1995

Evaluation of Diabetes Services Provided by IHS Model Diabetes Program

Native American Consultants, Inc.

J. Smith

M. Cole

Follow this and additional works at: http://digitalrepository.unm.edu/nhd

Recommended Citation

Smith J. Cole M. Evaluation of diabetes services provided by IHS Model Diabetes Program. Indian Health Service, Staff Office of Planning, Evaluation and Research, Rockville, MD 20857 (E-126). 1995

This Article is brought to you for free and open access by the Special Collections at UNM Digital Repository. It has been accepted for inclusion in Native Health Database Full Text by an authorized administrator of UNM Digital Repository. For more information, please contact amywinter@unm.edu.
EVALUATION OF DIABETES SERVICES PROVIDED BY IHS MODEL DIABETES PROGRAM

FINAL REPORT

SUBMITTED BY:

NATIVE AMERICAN CONSULTANTS, INC. (NCAI)
725 2nd Street, N.E.
Washington, D.C. 20002
(202) 547-0576
Prepared under Contract Number 282-91-0056, Delivery Order No. 9
April 1995

DEPARTMENT OF HEALTH AND HUMAN SERVICES
PUBLIC HEALTH SERVICE
INDIAN HEALTH SERVICE

OFFICE OF PLANNING, EVALUATION, AND LEGISLATION
Acting Associate Director: Edward Simermeyer
Acting Deputy Associate Director: Richard McCloskey
Division of Program Evaluation and Policy Analysis
Director: Leo J. Nolan
Delivery Order Officer: Frank E. Marion

OFFICE OF HEALTH PROGRAMS
Associate Director: Phillip L. Smith, M.D.

Indian Health Service Diabetes Program
Program Director: Dorothy Gohdes, M.D.
Co-Project Officer: Brenda Broussard, R.D., M.P.H., M.B.A.
EVALUATION OF DIABETES SERVICES PROVIDED BY IHS MODEL DIABETES PROGRAM

Final Report to Indian Health Service

Presented by

Native American Consultants, Inc.
725 2nd Street, N.E.
Washington, DC 20002

Researcher Juneal Smith
Project Manager Martha Cole

April 28, 1995

NACI Project No. 191-9
EVALUATION OF
SERVICES PROVIDED BY
INDIAN HEALTH SERVICE MODEL
DIABETES PROGRAM

FINAL REPORT

Prepared under
Contract Number 282-91-0056
Delivery Order Number 9

Issued by

Department of Health and Human Services
Public Health Service
Division of Acquisition Management, ASC/OM
General Acquisitions Branch
Parklawn Building, Room 5-101
5600 Fishers Lane
Rockville, Maryland 20857

by

Native American Consultants, Inc.
725 2nd Street, N.E.
Washington, D.C. 20002
(202) 547-0576

April 28, 1995
Juneal Smith was responsible for data collection and data analysis for this study.

NACI would like to thank Dr. Dorothy Gohdes and Brenda Broussard of the Diabetes Program staff for their leadership and guidance in conducting this study. Thanks to Frank Marion of the OPEL staff at IHS for his assistance.
ABBREVIATIONS


Burchfiel, C. M., Hamman, R. F., Marshall, J. A., Baxter, J., Kahn, L. B.,
Amirani, J. J.; Cardiovascular Risk Factors and Impaired Glucose Tolerance: The
131(1):57-70.

Bureau of the Census. We the ...First Americans (Washington, D. C.: U. S.
Department of Commerce, Economics and Statistics Administration), (Sep 1993).
Pg. 7.

Carter Center of Emory University; Closing the Gap: the Problem of Diabetes

Charlson, M. E., Pompei, P., Ales, K. L., MacKenzie C. R.; A New Method of
Classifying Prognostic Comorbidity in Longitudinal Studies: Development and

Davidson, J. K., Vander Zwaag, R., Cox, C. L., Delcher, H. K., Mainzer, I.,
Baggett, H., Runyan, J. W.; The Memphis and Atlanta Continuing Care Programs
for Diabetes Type II. Comparative Analyses of Demographic Characteristics,
Treatment Methods, and Outcomes over a 9-10 Year Followup Period. Diabetes

Dimatteo, M. R., Sherbourne, C., Hays, R. D., Ordway, L., Kravitz, R. L.,
McGlynn, E. A., Kaplan, S., Rogers W. H.; Physicians' Characteristics Influence
Patients' Adherence to Medical Treatment: Results from the Medical Outcomes

Dinicola, D. D, Dimatteo, M. R.; Chapter 14. Communication, Interpersonal
Influence and Resistance to Medical Treatment. In: Basic Processes in Helping
307-331.

Division of Diabetes Translation. Diabetes Surveillance, 1993. (Atlanta, GA:
National Center for Chronic Disease Prevention and Health Promotion, Centers for
Disease Control and Prevention), (Nov 1993), P51.

Division of Program Statistics. Regional Differences in Indian Health 1992.
(Rockville, MD: Office of Planning, Evaluation and Legislation, Indian Health
Service, Public Health Service, U. S. Department of Health and Human Services)

Donovan, J. L., Blake, D. R.; Patient Non-Compliance: Deviance or Reasoned


Hayes, T. M., Harries, J.; Randomized Controlled Trial of Routine Hospital Clinic Care Versus Routine General Practice Care for Type II Diabetics. New England Journal Medicine (Sep 22,1984) 289:728-30.


Health-Related Quality of Life in Patients with Non-Insulin-Dependent Diabetes Mellitus. Medical Care (1994) 29:1173-1181.


INDEX
INDEX

EXECUTIVE SUMMARY
IHS DIABETES PROJECT EVALUATION ........................................ i

MAJOR FINDINGS ................................................................. i
Statistical Analysis of Health Outcomes (Tables 1-2) .................. i
Poor Blood Sugar Control ................................................. i
First Diabetes-Related Hospitalization ................................ i

POLICY IMPLICATIONS ....................................................... ii

CHAPTER I
STUDY HYPOTHESIS AND LITERATURE REVIEW ....................... 1-1
1.1 INTRODUCTION .............................................................. 1-1
1.2 HYPOTHESES ................................................................. 1-3
  1.2.1 Hypothesis #1 ....................................................... 1-3
  1.2.2 Hypothesis #2 ....................................................... 1-3
1.3 CONCEPTUAL FRAMEWORK ............................................ 1-4
1.4 THE NATURE AND EXTENT OF DIABETES AMONG AMERICAN
  INDIANS ................................................................. 1-6
  1.4.1 Prevalence ......................................................... 1-6
  1.4.2 Complications .................................................. 1-7
  1.4.3 Mortality ........................................................ 1-9
  1.4.4 Hospitalizations ............................................... 1-10
  1.4.5 Concluding Remarks ......................................... 1-11
1.5 INTERVENTIONS AND OUTCOMES .................................. 1-11
  1.5.1 Comoribities .................................................... 1-16

CHAPTER II
METHODS ............................................................... 2-1
  2.1 DATA COLLECTION METHODS .................................... 2-1
    2.1.1 Medical Record Abstraction ................................ 2-1
      2.1.1.1 Design of the Medical Record Abstract Form .... 2-1
      2.1.1.2 Cohort Selection ....................................... 2-2
    2.1.2 Methods for Focus Groups ................................ 2-3
      2.1.2.1 Description of Focus Group Participants ....... 2-4
    2.1.3 Methods for Informant Interviews ...................... 2-5
  2.2 METHODS OF DATA ORGANIZATION AND VARIABLE
    CONSTRUCTION ....................................................... 2-6
    2.2.1 National IHS Utilization Data Sources .................. 2-6
    2.2.2 Organization of Analysis Files .......................... 2-7
    2.2.3 Description of Outcome Variables ...................... 2-7
      2.2.3.1 Categorical and Dichotomous Blood Sugar Score 2-8
      2.2.3.2 Occurrence of a First Diabetes-Related Hospitalization 2-8
  2.3 DIABETES PROGRAM AUDIT DATA FOR 1993 ....................... 2-14

CHAPTER III
RESULTS AND DISCUSSION OF INTERVIEWS AND FOCUS GROUPS DESCRIPTIVE
STATISTICS ............................................................... 3-1
3.1 RESULTS OF FOCUS GROUPS AND INFORMANT INTERVIEWS ...... 3-1
  3.1.1 Adherence Issues .............................................. 3-1
    3.1.1.1 Adherence to Medical Recommendations ....................... 3-1
    3.1.1.2 Adherence to Clinical Appointments ......................... 3-4
  3.1.2 Process of Care ................................................ 3-5
    3.1.2.1 Clinic-Based Care ........................................... 3-5
    3.1.2.2 Home-Based Care ............................................. 3-7
  3.1.3 Alternative Diabetic Care Providers .......................... 3-7
  3.1.4 Recommendations for Improving IHS Diabetes Care ............. 3-8
    3.1.4.1 Done Well for Patients with Diabetes ...................... 3-8
    3.1.4.2 Recommendations for Improvement .......................... 3-9

3.2 CONCLUSIONS ....................................................... 3-9

3.3 DISCUSSION FOCUS GROUPS AND INTERVIEWS ......................... 3-11
  3.3.1 Adherence and Its Relationship to Process of Care ............ 3-12
    3.3.1.1 Adherence ................................................... 3-13
    3.3.1.2 Process of Care ............................................. 3-14

CHAPTER IV
DESCRIPTION OF DIABETIC HEALTH CARE SERVICES ...................... 4-1
  4.1 BACKGROUND ...................................................... 4-1
  4.2 IHS DIABETES PROJECTS AND DIABETES CARE ......................... 4-2
    4.2.1 Distinguishing Features of Projects ........................ 4-4
    4.2.2 Funding and Authority ........................................ 4-4
    4.2.3 Monitoring and Followup ..................................... 4-4
  4.3 STATISTICAL COMPARISONS OF DIFFERENT COMPONENTS OF DIABETES CARE ......................................................... 4-5
    4.3.1 Diabetes Care During Followup for Blood Sugar Control ..... 4-6
    4.3.2 Diabetes Care During Followup for Hospitalizations ...... 4-7

CHAPTER V
DESCRIPTIVE STATISTICS ................................................. 5-1
  5.1 PLAN FOR DESCRIPTIVE DATA ANALYSIS ................................ 5-1
  5.2 DESCRIPTIVE STATISTICS FOR LONGITUDINAL COHORT .................. 5-1
    5.2.1 Demographics ................................................. 5-2
      5.2.1.1 Project Compared to Usual Care .......................... 5-2
      5.2.1.2 Comparisons by Poor Blood Sugar Control ................. 5-2
      5.2.1.3 Comparisons of Observed and Expected Hospitalizations .. 5-3
    5.2.2 Baseline Medical Indicators ................................... 5-3
      5.2.2.1 Project Compared to Usual Care .......................... 5-3
      5.2.2.2 Comparisons by Poor Blood Sugar Control ................. 5-3
      5.2.2.3 Comparisons of Observed and Expected Hospitalizations .. 5-4
  5.3 INCLUSION CRITERIA FOR VARIABLES ................................ 5-11
  5.4 OTHER UNMEASURED DEMOGRAPHIC CHARACTERISTICS ................... 5-14
    5.4.1 The Fort Totten Sample ..................................... 5-15
  5.5 DESCRIPTIVE STATISTICS FOR THE 1993 AUDIT DATA .................... 5-15

CHAPTER VI
STATISTICAL ANALYSIS .................................................. 6-1
  6.1 RESULTS OF STATISTICAL ANALYSIS .................................. 6-1
    6.1.1 Modeling Decisions ......................................... 6-1

II
6.1.2 Results for Poor Blood Sugar Control Poisson Regression Model
6.1.2.1 Diabetic Care Components
6.1.4 Results for First Hospitalization Cox Proportional Hazard Model
6.1.4.1 Diabetic Care Components
6.2 RESULTS OF GENERALIZABILITY ANALYSIS
6.3 DISCUSSION OF STATISTICAL ANALYSIS
6.3.1 Threats to Validity
6.3.2 Outcomes and Diabetic Care
6.3.3 Generalizability
CHAPTER VII
RECOMMENDATIONS AND POLICY IMPLICATIONS
7.1 RECOMMENDATIONS
7.1.1 Recommendations for Patient Education
7.1.2 Recommendations for Health Maintenance Activities
7.1.3 Recommendations for Service Units
7.2 POLICY IMPLICATIONS
APPENDIX A MEDICAL ABSTRACT FORM
APPENDIX B KEY INFORMANT INTERVIEWS
APPENDIX C UNIVARIATE COMPARISONS BY SITE
APPENDIX D UNIVARIATE COMPARISONS BY SUBSET
APPENDIX E UNIVARIATE COMPARISONS BY HOSPITALIZATION
APPENDIX F FOCUS GROUP DISCUSSION POINTS
TABLES AND FIGURES
CHAPTER I
INTRODUCTION AND STUDY HYPOTHESES

Table 1-1. Evaluation Conceptual Framework 1-4
Table 1-2. Percent of Adults with Self-reported Diabetes in the SAIAN and General U.S. Population 1-6
Figure 1-1. Diagram of Concept Framework 1-6
Table 1-3. Age-Adjusted Mortality Rates and Rank Among Other IHS Areas for Selected Chronic Disease Related Causes in Aberdeen, All IHS Areas and U.S. All Races (rate per 100,000) 1-10
Table 1-4. Experimental Studies of Diabetic Care Interventions and Outcomes 1-14
Table 1-5. Some Observational Studies of Diabetic Care and Outcomes 1-15

CHAPTER II
THE NATURE AND EXTENT OF DIABETES AMONG AMERICAN INDIANS

Table 2-1. Some Demographic Characteristics of Informants 2-6
Table 2-2. Baseline Demographic Variables 2-9
Table 2-3. Patient Medical Attributes 2-11
Table 2-4. Diabetes Care Variables in First Year and Cumulative 2-12
Table 2-5. Description of Audit 93 Variables 2-15

CHAPTER III.
METHODS

Table 3-1. Diabetic Health Care Topics by Group and Category 3-10

CHAPTER IV.
RESULTS AND DISCUSSION OF INTERVIEWS AND FOCUS GROUPS

Table 4-1. Population Estimates for Study Site 4-2
Table 4-2. Univariate Comparisons of Diabetes Care in the First Year by Project vs. Usual Care (N=634) 4-7
Table 4-3. Univariate Comparisons of Diabetes Care During Followup by Site for Blood Sugar Model 4-9
Table 4-4. Univariate Comparisons of Diabetes Care During Followup to Time of First Hospitalization or Exit by Site 4-10

CHAPTER V.
DESCRIPTION OF DIABETIC HEALTH CARE SERVICES

Table 5-1. Comparisons Baseline Demographic Variables by Project and Usual Care 5-4
Table 5-2. Contrasts of Baseline Medical Indicators by Project and Usual Care 5-6
Table 5-3. Demographic Contrasts for Poor Blood Sugar Control Using ANOVA 5-7
Table 5-4. Contrasts for Blood Sugar Control and Medical Indicators (mean number) . 5-8
Table 5-5. Logrank Contrasts of Baseline Demographics for First Hospitalizations (number) .............................. 5-9
Table 5-6. Logrank Contrasts of Baseline Medical Indicators for First Hospitalizations (number) .................................................. 5-11
Table 5-7. Changes in Observations with Successive Variable Inclusion ...................... 5-12
Table 5-8. Starting Variables for Modeling ........................................... 5-13
Table 5-9. Economic and Educational Statistics for American Indians Living in 'Study Site' States ................................. 5-14
Table 5-10. Univariate Comparisons of 1993 Audit Variables ............................... 5-16

CHAPTER VI.
DESCRIPTIVE STATISTICS

Table 6-1. Poisson Rate Ratios for Poor Blood Sugar Control (n=455) ............... 6-3
Table 6-2. First Hospitalization Hazard Ratios (n=480) ................................. 6-4
Table 6-3. Adjusted Rate Ratios for Poor Blood Sugar Control and Diabetes Care (n=455) ................................................................. 6-6
Table 6-5. Adjusted Odds Ratios for Poor Blood Sugar Control and Key Diabetes Care Variables Comparing IHS Sites Included in the Evaluation to Those Not Included. .................................... 6-9
Table 6-6. Adjusted Logit Odds Ratios for Poor Control by Sites In and Outside the Sample, Diabetic Care and In and Outside the Sample Plus Diabetic Care (N=2539) ................................. 6-9
EXECUTIVE SUMMARY
EXECUTIVE SUMMARY
IHS DIABETES PROJECT EVALUATION

This evaluation of the Indian Health Service diabetes model projects made use of data from 634 patient medical records, four focus groups and 20 informant interviews to describe these projects and examine their effect on two patient health outcomes, blood sugar control and hospitalizations. Two diabetes project sites (Winnebago and Fort Totten) and one 'usual care' site (Rosebud) were selected for the evaluation. Data from the 1993 Diabetes Program Audit was used to assess whether or not the findings from this evaluation of two diabetes projects could generally represent other diabetes 'team' approaches in other IHS Areas.

