indians and Alaska Natives." Pp. 683-701 in *Diabetes in America*, Second Edition. National Institutes of Health and National Institute of Diabetes and Digestive and Kidney Diseases. NIH Publication No. 95-1468.

Gorsuch, Richard L. 1983. *Factor Analysis*. Second edition, Hillsdale, New Jersey:Lawrence Erlbaum Associates.

Greenfield, S., W. Rogers, M. Mangotich, M. F. Carney, and A. R. Tarlov. 1995. "Outcomes of Patients With Hypertension and Non-Insulin Dependent Diabetes Mellitus Treated by Different Systems and Specialties. Results From the Medical Outcomes Study." *Journal of the American Medical Association* 274(18):1436-44.

Gregg, E. W., A. M. Kriska, K. M. Narayan, and W. C. Knowler. 1996. "Relationship of LOC to Physical Activity Among People With and Without Diabetes." *Diabetes Care* 19:1118-21. Hale, W. D., B. E. Hedgepeth, and E. B. Taylor. 1985-1986. "LOC and Psychological Distress Among the Aged." *International Journal of Aging and Human Development* 21:1-8.

Hamid, P. N. and W. T. Chan. 1998. "LOC and Occupational Stress in Chinese Professionals." *Psychological Reports* 82:75-9.

Harris, M.I. 1995. Summary. In: National Diabetes Data Group. Diabetes in America. 2nd ed. Washington DC: Government Printing Office, 1995: 1-14. (NIH publication no. 95-1468).

Hawai'i Department of Health, Office of Health Status Monitoring, 2002.

Hawai'i Diabetes Data Network, unpublished data, 1997.

Hawai'i State Department of Health. *Hawai'i State Practice Recommendations for Diabetes Mellitus*, 1998.

Hayes, R. P., A. M. Bernard, W. Slocum, I. el-Kebbi, D. Ziemer, D. Gallina, and L. S. Phillips. 2000. "Diabetes in Urban African Americans: Assessment of Diabetes-specific LOC in Patients with Type 2 Diabetes." *Diabetes Educator* 26:121-8.

Haynes, M.O. 1996. "Geriatric Gynecologic Care of Minorities." *Clinical Obstetrics and Gynecology* 39(4):946-58.

Hendrieckx, C., F. De Smet, I. Kristoffersen, and C. Bradley. 2002. "Risk Assessment for Developing Type 1 Diabetes: Intentions of Behavioural Changes Prior to Risk Notification." *Diabetes/Metabolism Research and Reviews* 18:36-42. Hiss, R. G. 1996. "Barriers to Care in Non-insulin-dependent Diabetes Mellitus. The Michigan Experience." *Annals of Internal Medicine* 124(1 Pt 2):146-8.

Hoffman-Goetz, L. 1999. "Cancer Experiences of African American Women as Portrayed in Popular Mass Magazines." *Psycho-oncology* Jan-Feb;8(1):36-45.

Holroyd, Eleanor A., Alex Molassiotis, and Ruth E. Taylor-Pilliae. 2001. "Filipino Domestic Workers in Hong Kong: Health Related Behaviors, Health LOC and Social Support." *Women and Health* 33[1-2],181-205.

Holt, Cheryl L., Eddie M. Clark, Matthew W. Kreuter, and Doris M. Rubio. 2003. "Spiritual Health LOC and Breast Cancer Beliefs Among Urban African American Women." *Health Psychology* May; 22(3):294-299; ISSN: 0278-6133.

Horie, Yuhko. 1991. "A Japanese Version of the Health LOC Scales." *Japanese Journal of Health Psychology* 4(1),1-7.

Hunt, L. M., N. H. Arar, and A. C. Larme. 1998. "Contrasting Patient and Practitioner Perspectives in Type 2 Diabetes Management." *Western Journal of Nursing Research* 20:656-76; discussion 677-82.

Husaini, B. A. and J. A. Neff. 1981. "Social Class and Depressive Symptomatology. The Role of Life Change Events and LOC." *Journal of Nervous and Mental Disease* 169:638-47. International Center for Health Promotion and Disease Prevention Research. 1994. <u>Community Epidemiology Work Group for Diabetes Mellitus 1993</u> <u>Monograph</u>. Honolulu, HI: University of Hawai'i at Manoa, School of Public Health.

