# KNOWLEDGE OF DIABETES MELLITUS IN THE PIMA INDIANS OF ARIZONA

# KNOWLEDGE OF DIABETES MELLITUS IN THE PIMA INDIANS OF ARIZONA

by

Elna J. Koopman, B.S.N.

A CLINICAL INVESTIGATION

Presented to
the University of Oregon School of Nursing
and the Graduate Council
of the University of Oregon Medical School
in partial fulfillment
of the requirements for the degree of
Master of Nursing

June 8, 1979

APPROVED:

[redacted]

Katherine Chavigny, RN, Ph.D., Associate Professor, Advisor

Evelyn Schindler, RN, MA, Professor, First Reader

[redacted]

Margaret Bruya, RN, MSN, Associate Professor, Second Reader

[redacted]

John M. Brookhart, Ph.D., Chairman of Graduate Council

LIST OF TABLES

LIST OF TABLES (Cont'd)

This study was supported by a United States
Public Health Service Traineeship from
Grant Number 5 A11 NU 00250-02

# KNOWLEDGE OF DIABETES MELLITUS IN THE PIMA INDIANS OF ARIZONA

## CHAPTER I

## INTRODUCTION TO THE PROBLEM

The present research "knowledge of diabetes mellitus in the Pima Indians of Arizona" is concerned with the relationship of knowledge of the diabetic condition to the severity of the illness and the occurrence of complications. Prevalence of diabetes among these people, as shown in epidemiological studies by Bennett et.al. (1976), is the highest in the world.(1) If the health needs of this population are to be met, a systematic organized approach should be made to identify knowledge of diabetes and its management in this group of patients. This study purports to accomplish this task and the results of this study will provide base-line information for the development of an effective instructional program designed to meet the specific needs of the Pima Indians. It may also indicate whether the absence of relevant information relates to the occurrence of sequalae of diabetes mellitus.

### A. Review of the Literature.

In 1971 statistics published by the Indian Health Service (IHS) accidents are the leading cause of death among Indian people. In the United States (US) population as a whole the primary reason for death is from heart disease (see table 1).(2) When overall death rates are age adjusted, the Indian and Alaskan Native death rate is 28 percent above

Table 1. Comparison of five leading causes of death between US (all races) and Native Americans.

| Indian and Native Alaska Population | US Population (all races) |
|---|---|
| 1. Accidents | 1. Diseases of the heart |
| 2. Diseases of the heart | 2. Malignant neoplasms |
| 3. Malignant neoplasms | 3. Cerebro-Vascular disease |
| 4. Cirrhosis of the liver | 4. Accidents |
| 5. Cerebro-Vascular disease | 5. Pneumonia |

(Indian Health Trends and Services, 1974)[3]

US rates; also cirrhosis of the liver, all forms of tuberculosis, accidents and acute respiratory illness are considerably higher than US mortality rates; however, age adjusted chronic respiratory disease rates are less. Native Americans die earlier than the general population and age-specific death rates increase in Indians until 60 years of age. Infant and maternal mortality rates, a traditional index of the efficiency of public health services, have considerably decreased since 1958. These rates in the Indian people now approximate rates in the general population.

The present population in the US totals over 200 million of whom less than one percent are Native Americans. The prevalence of diabetes mellitus is at least two percent in the general population, but in many Indian tribes the prevalence is increased over ten times. In the Pima tribe almost 50 percent of the age group 35 years and more have diabetes mellitus, and the specific vascular complications of this disease also

have high incidence among these people. Other morbidity data has shown some improvement. Since mid-century the incidence of tuberculosis (TB) has decreased from 8 per 1000 to 1 per 1000 in the last twenty years and trachoma now occurs 4 times per 100 Native Americans compared to 14 per 1000 in 1954. As the general health care needs of the Indians are steadily being fulfilled, the life span on the average is increasing. Competing causes of death are also being controlled and chronic illnesses such as diabetes and cirrhosis of the liver are becoming problems of importance and concern.