MAJOR FINDINGS

Statistical Analysis of Health Outcomes

Two multivariate statistical models were created to evaluate the protective effect of the diabetes projects against poor blood sugar control, and risk of a first hospitalization with a diabetes diagnosis. Many reasons exist for why patients have poor blood sugar control or must be hospitalized. The multivariate statistical models were constructed to control for the effects of 'other' factors on these outcomes. After controlling for these 'other' factors, if the effect of the diabetes projects still remains statistically significant, there is more certainty that the observed differences in rates or risk between the projects and 'usual care' are due to the intervention and not something else.

Poor Blood Sugar Control

Patients followed at diabetes project sites experienced lower rates of poor blood sugar control than patients followed at the usual care sites. Winnebago had a greater reduction in risk of poor control (IRR=0.64, 95% C.I. 0.52-0.79) than Fort Totten (IRR=0.88, 95% C.I. 0.73-1.07). If this same study were to be repeated 100 times on the same population under the same conditions, 95% of the time approximately 11% and 35% more project patients would have been in poor blood sugar control over time if they had been under 'usual care' instead of in the project. The definition of poor control is a fasting blood sugar greater than 200mg/dl and a random blood sugar or fingerstick greater than 250mg/dl.

The diabetic care model for poor control had three care components that were indicative of a protective effect, having seen a dietitian in the first year after diagnosis (IRR=0.80, 95% C.I. 0.69-0.93), having a hemoglobin A1c test performed one or more times in two years (IRR=0.88, 95% C.I. 0.75-1.03) and being seen for foot care in the first year following diagnosis (IRR=0.57, 95% C.I. 0.40-0.81).

First Diabetes-Related Hospitalization

Patients at Fort Totten (HR=0.52, 95% C.I. 0.34-0.80) and Winnebago (HR=0.84, 95% C.I. 0.60-1.17) were at reduced risk of having a first diabetes-related hospitalization over followup relative to patients at Rosebud.
The model that includes diabetes care variables suggests that seeing a dietitian less often than once year was associated with a lower risk of having a hospitalization (HR=0.41, 95% C.I. 0.27-0.63) compared to not seeing a dietitian at all over followup. Seeing a nurse educator at least once during followup was associated with a reduced risk of hospitalization (HR=0.68, 95% C.I. 0.46-1.01). Attending a diabetes or a prevention clinic or having one's blood sugar checked at home at least once a year (HR=0.32, 95% C.I. 0.22-0.46) also was associated with a reduced risk of hospitalization. Having a hemoglobin A1c test done once every two years or less (HR= 0.29, 95% C.I. 0.18-0.48) was protective against risk of hospitalization compared to having no test performed during followup or having the test done more frequently.

Are These Results Representative of Other Diabetes Projects? The results from the Audit 1993 data cannot provide a clear answer as to whether or not the results of this evaluation could be generalized to the larger IHS service population. However, projects in general seem to be similar in their rates of poor control and diabetes care characteristics.

Results from Focus Groups and Informant Interviews
Focus groups and informants reported that changes in diet were the most difficult lifestyle changes for patients with diabetes to make. Patients receiving 'usual care' had more problems communicating with and trusting their physician. Focus group participants and informants reported that patients felt more education about diabetes needed to be provided on a one-to-one basis, and in the community-at-large. Patients had questions about diabetes they needed competent professional answers to, and were relying mostly on CHRs to provide. CHRs expressed a need for better IHS technical support for their work with patients, and better lines of communication between themselves and the patients' primary diabetes care providers.

Health care providers (CHRs, and IHS staff) indicated that patient's lack of acceptance of a diabetic diagnosis was a real barrier to getting patients to adhere to medical recommendations for controlling their diabetes. This 'denial' appeared to be more common in younger patients according to CHRs. The data from medical records supports this observation. Patients who were diagnosed younger than 20, and those who were between 35 and 44 years of age at diagnosis were more likely to be in poor blood sugar control over time than patients who were over 45. Recent studies in other populations with diabetes have found this to be the case, as well.

POLICY IMPLICATIONS

The 'team' approach to diabetes management may offer some protection against adverse outcomes. Yet the qualitative and descriptive data from this evaluation suggest there is substantial room for improvement in the effectiveness and efficiency of the diabetes projects, particularly in Winnebago. This evaluation does reinforce the importance of the following diabetic care components:

1. Knowledgeable clinical staff are needed to deliver primary care to patients with diabetes (physicians, nurses, physician's assistants trained and kept current in diabetes management).
2. Providers should be available who can deliver the Standards of Care for foot and eye care.

3. Good clinical management of diabetes requires both blood sugar and hemoglobin A1c evaluation of patients at least once a year.

4. Patient education in the first year after diagnosis, and possibly at key times in disease progression (going from oral agents to insulin therapy) target important 'teachable' times with patients. Early patient education efforts need to focus on making lifestyles changes (diet, exercise and smoking behavior).

5. The psychosocial implications of a diabetic diagnosis should be addressed with all newly diagnosed patients. Diabetes care providers should be trained to provide counseling and support to patients for whom a diabetic diagnosis becomes a stressful life event.

6. Younger patients diagnosed with Type II diabetes (under 45 years of age) have different health care needs than patients diagnosed at an older age. Diabetic care at the community level should consider the needs of younger patients separately from older patients.

Some larger usual care sites such as the Rosebud and Pine Ridge Service Units may have enough clinical providers to create a 'team'. Yet, it is strongly recommended at least one additional position be allocated for a diabetes team coordinator so that patient care monitoring and management can be maintained over time. This would also assure better quality and continuity of care for patients with diabetes in these communities.
CHAPTER I
STUDY HYPOTHESIS AND LITERATURE REVIEW

1.1 INTRODUCTION

This study evaluates the Indian Health Service's (IHS) diabetes model projects. These projects were begun in 1979 as demonstration projects in five sites (Winnebago-Omaha in Nebraska, Fort Totten in North Dakota, Sacaton in Arizona, Blackfeet in Montana and Claremore in Oklahoma). They were later extended to include at least one site in each of the twelve regional areas of IHS. The projects at Winnebago-Omaha and Fort Totten were chosen by the Indian Health Service to represent those IHS model projects that use a team in managing diabetic health care. The Rosebud Service Unit in southern South Dakota was chosen by the investigator (myself) to represent the services or 'usual care' provided to diabetic patients through IHS in communities without model projects. All three of these Service Units are located in the IHS Aberdeen Area.

The hypothesis tested in this evaluation is that intensified patient education and community-oriented primary care outreach using a 'diabetes team' results in better blood glucose control, and reduced rates of hospitalization when compared with 'usual care'. An evaluation of the Indian Health Service model diabetes projects was mandated in the 1992 amendments to the Indian Health Care Improvement Act (P.L. 94-437) reauthorization (U.S. Congress 1992). The evaluation described below is intended to at least partially fulfill that legislative mandate.

The evaluation has an observational design making use of longitudinal data on patients diagnosed with diabetes between 1983 and 1992 at the two project and one usual care site. The evaluation has three components:

1) A qualitative analysis of five focus groups conducted with patients and Community Health Representatives, and twenty informant interviews of IHS and tribal health staff from all three sites. Focus groups and interviews provided descriptive information on diabetic care services, patient characteristics and perceptions of care that was not available in medical records or from other sources,

2) A quantitative statistical analysis of historical medical records information on a cohort of 634 patients with diabetes who were diagnosed in the last ten years of the model projects (January 1, 1983 to December 31, 1992). The statistical analysis links the type and amount of diabetic care, and the site of care (projects versus usual care) to health outcomes, and
3) A statistical examination of the generalizability of the longitudinal evaluation results from #2, using cross-sectional data for eleven diabetes project sites in eight IHS regions from the 1993 Diabetes Program Audit.

The final analysis assesses the overall effect of the diabetes model projects compared with usual care on blood sugar control and diabetes-related hospitalizations or use of Contract Health Services (CHS). Because of the nature of diabetes, quantitative evaluation of program impact employs statistical methods that allow for time dependent predictors of health status change. The qualitative data gathered in the key informant and focus group process are used to provide descriptive comparisons of diabetic care across intervention (model projects) and comparison (usual care) sites.


The underlying premise of the IHS diabetes model projects is that preventive care using a team approach to deliver patient education, intensified primary care or early intervention and community screening will help patients with diabetes to develop the knowledge, skills, and behaviors necessary for better blood sugar control. Though it has recently been demonstrated that tight blood sugar control results in fewer complications for Type I diabetics, the same has not as yet been demonstrated to be true for patients with Type II diabetes (DCCT Research Group 1993). Good blood sugar control is presumed to slow the rate of occurrence of diabetic complications and to reduce the frequency of other conditions that may result in the need for hospitalization (DCCT Research Group 1993, Ekoe 1988).

Few researchers have been able to find more than a weak association between the medical care process and patient health outcomes (Romm 1979, Dubois 1987, Hulka 1975).

---

*a Contract Health Services are provided under a special budget for each IHS Service Unit. Health care is purchased in the private sector using CHS funds, if IHS itself cannot provide it locally.
The linkage between patient behaviors and good blood sugar control (Kravitz 1993), and between good blood sugar control and the reduced frequency of diabetic complications (Nathan 1994) are not well established for patients with Type II diabetes (NIDDM). Only a limited array of information exists to confirm patient education and similar intervention strategies may actually be efficacious or effective in blood sugar control and complications prevention (Hanefeld 1991, Litzelman 1993).

This evaluation takes health outcomes and evaluation research a step further than health services research in diabetic care has done to-date. It is designed to examine outcomes over time. Which few, if any, observational studies of diabetes care have attempted to do to-date. The evaluation associates the prevention of these adverse outcomes with the presence of a specific health care delivery approach. The Indian Health Service 'team' approach utilizes mid-level health providers to augment primary care, and coordinate the delivery of diabetes-related specialty services under a set of diabetes care standards. Unlike most of the studies reported in the literature, this evaluation does not examine the effects of a specific intervention strategy (e.g., patient education, weight loss or exercise). Nor does it cast so broadly as to examine the effects of the system of care (e.g., hospital versus public clinic, or HMO vs FFS). It is simply designed to suggest that a certain combination of health care services in addition to primary care can help to reduce the risk of poor outcomes over time for diabetic patients.

1.2 HYPOTHESES

1.2.1 Hypothesis #1

IHS patients with diabetes in the model project sites have lower rates of poor blood glucose control over time compared to diabetics receiving 'usual care'.

Operational Definition – Poor Glucose Control is defined as a random blood sugar or fingerstick of 250 mg/dl or greater, or a fasting blood sugar of 200 mg/dl or greater.

1.2.2 Hypothesis #2

IHS patients with diabetes in the model project sites require hospitalization or Contract Health Services for diabetes-related diagnoses less often and at a slower rate than diabetics receiving 'usual IHS care'.

Operational Definition – A diabetes-related hospitalization or use of Contract Health Service is any in-patient admission (in an IHS or CHS facility) where diabetes (ICD-9 codes 250.00 to 250.91, 648.0) was identified as one of the first four diagnoses at the time of discharge (in the case of CHS out-patient visits this was applicable to one of two diagnoses at discharge/contact). CHS outpatient contacts represented only 4% (11 of 296) of all first occurring 'diabetes-related hospitalizations'.
1.3 CONCEPTUAL FRAMEWORK

The design of this observational study is based on the assumption that Type II non-insulin dependent diabetes (NIDDM) once present is a progressive degenerative disease. The rate at which prognostic factors (blood sugar control) change and adverse events (diabetes-related hospitalizations) occur is hypothesized to be dependent upon a number of inputs that fall into two categories: patient-related factors and diabetic care components.

After measuring and statistically adjusting for baseline differences in patient related factors and certain IHS system-related characteristics between those American Indians receiving diabetic care in a model project and those receiving care at a usual care site, it is assumed for the purpose of evaluating the effectiveness of IHS model projects that any remaining difference in the rates of degenerative prognostic factors and occurrence of adverse events can be attributed to the diabetic care process. It is assumed patient adherence to medical recommendations and scheduled appointments are mediating factors in the causal pathway between the diabetic care provided and the rate of change in prognostic factors, or the time to occurrence of adverse outcomes. Few system related factors are considered in this conceptual framework, since this evaluation does not attempt to make across system comparisons of care. Table 1-1 outlines the conceptualized groupings of inputs and outcomes considered in this evaluation and Figure 1-1 provides a diagrammatic representation of their relationship.

| INPUTS |
|-----------------|-----------------|
| **DIABETES CARE COMPONENTS** | **PATIENT-RELATED FACTORS** |
| Care Process | Gender |
| Education — Diet, Exercise, Self-Care, Medications Management | Tribal Affiliation |
| Blood Sugar Monitoring — HbgA1c monitoring | Age at Diagnosis |
| Health Maintenance — Foot and Eye Exams, Laboratory Services (proteinuria, blood lipids) | Baseline Health Status Indicators — preexisting conditions, blood sugar, blood pressure, diabetic treatment prescribed |
| Community Screening and Interaction | Use of Other or Outside Health Providers |
| System Feature | Distance of residence from index IHS facility |
| Access to an IHS Inpatient Facility. | Insurance Coverage — Private, Medicare, Medicaid, VA |

**Not Measured in Evaluation**

- Income
- Education
- Health Beliefs and Knowledge
Table 1-1. Evaluation Conceptual Framework (Cont.)