Jacques, C. H., R. L. Jones, P. Houts, L. C. Bauer, K. M. Dwyer, J. C. Lynch, and T. S. Casale. 1991. "Reported Practice Behaviors for Medical Care of Patients with Diabetes Mellitus by Primary-care Physicians in Pennsylvania." *Diabetes Care* 14(8):712-7.

Javitt, J. C., L. P. Aiello, Y. Chiang, F. L. Ferris, III, J. K. Canner, and S. Greenfield. 1994. "Preventive Eye Care in People with Diabetes is Cost-saving to the Federal Government. Implications for Health-care Reform." *Diabetes Care* 17(8):909-17.

Jensen, L., J. Olsen, and C. Hughes. 1990. "Association of Country, Sex, Social Class, and Life Cycle to LOC in Western European Countries." *Psychological Reports* Aug; 67(1):199-205.

Johnson, David B. 1989. "Diabetes Epidemiology and Disability." In *The Health of Native Hawaiians, Social Process in Hawai'i*, Wegner, E. L. ed. Vol 32, Honolulu, Hawai'i:University of Hawai'i Press, p.104-12.

Joppke, Christian. 1986. "The Cultural Dimensions of Class Formation and Class Struggle: On the Social Theory of Pierre Bourdieu." *Berkeley Journal of Sociology* 31:52-78.

Kaur, J. S. 1996. "The Potential Impact of Cancer Survivors on Native American Cancer Prevention and Treatment." *Cancer* Oct 1;78(7 Suppl):1578-81.

Kennedy, Catherine A., Dale Devoe, Kimberly Ramer-Henry, and Janna West-Kowalski. 1999. "Influence of Self-Care Education on Illness Behaviors and Health LOC of Mexican American Women." *Women and Health* 28(3):1-13; ISSN: 0363-0242.

Kenny, Susan J., Ronald E. Aubert, and Linda S. Geiss. 1995. "Prevalence and Incidence of Non-Insulin Dependent Diabetes." Pp. 47-67 in *Diabetes in America*, Second Edition. National Institutes of Health and National Institute of Diabetes and Digestive and Kidney Diseases. NIH Publication No. 95-1468.

Kenny, S. J., P. J. Smith, M. G. Goldschmid, J. M. Newman, and W. H. Herman.
1993. "Survey of Physician Practice Behaviors Related to Diabetes Mellitus in the
U.S. Physician Adherence to Consensus Recommendations." *Diabetes Care*16(11):1507-10.

Kerr, E. A., R. B. Gerzof, S. L. Krein, J. V. Selby, J. D. Piette, J. D. Curb, W. H.
Herman, D. G. Marrero, K. M. V. Narayan, M. M. Safford, T. Thompson, and C.
M. Mangione. 2004. "Diabetes Care Quality in the Veterans Affairs Health Care
System and Commercial Managed Care: The TRIAD Study." *Ann Intern Med*141(4):272-81. Editorial Greenfield, Sheldon. and Sherrie H. Kaplan. 2004
"Creating a Culture of Quality: The Remarkable Transformation of the
Department of Veterans Affairs Health Care System." *Ann Intern Med*141(4):316-18.

Kiberd, B. A. and K. K. Jindal. 1995. "Screening to Prevent Renal Failure in Insulin Dependent Diabetic Patients: an Economic Evaluation." *British Medical Journal* 311(7020):1595-9.

Kleinman, A. 1977. "Lessons from a Clinical Approach to Medical Anthropological Research." *Medical Anthropology Newsletter* 8:11-15.

Kneckt, M. C., A. M. Syrjala, and M. L. Knuuttila. 1999. "LOC Beliefs Predicting Oral and Diabetes Health Behavior and Health Status." *Acta de Odontologica Scandinavica* Jun;57(3):127-31.

Konen, J. C., J. H. Summerson, and M. B. Dignan. 1993. "Family Function, Stress, and LOC. Relationships to Glycemia in Adults with Diabetes Mellitus." *Archives of Family Medicine* Apr;2(4):393-402.

Kuther, T. L. 1998. "Sex and Sex-role Differences in LOC." *Psychological Reports* Feb; 82(1):188-90.

Landau, R. 1995. "LOC and Socioeconomic Status: Does Internal LOC Reflect Real Resources and Opportunities or Personal Coping Abilities?" *Social Science and Medicine* 41:1499-505.