Diabetes mellitus occurs in all populations across the globe. When frequency of this disease is controlled for ethnicity there is supporting evidence for a possible genetic association. For instance the Nauruans from Micronesia have a prevalence rate of 40 percent, and the Funafuti, a Polynesian tribe, only ten percent. Diabetes is rare among the Athabaskan Indians of Alaska and the Alaskan Eskimos. However, some other Native Americans have extremely high prevalences. The Seneca and Cherokee Indians, respectively, have been reported to have diabetes prevalence rates of 22 percent in those age 25 and over, and 31 percent in those 35 years and over. A related tribe to the Pima, the Papago, has a prevalence rate of 42 percent. Other tribes with high rates are the Cocopah, 33 percent, Zuni, 31 percent, Paiute, 25 percent, Washoe, 17 percent, and the Navajo, 13 percent (Bennett et.al., 1976).[4]
The Pima Indians have the rare and questionable distinction of having

the highest prevalence rate of adult onset diabetes in the world.

In any situation where community services improve the quality of life by controlling the onslaught of acute communicable disease, the identification and incidence of chronic illness and their precursors increase. Early detection and control usually requires an informed population. Seligman and then Rosenberg have completed several investigations which indicate that patients in general know little about commonly occurring illnesses.[5,6] These authors established that the presence of a diagnosed disease did not necessarily increase the level of knowledge in patients suffering from the condition. In a follow-up study, Seligman (1957) tested 50 patients about the condition for which they sought treatment.[7] Results revealed that none had a thorough understanding about their illness. It was also observed that one-third of these patients asked no questions during their visit.

Diabetic patients must have a firm knowledge of their condition in order to manage their disease adequately. Therefore, efforts should be made to determine individual patient's knowledge of diabetes. Patient knowledge of diabetes has been studied by several investigators (Beaser, 1956; Stone, 1961; Watkins, 1967; Nickerson, 1972; Etzwiler, 1962; and Simon and Stewart, 1976).[8-13] Beaser was one of the first to report the results of a questionnaire which was given to 128 adult diabetics. His results showed that all were deficient in knowledge of their disease (Beaser, 1956). Another early study analyzed features that accompanied unsatisfactory control among 126 diabetic patients.

Stone (1961) found that 83 were ignorant of the diabetic regimen and established that only four of them were unable to learn.

Sixty diabetic patients from two metabolic clinics were studied to determine the relationships among knowledge, management, and control of the disease (Watkins et. al., 1967). Patients were rated on management of insulin, urine tests, diet, foot care, and level of disease control. Control was based on information concerning insulin reactions, blood sugar values, urine sugars, episodes of diabetic acidosis, and body weight. Knowledge and the occurrence of complications of diabetes were not addressed in this research. The Watkins study involved 60 patients. It was found that 80 percent were using unacceptable insulin administration technique; 31 percent erred in drawing up their correct insulin dosage; over 33 percent had improper urine testing techniques; and 51 percent carried out poor foot care. Other findings included:

(1) The length of time a person had diabetes did not appear to be related to his knowledge.

(2) The longer a patient had diabetes, the more errors he made in performing management skills.

(3) Knowledge about diabetes was found to be inversely related to control; and

(4) Those patients who knew more about diabetes were more proficient in performing their prescribed regimens.

Nickerson (1972) tested 74 diabetic patients at the University of Florida teaching hospital to determine how much they knew about their

disease. The importance of foot care was unknown to 57 percent; but four of these patients were in the hospital with gangrene foot ulcers. Thirty of the 40 patients who did not test their urine at home stated they had never been shown how to perform the test. The remaining 34 patients tested their urine at home but only five of them were able to give a correct demonstration. Of the 43 insulin dependent patients 68 percent could not list one symptom associated with hypoglycemia or insulin reaction and 80 percent could not name any signs of high blood sugar. Twenty-four of 26 patients taking insulin did not know the difference between U-40 and U-80 insulin while only 27 percent of the total group of patients knew the action of insulin. In another study of knowledge, Etzwiler (1962) found that the majority of insulin requiring diabetics tested did not know the difference between the regular and long acting insulin. Only 50 percent realized that the presence of acetone in urine was an indication for additional insulin.