<table>
<thead>
<tr>
<th>HEALTH BEHAVIORS</th>
<th>PROGNOSTIC FACTORS</th>
<th>ADVERSE OUTCOMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Adherence to:</td>
<td>Blood Glucose Control</td>
<td>Hospitalizations</td>
</tr>
<tr>
<td>Diet</td>
<td>Blood Pressure Control</td>
<td>Complications</td>
</tr>
<tr>
<td>Exercise</td>
<td>Proteinuria</td>
<td></td>
</tr>
<tr>
<td>Medications</td>
<td>Foot Ulcers</td>
<td></td>
</tr>
<tr>
<td>Self BS monitoring</td>
<td>Infections</td>
<td></td>
</tr>
<tr>
<td>Weight Control</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scheduled Appointments</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**OUTCOMES**

**INPUTS**

- Diabetes Care and System Characteristics
- Patient Related Factors

**OUTPUTS**

- Patient Health Behaviors: Change and Adherence to Medical Recommendations
- Patient Prognostics Factors
- Adverse Outcomes

- Microvascular
  - Retinopathy
  - Neuropathy
  - Nephropathy

- Macrovascular
  - Ischemic Heart Disease
  - Cerebrovascular Disease

**Figure 1-1. Diagram of Concept Framework**
1.4  THE NATURE AND EXTENT OF DIABETES AMONG AMERICAN INDIANS

1.4.1  Prevalence

National estimates of the prevalence of diabetes among American Indians come from two different sources. Valway et al. provided estimates using 1987 Indian Health Service ambulatory care data and population estimates extrapolated from the 1980 Census. The age-adjusted prevalence ranged from 15.3/1000 for the Alaska Area to 119.2/1000 in the Tucson Area. The Aberdeen Area ranked second only to Tucson among IHS Area with an overall age-adjusted prevalence of 105.4/1000. The overall IHS prevalence was reported to be 69.0/1000 compared to the U.S. general population prevalence of 24.0/1000. Better than 1 in 4 IHS patients age 45-64 years in the Aberdeen Area had a diagnosis of diabetes. For the IHS population as whole this ratio was better than 1 in 6 (Valway 1993).

The Survey of American Indians and Alaska Natives (SAIAN) was conducted in 1987 as a special version of the National Medical Expenditure Survey (NMES). The survey was designed to obtain a nationally representative sample of IHS eligible American Indians so that national estimates of health services utilization and costs could be derived. Estimates of diabetes prevalence in this survey are based on patient self-reported data. The following table of estimates is taken from Data Summary 3 of the National Medical Expenditure Survey, Prevalence of Chronic Diseases: A Summary of Data From the Survey of American Indians and Alaska Natives (Johnson 1991):

Table 1-2. Percent of Adults with Self-reported Diabetes in the SAIAN and General U.S. Population*

<table>
<thead>
<tr>
<th>Type of Estimate</th>
<th>SAIAN Population</th>
<th>U.S. Population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>Male</td>
</tr>
<tr>
<td>Age/sex-adjusted</td>
<td>12.2</td>
<td>11.0</td>
</tr>
<tr>
<td>Age Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19-44</td>
<td>3.7</td>
<td>3.2</td>
</tr>
<tr>
<td>45-64</td>
<td>21.5</td>
<td>21.2</td>
</tr>
<tr>
<td>65 or older</td>
<td>27.4</td>
<td>22.2</td>
</tr>
</tbody>
</table>

* Abstracted from Johnson, Taylor 1991

The IHS estimates are somewhat more conservative than the SAIAN estimates. This may be a result of the denominator chosen (1980 Census all ages versus all American Indian and Alaska Native adults 19 years old and above in the sample, respectively). Nonetheless, the conclusions are similar, American Indians and Alaska Natives have on average about
twice the amount of diabetes in their populations as the general U.S. population, and about 1 in 5 adults over 45 have diabetes. However, Valway et al.'s analysis shows that this varies widely by IHS Area (Valway 1993).

Diabetes occurs among American Indian children under 15 years of age at more than twice the rate reported in the general U.S. population (2.3 vs. 0.8 per 1000) (Valway 1993). However, what proportion of American Indian children suffer from the labile insulin dependent form of diabetes has yet to be determined. Evidence from recent studies indicate overweight and obesity are more prevalent among American Indian children of all ages than is observed among U.S. all races (Broussard 1991), and their insulin responses to increasing relative weight would put these children at greater risk of developing the non-insulin dependent form of diabetes than children in the general U.S. population (Pettitt 1993).

An ecological analysis of the geographical distribution of diabetes in Canadian Indians by linguistic and cultural groups illustrated the intermingling of genetic and lifestyle factors affecting the occurrence of diabetes in North American native populations. The Algonkian, Siouan and Iroquoian linguistic groups residing in the southeastern areas of Canada exhibited the highest rates. While the Eskimos residing in the northern reaches of Canada experienced the least amount of diabetes. Eskimos in both the U.S. and Canada are the ethnic groups most likely to still maintain a hunter/gather lifestyle and diet (Young 1990). Similar patterns of prevalence are evident in the regional distribution of diabetes by IHS Areas (Valway 1993).

Within the Aberdeen Area in 1987, Stahn et al. estimated the prevalence of diabetes to be highest among the Winnebago-Omaha at 218.1/1000 followed by the Yankton/Santee Sioux (southeastern South Dakota) at 196.4/1000. The Ft. Totten (Devil’s Lake) Sioux had a prevalence of 111.4/1000 and the Rosebud a prevalence of 81.5/1000. Stahn et al. used the diabetes registries at Winnebago-Omaha, and Ft. Totten to derive the numerator for the prevalence calculation in these communities, and IHS ambulatory care data to obtain the numerators for the remaining service unit populations (Stahn 1993). For the Winnebago-Omaha population this method for calculation could result in an inflated estimate if tribal affiliation of those on diabetic registry was not considered. Forty percent of the individuals on this registry are neither Winnebago nor Omaha. If indeed, the denominator is an estimate of only the Winnebago and Omaha populations in 1980, then the reported prevalence is an overestimate of the actual prevalence in these two tribes.

1.4.2 Complications

Poor glycemic control over the long-term however measured (by repeated sequential random, fasting or two-hour postprandial blood glucose values or by periodic hemoglobin A1c determination) has been repeatedly associated with the occurrence of retinopathy, neuropathy and nephropathy (Ekoe 1988, Pirart 1978, Strowig 1992, Knowler 1980). Also evidence from the Framingham Heart Study indicates that poor glycemic control (Singer 1992), and the occurrence of retinopathy at a young age (52-64 years old) in Type II diabetics (Hiller 1988) are associated with an increased risk of cardiovascular disease. Two studies have reported the incidence of retinopathy among American Indian diabetic populations. In 1980, the Pima Indian study reported the incidence of retinal exudates after
six years of follow-up to be 24%, and the incidence of retinal hemorrhages to be 24% among non-insulin treated diabetics, and 54% and 64%, respectively, for the insulin-treated. The occurrence of retinopathic events increased dramatically five years after the diagnosis of diabetes. Retinopathy occurred three times more often in diabetics who had the disease five or more years compared to those who had been diagnosed with diabetes for less than a year (Knowler 1980). An Oklahoma cohort of American Indians with diabetes that was followed for an average of seven years exhibited an incidence rate of 72% over a mean follow-up period of 12.7 years (Lee 1992). A similar association between the duration of diabetes been reported for other populations (Pirart 1978, Nathan 1986).

Cardiovascular disease mortality was 2.5 times higher among diabetic men in the MRFIT study than among non-diabetic men (Stamler 1993) and the relative risks of stroke morbidity and mortality for men and women in the Rancho Bernardo cohort were 1.8 and 2.2, respectively. A similar risk ratio (RR=2.0) for stroke among men in the Honolulu Heart Study was also reported (Abbott 1987). An analysis of cardiovascular disease mortality by IHS Area could not directly tie cardiovascular disease deaths to the presence of diabetes in the individual. However, American Indians in general have had low rates of cardiovascular disease compared to the U.S. population. The American Indians served by IHS in the Aberdeen Area have higher rates of cardiovascular disease mortality (both due to ischemic heart and cerebrovascular disease) than the national average (Welty 1993). Comparing diabetic and non-diabetic Pima Indians, a recent study of diabetes and mortality computed an age/sex adjusted ischemic heart disease death rate ratio of 43.4 (CI 5.9-317.0). Ischemic heart disease death rates were second only to diabetic nephropathy in this population known for its high prevalence of diabetes (Sievers 1992).

Probably the two most severe complications of diabetes among American Indians are neuropathy resulting in lower extremity amputations (LEA's), and nephropathy resulting in end-stage renal disease (ESRD). IHS examined the incidence of LEA's for the years of 1982-1987 in four IHS Areas (Navajo, Oklahoma, Phoenix, Tucson). Compared to non-diabetics ages 15 to 44, diabetics had 158-fold increased risk of experiencing a LEA during the study period. Though the rate of LEA's among diabetics was higher than non-diabetics in all age intervals, the difference in risk diminished with increasing age. While the risk of experiencing an LEA (due to any cause) in the Navajo and Oklahoma Areas was little different from the risk of those surveyed in the National Hospital Discharge Survey, the Phoenix and Tucson Area relative risks were 2.78 and 3.29 times greater (Valway, Linkins 1993).

Other related IHS sponsored studies estimated prevalences of LEA's among various American Indian tribes and IHS Area diabetics to be less than 1% to as high as 10% (Schraer 1993, Farrell 1993, Rith-Najarian 1993, Wirth 1993, Freeman 1993, Stahn 1993). The reported LEA incidence rate for Sioux tribes in the Aberdeen Area was 86.7/1000. In two of these studies, the authors reported that male diabetics were more likely than female diabetics to have had a LEA(Wirth 1993, Freeman 1993).

End Stage Renal Disease is by far the most costly long-term complication of diabetes. Increasingly, renal dialysis units have become a part of care delivered on the reservation. Independent provider organizations funded with Medicare dollars have built free-standing
units on or near reservation communities with a high volume of demand for these services. Community Health Representatives and other health care providers at the sites in this study mentioned some of the needs associated with end-staged renal disease in their communities. In Rosebud, a dialysis unit is located at the site of the old hospital. Whereas, at Ft. Totten and Winnebago-Omaha, patients must travel off the reservation to receive dialysis. Several individuals in Ft. Totten mentioned the need for developing the capacity to provide dialysis on the reservation so that patients would not have to travel to Grand Forks (100 miles away) or Fargo (168 miles away) to receive dialysis.

NIDDM is the leading cause of ESRD among the Pima Indians accounting for 93% of all cases. The ESRD incidence rate among the Pimas is 23 times that of U.S. population (Nelson 1993). On average, NIDDM can account for more than 50% of all cases of ESRD among the American Indians (Nelson 1993, Muneta 1993). Differences among tribes in the incidence and age at onset of NIDDM are likely to be primarily responsible for the differences in ESRD rates observed across tribes. Nearly all the excess mortality associated with NIDDM in the Pimas is observed in individuals with overt nephropathy. Mildly elevated levels of urine albumin excretion that may be observable soon after NIDDM onset are predictive of the development of overt nephropathy in Pimas Indians with diabetes (Nelson 1993).

1.4.3 Mortality

Using the National Mortality Followback Study, Newman et al. reported that age-adjusted mortality rates for American Indians where diabetes was the underlying cause. American Indians exhibit a rate of 96/100,000 or 4.3 times the rate calculated for whites and twice the rate of other ethnic groups in the U.S. Where diabetes was a contributing cause of death (264/100,000), the American Indian rate was 3.7 times that for whites and 2.4 times that for blacks (Newman 1993).

A survival analysis was conducted on a cohort of Oklahoma Indians at follow-up (10 years post-study entry). Those study participants with a diabetic diagnosis before the age of forty were projected to have a reduced life expectancy of 16.5 years. Those diabetics who were 65 and over at baseline were projected to lose only two years of their life expectancy compared to those in the same age group in the general population (Lee 1993).

Results from a cohort study of Mexican American diabetics in Starr County, Texas shared similarities with the Oklahoma diabetic Indian cohort. One-third of all deaths in this cohort occurred among diabetics younger than sixty-five, and were most often attributed to diseases of the heart. None of the deaths were attributed to diabetes, yet in 25.5% of the cases it was listed as a contributing cause. These researchers found that baseline retinopathy was predictive of subsequent death (Hanis 1993).
Table 1-3. Age-Adjusted Mortality Rates and Rank Among Other IHS Areas for Selected Chronic Disease Related Causes in Aberdeen, All IHS Areas and U.S. All Races (rate per 100,000).*

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Area Rank</th>
<th>Aberdeen</th>
<th>All IHS Areas</th>
<th>U.S. All Races</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Causes</td>
<td>2nd</td>
<td>1,056.3</td>
<td>665.8</td>
<td>535.5</td>
</tr>
<tr>
<td>Diabetes</td>
<td>6th</td>
<td>35.4</td>
<td>29.7</td>
<td>9.8</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>1st</td>
<td>287.8</td>
<td>156.1</td>
<td>169.6</td>
</tr>
<tr>
<td>Cerebrovascular Disease</td>
<td>1st</td>
<td>47.8</td>
<td>30.3</td>
<td>30.3</td>
</tr>
<tr>
<td>Alcoholism</td>
<td>1st</td>
<td>69.9</td>
<td>32.7</td>
<td>6.0</td>
</tr>
</tbody>
</table>


American Indians living in the Aberdeen Area suffer a disproportionate share of deaths due to some chronic conditions. Seen in this way, diabetes mortality appears to be a less severe problem relative to other chronic diseases. And again, diabetes could be a contributing cause to heart disease and cerebrovascular disease related deaths in the Aberdeen Area. Since alcoholism is one of the five leading causes of death in this Area, it should be considered a significant competing cause of death relative to diabetes.

1.4.4 Hospitalizations

In 1990, hospitalizations where diabetes was listed as one of the diagnoses accounted for 2.8 million discharges. Diseases of the circulatory system were listed as the primary diagnosis in 33% of these hospitalizations, and were the most frequently listed primary diagnosis. Diabetes as the primary diagnosis represented 15% of diabetes-related hospitalizations. Age-adjusted hospital discharge rates with diabetes as the primary diagnosis and the lengths of stay associated with these discharges have been decreasing since 1983, and with the advent of Medicare's prospective payment system (Division of Diabetes Translation, CDC 1993).

The Carter Center reported that people with diabetes are 2.3 times as likely to be hospitalized when compared to age-matched non-diabetics (Carter Center 1985). A study of the Mutual of Omaha claims records, reported 2.5 times the number of physician hospital visits for their diabetic compared to their non-diabetic claimants (Rendell 1993). In a matched retrospective cohort study of Navajos in the Tuba City region of the Navajo Area, diabetics had two times the risk of being hospitalized compared to their matched control (non-diabetic) (O'Connor 1990).

Diabetes as a primary diagnosis at discharge represented 2% of all American Indian discharges from IHS and IHS contracted facilities in 1989. Across eleven of the twelve IHS
Areas discharges for a primary diagnosis of diabetes varied from 0.6% in Alaska to a high of 4.5% for the Nashville Area. IHS groups diabetes diagnoses together with other ICD9-CM codes (240-279) labelling them Endocrine, Nutritional and Metabolic Diseases. When compared by this grouping, IHS has a higher discharge rate relative to U.S. short-stay non-federal hospitals for age groups 45 to 64, and 65 and over (Patient Care Statistics Branch, IHS 1991).

Diabetics are often admitted to the hospital under other diagnoses. The Mutual of Omaha claimant study reported higher age and sex adjusted odds ratios (AOR) for physician care delivered to diabetics versus non-diabetics in the following categories: ischemic heart disease (AOR=3.32), peripheral vascular disease (AOR=3.14) and eye disease (AOR=3.10). However, in some categories such as neoplasms the adjusted odds ratio was only slightly above one (Rendell 1993). The Navajo study, mentioned earlier, reported patients with diabetes to be at more than three times the risk of non-diabetics to be hospitalized for an infectious disease (Young 1990). Authors of a New Zealand study concluded that observed frequent admissions for infectious diseases among diabetics could be prevented with better diabetes education coverage of the at-risk population (Scott 1985). The Navajo study found that diabetic patients on insulin exhibited poorer blood glucose control than those not on insulin (O’Connor 1990). In another study of this Navajo population, O’Connor et al. found an association between better blood sugar control and better adherence to clinic appointments (O’Connor 1987). A question that might naturally arise considering the findings of these researchers, is whether or not patient education delivered in the clinic setting could reduce the number of hospitalizations resulting from poor blood sugar control.