Langewitz, W., B. Wossmer, J. Iseli, W. Berger. 1997. "Psychological and Metabolic Improvement After an Outpatient Teaching Program for Functional Intensified Insulin Therapy (FIT)." *Diabetes Research and Clinical Practice* Sep;37(3):157-64. La Porte, Ronald E., M. Matsushima, and Yue-Fang Chang. 1995. "Prevalence and Incidence of Insulin-Dependent Diabetes." Pp. 37-46 in *Diabetes in America*, Second Edition. National Institutes of Health and National Institute of Diabetes and Digestive and Kidney Diseases. NIH Publication No. 95-1468.

Larsen, I. F. 2000. "Diabetes Among Immigrants from Non-western Countries." *Tidsskrift for den Norske Laegforening* Sep 30;120(23):2894-6.

Laws, M. B. and S. J. Mayo. 1998. "The Latina Breast Cancer Control Study, Year One: Factors Predicting Screening Mammography Utilization by Urban Latina Women in Massachusetts." *Journal of Community Health* Aug;23(4):251-67.

Lee, M. C. 2000. "Knowledge, Barriers and Motivators Related to Cervical Cancer Screening Among Korean-American Women: A Focus Group Approach." *Cancer Nursing* Jun;23(3):168-75.

Lefcourt, Herbert M. 1982. LOC:Current Trends in Theory and Research. Hillsdale NJ: Lawrence Erlbaum Associates.

Lefkowitz, M. M., E. P. Tesiny, and N. H. Gordon. 1980. "Childhood Depression, Family Income, and LOC." *Journal of Nervous and Mental Disease* 168:732-5.

Levenson, H. 1973. "Multidimensional LOC in Psychiatric Patients." *Journal of Consulting and Clinical Psychology* 41:397-404.

Link, B. G. and J. C. Phelan. 2000. "Evaluating the Fundamental Cause Explanation for Social Disparities in Health." Pp. 33-46 in *Handbook of Medical Sociology*, Fifth ed. Edited by Bird Chloe E., Conrad Peter, and Fremont Allen M. Upper Saddle River, New Jersey: Prentice Hall.

Lohr, K. N. 1997. "How Do We Measure Quality?" *Health Affairs* 16(3):22-5.

Lowery, B. J. and J. P. DuCette. 1976. "Disease-related Learning and Disease Control in Diabetics as a Function of LOC." *Nursing Research* 25:358-62.

Mackenbach, J. P., G. J. Borsboom, W. J. Nusselder, C. W. Looman, and C. T. Schrijvers. 2001. "Determinants of Levels and Changes of Physical Functioning in Chronically III Persons: Results from the GLOBE Study." *Journal of Epidemiology and Community Health* 55:631-8.

Mann, J. K. and D. E. Yett. 1968. "The Analysis of Hospital Costs: A Review Article." *Journal of Business* 41:191-202.

Marmot, M. and R. G. Wilkinson. 1999. editors. *Social Determinants of Health*. New York: Oxford University Press.

Marmot, M.G., M. Shipley, and G. Rose. 1984. "Inequalities in Death – Specific Explanations of a General Pattern." *Lancet* 1(8384):1003-6.

Marshall, C. L., M. Bluestein, C. Chapin, T. Davis, J. Gersten, C. Harris, A. Hodgin, W. Larsen, H. Rigberg, V. Krishnaswami, and B. Darling. 1996. "Outpatient Management of Diabetes Mellitus in Five Arizona Medicare Managed Care Plans." *American Journal of Medical Quality* 11(2):87-93. McGlynn, E. A. 1996. "Choosing Chronic Disease Measures for HEDIS: Conceptual Framework and Review of Seven Clinical Areas." *Managed Care Quarterly* 4(3):54-77.

Meize-Grochowski, A.R. 1990. "Health LOC and Glycosylated Haemoglobin Concentration of Implantable Insulin Pump Recipients in Austria." *Journal of Advanced Nursing* Jul;15(7):804-7.

Milgram, S. 1963. "Behavioral Study of Obedience." *Journal of Abnormal Psychology* Oct;67:371-8.

Miller, R. H. and H. S. Luft. 1997. "Does Managed Care Lead to Better or Worse Quality of Care?" *Health Affairs (Millwood)* 16(5):7-25.

Moffatt, M. E. and I. B. Pless. 1983. "LOC in Juvenile Diabetic Campers: Changes During Camp, and Relationship to Camp Staff Assessments." *Journal of Pediatrics* 103(1):146-50.