Through the use of a 30-item multiple choice questionnaire, Simon and Stewart (1976) studied the knowledge of diabetic management in 99 patients and found that only 81 percent of patients using insulin knew its action, while questions relating to insulin shock and alcohol intake were answered correctly by less than half. Mean scores were 47 percent, which indicated serious deficiencies in the understanding of diabetes, its natural history and its management. Those patients with low scores tended to be older and to have less formal education.

Dietary management is considered to be the cornerstone of diabetic care. Moreover, a critical relationship exists between the maturity-onset diabetic and diet. For persons over 40 years of age, prevention of obesity can delay or prevent the onset of frank diabetes (West, 1975).[14] Considering how important diet is in the treatment of diabetes, studies on knowledge of diet are surprisingly scarce. Williams (1967a)[15] has noted that on observing diabetic patients' performance of carrying out a regimen, 65 to 90 percent of patients studied had major errors in the types of foods selected, in proper spacing of meals or snacks, and/or in regularity of diet. In a follow-up study Williams (1967b)[16] indicated that only one patient out of eight adhered to the recommended diet on a given day, based on a one-day recall. When 7-day records were examined, it was apparent that over three-fourths of the patients were not complying with the dietary recommendations.

It is a common finding that patients have not acquired the ability to apply information to self-care management. In one survey (Holland, 1968)[17] it was found that 22 percent of the respondents said that they were given a diet plan but did not follow it. Of the 77 percent of respondents who reported using the exchange system, only 25 percent made acceptable choices. Nickerson's study (1972)[18] revealed that although 63 percent of the insulin dependent patients in her study believed that frequency of eating was important, only 40 percent knew why it was important.

As indicated in the studies just described, the majority of diabetic patients have insufficient knowledge to manage their disease adequately. These results raise some important questions concerning patient compliance with therapeutic regimens, quality of care, and nursing responsibilities to the diabetic patients.

In diabetes mellitus, more than in most other diseases, the success of treatment in disease control depends upon the degree to which the patient adheres to the therapeutic regimen. Only recently, the issue of better control to prevent or delay diabetic complications has been urged by physicians specializing in the care of diabetes mellitus (Diabetes Course, 1978).[19] However, control of hyperglycemia to prevent or delay outcomes of disease will ultimately depend upon how well the diabetic understands the nature of diabetes and understands the rationale for the care that is required. Therefore, before the responsibility of self-management can be delegated to the diabetic patients, it is essential first to assess their current knowledge about the disease to determine if they have the necessary information, and second, to plan effective nursing intervention to improve compliance.

B. Purpose and Objectives of the Study.

The Pima Indians suffer extensively from the problem of diabetes mellitus. Diabetes is a disorder of carbohydrate, protein and lipid metabolism and is clinically characterized by glycosuria and hyperglycemia. The diagnosis of overt diabetes is based on the classical symptoms of polyuria, polyphagia, and polydipsia.

Ketoacidosis can result if these symptoms are not treated with insulin. This disease occurs when the β cells of the pancreas fail to secrete a hormone called insulin. This deficiency may be relative or absolute.

In discussing diabetes, first it is essential to recognize the two types. The first of these is Juvenile onset diabetes which develops in childhood. In Juvenile diabetes, the serum glucose levels become dangerously high and ketoacidosis can develop. When insulin levels are low or absent, changes occur in the liver metabolism. In addition to the accelerated glyconeogenesis (the production of glucose from fats and proteins), there is activation of hepatic ketogenesis whereby free fatty acids mobilized from fat stores are converted to ketones. The accumulation of these ketones in the blood leads to a state known as diabetic ketoacidosis. The other form of diabetes is milder and usually develops during adulthood. Adult diabetes occurs over a period of several years and commonly occurs in people who are overweight. Glucose intolerance levels gradually rise over several months or years and when they reach moderately high levels the patient becomes symptomatic. Although not as severe, the symptoms of adult diabetes are basically the same as those found in Juvenile diabetes.