### 1.4.5 Concluding Remarks

Relative to other Americans, Indians suffer disproportionately from the effects of diabetes. Not only is diabetes associated with the increased risk of other chronic conditions and mortality, but it places substantial demands on the health care system by increasing the rate of hospitalizations (O’Connor 1990, Division of Diabetes Translation, CDC 1993, Aro 1994, Munoz 1989) and the use of medications (Rendell 1983, Isacson 1987, Glauber 1992).

In the Aberdeen Area of the Indian Health Service, American Indian patients with diabetes are likely to experience a higher rate of other chronic health problems in addition to, or as a partial consequence of their diabetes than might be observed in other Areas of IHS. Targeting specially designed primary care and prevention efforts at diabetes in the high risk IHS Areas, such as Aberdeen, could help relieve some of the burden that diabetes and its associated conditions place on the already constrained capacity of the Indian Health Service to meet the health care needs of its service population.

### 1.5 INTERVENTIONS AND OUTCOMES

Jean Pirart in his 1978 analysis of twenty-five years of follow-up data on a cohort of 4,400 Belgian diabetics concluded that poor blood sugar control was associated with the accelerated onset of retinopathic, neuropathic and nephropathic complications. However, he did not feel he could claim that the opposite was true: that good blood sugar control resulted in fewer and less rapid onset of complications (Pirart 1978). The Diabetes Control and
Complications Trial was designed to answer this question for insulin-dependent diabetics. Intensive versus conventional therapeutic protocols were used. Intensive therapy involved the use of more than three insulin injections per day or the use of an insulin pump to tightly control blood sugar as near to normal levels as possible. The number of injections and dose per injection of insulin was modulated with self blood glucose monitoring, and to account for changes in the patient's eating and exercise patterns. The findings of this study were: "Intensive therapy of patients with IDDM delays the onset and slows the progression of clinically important retinopathy, including vision-threatening lesions, nephropathy and neuropathy, by a range of 35 to more than 70 percent." However, the authors did note the risk of severe hypoglycemia was 3 times higher with intensive therapy (DCCT Research Group 1993). It is as yet unknown whether or not the intensive therapeutic goals set by the DCCT can be endorsed for Type II diabetics with the same degree of confidence. Type II diabetics being treated with oral hypoglycemic agents or insulin face a risk of hypoglycemia, and because of the greater prevalence of coronary and cerebrovascular disease in these patients, the clinical sequelae may be more severe in these patients than among Type I patients (Nathan 1994). The UK Prospective Diabetes Study is a large prospective cohort study of Type II diabetics with similar therapeutic management goals, and endpoints or outcomes as the DCCT. It is scheduled to report out its results within the next year (UK Prospective Diabetes Study Group 1991).

Randomized clinical trials like the DCCT are important for answering questions like the one Jean Pirart raised in the 1970's, does good blood sugar control reduce or lengthen the time to occurrence of complications? Yet they cannot answer questions about how effectively 'tight control' can be achieved in the patients with diabetes living in varying environmental circumstances. If indeed 'tight control' is efficacious for Type II diabetics, is it practically possible for low income residents of rural Indian communities? Though DCCT study participants on the intensive therapeutic regimen did not evaluate their quality of life to be lower than those on the conventional therapy, necessarily all these participants had to be highly motivated individuals. This level of patient motivation is not easy to achieve outside a clinical trial environment.

A number of experimental and observational studies have been reported in the literature that examine the efficacy and effectiveness of different aspects of diabetic patient management. Table 1-4 outlines major experimental studies, and Table 1-5 outlines some of the relevant observational studies that have examined the effects of specific interventions on clinical and behavioral outcomes in diabetic individuals.

The majority of studies whether experimental or observational in design have focused on blood sugar control, assuming better blood sugar control translates into reduced risk of complications and other adverse outcomes such as hospitalizations and death. In those studies that examined the effects of patient education, the results have varied. Some researchers found improvements in blood sugar control (Hanefeld 1991, Litzelman 1993, Neresian 1982, O'Connor 1992), and others observed no real improvements in the outcomes measured (Mazzuca 1986, Rettig 1986, Bloomgarden 1987).

Others have sought to assess the impact of the process of medical care from different vantage points. Some have looked at the system or site of care (Hayes 1984, Singh 1984,
DiMatteo 1993, Boucher 1987). Some have endeavored to quantify the important elements in the diabetic care process (Romm 1979, Hulka 1975, DiMatteo 1993). The system or site of care (Hayes 1984, Singh 1984), and provider characteristics (Hulka 1975, DiMatteo) may have important influences on patient outcomes. How the system of care and provider characteristics actually affect patient outcomes is only now becoming better understood through studies like the Medical Outcomes Study and the Patient Outcome Research Team (Greenfield 1994).

The equivocal support for patient education’s effect on blood sugar control, may be a function of patient characteristics associated with adherence to medical recommendation (Sherbourne 1992). Kravitz, et al. reported that the only strong correlations between adherence and physiological outcomes in the Medical Outcomes Study were between self-reported adherence to specific medical recommendations and glycemic control among insulin-dependent diabetics, and general adherence and body mass index (Kravitz 1993). Other investigators have not been able to effectively link patient adherence characteristics with physiological outcomes (Hulka 1975, DiMatteo 1993).

What is deemed by the medical profession as good clinical practice may not be the most critical element in the process of care. Results from the Medical Outcomes Study have linked the patient-provider relationship and communication, and other characteristics of providers to patient adherence (DiMatteo 1993). Romm and Hulka were not able to show any impact of improved diabetic medical care practice on blood sugar control (Romm 1979). Hulka et al. (1975) were unable to link better patient-physician communication with diabetic control, frequency of hospitalizations, or adherence to a medication regimen.

The characteristics of the health delivery system, the provider of diabetic care and the diabetic patients themselves are likely to affect glycemic control and the subsequent complications. In the MOS, poor adherence to medical recommendations at baseline was the strongest predictors of poor adherence two years later. Sherbourne et al. (1992) conclude that early intervention should be the goal of the medical management of chronic disease in order to assure better patient adherence, and ultimately, better patient outcomes.

The Indian Health Services diabetes projects were designed to provide an alternate provider relationship with diabetic patients and their families, and to intervene early in the course of the disease. They combine the services of medical specialists with a team of mid-level health professionals trained in diabetes management. The impact of this form of diabetes management has yet to be evaluated.
<table>
<thead>
<tr>
<th>Authors</th>
<th>N</th>
<th>Intervention</th>
<th>Outcomes</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knatterud (1978)</td>
<td>619</td>
<td>Insulin, oral agents or diet alone</td>
<td>Blood Sugar, Fatal Events</td>
<td>Better BS control w/ flexible insulin. No difference in fatal events.</td>
</tr>
<tr>
<td>Hayes (1984)</td>
<td>200</td>
<td>Hospital vs. General Practice Care</td>
<td>Death, Hospital Admissions, HgA1c</td>
<td>More deaths, admissions and poorer BS control in GP care.</td>
</tr>
<tr>
<td>Mazzuca (1986)</td>
<td>532</td>
<td>Patient Education</td>
<td>Knowledge, Blood Sugar Control</td>
<td>No difference in knowledge level, but greater reductions in FBS and HgA1c levels.</td>
</tr>
<tr>
<td>Rettig (1986)</td>
<td>393</td>
<td>Home Visiting Nurse – Individual Patient Education</td>
<td>Knowledge, Skills, Hospital Admissions, ER contacts, sick days, foot problems</td>
<td>Greater knowledge and skills, no difference in other outcomes.</td>
</tr>
<tr>
<td>Bloomgarden (1987)</td>
<td>345</td>
<td>Patient Education</td>
<td>Knowledge, BS Control, Foot Problems, BP Control, Sick Days, Hospital Admissions, ER visits</td>
<td>No significant differences between intervention and control groups observed.</td>
</tr>
<tr>
<td>Smith (1987)</td>
<td>840</td>
<td>Intensive Appointment Followup</td>
<td>Risk of Hospital Admission</td>
<td>No improvement in risk observed.</td>
</tr>
<tr>
<td>Hanefield (1991)</td>
<td>1139</td>
<td>Intensive Health Education and clofibric acid Tx</td>
<td>Lifestyle Behaviors, Blood Lipids, BS Control, Mortality</td>
<td>Some lifestyle behaviors changed, improved BS control, lower mortality w/ education and drug Tx. No improvement in blood lipids</td>
</tr>
</tbody>
</table>
Table 1-5. Some Observational Studies of Diabetic Care and Outcomes

<table>
<thead>
<tr>
<th>Authors</th>
<th>N</th>
<th>Intervention</th>
<th>Outcomes</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Romm (1975)</td>
<td>164</td>
<td>Improving medical care process</td>
<td>Blood Sugar Control</td>
<td>No impact of process on BS control</td>
</tr>
<tr>
<td>Pirart (1978)</td>
<td>4400</td>
<td>Flexible medication use and close DM monitoring</td>
<td>Blood Sugar Control, Complications</td>
<td>Improved blood sugar control, no clear effect on complications.</td>
</tr>
<tr>
<td>Hulka (1979)</td>
<td>242</td>
<td>Patient-Physician communication</td>
<td>Blood Sugar Control, Patient Satisfaction, Meds Adherence, Hospital Admissions, Self-care Behaviors</td>
<td>Better communication score associated with self-care behavior, but none of the other outcomes.</td>
</tr>
<tr>
<td>Nersesian (1982)</td>
<td>533</td>
<td>Outpatient Diabetic Education</td>
<td>Hospital Admissions</td>
<td>33% fewer admissions pre- and post- intervention</td>
</tr>
<tr>
<td>Davidson (1984)</td>
<td>1467</td>
<td>Diet Alone, Oral Agents, Insulin</td>
<td>Standardized Mortality</td>
<td>Mortality was lowest for those on diet alone, and higher on insulin</td>
</tr>
<tr>
<td>Singh (1984)</td>
<td>221</td>
<td>Hospital vs care in mini clinic</td>
<td>BS Control</td>
<td>No differences in BS control between site of care</td>
</tr>
<tr>
<td>Broucher (1987)</td>
<td>242</td>
<td>Computerized tracking and monitoring of diabetic care</td>
<td>BS Control (HgA1c)</td>
<td>Improved glycemic control all DM patients tracked using the system</td>
</tr>
<tr>
<td>O'Connor (1992)</td>
<td>169</td>
<td>Patient Education</td>
<td>BS Control (HgA1c)</td>
<td>Recently diagnosed and those w/higher baseline BS had greatest improvement.</td>
</tr>
<tr>
<td>DiMatteo (1993)</td>
<td>1198</td>
<td>System of Care and Type of Provider</td>
<td>Patient Adherence to Medical Treatment</td>
<td>Adherence better with endocrinologist and provider’s global job satisfaction.</td>
</tr>
</tbody>
</table>
1.5.1 Comorbidities

Kaplan and Feinstein as long ago as 1973, advocated the importance of comorbid conditions in evaluating diabetic patient outcomes. In their review of 149 studies published on the occurrence of vascular complications among diabetic patients, they pointed out that a vast majority of these studies failed to satisfactorily distinguish between what was a new complication and what was a pre-existing condition (Kaplan 1973). Increasingly, comorbidity indices have been used to control for or correct for patient differences in health status at baseline in observational studies of adverse outcomes such as hospitalizations and mortality (Kaplan 1973, Kahn 1988, Greenfield 1987, Kravitz 1992, Iezzoni 1992). The comorbidity index development by Kaplan and Feinstein was the only one reviewed for this study to be specifically designed for use with diabetic outcomes studies, and to include alcohol associated comorbidities which were likely to be prevalent in this study population (Kaplan 1974). Thus, the Kaplan and Feinstein comorbidity index was used in the design and analysis of this evaluation of diabetic patient outcomes.

The Kaplan and Feinstein comorbidity index incorporated what they termed as 'cogent' comorbidities from twelve different system areas. These areas could be grouped for analysis into vascular and non-vascular comorbidities or left as an overall index of comorbidity. The authors structured the index into three severity categories with a zero category reserved for those with no known comorbidities. This index was validated by the authors using death among diabetic patients as the dependent variable (Charlson 1987). Also, some years later Charlson et al. used the Kaplan and Feinstein index to validate their comorbidity index as a predictor of mortality among patients with chronic disease (Kaplan 1974).
CHAPTER II
METHODS

2.1 DATA COLLECTION METHODS

All data collection was performed by the investigator, a nutritionist, and another nutritionist with clinical, research, and Indian Health Service experience.

2.1.1 Methods for Medical Record Abstraction

2.1.1.1 Design of the Medical Record Abstract Form

The medical record abstract form was initially designed to be a computerized data collection tool. Epiinfo was used to develop the database and program error checking. Six database files were linked to an ID number that represented the medical record of each patient determined to meet the inclusion criteria. An abstraction guide and code books were developed for use during the abstraction process (see Appendix A. for Abstraction Guide). The database was developed in advance of field testing keeping in mind how the IHS medical record was organized, the time constraints that would be placed on the abstractors, and the minimum amount of information that needed to be collected.

ICD-9 codes were used to organize the abstraction of inpatient discharge diagnoses and procedures. The 1974 article by Kaplan and Feinstein was used to construct the comorbidity questions and data fields for the abstract (see Table 2. Classification of Severity of Cogent Comorbidity in Kaplan and Feinstein). Data fields related to diabetic medications and medications that contribute to hyperglycemia were identified and organized using the Nursing94 Drug Handbook (Springhouse Corporation 1994).

Once in the field, the medical record abstract form was modified in several ways. Questions concerning the patient’s family history of diabetes were dropped because they may only have an indirect association with the outcome and required a considerable amount of searching in some records to find the answer. Three data fields were added to capture the use of outside providers for diabetic care. The abstract was transferred from computerized entry to a seven page paper abstraction form to speed up the collection process. IHS clinic codes were used in place of the original code list to simplify the recording of IHS diabetes-related outpatient contacts. A 20% random sample (stratified by year of diagnosis) of medical records were abstracted with details of each diabetes-related outpatient contact. Details of diabetic outpatient contacts were related to the types of providers seen, whether or not patient education was provided and what types were offered, whether or not screening for complications was
performed, and what type of screening was done, and so on (See Appendix A. Medical Record Abstract Form and Guide). For those medical records that were in the 20% random sample, all diabetes-related outpatient contacts were directly entered into the computerized database, and concurrently recorded on the paper form.

Each medical record abstractor had a copy of the updated Medical Record Abstract Form and Guide as well as the codebook for medications and diagnoses to refer to. The ICD-9-CM International Classification of Diseases 9th Revision, 4th Edition Clinical Modification Volumes 1,2 & 3, 1992 (Practice Management Information Corporation 1992) and Nursing94 Drug Handbook (Springhouse 1994) were also used as references during abstraction.