Molinari, V. and G. Niederehe. 1984-1985. "LOC, Depression, and Anxiety in Young and Old Adults: A Comparison Study." *International Journal of Aging and Human Development* 20:41-52.

Molloy, G. N., K. Wolstencroft, N. J. King, A. R. Lowe, P. L. Gardner, G. L. Rowley, E. K. Molloy, and G. C. Murphy. 1997. "LOC of Smokers, Nonsmokers, and Nonpracticing Smokers." *Psychological Reports* 81:781-2.

Myers, G. S. 1968. Quoted in Lasagna, L., *Life, Death and the Doctor.* New York:Alfred Knopf.

Nagasawa, M., M. C. Smith, J. H. Barnes Jr., and J. E. Fincham. 1990. "Metaanalysis of Correlates of Diabetes Patients' Compliance with Prescribed Medications." *Diabetes Educator* 16:192-200.

Nagata, H., T. Ohta, and H. Aoyama. 1999. "Medical Students' Perception of Inpatients' Anxiety, Self-esteem, Purpose-in-life and Health LOC as Compared with Nursing Practitioners'." *Acta Medica Okayama* 53:141-5.

Nagata, H., T. Ohta, and H. Aoyama. 1998. "Nursing Practitioners' Perception of Inpatients' Anxiety, Self-esteem, Purpose-in-life and Health LOC." *Acta Medica Okayama* 52:271-8.

Neel, J.V. 1962. "Diabetes Mellitus: A Thrifty Genotype Rendered Detrimental by "Progress"?" *Am J Hum Genet* 14:353-62.

Norman, Paul, Paul Bennett, Christopher Smith, and Simon Murphy. 1997. "Health LOC and Leisure-Time Exercise. Personality & Individual Differences 23[5], 769-74.

Norris, S. L., M. M. Engelgau, and K. M. Narayan. 2001. "Effectiveness of Self-Management Training in Type 2 Diabetes: A Systematic Review of Randomized Controlled Trials." *Diabetes Care* 24 (3):561-87.

O'Connor, P. J., B. F. Crabtree, and N. N. Abourizk. 1992. "Longitudinal Study of a Diabetes Education and Care Intervention: Predictors of Improved Glycemic Control." *Journal of the American Board of Family Practice* 5:381-7. Ohldin, A. and A. Mims. 2002. "The Search for Value in Health Care: A Review of the National Committee for Quality Assurance Efforts." *Journal of the National Medical Association* 94(5):344-50.

Paterson, B. 2001. "Myth of Empowerment in Chronic Illness." *Journal of Advanced Nursing* 34(5):574-81.

Pawar, B. K., S. Walford, and B. M. Singh. 1999. "Type 1 Diabetes Mellitus in a Routine Diabetes Clinic: The Association of Psycho-social Factors, Diabetes Knowledge and Glycaemic Control to Insulin Regime." *Diabetes Research and Clinical Practice* 46 (1999):121-6.

Peters, A. L., A. P. Legorreta, R. C. Ossorio, and M. B. Davidson. 1996. "Quality of Outpatient Care Provided to Diabetic Patients. A Health Maintenance Organization Experience." *Diabetes Care* 19(6):601-6.

Petitti, Diana B., Richard Contreras, Frederick H. Ziel, James Dudl, Edward S. Domurat, and Joel Hyatt. 2000. "Evaluation of the Effect of Performance Monitoring and Feedback on Care Process, Utilization, and Outcome." *Diabetes Care* 23(2):192-6.

Petty, Richard, Tom Sensky, and Robert Mahler. 1991. "Diabetologists' Assessments of Their Outpatients' Emotional State and Health Beliefs: Accuracy and Possible Sources of Bias." *Psychotherapy and Psychosomatics* 55[2-4],164-9.

Peyrot, M. and R. R. Rubin. 1994. "Structure and Correlates of Diabetes-specific LOC." *Diabetes Care* 17(9):994-1001.

Peyrot, Mark and James F. McMurry. 1985. "Psychosocial Factors in Diabetes Control: Adjustment of Insulin-Treated Adults." *Psychosomatic Medicine* 47[6], 542-57.

Philis-Tsimikas, A., C. Walker, L. Rivard, G. Tavares, J. O. Reimann, M. Salmon, and R. Araujo. 2004. "Improvement in Diabetes Care of underinsured patients Enrolled in Project Dulce: A Community-based, Culturally Appropriate, Nurse Case Management and Peer Education Diabetes Care Model." *Diabetes Care* Jan; 27(1):110-5.