In both types of diabetes, there are complications which develop. These complications are divided into two types; acute complications occur suddenly when serum glucose levels rise rapidly and ketoacidosis develops; chronic complications which develop over a number of years include retinopathy, nephropathy, arteriosclerosis and neuropathy. Not

all diabetic patients will develop complications; some patients may have only one or two whereas others may have multiple complications. However, most important of all is that something can be done to postpone or prevent some of these complications through proper management of disease.

Only part of the answer to the question "What causes diabetes?" is known. Diabetes mellitus appears to have a large genetic component in its etiology. If someone has two parents who are diabetic, his chances of developing diabetes as he gets older are considerably higher than someone whose parents are both non-diabetic. However, it has been established that the risk of becoming diabetic is related to being overweight. The more overweight a person is, the more he increases the risk he inherited of developing adult diabetes. Patients concerned about their risk of diabetes must understand that if they can control their weight they are doing the best single thing possible to reduce their risk of developing this illness. Diabetes in the American Indians appears to be basically the same disorder as seen in other persons throughout the world. There is however, an increased risk of developing adult onset diabetes among the American Indians and especially among members of Indian tribes living in the Southwestern deserts. Diabetes is thus one of the most important health problems of the Pima and other Southwestern Indians.

At present, there is not yet a cure for diabetes. However, there are effective treatments available that include diet, and diet in

combination with exogenous insulin or certain oral hypoglycemic agents. Exercise is a useful adjunct to these modalities of treatment in decreasing hyperglycemia or glycosuria.

Because the spectrum of patients requiring treatment extends from the totally asymptomatic person to the one with life threatening diabetic ketoacidosis, the objectives of treatment are highly individualized. The goal of treatment is to relieve symptoms of hyperglycemia and glycosuria as well as prevention of the acute complications of ketoacidosis, hyperosmolar coma, hypoglycemia and the prevention of many of the vascular complications of diabetes.

The oral hypoglycemic agent has been useful in the management of hyperglycemia in adult diabetes. Two types of compounds are available, the sulfonylureas and the biguanides. The sulfonylurea drugs (Dymelor, Diabinese, Tolinase and Orinase) stimulate the β cells of the pancreas to secrete insulin and biguanide's (Phenformin Hydrochloride) major action is on the gastrointestional tract, retarding carbohydrate absorption. Although the benefits and safety of these drugs remain controversial as a result of the UGDP (University Group Diabetes Program) study,[20] they remain a common form of treatment for the adult diabetic. Toxic reactions are generally mild. Persons who are allergic to sulfa drugs should avoid the sulfonylurea agents. Blood dyscrasias, skin reactions, juandice, hypothyroidism, and gastrointestinal symptoms have been reported. Except for symptoms of nausea or diarrhea, side effects to the biguanides are rare. Mild hypoglycemia can occur with the

sulfonylureas but is unknown with the biguanides.

Insulin therapy is generally indicated for those diabetic patients who have an absolute insulin deficiency. Many types of insulin are available and differ primarily in the onset on action and duration of effects. Crystalline Zinc insulin (regular) has a rapid onset of action. The longer acting single peak insulins include NPH and the Lente family of insulins. The major goal of treatment using insulin is to promote utilization of glucose throughout the day while avoiding hyperglycemia or hypoglycemia. With insulin therapy it is important that the patient be able to recognize the early symptoms of hypoglycemia, such as a feeling of hunger, weakness, sweaty and nervous irritability, and be aware of the possible precipating factors. Instructions should emphasize that omitting meals, vigorous exercise, errors in insulin dose, poor injection techniques, drinking alcohol and erratic urine testing predispose the patient to hypoglycemia. Education and prevention are the most important aspects of treating hypoglycemia.

A balanced diet with resultant weight loss is the treatment of choice for the majority of adult diabetics to maintain glucose levels within normal limits. This will maintain blood sugar levels within the normal range better than any medication and this is something that can be done by the patient with the help of nursing and other health care personnel. The purpose of this study is to determine if the Pima Indian diabetic has knowledge of the disease to help himself and therefore reduce the damage and the illness caused by diabetes.