2.1.1.2 Cohort Selection

The diabetes registries kept at the Diabetes Project sites (Winnebago and Ft. Totten) were used to identify patient records that met the cohort criteria of having been diagnosed between January 1, 1983 and December 31, 1992. Patients with diabetes insipidus or who were non-Indian were to be excluded from the cohorts. At the time of abstraction the date of diabetic diagnosis reported in the diabetes registry was verified in the medical record.

A diabetes registry was not kept by the Rosebud Service Unit. Therefore, one had to be constructed. Three computer generated lists with the medical record numbers of patients seen for a diabetes-related reason in an outpatient clinic during the study period (January 1, 1983 to December 31, 1993) or with a diabetic diagnosis upon inpatient admission during that time period were combined to create a list of record numbers where the date of diabetic diagnosis had to be verified by screening each medical record on the list (934 records). This list was narrowed down to a list of 679 patients with recorded indications of a positive diabetes screening test or diagnosis. Those patient records where the apparent date of diabetic diagnosis that fell within the time period for inclusion in the study cohort were slated for abstraction (375). At the time of abstraction, the date of diagnosis was verified before abstraction started. This resulted in 324 medical records being identified to be eligible for inclusion into the study cohort. Reasons for exclusion during abstraction were as follows:

Twenty-seven patients were found to have been diagnosed either earlier or later than the inclusion criteria period.

- One was found to be non-Indian
- One had diabetes insipidus
- One patient record could not be located for abstraction
- Two had impaired glucose tolerance secondary to medications and no other indications of diabetes
- Three had impaired glucose tolerance secondary to concurrent cardiac problems or pneumonia and no other indications of diabetes
- One died of acute pancreatitis the day after diagnosis
One patient was mistakenly included on the list, and had no indication in the medical record he was ever screened for diabetes.

Sixteen patients were screened for diabetes at one time or another, but never were diagnosed with diabetes.

Determination of cohort eligibility for the Rosebud cohort presented some problems because providers at this facility frequently did not make use of the American Diabetes Association criteria for diagnosing Type II diabetes mellitus (American Diabetes Association 1984). No distinction was made between patients with impaired glucose intolerance and those with diet-controlled Type II diabetes. Diagnostic testing was insufficient in many cases for the clinician to be able to make this distinction. In some cases, concurrent infections or illness were not considered before a diagnosis was made. Consequently, differential misclassification of age at diagnosis is a possible threat to internal validity in this study, which has been controlled for using baseline measures of blood sugar and diabetic medication prescription.

Because time was a factor in the data collection process, and the cohort at Rosebud was smaller than expected, the researcher decided to abstract a stratified random sample of the medica records of diabetics who were on the Ft. Totten registry, and eligible to be included in the cohort. Rather than take all cohort eligible medical records at Fort Totten, a 50% sample of these records was taken from each strata of diagnosis year (1983 to 1992 or 10 strata). Seventy-five out of 144 medical records of patients who were on the 'active' diabetes registry and who were cohort eligible were abstracted. An additional fourteen patients who were deemed by the Diabetes Program to be 'inactive' and not receiving services through their program were not included in the random sampling process because the researchers were not told about these patients until after the sample had been selected and abstraction had begun.

Available variables obtained from Contract Health Services use records at the national IHS data center have been used to compare those diabetics included and excluded in the abstraction process at Ft. Totten on some important key variables. See the Descriptive Statistics, the Fort Totten Sample for the results and discussion of statistical comparisons.

2.1.2 Methods for Focus Groups

The intent of holding focus groups for this evaluation was to obtain information from patients about problems they had with adherence to medical recommendations for the management of their diabetes, and to determine qualitatively how patients viewed the diabetic health care services they received at the respective sites. Problems with adherence were hypothesized to influence blood sugar control, and the patient's views of what were valuable services, barriers to appointment attendance, and the use of other providers could influence utilization of IHS diabetic health care services at the different sites.

Two patient focus groups were planned for Winnebago. These focus groups sessions were advertised at local stores and government buildings and at the annual Winnebago Pow-
Wow. Only enough participants for one patient focus group arrived on the appointed day. This focus group consisted of members of one family and a friend. After conducting this focus group, we recognized that for the time we had available, we might get a broader range of patient input by holding focus groups with Community Health Representatives (CHR) at each of the three sites. CHRs are local paraprofessional tribal employees funded by the Indian Health Service. CHRs have varying levels of health training and skills, and as will become apparent in the analysis, they perform a variety of health services in the home and community. They are all American Indian and usually are from the communities they serve. CHR programs can be found on most reservations served by IHS.

We provided CHRs at each site with a log booklet that outlined the intent of the evaluation, and the purpose of the focus groups. Eight questions were listed for CHRs to ask or discuss with patients in the course of their regular routine over a period of two weeks to a month. They were to note down patient responses to those questions and their own thoughts or interpretation of those responses. The log booklets were not collected, but we asked the CHRs to bring them in and refer to them as we discussed each topic.

The four focus groups (one at Ft. Totten, one at Winnebago and two at Rosebud) were held over a three day period after most of the data from medical records had been abstracted at all the sites. Two focus groups were held at Rosebud because of the size of their client population and CHR staff (twelve regions of the reservation were represented in the two groups). The focus group sessions were one and a half to two hours in length covering seven questions (eight at Rosebud) and discussion afterwards. The seven topics covered in the focus groups are listed in Appendix B. along with the topics covered in the informant interviews. Prior to starting each of the focus group sessions, informed consent was obtained from each focus group participant.

As each question was discussed, the moderator noted down key points on poster paper for the purpose of summarization at the end of the process. These poster paper notes formed the framework of the analysis. All sessions were tape recorded and later transcribed. The tapes, transcriptions and recorder's notes were used along with the poster notes to complete the summary of findings.

2.1.2.1 Description of Focus Group Participants

Ft. Totten: one male, five females, ages ranged from mid-twenties to late forties.

Winnebago: one male, two females, ages ranged from mid-twenties to late forties.

Rosebud #1: two males, four females, ages ranged from thirties to late forties.

Rosebud #2: three males, four females, ages ranged from late thirties to late fifties.
Only two individuals (one at Ft. Totten and one at Rosebud) were identified by themselves or others as having diabetes. The Ft. Totten group was more positive about the DM Project in their community compared to the Winnebago group. The one male in the group at Ft. Totten tended to dominate the discussion, while the three group participants at Winnebago shared the discussion more evenly among themselves.

The first group of CHRs at Rosebud was less critical of IHS diabetic services when compared with the second group. Though both groups raised a lot of the same issues and concerns about diabetic care, the second group offered the most criticism of IHS, and provided some of the more insightful recommendations for improvements. Two women and one man provided most of the input in the first Rosebud group. Three women and three men offered the most input in the second Rosebud group.

2.1.3 Methods for Informant Interviews

The use of informants in this evaluation did not follow the ethnographic research tradition of 'key informant' interviews. But instead were one time interviews of IHS and tribal staff to obtain a snapshot of their perspectives on IHS's delivery of diabetic health care services in the community. Therefore, all reference to those who were interviewed will be as 'informants', 'IHS staff' or 'tribal staff'. Informants were selected at each site based on recommendations from Service Unit Directors or from the Diabetes Project Coordinator in the Service Unit. The selection of informants within IHS itself was done to obtain varying perspectives (administrative, clinical providers and ancillary providers) from a limited panel of interviewees. The tribal program informants were chosen on the basis of their familiarity and/or interaction with IHS diabetic care providers and/or with diabetic members of the community.

The goals of the informant interviews were to obtain descriptive information about the content and perceived quality of diabetic care services for each site from the perspectives of IHS and tribal program staff.

Prior to the interview all informants read and provided informed consent (see Appendix F for form). A set of six questions were asked of IHS informants, and a set of seven questions were asked of tribal program informants. Several similar questions were asked of informants (IHS and tribal) and in the focus groups for the purpose of comparison (see Appendix B. for Question Topics by Different Group Types). Table 1. provides some of the demographic characteristics of informants.
### Table 2-1. Some Demographic Characteristics of Informants

<table>
<thead>
<tr>
<th>Demographics</th>
<th>IHS Informants</th>
<th>Tribal Informants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Interviewed</strong></td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td><strong>Number</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Men</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Number</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Non-Indians</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td><strong>AGE RANGES:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-39</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>40-59</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td><strong>Number w/diabetes or diabetic family member</strong></td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td><strong>ROLE TYPE:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administrative</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Clinical</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Ancillary</td>
<td>4</td>
<td>1</td>
</tr>
</tbody>
</table>

#### 2.2 METHODS OF DATA ORGANIZATION AND VARIABLE CONSTRUCTION

##### 2.2.1 National IHS Utilization Data Sources

In addition to quantitative data obtained from medical record abstraction several other sources were used to augment missing or incomplete information on patients included in the cohort. This data came from the national IHS health services utilization databases for patient registration, IHS facility admissions, Contract Health Services inpatient and outpatient contacts, and the ambulatory patient care (APC) or patient care contact (PCC) system as it is now called. The IHS inpatient and CHS contact data was merged with data collected from medical records by patient identifiers and date of admission or initial contact. This process added 132 new data points to the hospitalizations and CHS contacts file.

A similar procedure was used to merge the medical record abstract file containing diabetic outpatient visits and the ambulatory patient care files from the national database. Considerable mismatch by date occurred. This was probably due to differences in the way outpatient visits were recorded in abstraction, and how they are entered by data entry personnel.
at the service unit level. In the construction of patient contact variables, either the medical abstract data was used or the ambulatory patient care data was used to generate counts of different types of patient care contacts.

Patient registration data was used to augment incomplete information on patient health insurance coverage. During medical record abstraction at the Rosebud Service Unit, up-to-date information on patient insurance coverage was particularly difficult to locate because the computer generated patient registration summary sheets were not available with the medical record as they were in the project sites.

2.2.2 Organization of Analysis Files

An analysis file has been created; with baseline and fixed variable data; counts of intervals at different levels of blood sugar control and variables for time to first occurrence of a diabetes-related hospitalization/CHS event. Outpatient data has been collapsed into cumulative counts of specific types of diabetes-related care (e.g. visits where patient was seen by a dietitian) by patient over the time they were followed, and for the same types of care occurring in the first year of followup.

Followup time was defined differently for each model and thus each diabetes care variable of interest. Followup time for the blood sugar model was defined as the difference between the date of diagnosis and the date of the last blood sugar test recorded. Followup time for the hospitalization model was defined as the difference between the date of diagnosis and the time to first occurrence of a 'hospitalization' event or exit from study followup. Separate visit rates were calculated based upon followup times, and categorical variables of different types of outpatient visit rates were constructed for use in each model. Highly skewed distributions of visit rates were not amenable to reasonable forms of transformation.

The following three tables provide descriptions of demographic, patient medical attributes, and diabetic care variables in the first year of followup, and cumulatively over the time they were followed until the first hospitalization or exit from the study, and the time they were followed for blood sugar control.

2.2.3 Description of Outcome Variables

Outcome variable descriptions are summarized on the second page of Table 2. Patient Medical Attributes.
2.2.3.1 Categorical and Dichotomous Blood Sugar Score

Each fasting, random, two-post prandial and fingerstick blood sugar test recorded was placed into one of four categories based on criteria set out by the International Diabetes Center for Staged Diabetes Management (Mazze 1994). Hemoglobin A1c determinations were not used because they were usually taken at the same time as at least one other blood sugar reading, and because there is considerable variation in laboratory standards for this test within the Aberdeen Area (personal communication Dr. Dorothy Gohdes). Followup time began on the date of the first blood sugar test occurring after the first six months with a diabetic diagnosis and ended with the last test performed. A mean of the categorical score for each person observed during each six month interval was taken. These means were then regrouped into the four categories using the following criteria: a mean score of less than two was regrouped into category one, a mean score of two and less than three was regrouped into group two and so on to category four.

Using these same scores a Dichotomous variable has been constructed for poor control. POORCONT includes categories three and four of the categorical blood sugar score or the levels of blood sugar control where oral agents or insulin should be taken in order to achieve good blood sugar control. Then a count of six month intervals of poor control was taken for each individual observed in followup. A poisson rate model will be estimated for:

\[
\frac{\text{No. of 6 month intervals in Poor Control}}{\text{No. of 6 month intervals Patient's Blood Sugar Was Observed}}
\]

It was decided to use means of blood sugar scores over a six month period because the frequency of clinical blood sugar monitoring of patients could be influenced by the patient being in poor control. The providers would check the blood sugar in these cases more often over a short period of time until they were able to adjust the medications enough to bring these high blood sugars down.

Sixty out of the 634 patients in the cohort (9.5%) had no blood sugars taken after the first six months of diagnosis.

2.2.3.2 Occurrence of a First Diabetes-Related Hospitalization

Of 1,463 hospitalizations or uses of Contract Health Services (both Inpatient and Outpatient), 857 (58.6%) were diabetes-related. Diabetes-related was defined as any hospitalization or CHS use where diabetes was listed at one of the first four ICD9 coded conditions at discharge (250.0 to 250.9, 648.0). Of the 857 diabetes-related discharges, 364 (42.5%) had diabetes listed as the primary diagnosis. In the case of CHS outpatient, it had to be listed as the first or second reason for the contact, because the first two were usually all that were listed. Out of the 634 patients in the study population 296 (46.7%) of them had at least one diabetes-related IHS inpatient or CHS contact during the followup period.
# Table 2-2. Baseline Demographic Variables