Phillips, J. M. 1999. "Breast Cancer and African American women; Moving Beyond Fear, Fatalism and Silence." *Oncology Nursing Forum* Jul;26(6):1001-7.

Plescia, M. and M. Groblewski. 2004. "A Community-oriented Primary Care Demonstration Project: Refining Interventions for Cardiovascular Disease and Diabetes." *Ann Fam Med* 2:103-9.

Pouwer, F., A. T. Beekman, G. Nijpels, J. M. Dekker, F. J. Snoek, P. J. Kostense, R. J. Heine, and D. J. Deeg. 2003. "Rates and risks for co-morbid depression in patients with Type 2 diabetes mellitus: results from a community-based study." *Diabetologia* 46:892-8.

Powe, B. D. 1994. "Perceptions of Cancer Fatalism Among African Americans: The Influence of Education, Income, and Cancer Knowledge." *Journal of National Black Nurses Association* Fall-Winter;7(2):41-8.

Powe, B. D. 1996. "Cancer Fatalism Among African-Americans: A Review of the Literature." *Nursing Outlook* 44 (1):18-21.

Pyorala, K., T. R.Pederson, J. Kjekshus, O. Faergeman, A. G. Olsson, and G. Thorgeirsson. 1997. "Cholesterol Lowering with Simvastatin Improves Prognosis of Diabetic Patients with Coronary Heart Disease." *Diabetes Care* 210:614-20.

Quatromoni, P.A., M. Milbauer, B. M. Posner, N. P. Carballeira, M. Brunt, and S. R. Chipkin. 1994. "Use of Focus Groups to Explore Nutrition Practices and Health Beliefs of Urban Caribbean Latinos with Diabetes." *Diabetes Care* Aug; 17(8):869-73.

Renders, Carry M., Gerlof D. Valk, Franse V. Lonneke, Francois G. Schellevis, Th.M. van Eijk, Jacques, Gerrit van der Wal. 2001. "Long-Term Effectiveness of a Quality Improvement Program for Patients With Type 2 Diabetes in General Practice." *Diabetes Care* 24(8)1365-70.

Reynaert C, P. Janne, J. Donckier, M. Buysschaert, N. Zdanowicz, D. Lejeune, and L. Cassiers. 1995. "LOC and Metabolic Control." *Diabete Metab* Jun;21(3):180-7.

Rhee, C. and M. Gatz. 1993. "Cross-generational Attributions Concerning LOC Beliefs." *International Journal of Aging and Human Development* 37:153-61.

Robinson-Whelen, S. and M. Storant. 1992. "Factorial Structure of Two Health Belief Measures Among Older Adults." *Psychology and Aging* 7:209-13.

Rodriguez, B. L., C. M. Burchfiel, B. Huang, D. S. Sharp, K. Yano, J. Lu, and W. Fujimoto. 1996. "Cardiovascular Risk Factor Profiles, Impaired Glucose Tolerance and Diabetes in the Elderly; The Honolulu Heart Program." *Diabetes Care*.

Rose A. 1948. *The Negro in America*. New York: Harper and Row.

Rotter, J. B. 1954. *Social learning and clinical psychology*. Englewood Cliffs, NJ: Prentice-Hall.

Rotter, J. B. 1966. "Generalized Expectancies for Internal Versus External Control of Reinforcement." *Psychological Monographs* 80 (Whole no. 609).

Rubin, R.J., W. M. Altman, and D. N. Mendelson. 1997. "Health Care Expenditures for People with Diabetes Mellitus." *Journal of Clinical Endocrinology and Metabolism* 78:809.

Ruzicki, Dorothy A. 1984. "Relationship of Health LOC to Preference for a Participatory or Prescriptive Approach in Diabetes Education. Dissertation Abstracts International 44[7-B], 2106-7.

Saadine, J. B., M. M. Engelgau, G. L. Beckles, E. W. Gregg, T. J. Thompson, and K. M. Narayan. 2002. "A Diabetes Report Card for the United States: Quality of Care in the 1990's." *Ann Intern Med* 136:565-74.

Sadowski, C. J., H. R. Woodward, S. F. Davis, and D. L. Elsbury. 1983. "Sex Differences in Adjustment Correlates of LOC Dimensions." *Journal of Personality Assessment* 47:627-31.