Many studies on the relationship of knowledge to management of diabetes mellitus have been done to date; however, there is a paucity of studies which relate knowledge to the occurrence of complications of diabetic condition. Also, information relating knowledge to degree of illness is very scarce. Due to the enormity of this problem, the federal government has recently allocated funds for a diabetes intervention and education center for the Pima Indians. If successful, this program will be duplicated in several other areas of Indian Health Service throughout the United States.

The purpose of this research study is to establish directives to guide programs of education to improve the self-care of diabetic patients in the high-risk population of the Pima Indians. The study also intends to show the association between knowledge of this disease, and severity of the illness and occurrence of complications. It is hoped that this research will provide base-line data to estimate the impact of education of these patients in future prospective studies.

Objectives.

(1) To discover those areas of knowledge of diabetes mellitus which need to be emphasized in educational programs for patient management of the disease.

(2) To establish if knowledge of the disease is increased when control of the disease is more complex; and

(3) To associate knowledge of the disease with the occurrence of complications of diabetes mellitus.

For the person with diabetes mellitus, the success of treatment and control is dependent upon how knowledgeable the patients are about their disease. Those physicians specializing in the care of diabetes are now appealing for improved control in order to prevent or delay diabetic complications (Diabetes Course, 1978). The results of this investigation can be applied to produce efficient methods of instruction and nursing care to improve the delivery of services to the diabetic patients.

# CHAPTER II

## RESEARCH METHODS

### A. Selection of Sample.

One hundred maturity-onset diabetic Pimas were used for this study. They were of both sexes, diagnosed as having diabetes for a minimum of one year, and all patients reported to have received some diabetes instruction since the occurrence of the disease. Their ages ranged from 21 to 59 years of age. The patients were physically and mentally able and willing to answer questions relating to their personal history through a guided interview questionnaire.

Those patients interviewed were drawn from four settings: 1) those patients hospitalized at Phoenix Indian Medical Center (PIMC), 2) those patients attending diabetes clinic at PIMC, 3) those patients attending diabetes clinic at the Sacaton Indian Health Service (IHS) clinic, and 4) those patients attending diabetes clinic at Salt River IHS clinic. The population was drawn from the four named settings which provide patients from the entire Pima settlement. Although it was safe to assume that all patients received similar diabetes instruction including both method and content, the data will be analyzed to test this assumption. The sample consisted of 43 insulin-requiring diabetic patients, and the remaining patients managed their disease either by by oral hypoglycemic agent or diet alone.

B. Data Collection.

The diabetes questionnaires found in the literature used highly technical words with multiple choice format. One such questionnaire was used by the researcher and tested for suitability for this study on several diabetic patients. It was found to be inadequate, primarily because questions requiring a choice of 'yes', 'no', or 'I don't know' as their answer proved most acceptable to the patient. Therefore, it was decided to construct a more appropriate tool to assess the level of knowledge in this patient population.

Two instruments were used for this study: First an interview questionnaire of 99 items entitled Diabetes Mellitus Guided Interview was developed by the author to test patient knowledge of diabetes. The questionnaire covers five areas which are considered important in successful management: 1) general knowledge of diabetes mellitus, 2) knowledge of diet to control diabetes, 3) knowledge of insulin use, action and dosages, 4) self-administration of insulin, and 5) testing urine for sugar and acetone. The second instrument was a patient assessment form which was used to obtain demographic data and personal and past history. These data were later verified by collating with the medical records of the patients. Wording of questions was as non-technical as possible. Synonyms to simplify medical terms were used freely and primarily consisted of those words commonly used by patient and family, physicians, nurses and dieticians while providing patient care.

The questionnaire was reviewed by a physician who is active in research, treatment and education for the diabetic Pima. The questions were judged to be reasonable, in that most diabetic patients should be able to answer them.