<table>
<thead>
<tr>
<th>DESCRIPTION</th>
<th>N</th>
<th>MEAN (PERCENT)</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>PROJECT</td>
<td>634</td>
<td>50.5%</td>
<td></td>
</tr>
<tr>
<td>SITE</td>
<td>634</td>
<td>38.6%</td>
<td>11.8%</td>
</tr>
<tr>
<td>WINNEBAGO</td>
<td></td>
<td>11.8%</td>
<td></td>
</tr>
<tr>
<td>FORT TOTTEN</td>
<td></td>
<td>49.5%</td>
<td></td>
</tr>
<tr>
<td>ROSEBUD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MALE</td>
<td>634</td>
<td>40.1%</td>
<td></td>
</tr>
<tr>
<td>FIRST5</td>
<td>634</td>
<td>44.6%</td>
<td></td>
</tr>
<tr>
<td>YYDX</td>
<td>634</td>
<td>6.5%</td>
<td>9.1%</td>
</tr>
<tr>
<td>YYDX1 (1983)</td>
<td></td>
<td>6.5%</td>
<td></td>
</tr>
<tr>
<td>YYDX2 (1984)</td>
<td></td>
<td>6.3%</td>
<td></td>
</tr>
<tr>
<td>YYDX3 (1985)</td>
<td></td>
<td>9.1%</td>
<td></td>
</tr>
<tr>
<td>YYDX4 (1986)</td>
<td></td>
<td>10.1%</td>
<td></td>
</tr>
<tr>
<td>YYDX5 (1987)</td>
<td></td>
<td>12.6%</td>
<td></td>
</tr>
<tr>
<td>YYDX6 (1988)</td>
<td></td>
<td>8.4%</td>
<td></td>
</tr>
<tr>
<td>YYDX7 (1989)</td>
<td></td>
<td>10.1%</td>
<td></td>
</tr>
<tr>
<td>YYDX8 (1990)</td>
<td></td>
<td>12.5%</td>
<td></td>
</tr>
<tr>
<td>YYDX9 (1991)</td>
<td></td>
<td>13.4%</td>
<td></td>
</tr>
<tr>
<td>YYDX10 (1992)</td>
<td></td>
<td>11.0%</td>
<td></td>
</tr>
<tr>
<td>TRIBE</td>
<td>634</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OMAHA</td>
<td></td>
<td>7.7%</td>
<td></td>
</tr>
<tr>
<td>WINNEBAGO</td>
<td></td>
<td>15.3%</td>
<td></td>
</tr>
<tr>
<td>SIOUX</td>
<td></td>
<td>69.4%</td>
<td></td>
</tr>
<tr>
<td>OTINDIAN</td>
<td></td>
<td>7.6%</td>
<td></td>
</tr>
<tr>
<td>DISTANCE</td>
<td>634</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DISTANC1 -- Less Than 5 Miles</td>
<td>27.4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DISTANC2 -- Five up to 15 Miles</td>
<td>29.5%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DISTANC3 -- Fifteen up to 30 Miles</td>
<td>20.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DISTANC4 -- Thirty or more Miles</td>
<td>22.2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DESCRIPTION</td>
<td>N</td>
<td>MEAN (PERCENT)</td>
<td>S.D.</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>------</td>
<td>----------------</td>
<td>------</td>
</tr>
<tr>
<td>DMDXS Dichotomous, Diagnosed with Diabetes at the Study Site</td>
<td>616</td>
<td>71.8%</td>
<td></td>
</tr>
<tr>
<td>DMOTPROV Dichotomous, Received Any Diabetic Care from Outside Providers during Followup Period</td>
<td>571</td>
<td>55.3%</td>
<td></td>
</tr>
<tr>
<td>DEAD Dichotomous, Died during Followup</td>
<td>624</td>
<td>2.9%</td>
<td></td>
</tr>
<tr>
<td>INSURE Categorical, 3 groups of Any Insurance Coverage During Followup</td>
<td>634</td>
<td>NOINSUR -- no known outside coverage 61.2% PRVMEDCR -- private or Medicare 19.4% MEDAIDVA -- Medicaid or Veteran 19.4%</td>
<td></td>
</tr>
<tr>
<td>CHS Dichotomous, Eligible for Contract Health Services or Not</td>
<td>634</td>
<td>80.3%</td>
<td></td>
</tr>
<tr>
<td>EXITTIME Continuous, Months in Study Followup</td>
<td>634</td>
<td>61.5 (34.8)</td>
<td></td>
</tr>
<tr>
<td>AUTHOR Dichotomous, Abstraction of Individual's Medical Record done by Author of the Evaluation</td>
<td>634</td>
<td>53.8%</td>
<td></td>
</tr>
</tbody>
</table>
Table 2-3. Patient Medical Attributes

<table>
<thead>
<tr>
<th>DESCRIPTION</th>
<th>N</th>
<th>MEAN (PERCENT)</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGEDX Continuous, Age at the Time of Diabetic Diagnosis (Years)</td>
<td>634</td>
<td>46.3</td>
<td>(13.3)</td>
</tr>
<tr>
<td>BST_DX Categorical, Range 1-4 for Mean Level of Blood Sugar at Diagnosis or Within Six Months of Diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BST_DX1 FBS &lt;150, or RBS &lt;200</td>
<td>522</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BST_DX2 FBS 150-200, or RBS 200-250</td>
<td></td>
<td>20.3%</td>
<td></td>
</tr>
<tr>
<td>BST_DX3 FBS 200-250, or RBS 250-350</td>
<td></td>
<td>22.8%</td>
<td></td>
</tr>
<tr>
<td>BST_DX4 FBS 250+, or RBS 350+</td>
<td></td>
<td>26.4%</td>
<td></td>
</tr>
<tr>
<td>SQBMIDX Square Root of Body Mass Index at Baseline sqrt(kg/m²)</td>
<td>613</td>
<td>5.7</td>
<td>(0.6)</td>
</tr>
<tr>
<td>BPDX Dichotomous, 2 or More BP Readings greater than (140/90)</td>
<td>611</td>
<td>1.1%</td>
<td></td>
</tr>
<tr>
<td>DMMED_DX Categorical, 3 groups for Whether or not Patient was Prescribed Specific Diabetic Meds Within 6 Months of Diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NOMEDS -- No Medications Prescribed</td>
<td>560</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OA_DX -- Oral Agents Prescribed</td>
<td></td>
<td>75.9%</td>
<td></td>
</tr>
<tr>
<td>INSUL_DX -- Insulin or Combination</td>
<td></td>
<td>10.2%</td>
<td></td>
</tr>
<tr>
<td>COMORBDX Index Incorporates Medical Conditions in 12 Physiological Systems into a Severity Scale with 4 Levels at the Time of Diabetic Diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>COMORBDX0 - No co-existing conditions</td>
<td>610</td>
<td>42.0%</td>
<td></td>
</tr>
<tr>
<td>COMORBDX1 - Conditions at Level 1</td>
<td></td>
<td>45.2%</td>
<td></td>
</tr>
<tr>
<td>COMORBDX2 -Conditions at Level 2</td>
<td></td>
<td>7.7%</td>
<td></td>
</tr>
<tr>
<td>COMORBDX3 -Conditions at Level 3</td>
<td></td>
<td>5.1%</td>
<td></td>
</tr>
<tr>
<td>OUTCOME VARIABLES</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMDC1ST Dichotomous, First Diabetes-Related Hospitalization or Contract Health Service Use</td>
<td>634</td>
<td>46.7%</td>
<td></td>
</tr>
<tr>
<td>TFAIL1ST -Continuous, Time in Months From Diagnosis to Hospitalization or End of Followup</td>
<td>634</td>
<td>39.2</td>
<td>(34.0)</td>
</tr>
</tbody>
</table>
## Table 2-4. Diabetes Care Variables in First Year and Cumulative

<table>
<thead>
<tr>
<th>DESCRIPTION</th>
<th>N</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DIABETES CARE IN FIRST YEAR</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DIETYR1----</td>
<td>634</td>
<td>29.8</td>
</tr>
<tr>
<td>DMEDYR1----</td>
<td>634</td>
<td>20.5</td>
</tr>
<tr>
<td>EXERYR1----</td>
<td>634</td>
<td>2.8</td>
</tr>
<tr>
<td>MONTR1Y1--</td>
<td>634</td>
<td>58.2</td>
</tr>
<tr>
<td>HGAICY1--</td>
<td>634</td>
<td>11.8</td>
</tr>
<tr>
<td>PEYR1--</td>
<td>634</td>
<td>73.2</td>
</tr>
<tr>
<td>FOOTEXY1--</td>
<td>634</td>
<td>3.0</td>
</tr>
<tr>
<td>EYEYR1--</td>
<td>634</td>
<td>8.2</td>
</tr>
<tr>
<td><strong>DIABETES CARE OVER Followup for Hospitalization Model</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DIETITIAN GROUPS -- 3 groups:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RDVSTH1 ----</td>
<td></td>
<td>52.7</td>
</tr>
<tr>
<td>RDVSTH2 ----</td>
<td></td>
<td>31.4</td>
</tr>
<tr>
<td>RDVSTH3 ----</td>
<td></td>
<td>15.9</td>
</tr>
<tr>
<td>DESCRIPTION</td>
<td>N</td>
<td>PERCENT</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td>----</td>
<td>---------</td>
</tr>
<tr>
<td>NURSE EDUCATOR GROUPS -- 3 groups:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RNVSTH1 -- Not Seen by a Nurse Educator</td>
<td>634</td>
<td>63.4</td>
</tr>
<tr>
<td>RNVSTH2 -- Seen Less Than Once/Year</td>
<td></td>
<td>22.1</td>
</tr>
<tr>
<td>RNVSTH3 -- Seen Once or More/Year</td>
<td></td>
<td>14.5</td>
</tr>
<tr>
<td>ANY PODIATRY VISITS (FOOTCARH)</td>
<td>634</td>
<td>22.4</td>
</tr>
<tr>
<td>ANY PODIATRY VISITS (FOOTCARH)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EYE CARE GROUPS -- 3 groups:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EYECAREH1 - Not Seen by an Optometrist or</td>
<td>634</td>
<td>55.8</td>
</tr>
<tr>
<td>Ophthalmologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EYECAREH2 - Seen Less Than Once Every Two Years</td>
<td></td>
<td>22.6</td>
</tr>
<tr>
<td>EYECAREH3 - Seen More Than Once Every Two Years</td>
<td></td>
<td>21.6</td>
</tr>
<tr>
<td>PHYSICIAN CONTACT GROUPS -- 3 groups:</td>
<td>634</td>
<td></td>
</tr>
<tr>
<td>MDVSTH1 -- Not Seen by M.D., or Contract M.D.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>in DM Clinic, or in Family Practice or Internal Medicine Clinic.</td>
<td></td>
<td>45.0</td>
</tr>
<tr>
<td>MDVSTH2 -- Seen Less Than Once Per Year</td>
<td></td>
<td>21.9</td>
</tr>
<tr>
<td>MDVSTH3 -- Seen Once or More Times Per Year</td>
<td></td>
<td>33.1</td>
</tr>
<tr>
<td>DIABETES MONITORING GROUPS -- 3 groups:</td>
<td>634</td>
<td></td>
</tr>
<tr>
<td>DMCLH1 -- Not Seen in DM Clinics, Home Visits,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>or Prevention Clinics</td>
<td></td>
<td>30.9</td>
</tr>
<tr>
<td>DMCLH2 -- Seen Less Than Twice per Year</td>
<td></td>
<td>31.4</td>
</tr>
<tr>
<td>DMCLH3 -- Seen More Than Twice Per Year</td>
<td></td>
<td>37.7</td>
</tr>
<tr>
<td>HEMOGLOBIN A1c MONITORING GROUPS -- 3 groups</td>
<td>634</td>
<td></td>
</tr>
<tr>
<td>HGA1CH1 -- Not Seen for HgA1c Test</td>
<td></td>
<td>67.7</td>
</tr>
<tr>
<td>HGA1CH2 -- Seen Less Than Once Per Year</td>
<td></td>
<td>20.0</td>
</tr>
<tr>
<td>HGA1CH3 -- Seen One or More Times Per Year</td>
<td></td>
<td>12.5</td>
</tr>
<tr>
<td>DIABETES CARE OVER Followup for Blood Sugar Model</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DIETITIAN GROUPS -- 3 groups:</td>
<td>634</td>
<td></td>
</tr>
<tr>
<td>RDVST1 -- Not Seen by Dietitian</td>
<td></td>
<td>39.0</td>
</tr>
<tr>
<td>RDVST2 -- Seen Less Than Once Per Year</td>
<td></td>
<td>43.5</td>
</tr>
<tr>
<td>RDVST3 -- Seen One or More Times Per Year</td>
<td></td>
<td>17.5</td>
</tr>
<tr>
<td>NURSE EDUCATOR GROUPS -- 3 groups:</td>
<td>634</td>
<td></td>
</tr>
<tr>
<td>RNVST1 -- Not Seen by a Nurse Educator</td>
<td></td>
<td>44.8</td>
</tr>
<tr>
<td>RNVST2 -- Seen Less Than Once Per Year</td>
<td></td>
<td>37.1</td>
</tr>
<tr>
<td>RNVST3 -- Seen Once or More Times Per Year</td>
<td></td>
<td>18.1</td>
</tr>
<tr>
<td>PODIATRY VISIT GROUPS -- 3 groups:</td>
<td>634</td>
<td></td>
</tr>
<tr>
<td>FOOTCAR1 -- Not Seen by a Podiatrist or in a</td>
<td></td>
<td>63.9</td>
</tr>
<tr>
<td>Podiatry Clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FOOTCAR2 -- Seen Less Than Once Every Two Years</td>
<td></td>
<td>18.0</td>
</tr>
<tr>
<td>FOOTCAR3 -- Seen Once Every Two Years or More</td>
<td></td>
<td>18.1</td>
</tr>
<tr>
<td>DESCRIPTION</td>
<td>N</td>
<td>PERCENT</td>
</tr>
<tr>
<td>-------------------------------------------------------</td>
<td>----</td>
<td>---------</td>
</tr>
<tr>
<td><strong>EYE CARE GROUPS</strong> – 3 groups:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EYECARE1 – Not Seen by an Optometrist or Ophthalmologist</td>
<td>634</td>
<td>36.9</td>
</tr>
<tr>
<td>EYECARE2 – Seen Less Than Once Every Two Years</td>
<td></td>
<td>31.9</td>
</tr>
<tr>
<td>EYECARE3 – Seen Once Every Two Years or More</td>
<td></td>
<td>31.2</td>
</tr>
<tr>
<td><strong>PHYSICIAN CONTACT GROUPS</strong> – 4 groups:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MDVST1 – Not Seen by M.D., or Contract M.D. in DM Clinic, or in Family Practice or Internal Medicine Clinic.</td>
<td>634</td>
<td>27.1</td>
</tr>
<tr>
<td>MDVST2 – Seen Less Than Once Per Year</td>
<td></td>
<td>29.2</td>
</tr>
<tr>
<td>MDVST3 – Seen One up to Two Times Per Year</td>
<td></td>
<td>18.3</td>
</tr>
<tr>
<td>MDVST4 – Seen Two or More Times Per Year</td>
<td></td>
<td>25.4</td>
</tr>
<tr>
<td><strong>DIABETES MONITORING GROUPS</strong> – 3 groups:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMCL1 – Seen in DM Clinics, Home Visits, or Prevention Clinics Less Than Once Per Year</td>
<td>634</td>
<td>30.0</td>
</tr>
<tr>
<td>DMCL2 – Seen One up to Three Times Per Year</td>
<td></td>
<td>32.0</td>
</tr>
<tr>
<td>DMCL3 – Seen Three or More Times Per Year</td>
<td></td>
<td>38.0</td>
</tr>
<tr>
<td><strong>HEMOGLOBIN A1c MONITORING GROUPS</strong> – 3 groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HGA1C1 – HgA1c Test not Done</td>
<td></td>
<td>51.7</td>
</tr>
<tr>
<td>HGA1C2 – Tested Less Than Once Every Two Years</td>
<td></td>
<td>20.5</td>
</tr>
<tr>
<td>HGA1C3 – Tested One or More Times in Two Years</td>
<td></td>
<td>27.8</td>
</tr>
</tbody>
</table>

### 2.3 DIABETES PROGRAM AUDIT DATA FOR 1993

This dataset comes from the Diabetes Program Headquarters office in Albuquerque. It was the only one of three diabetes audit datasets available at the individual patient level. Project sites in each of eight IHS Areas will be compared to the project sites included in the cohort for this evaluation using the audit 1993 data. Usual care sites in the same areas as the project sites will be compared with the usual care site included in this evaluation.

Differences in proportions of patients in poor control, receiving patient education and health maintenance care (foot and eye exams) will be analyzed for projects and usual care sites, in and outside the cohort. If no difference between sites in and outside the cohort exists in audit’s cross-sectional sample, hypothetically some assumptions can then be made about the generalizability of the evaluation’s results to other diabetes program projects in IHS.

The eight IHS Areas were chosen by the IHS Diabetes Program Director, Dr. Dorothy Gohdes. Her criteria for choosing those eight Areas was: (1) each has functioning diabetes...
'team' in at least one Indian community, and (2) the project(s) in the Area placed at least part of their program emphasis on the clinical management of diabetic patients.

It was originally thought that imputation of some covariates would have to be done because of a high rate of missing values, particularly at the usual care sites. Age at diagnosis, duration of diabetes and body mass index were to be the imputed covariates. However, when the models to test generalizability were run, the results and conclusions were the same as when only the observations without missing variables were used. So all tables and models will be presented using the original variables.