Santiago, J. H. and S. J. Tarantino. 2002. "Individualism and Collectivism: Cultural Orientation in LOC and Moral Attribution Under Conditions of Social Change." *Psychological Reports* 91:1155-68. Schlenk, E. A. and L. K. Hart. 1984. "Relationship Between Health LOC, Health Value, and Social Support and Compliance of Persons with Diabetes Mellitus." *Diabetes Care* 7:566-74.

Schwab, T., J. Meyer and R. Merrell. 1994. "Measuring Attitudes and Health Beliefs Among Mexican Americans with Diabetes." *Diabetes Education* May-June;20(3):221-7.

Schwartz, J. S., S. J. Boccuzzi, H. Glick, J. R. Cook, B. Kinosian, T. R. Pedersen, and J. Kjekshus. 1997. "Cost Effectiveness of LDL-C Reduction in Diabetic CHD Patients: Implications from the Scandinavian Simvastatin Survival Study. *Circulation* 96(suppl 1):I 504-I 505.

Schwartz, L. S., L. R. Coulson, D. Toovy, J. S. Lyons, and J. A. Flaherty. 1991. "A Biopsychosocial Treatment Approach to the Management of Diabetes Mellitus." *General Hospital Psychiatry* Jan;13(1):19-26.

Scott, Catherine. 1997. "Gender and Attribution of Control Over Health and Physical Size." *Journal of Social Psychology* 137[3], 387-8.

Scott, R. W. 1992. *Organizations: Rational, Natural and Open Systems.* Englewood Cliffs. N.J.: Prentice Hall.

Seeman, M. and J. W. Evans. 1963. "Alienation and Learning in a Hospital Setting." *American Sociological Review* 27:772-83.

Sensky, T. and R. Petty. 1989. "Type A Behaviour Pattern and Glycemic Control in Type 1 Diabetes." *Psychotherapy and Psychosomatics* 52(1-3):96-100.

Siegel, J. E., et al. 1992. "Cost-effectiveness of Screening and Early Treatment of Nephropathy in Patients with Insulin-dependent Diabetes Mellitus." *Journal of the American Society of Nephrology* 3 (4 Suppl): S111-9.

Simon, L.P., A. Albright, M. J. Belman, E. Tom, and J. A. Rideout. 1999. "Risk and Protective Factors Associated with Screening for Complications of Diabetes in a Health Maintenance Organization Setting." *Diabetes Care* 22(2):208-12.

Siu, O., C. L. Cooper, P. E. Spector, and I. Donald. 2001. "Age Differences in Coping and LOC: A Study of Managerial Stress in Hong Kong." *Psychology and Aging* 16:707-10.

Sloan, N. R. 1963. "Ethnic Distribution of Diabetes Mellitus in Hawai'i." *Journal of the American Medical Association* 183:419-24.

Smaje C. 2000. "Race, Ethnicity and Health." Pp. 114-128 in *Handbook of Medical Sociology*, Fifth ed. Edited by Bird Chloe E., Conrad Peter, and Fremont Allen M. Upper Saddle River, New Jersey: Prentice Hall.

Smiley, M. R., S. C. McMillan, S. Johnson, and M. Ojeda. 2000. "Comparison of Florida Hispanic and Non-Hispanic Caucasian Women in their Health beliefs Related to Breast Cancer and Health LOC." *Oncology Nursing Forum* 27:975-84.

Spangler, J. G., J. H. Summerso, R. A. Bell, and J. C. Konen. 2001. "Smoking Status and Psychosocial Variables in Type 1 Diabetes Mellitus." *Addiction Behavior* Jan-Feb;26(1):21-9.

Spikmans, F. J., J. Brug, M. M. Doven, H. M. Kruizenga, G. H. Hofsteenge, and M. A. van Bokhorst-van der Schueren. 2003. "Why do Diabetic Patients Not Attend Appointments with their Dietitian?" *Journal of Human Nutrition Diet* 16:151-8.

SPSS Graduate Pack 12.0 for Windows. 2003. Chicago, Illinois.

State of Hawai'i, Department of Business, Economic Development & Tourism. *The State of Hawai'i Data Book 1992*. 1993.

Stein, Mitchell J., Maribeth Smith, and Kenneth A. Wallston. 1984. "Cross-Cultural Issues of Health LOC Beliefs." *Psychological Studies* 29[1], 112-6.