C. Pilot Study of Questionnaire.

A pilot study using the questionnaire was done, using as patients, 15 Pima Indian Community Health Representatives (CHR). Because the CHR responsibilities include some diabetes teaching, it seemed appropriate to use the CHRs to test the instrument. The questionnaire was administered prior to 15 patients receiving six hours of training in the management of diabetes. Group age range was from 21 to 60 years of age. The full range of education level was not known but did not include any college experience. Of the 15 respondents, nine reported having diabetes. Of these nine diabetic Pimas, two were on insulin, three were on oral hypoglycemic agents and four reported using diet alone to control their diabetes. All but two of the nine considered themselves to be overweight. All nine reported to have received some form of diabetes instruction. Knowledge questionnaire scores for the nine diabetic Pimas ranged from 38-86 percent with a mean score of 59 percent; for the six non-diabetics the range of scores were 43-80 percent with a mean score of 65 percent and for the total group of 15 respondents the range of scores were 38 to 86 percent with a mean score of 62 percent.

After the pilot study the questionnaire was reviewed for validity and for clarity. It was slightly reorganized and items that consistently

created some confusion for the patients were either eliminated or rewritten. Once again, the instrument was reviewed by the diabetologist. It was decided that the questionnaire should be administered by the researcher because a self-administered test was dependent upon reading and comprehension skills and possible areas of concern could be quickly expedited through person-to-person contact.

D. Method of Collection of Data.

The patients arrived at the diabetic clinic by 8:00 a.m. The screening nurse took their blood pressure, temperature, pulse, respiration and tested their urine sample for sugar, acetone and protein using the combo-ketodiastix method. Following this, blood was taken for a fasting blood sugar (FBS). The patients were then free to either eat a snack of milk and fruit provided by the hospital or eat at the snack shop if at PIMC. Patients meeting the sampling requirements of at least 40 percent insulin users, to 60 percent non-insulin users, were asked to participate in the study. They were told the purpose of the study and received assurance that their names and hospital numbers would not be used to identify their questionnaire. No one refused. Signed permission forms were then obtained individually (see Appendix A). An effort was made to eliminate anxiety and create a comfortable environment. The interview was conducted in a room that provided privacy and space for the two performance components applying the test for sugar and demonstrations in injection method. (Dextrose solution was substituted for the urine sample). Upon completion of the interview, patients were

encouraged to ask questions they may have about any items on the questionnaire. Concurrent feedback was freely given. The interview lasted about 45 minutes. This instrument was assigned scores. A total possible score of 99 points is distributed as follows:

| | | |
|---|---|---|
| 1) | Knowledge of diabetes | 27 points |
| 2) | Knowledge of diet | 21 points |
| 3) | Knowledge of insulin | 31 points |
| 4) | Self-administration of insulin (skills assessment) | 11 points |
| 5) | Testing of urine (skills assessment) | 9 points |

A separate form was used to collect demographic data. Information about diabetes education received, education and income levels, amount and type of exercise, and information regarding family members who have diabetes was obtained through patient interview and recorded on the patient assessment form. This information was later collated with data taken from the medical record, including chronological age, duration of diabetes, sex, diabetes status at time of assessment, and medication used. If there was a discrepancy between patient information and chart information this was recorded and then the M.D. and nurse in charge of the patient were consulted to verify the correct status of the patient.

When all data had been collected in 100 patients, the information was coded and placed in tape in the computer for subsequent analysis.

E. Definition of Terms.

Knowledge-as defined by Thorndike-Barnhart, "all that is known or can be learned."

Peripheral neuropathy-symmetric distal loss of sensation, reflexes, and strength, usually most severe in feet, sometimes associated with foot and leg pain and visible foot deformities.

Foot ulcers-a loss of substance located on a cutaneous surface, causing gradual disintegration and necrosis of the tissue.

Insulin-a protein hormone formed by the islet cells of Langerhans in the pancreas and secreted into the blood, where it regulates carbohydrate metabolism. Used therapeutically in diabetes and sometimes in other conditions.

Oral hypoglycemic-an agent that acts to lower the level of glucose in the blood.

Severity of illness-is stipulated for this study to be:

1) Mild when the disease is controlled by dietary and/or weight reduction methods only.
2) Moderate when oral medication is prescribed, and
3) Severe when insulin injections are necessary to control the disease.