Table 2-5. Description of Audit 93 Variables

<table>
<thead>
<tr>
<th>DESCRIPTION OF VARIABLES</th>
<th>NUMBER</th>
<th>MEAN</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>MALE (%)</td>
<td>6459</td>
<td>39.3</td>
<td></td>
</tr>
<tr>
<td>AGE AT DIAGNOSIS (years)</td>
<td>5408</td>
<td>45.5</td>
<td>13.3</td>
</tr>
<tr>
<td>DURATION OF DIABETES (years)</td>
<td>5437</td>
<td>9.5</td>
<td>7.5</td>
</tr>
<tr>
<td>SQUARE ROOT OF DURATION sqrt(yrs)</td>
<td>6434</td>
<td>2.8</td>
<td>1.2</td>
</tr>
<tr>
<td>BODY MASS INDEX (kg/m²)</td>
<td>4175</td>
<td>32.2</td>
<td>6.8</td>
</tr>
<tr>
<td>BLOOD PRESSURE CATEGORIES (%)</td>
<td>5956</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Normal</td>
<td>39.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controlled</td>
<td>26.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uncontrolled</td>
<td>26.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>8.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DIABETES TREATMENT GROUPS (%)</td>
<td>6249</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet Alone</td>
<td>12.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral Agents</td>
<td>50.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insulin</td>
<td>32.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insulin + Oral Agents</td>
<td>4.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BLOOD SUGAR CATEGORIES (%)</td>
<td>5914</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good Control</td>
<td>29.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fair Control</td>
<td>40.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor Control</td>
<td>22.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Poor Control</td>
<td>7.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>POOR CONTROL -- Dichotomous Variable</td>
<td>5914</td>
<td>30.4</td>
<td></td>
</tr>
<tr>
<td>DIET INSTRUCTION IN LAST YEAR GROUPS (%)</td>
<td>6353</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>37.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>By Non-Dietitian</td>
<td>28.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>By Dietitian</td>
<td>34.2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER III
RESULTS AND DISCUSSION OF INTERVIEWS AND FOCUS GROUPS
DESCRIPTIVE
STATISTICS

3.1 RESULTS OF FOCUS GROUPS AND INFORMANT INTERVIEWS

The topic questions for the focus groups and informant interviews were structured so that several key questions overlapped in content (see Appendix B. Question Topics by Different Group Types). Thus, the results of focus groups and informant interviews will be discussed together and in the following order:

1. Focus Groups:
   a. across focus groups,
   b. across sites and by project versus usual care,
   c. comparing similar responses to informant responses (where appropriate).

2. IHS Staff Informants:
   a. across sites and by project versus usual care,
   b. comparing similar responses to tribal informant responses (where appropriate).

3. Tribal Informants: across sites and by project versus usual care. Results for topics/questions will be grouped by: Adherence Issues, Process of Care, Alternative Diabetic Care Providers and Recommendations for Improving IHS Diabetic Care.

3.1.1 Adherence Issues

The first two of eight questions asked in the focus group sessions dealt with adherence issues for clients. The goals of these first two topics were to explore issues around adherence to medical recommendations for diabetes management, and adherence to diabetic care appointments considering the patient’s perspective.

3.1.1.1 Adherence to Medical Recommendations

Across groups, problems with adherence to medical recommendations fell into seven major categories: external factors preventing adherence to the diabetic diet, the ability/willingness to change eating habits, patient acceptance/denial of their diabetic condition, problems taking medications and monitoring blood sugar, internal (to the patient) and external barriers to exercise program adherence, alcoholism and obtaining family support for necessary lifestyle changes.
The second Rosebud group and the Winnebago group talked about the economic and knowledge deficit problems patients face when trying to implement the diabetic diet recommendations. The foods needed for the diet are seen as too expensive to be able to eat them regularly (only at the beginning of the month when paychecks and SSI checks come in). Patients that are dependent upon the USDA commodity food program or the Elderly Nutrition Program lack the knowledge to be able to use or eat these foods, and still adhere to a diabetic diet. Both the Winnebago and the second Rosebud group expressed concern that the staff and cooks in their respective Elderly Nutrition Program did not know how to properly prepare food for their diabetic clients.

Three of the CHR focus groups and the Winnebago patient focus group also discussed patient-centered problems in changing eating habits. Patients had problems with eating habit changes in the following areas: giving up high sugar and high fat foods, changing food preparation methods, getting used to unfamiliar foods that are recommended, reducing portions of foods consumed, and boredom with the diet. To the Ft. Totten CHRs these problems with changing eating habits were related to the patient’s attitude (i.e. “They eat what they want”).

The inability of many patients to accept the diagnosis of diabetes was the barrier to adherence most universally identified by care providers, whether they be CHRs or IHS staff. Numerous stories and repeated discussion in focus groups, IHS interviews and informal discussion with Diabetes Project staff indicated denial of the diabetic condition resulted in patients taking few or no steps to control their blood sugars until they became ill or developed complications. However, the issue of acceptance was conspicuously missing from the discussion in the Winnebago patient focus group and among tribal program staff responding to a similar question about adherence. Examples were given by CHRs and IHS informants of diabetic patients expressing a belief that the condition is temporary, or that they wished not to be treated 'different', therefore did not tell other family members. Though problems with denial were brought up in all the focus groups, some CHRs felt more strongly than others that it was a serious problem. The Ft. Totten CHRs placed the least emphasis on it, while one CHR in Winnebago explained some of the complex feelings generated around a diagnosis of diabetes in some of his younger diabetic clients.

Both patients and health care providers identified certain aspects of taking medications that made it difficult for patients to control their diabetes. This was especially true of giving one’s self insulin injections. Several focus group participants and informants expressed patient and personal fears about injecting insulin. Also, performing blood sugar checks regularly seemed to present a similar problem, but not the same level of fear. It was mentioned briefly in the first Rosebud group that family members of diabetics were also reluctant to give the patient their insulin injection, resulting in the patient simply not taking their insulin, or coming into the emergency room for their injections.

Remembering to take oral medications was considered to be a problem by the Winnebago patient group and the Ft. Totten CHRs. A lengthy story was related in the Winnebago patient group about an elderly diabetic woman who forgot she had taken her earlier dose of glyburide and took a second dose which resulted in her having a hypoglycemic reaction that frightened her relatives.
Exercise was mentioned by all the focus groups as a difficult change to make. The second Rosebud group was the only one to discuss the lack of places one could go to exercise, while the remainder discussed the problem of patients being able to find the time or making the time to do it. Both the second Rosebud and Winnebago groups mentioned alcoholism and the lack of family/social support for lifestyle change as problems for clients trying to control their diabetes. However, very little discussion took place around these two issues when they were brought up in the groups.

The Ft. Totten group and the second Rosebud group brought up issues around obtaining health care. A lengthy discussion about the quality of care, continuity of care and patient-physician communication problems at Rosebud took place in the second CHR group at Rosebud. The Ft. Totten CHRs felt not coming to diabetic clinic resulted in problems for patients trying to control their diabetes. Other issues brought up were: the psychological effects of diabetic complications (specifically impotence was discussed), inappropriately targeted health education, worries about complications and weight reduction.

A similar question was asked of tribal informants. The majority of responses from informants centered around diet and changing eating habits. One person out of nine discussed problems with taking medications and insulin, and one pointed out problems with obtaining transportation to clinic.

The second Rosebud CHR group talked about trusting IHS doctors under the question of difficult changes to make. Not being able to see the same doctor over time, the fact that doctors come and go, and that some of the doctors (foreign physicians) were difficult for both patients and CHRs to understand were topics brought up later by both Rosebud CHR groups. In the context of this question, CHRs saw not being able to get 'good' diabetic medical care at IHS as a barrier to diabetic control for patients.

*Quoteables-- Patient's Role in Adherence (Rosebud Informant):*

"... you have to understand Indian thinking that says once we have to give up so many things, we’re not really sure it is worth doing. If you have to take insulin every day to stay alive, if you have to live on this diet, if you have to be going towards blindness, is it really worth living? Indians have this ... they want to live, but they also want a higher quality. If you can’t, then we’ll do as we please, and so we’ll die, that’s part of life...Now, with so many mixed marriages where the culture is diluted, there is this constant internal war. I deal a lot with our dialysis patients, and sometimes they just don’t want to go on, get tired of living on a machine. And then they start to get real sick and then they’re dying, and yes they come back and we try to straighten them out again. But our basic cultural belief is, if your quality of life is not where you can be free ... to ... and we love our feasts, we love our flour, we love our fry bread, we love to celebrate birthdays with cake, that’s family. But it’s much more important than preventing a complication I don’t see yet. We live today. And every day is Sunday. You know what happens on Sunday? We can pray on
Sundays, we can party on Sundays, we can celebrate on Sundays, family gets together on Sundays. Well, for us every day is Sunday. It’s real hard to be in compliance when everyday is Sunday.”

3.1.1.2 Adherence to Clinical Appointments

Across all sites CHR’s indicated that patients didn’t like to go or want to go to clinic appointments for a variety of reasons. The most commonly cited reasons were not wanting to wait at the clinic and go through the whole clinic process, as well as, being too busy. Waiting times for dispensing of medications were noted to be particularly long by both focus groups in Rosebud. The first Rosebud group pointed out that if a patient’s blood sugar is too high, the patient may be made to wait even longer until their blood sugar comes down.

According to the CHR’s, younger patients at Winnebago saw it as a waste of time because they had no complications. While the second CHR group at Rosebud indicated that patients didn’t want to go to clinic because they didn’t trust the doctors. CHRs at Ft. Totten stated that some patients were afraid of finding out results of lab tests, while others would not want to come in because their blood work was fine last month, so did not see a reason to come in this month.

The two CHR groups at Rosebud discussed the difficulties of transportation to the clinic. Weather, road conditions and distance were mentioned by Rosebud CHRs but not by the CHRs at the two project sites. Though CHRs do provide transportation to clinics in all three sites, Rosebud CHRs have had to cut back on their transport of patients because of travel reimbursement cuts in their budget. The need for public transportation services was mentioned by the second Rosebud CHR group (according to the Rosebud CHR Director public transport services did exist at one time, but had recently been discontinued due to loss of government funding).

There were IHS "organizational access barriers" at the Rosebud Service Unit that discouraged appointment attendance. An example given was that if a patient doesn’t make it in on time for their appointment (no matter what the reason), they may not be seen if all the limited walk-in slots were already filled.

The Winnebago CHRs brought up the attitude of younger diabetic clients. These clients felt the diabetic clinic was a waste of time. The younger diabetic’s perspective was also brought up by the second CHR group at Rosebud in the context of another question. Younger clients told CHRs, they went to outside providers because they feel uncomfortable sitting in the waiting room during diabetic clinic with allot of the elderly diabetic patients.

Patients with diabetes at Rosebud face more physical (e.g. transportation, weather, road conditions) and organizational barriers (e.g. limited walk-in slots) to appointment attendance than do patients at Winnebago and Ft. Totten.
3.1.2 Process of Care

The important kinds of care a patient with diabetes could receive were discussed as the third and fourth questions in the focus group sessions. Two related or similar questions were asked of IHS staff about the major components of care and what types of care newly diagnosed diabetics should receive.

3.1.2.1 Clinic-Based Care

Across focus groups, foot care, routine medical examination, blood sugar monitoring, medications, eye care, diet monitoring and education were mentioned more than once as the important components of care in the clinic setting. Blood glucose monitoring and medications were mentioned by all four CHR groups. The provision of medications was the emphasis among the focus groups in Rosebud. The focus groups in the project sites emphasized medications adjustment, and education as important services. Both project site focus groups mentioned foot care and routine medical examination as important, and only one of the two Rosebud groups identified these as important diabetic services. Diet monitoring was mentioned by both project site CHR groups, but not by either of the usual care focus groups. Eye care was identified by one Rosebud group and the Ft. Totten group.

The patient group at Winnebago felt different patient education topics were the most important kinds of care to receive (e.g. using diabetic medications, diet education, exercise guidance, general diabetic education and family education). Only one CHR focus group in the usual care site and one in a project site identified patient education as important health care. The second Rosebud group and Winnebago CHRs discussed patient education in terms of what was needed rather than what currently was being provided. Particularly in Winnebago, patients told CHRs that they needed to be given more information and education during clinics and to have the opportunity to have their questions answered.

IHS informants tended to identify a wider range of services than the focus groups did (this could be a function of the different ways the questions were worded). In addition to foot care, routine medical care, education, monitoring (blood sugar and pressure) were mentioned by several informants. One Rosebud IHS informant identified laboratory services and in-patient care as major components of diabetic care. Informants from the two project sites included eye care in the list along with the others previously mentioned, as well as psychological counseling (one person at Winnebago), in-patient care (two people at Winnebago), continuity of care and routine access to a provider (one person at Ft. Totten) and diet counseling (two people at Ft. Totten). Six out of seven informants from the project sites versus three out of four at the usual care site identified patient education as a major component of care.

When asked what health care services all new diabetics should receive, IHS informants emphasized either patient education or receiving a comprehensive medical examination. Three out of four IHS informants at Rosebud felt patient education should be provided about such
aspects as managing medications, blood sugar monitoring, and nutrition. Five out of seven informants at the project sites felt patient education on similar topics was a necessary part of health care for the newly diagnosed diabetic.

Two out of four informants at Rosebud, and four out of seven at the project sites felt new diabetics should receive a thorough physical exam upon diagnosis to determine if there are any other underlying health problems. Two informants at the project sites indicated the need for considering patient acceptance of the diagnosis. In one case, the informant suggested that time should be allotted in the care process for the patient to consider and accept the diagnosis. While the other informant felt psychological counseling was necessary to help the patient through the process of acceptance.

At Rosebud, informant estimates of the percentage of new diabetics who actually received the health services they were recommending ranged from less than 50% up to 80% if they come to diabetic clinic at the Service Unit. Two out of four Rosebud informants provided estimates. The lowest estimate for a project site was 60% at Winnebago up to 100% at Ft. Totten (five out of seven project site informants provided estimates). The informant providing the lowest estimate at Winnebago attributed this low success rate to patient denial of their diabetes.

Across focus groups and IHS informants, the important or major components of diabetic care encompassed routine medical exam, foot care, medications, patient education, and blood sugar monitoring. Patient education received greater emphasis in the patient focus group and among IHS informants than it did among CHRs. CHRs in the project site focus groups recognized the importance of diet counseling and monitoring, and mentioned the importance of foot care, psychological counseling, and routine medical care more often than CHRs from the usual care site.

One Ft. Totten IHS informant identified the continuity of care that the Diabetes Project provides as being a key component of the diabetic care there. The CHRs at Ft. Totten alluded to this continuity of care when they discussed the importance of patients receiving a routine exam from the project's endocrinologist. In contrast to this, is the situation at the usual care site where there is a high and frequent turnover of primary care providers. Patients at Rosebud were said to be unable to establish a long-term doctor-patient relationship.

**Quoteables** (Rosebud) - "... I know one patient that the sugar was so high, and the IHS doctor said, 'Well, your sugar's way up there'... 'It won't go back down, you know.' So she went down to Valentine to get a second opinion from another doctor, and here this person had a kidney infection, and the doctor said, 'It's not sugar that's causing this. It's your kidney infection you have causing it to go up and stay up there.' So she was treated for this kidney infection. After that kidney infection was gone away, the sugar came back down. But some of the things IHS doctor is not telling the people, you know. I think that's something that should be brought more out to each individual. Maybe they have some other problems besides just diabetes."
3.1.2.2 Home-Based Care

Generally speaking, home based services are usually provided by CHRs and public health nurses. The following types of care were the ones most often mentioned across all groups: education, social support, monitoring (blood sugars and blood pressures), explanation of medical issues (usually pertaining to what an IHS provider tells the patient or instructs the patient to do). At Rosebud, the disparate languages of medical providers and patients are serious barriers to communication. English is often a second language for both the physician and the patient, with English frequently being the only language they have in common. Rosebud CHRs told of finding themselves in the position of interpreter, where they must try to translate the heavily accented English instructions of the physician into Lakota or simple understandable English. Both groups of CHRs at Rosebud found this interpreter role difficult to perform.