Stenstrom, U., and P. Andersson. 2000. "Smoking, Blood Glucose, and LOC Beliefs in People With Type 1 Diabetes Mellitus." *Diabetes Research and Clinical Practice* Oct;50(2):103-7.

Stephen, M. W., and P. Delys. 1973. "External Control Expectancies Among Disadvantaged Children of Preschool Age." *Child Development* 44:670-4.

Steptoe, A. and J. Wardle. 2001. "LOC and Health Behaviour Revisited: A Multivariate Analysis of Young Adults from 18 Countries." *British Journal of Psychology* 92:659-72.

Stewart, A.L., R. D. Hays, and J. E. Ware. 1988. "The MOS Short-Form General Health Survey: Reliability and Validity in a Patient Population." *Medical Care* 26:724-32.

Strickland, B. R. 1972. "Delay of Gratification as a Function of Race of the Experimenter." *Journal of Personality and Social Psychology* 22:108-12.

Sun, Lina N. N. and Sunita Mahtani Stewart. 2000. "Psychological Adjustment to Cancer in a Collective Culture." *International Journal of Psychology* 35[5],177-85.

Surgenor, L. J., J. Horn, S. M. Hudson, H. Lunt, and J. Tennent. 2000. "Metabolic Control and Psychological Sense of Control in Women With Diabetes Mellitus. Alternative Considerations of the Relationship." *Journal of Psychosomatic Research* Oct;49(4)267-73.

Swinney, Jean E. 2002. "African Americans With Cancer: the Relationships Among Self-Esteem, LOC, and Health Perception." *Research in Nursing and Health* 25[5], 371-82.

Tabachnick, Barbara G., and Linda S. Fiddell. 2001. *Using Multivariate Statistics*. Fourth Edition, Boston:Allyn and Bacon.

Tabb, S. L. 1990. "LOC in the Black Elderly." *Journal of Human Hypertension* 4:108-9.

Tashakkori, A. and V. D. Thompson. 1991. "Race Differences in Self-perception and LOC During Adolescence and Early Adulthood: Methodological Implications." *Genetic, Social, and General Psychology Monographs* 117:133-52. Testa, M. A., and D. C. Simonson. 1998. "Health Economic Benefits and Quality of Life During Improved Glycemic Control in Patients with Type 2 Diabetes Mellitus: A Randomized, Controlled, Double-Blind Trial." *Journal of the American Medical Association* 280-1490-6.

The Carter Center of Emory University. Closing the gap: the problem of diabetes mellitus in the United States. The Carter Center of Emory University. *Diabetes Care* 1985; 8(4):391-406.

The Diabetes Control and Complication Trial Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Medical Journal.* 1993;329:977-86.

The Diabetes Control and Complications Trial Research Group. Lifetime benefits and costs of intensive therapy as practiced in the diabetes control and complications trial. The Diabetes Control and Complications Trial Research Group [see comments] [published erratum appears in JAMA 1997 Jul 2;278(1):25]. *Journal of the American Medical Association* 1996; 276(17):1409-15.

The TRIAD Study Group. 2002. "The Translating Research Into Action for Diabetes (TRIAD) Study: A Multicenter Study of Diabetes in Managed Care." *Diabetes Care* 25(2):386-9.

The UK Prospective Diabetes Study Group. Cost effectiveness analysis of improved blood pressure control in hypertensive patients with type 2 diabetes: UKPDS 40. *British Medical Journal* 1998; 317(7160):720-6.

The UK Prospective Diabetes Study Group. Tight blood pressure control and risk of macrovascular and microvascular complications in type 2 diabetes: UKPDS 38. [published erratum appears in BMJ 1999 Jan 2;318(7175):29]. *British Medical Journal* 1998a; 317(7160):703-13.

Thompson, J. W., J. Bost, F. Ahmed, C. E. Ingalls, and C. Sennett. 1998. "The NCQA's Quality Compass: Evaluating Managed Care in the United States." *Health Affairs (Millwood)* 17(1):152-8.

Tillotson, L.M. and M. S. Smith. 1996. "LOC, Social Support, and Adherence to the Diabetes Regimen." *Diabetes Education* Mar-Apr;22(2):133-9.

Tsukamoto, Naoko. 1999. "The Effects of Health LOC and Medical Variables on Cancer Patients' Psychological Adaptation: Analysis of Main Effects and Interaction Effects of HIc and Social Support." *Japanese Journal of Health Psychology* 12[1], 28-36.