Both groups of CHRs at Rosebud indicated they did nutrition-related education in the home. Both CHR groups at the project sites indicated they did foot checks, while the first Rosebud group indicated they do check on, and care for post-operative patients.

According to the CHRs in the first Rosebud group and at Winnebago, patients felt they needed more contact with qualified health care providers such as a public health nurse or the diabetes project nurse in the home.

CHR's are providing a wide range of services for patients in the home. The focus group results indicate that the CHRs appear to perform similar services for diabetic patients across the three sites. Currently none of these services are documented in the medical record at any of the sites. Therefore, the impact of CHR services on the health status of diabetics cannot be evaluated at the individual level. However, it appears safe to assume that home care services provided by CHRs for diabetics are not so different across sites as to bias the statistical results in the quantitative analysis of the medical records data and health outcomes.

3.1.3 Alternative Diabetic Care Providers

Focus groups and both types of informants were asked about other health care providers that a patient with diabetes could go to outside of their local service unit. These questions were originally asked to identify reasons patients might choose to go elsewhere for care and how common "going elsewhere" was among diabetic patients in the different study sites. More consistent information was available in the patients' medical records than was expected originally, and these questions turned out to be somewhat biased because of the nature of the groups and individuals who were asked the question.

Half of the informants at Rosebud avoided answering the "outside provider" question, two were unfamiliar with other providers outside the local Service Unit and two of the informants concurred with what was reported by CHRs in the focus groups. At Rosebud, a number of private clinics exist in the outlying communities of the reservation and trust lands. Private providers in Mission, Winner and Valentine were mentioned by the CHRs and two informants. There are patients who make use of the Veteran's Administration hospital at Hot Springs, South Dakota, and other IHS Service Units in Southern South Dakota (Pine Ridge and Wagner). CHRs and informants indicated patients go to these other providers for a number of
reasons: the provider is closer to where they live, there is less waiting time, the patient trusts the outside provider more than the doctors at Rosebud, and the patient believes the quality of care is better.

In the case of the Winnebago Service Unit, a number of private providers are available in Sioux City (about 19 miles away from Winnebago). Two out of the eight informants at Winnebago were unfamiliar with other IHS service units or the local private providers. Those informants who were familiar with other providers in the area felt diabetic health care services were more comprehensive and more community-oriented at Winnebago than were available elsewhere. The CHRs at Winnebago had only a few diabetic patients (3 or less) who received their health care elsewhere. However, Winnebago CHRs serve only Winnebago tribal members who live on the reservation. Medical record abstracts show that 61% of patients in the Diabetes Project’s service population at Winnebago are from other tribes, and 64% of patients live outside Winnebago (Sioux City or elsewhere).

At Ft. Totten, the observations of the CHRs in the focus group, and the IHS and tribal informants generally supported what was apparent from the medical records. Only a few diabetic patients go off the reservation for their diabetic care unless they are referred by IHS. Medical records abstracts indicate 27% of Ft. Totten clients in the study receive some diabetic care outside the Service Unit compared to 49% at Winnebago and 50% at Rosebud. If the patient does go outside for diabetic care on their own, they usually have private insurance, Medicare or Medicaid coverage according to the CHRs. One of the four informants in Ft. Totten was unfamiliar with providers outside IHS and did not respond to this question. The other informants believed services would be the same at other IHS facilities. One informant felt the Diabetic Project providers were more knowledgeable and were more accessible than the local private providers.

3.1.4 Recommendations for Improving IHS Diabetes Care

3.1.4.1 Done Well for Patients with Diabetes

CHR focus groups in all sites felt foot care was done well. Vision care was noted to be good in Rosebud and Ft. Totten. This is where the similarities across the project and usual care sites end. The Rosebud CHRs thought ancillary services (podiatry, vision, dental, public health nursing) were done well by the Service Unit. Also, they indicated that assuring basic medical care and urgent care was available to patients was a strong point of the Rosebud Service Unit's diabetic care delivery. Informants at Rosebud also emphasized the delivery of basic diabetic clinic care and the currently improving patient education activities.

The focus groups at the project sites pointed out that exercise and education activities were done well. Most IHS and tribal informants were in agreement with this view. Winnebago informants placed particular emphasis on the value of patient education and community diabetes education activities carried out by the team. The Ft Totten CHRs and three of the four informants felt the caring attitude of the team, and the continuity of care that the team provides benefited patients with diabetes in their community.
3.1.4.2 Recommendations for Improvement

Suggestions provided in the Rosebud CHR groups focused on reducing the organizational barriers to clinic attendance (e.g. reducing waiting time, dispensing medications quicker, and providing more walk-in slots), improving the quality of medical care, and on patient and community education. Suggestions were made to increase the number of diabetic clinic days or hold more diabetic field clinics, and possibly have separate clinics for younger (adolescent) and older diabetic patients. The Rosebud CHRs felt provider attitudes and knowledge of diabetes needed improvement in order to improve the quality of care at the service unit. Three of the eight Rosebud informants echoed this concern, indicating a better means of coordinating diabetes care providers needed to be found.

The second CHR group at Rosebud, the four tribal and one IHS informant offered various suggestions to expand diabetic patient and preventive education in the community. Communicating the risks of complications more effectively was an important educational theme among CHRs in the second focus group. Rosebud tribal informants provided diverse suggestions about the topics and types of educational interventions needed. However, food preparation education was brought up by three of the four Rosebud tribal informants and one of the IHS informants.

More patient and community education about diabetes was also the theme of recommendations made in the focus groups (CHR and patient) and from informants in Winnebago. Overwhelmingly, focus group participants and informants felt the Winnebago Diabetes Project team needed to be providing more education and services in the patient's home, at diabetic clinics, and in the community. Though most of the informants who recommended this also acknowledged some community and patient education was already being provided by the team, more was needed. CHRs also wanted to see a closer working relationship between themselves and the Diabetes Project staff.

The same refrain for more patient and community education was not heard at Fort Totten in either the CHR focus group or the informant interviews. Most recommendations centered around reducing waiting time, increasing the number of staff, and administrative problems created by the physical separation of the diabetic clinic from the general IHS clinic.

3.2 CONCLUSIONS

The following statements made in the CHR focus groups are fairly representative of the evaluative tone of both focus groups and interviews at each site:

**Ft. Totten**

"Good they are here so people don't have to go off the reservation"

"We work closely with them"

Doing a great job, they are knowledgeable, understanding, and you know that they care.

**Winnebago**

"Glad to have the Program, but could do more."

**Rosebud #1**

Good Services, overall diabetic care is good. Just need to iron out a few things.
"...you know what it sums up to is that they are only addressing immediate concerns, they are not bothering with the before or the after. They (IHS providers) don't have that much time for 'em (patients), and so long as they (providers) continue doing that, you know then we'll just continue getting more and more people, and they're going to be out of control and they don't know how or aren't motivated to keep control of their diabetes. They (patients) don't have the means to do it anyway; they don't have the diet or the money to buy the proper food or eat that sugar-free stuff...You know, it is just going to continue getting worse until IHS will start doing more health education and taking more time with us, and making sure that they (patients) understand what's going on with them. Now they're just getting them in to get their meds, and hurrying them on out."

This general tone was borne out in the proportion of time spent by each focus group talking about each topic. The following table sets out topics by group and category of time spent discussing the topic.

Table 3-1 Diabetic Health Care Topics by Group and Category

<table>
<thead>
<tr>
<th>TOPIC/GROUP</th>
<th>ROSEBUD #1</th>
<th>ROSEBUD #2</th>
<th>WINNEBA GO</th>
<th>FORT TOTTEN</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHERENCE (Q1) Medical Recommendations</td>
<td>Somewhat</td>
<td>Important</td>
<td>Important</td>
<td>Important</td>
</tr>
<tr>
<td>ADHERENCE (Q2) Keeping Appointments</td>
<td>Somewhat</td>
<td>Not Too</td>
<td>Not Too</td>
<td>Somewhat</td>
</tr>
<tr>
<td>PROCESS OF CARE Clinic (Q3)</td>
<td>Not Too</td>
<td>Not Too</td>
<td>Somewhat</td>
<td>Somewhat</td>
</tr>
<tr>
<td>PROCESS OF CARE Home (Q4)</td>
<td>Important</td>
<td>Somewhat</td>
<td>Somewhat</td>
<td>Somewhat</td>
</tr>
<tr>
<td>ALTERNATIVE PROVIDERS (Q5)</td>
<td>Somewhat</td>
<td>Somewhat</td>
<td>Not Too</td>
<td>Somewhat</td>
</tr>
<tr>
<td>RECOMMENDATIONS (Q7)</td>
<td>Somewhat</td>
<td>Somewhat</td>
<td>Somewhat</td>
<td>Not Too</td>
</tr>
</tbody>
</table>

categories: Important >20% time spent, Somewhat 10-19%, Not Too < 10%

All the groups devoted a good portion of their time to talking about the problems patients face in making changes in their lifestyles so that they can control their diabetes. What is striking is how little time the two groups in Rosebud spent talking about what were the important services patients received at the clinic. CHRs at Rosebud also spent proportionally more time talking about the services they delivered to patients in the home than did CHRs at the two projects. The Winnebago CHRs had little to say about their clients going to providers outside of Winnebago, and the Ft. Totten CHRs devoted little time to making recommendations on ways the health services for diabetics could be improved.
As one CHR put it, "(Patients) don't realize... that they have to do a lot of self-examinations and, well, the whole lifestyle of the diabetic is a dramatic change for them." Adherence to medical recommendations for the management of diabetes is at best difficult. Instead of focusing the energy of IHS providers on managing the patient's blood sugar, CHRs, patients and informants appear to be telling us that reducing the barriers to adherence should be the goal of diabetes management. This translates into providing more information, education, support and guidance with the daunting task of first accepting the fact they must make the change, then how to do so with limited resources and without having to be 'different' or the 'sick' one in the family.

The clinical care and health maintenance activities that go on in the diabetic clinic setting are only somewhat more valued in the project sites than at Rosebud. Though organizational and physical barriers (distance and transportation) are an inhibiting force in patient appointment adherence at Rosebud, the poor physician-patient relationships are clearly significant barriers to patient adherence at all levels. The continuity of care provided by the consulting endocrinologist and diabetes staff at Ft. Totten, and the diabetes team at Winnebago are clear contrasts to the situation often seen in IHS Service Units where no formal program exists.

The Ft. Totten Diabetes Project is perceived to work more closely with tribal programs and to provide more community-based services than the Winnebago Project. Though the Winnebago Project was seen by some Winnebago tribal programs and patients as providing valuable services, consistently IHS staff, CHRs and some of their patients felt the Winnebago program should be more involved in the diabetes clinic, home visiting and community outreach. The Winnebago Diabetes Project is a referral source rather than the actual providers of diabetic clinic services is in contrast to Ft. Totten where the regular diabetic clinic is conducted by the diabetes team and their consulting endocrinologist. These differences in program management may influence the amount of actual patient and community contact each diabetes team has, and consequently, the patients' perceptions of the diabetes team's performance.

3.3 DISCUSSION FOCUS GROUPS AND INTERVIEWS

Focus groups are being used increasingly in social science and evaluation research to gain better insight into what clients of social programs think about the services they receive (Krueger 1988) Several recent studies have made use of focus groups to look at health promoting and nutrition related behaviors and beliefs among several different ethnic groups (White 1990, Reicks 1994, Quatromoni 1994). The authors of these studies saw focus groups as an optimal way to obtain information about health behaviors, beliefs and opinions of health programs from 'hard-to-reach' segments of the population (White 1990, Quatromoni 1994).

Krueger points out that focus groups work well if the purpose is to determine the perceptions, feelings and manner of thinking of consumers about products, services or opportunities. He also suggests that one advantage focus groups have over mail, telephone or structured face-to-face interviews is that one does not have to assume an individual who participates really does know how he or she feels before the process begins, or that individuals form opinions in isolation. Krueger states focus groups should ideally be conducted with participants who are total strangers and allowed to develop group approach under the passive guidance of the moderator (Krueger 1988). Kitzinger makes a strong argument for the use of
pre-existing groups, such as families, and friends to provide the actual social context in which groups will form their views (Kitzinger 1994). However, both agree, it is the group interaction in the formation of opinions and perceptions on a focussed topic that is what distinguishes focus groups from other qualitative research methods (Krueger 1988, Kitzinger 1994).

It has been my experience that group interaction among unrelated American Indian individuals is difficult to achieve. Other researchers and health professionals have told me of similar experiences working with American Indian groups. Though familiarity may have inhibited interaction within the CHR focus groups, it is difficult to determine whether or not there would have been more interaction if they had all been strangers. Because Indian communities are generally small, it would also have been difficult to find participants who were total strangers to one another. As the focus groups were structured, participants were to share the opinions and perceptions of their clients as well as their own views. Because the topics did not focus on their own personal health problems or care, the CHRs may have been more willing to express opinions on behalf their clients than for themselves. More personal health related anecdotes came up in the informant interviews than in the CHR focus groups. However, the responses from the focus groups were not inconsistent with the responses from the interviews. Nor were they altogether similar to the interviews on related questions.

The focus group and interview data gathered in this evaluation can only provide some qualitative indicators of what might be commonly held opinions and beliefs among diabetic patients, IHS and tribal staff in these communities. These data hint at patterns and trends in patient attitudes, beliefs and behaviors that need further exploration. However, some of the patterns in these data have been found by other researchers studying other populations, and using stronger qualitative and quantitative methods.

3.3.1 Adherence and Its Relationship to Process of Care

The cornerstone of diabetes management is a set of self-care behaviors that the health care provider has to convince the patient is in their best interest to perform. They are in order of usual emphasis: changing diet (explicitly to control blood sugar first and often implicitly to lose weight), increasing exercise, using diabetic medications appropriately (if necessary, to control blood sugar), and blood sugar monitoring (American Diabetes Association 1984).

The literature on adherence to medical recommendations for diabetes falls into two categories: adherence to recommended lifestyle changes (diet and exercise) and medications use. Researchers have approached the problems of adherence or 'compliance' from a number of different theoretical frameworks: the health beliefs model (Woolridge 1992), focus of control (Sclenk 1984), personal responsibility attitude assessment (Masaki 1990), quality of life (Hanestad 1991), patient satisfaction with care (Sherbourne 1992), social learning (Glasgow 1989), coping strategies (Hanestad 1991) and reasoned decision-making (Donovan 1992). To spite the varying approaches to studying adherence, several researchers have reached similar conclusions: Diet and exercise recommendations are adhered to less often than medication use recommendations (Masaki 1990, Hanestad 1991, Glasgow 1989, Kravitz 1993, Ary 1986), and that they are perceived as more difficult to do by patients (Hanestad 1991, Glasgow 1989, Ary 1986). Also findings from the Medical Outcomes Study support earlier work showing that the physician-patient relationship and communication, and patient satisfaction with the interpersonal