Vinicor, F. 1994. "Is Diabetes a Public-Health Disorder?" *Diabetes Care* 17 Suppl 1:22-7.

Wagner, Edward H., Brian T. Austin, Connie Davis, Mike Hindmarsh, Judith Schaefer, and Amy Bonomi. 2001. "Improving Chronic Illness Care: Translating Evidence into Action." *Health Affairs* 20(6):64-78. Wallhagen, M. I. and M. Lacson. 1999. "Perceived Control and Psychosocial/Physiological Functioning in African American Elders with Type 2 Diabetes." *Diabetes Education* Jul-Aug;25(4):568-75.

Wallston, B. S., K. A. Wallston, G. D. Kaplan, and S. A. Maldes. 1976. "Development and Validation of the Health LOC Scale." *Journal of Consulting and Clinical Psychology* 44:580-5.

Wallston, K. A., B. S. Wallston, and R. F. DeVellis. 1978. "Development of the Multidimensional Health LOC (MHLC) Scales." *Health Education Monographs* (6)160-70.

Wallston, K.A., and B. S. Wallston. 1981. Health LOC Scales, in H. M. Lefcourt (Ed.), *Research with the LOC Construct* (Vol1), New York:Academic Press.

Wallston, K.A., M. J. Stein, and C. A. Smith. 1994. "Form C of the MHCL Scales: A Condition Specific Measure of LOC." *Journal of Personality Assessment* 63(3):534-53.

Wallston, Kenneth A., Vanessa L. Malcarne, Lise Flores, Ingunn Hansdottir, Craig A. Smith, Mitchell J. Stein, Michael H. Weisman, and Philip J. Clements. 1999. "Does God Determine Your Health? The God Locus of Health Control Scale." Cognitive Therapy & Research. Special Issue: Cognitive factors in Chronic Illness: Empirical Approaches 23[2], 131-42. Ware, J. E., M. S. Bayliss, W. H. Rogers, M. Kosinski, and A. R. Tarlov. 1996.
"Differences in 4-year Health Outcomes for Elderly and Poor, Chronically III
Patients Treated in HMO and Fee-for-service Systems." *Journal of the American Medical Association* 276(13):1039-47.

Ware. J., Jr., M. Kosinski, and S. D. Keller. 1996. "A 12-Item Short-Form Health Survey: Construction of Scales and Preliminary Tests of Reliability and Validity." *Medical Care* 34:220-33.

Weiner, J. P., S. T. Parente, D. W. Garnick, J. Fowles, A. G. Lawthers, and R. H. Palmer. 1995. "Variation in Office-based Quality. A Claims-based Profile of Care Provided to Medicare Patients with Diabetes [see comments]. *Journal of the American Medical Association* 273(19):1503-08.

Welton, Gary L., A. Gelene Adkins, Sandra L. Ingle, and Wayne A. Dixon. 1996. "God Control: the Fourth Dimension." *Journal of Psychology & Theology* 24[1], 13-25.

Westbrook, M. T., L. A. Nordholm, and J. E. McGee. 1984. "Cultural Differences in Reactions to Patient Behaviour: A Comparison of Swedish and Australian Health Professionals." *Social Science and Medicine* 19:939-47.

White, N., J. Carnahan, C. A. Nugent, T. Iwaoka, and M. A. Dodson. 1986. "Management of Obese Patients with Diabetes Mellitus: Comparison of Advice Education with Group Management." *Diabetes Care* 9:490-6. White, R., P. Tata, and T. Burns. 1996. "Mood, Learned Resourcefulness and Perceptions of Control in Type 1 Diabetes Mellitus." *Journal of Psychosomatic Research* 40:205-12.

Wingard, D.L., and E. Barrett-Conner. 1995. "Heart disease and diabetes." In: National Diabetes Data Group. Diabetes in America. 2nd ed. Washington DC: US Government Printing Office, 429-448.

Wrightson, K. J. and Jane Wardle. 1997. "Cultural Variation in Health LOC." *Ethn Health* 2(1-2):13-20.

Zimmet, P., S. Ainuu, W. DeBoer, J. Faaiuso, and S. Whitehouse. 1981. "The Prevalence of Diabetes in the Rural and Urban Polynesian Population of Western Samoa." *Diabetes* 30:45-51.

Zola, Irving K. 1983. Socio-Medical Inquiries: Recollections, Reflections, and Reconsiderations. Philadelphia: Temple University Press.