F. Hypotheses.

The independent variable is knowledge using Thorndike-Barnhart definition of "all that is known or can be learned." The level of knowledge is measured by the interview questionnaire which has a maximum high score for greatest knowledge of 99 points divided into five areas of information needed for diabetic management. The dependent variables are several, and include first, the intensity of degree of illness, (just described in definition of terms) and second, the complications associated with the diagnosis of diabetes mellitus. These complications are:

1) The presence of peripheral neuropathy measured by a loss of feeling or sensation or numbness in the feet as experienced and reported by the patient,
2) Presence of ulcerated skin lesions of the lower extremity and,
3) Frequency of occurrence of amputation of any part of the lower extremity.

## HYPOTHESES

1) There will be no significant association between the score of the interview questionnaire to estimate the level of knowledge of diabetes in Pima Indians and the degree of illness estimated by prescription for the control of the disease.

$H_{01}$: $pij = pi \cdot pj$

2) There will be no significant association between the score of the interview questionnaire to estimate level of knowledge of diabetes and the occurrence of three peripheral complications-peripheral neuropathy, skin lesions and amputation of lower extremities.

$H_{02}$: $pij = pi \cdot pj$

3) There will be no significant difference between the scores of the interview questionnaire to estimate the level of knowledge of diabetes for each group of patients from each clinic.

$H_{03}$: $pij = pi \cdot pj$

4a) There will be no significant association between the insulin skills score and the insulin cognitive score of insulin users in this population.

$H_{04a}$: $r = o$

4b) There will be no significant association between the skills score in urine testing and cognitive score of all diabetics patients in this population.

$H_{04b}$: $r = o$

4c) There will be no significant associaton between non-insulin users and insulin users and their skills score on urine testing.

$H_{04c}$: $r = o$

Other hypotheses will be generated when necessary. The first, second and third hypotheses will be tested by ranking the scores of the questionnaire according to level of accomplishment. The fourth hypothesis tests the relationship of the cognitive area of the questionnaire and the skills associated with management of the diabetic condition-specifically urine testing and administration of insulin. Patients who do not require insulin to control their disease are omitted from this part of the analysis and patients who require insulin administration are analyzed separately.

Age may influence knowledge. Also, Watkins' study found that knowledge and the length of time (LOT) disease had been diagnosed was significantly correlated with his estimate of knowledge of diabetes. These two variables, age and LOT, must be taken into consideration.

G. Statistics.

The $X^2$ of independence is used when marginal values are not fixed and this non-parametric statistic has no distributional requirements. There is a restriction on cell sizes; no table may have 20% of cells with less than five observations. This test statistic will be used to test the hypotheses for statistical significance. Hypothesis #1 will use continuous data from the test scores and Pearson product moment, will be used as the most appropriate test of significance.

H. Processing data.

Data was prepared for computer use by grouping and labelling as follows:

1) Income level was divided into four bands of $4,000 each.

2) Education level was divided into four levels. The levels included grades 1-6, grades 7-9, grades 9-12, and education beyond high school.

3) Fasting blood sugars were divided into three groups. The first group (1) consisted of blood sugar values that ranged from 105-159 mg%, the second group (2) includes blood sugar values of 160-204 mg%, and the third group (3) were values of 205 and above.

4) Duration of diabetes was defined as the length of time a patient had the disease. This variable was divided into three groups:

Group one (1) consisted of those persons who were found to have the disease from 1-3 years. Group two (2) consisted of those persons who had the disease for more than three years and less than seven years. Group three (3) consisted of persons who had the disease for seven years or more.

5) Percent of ideal body weight is the ratio between ideal body weight and the patient's real weight. Ideal body weight is calculated from the National Research Council American Academy of Science.[21]

6) Severity of illness was based on the type of prescribed treatment which included Diet (1), Oral hypoglycemic agent (2), and Insulin (3). When severity was used as a controlling variable, this was redefined as follows: patients on insulin (1) and patients not on insulin (2) which combined groups 1 and 2.

7) Diabetes instruction is given to patients at four different clinics identified as PIMC (0), Sacaton (1), Gila Crossing (2), Salt River (3) and other (4). Community health nurses who instruct the patients at Salt River also instruct the patients at Gila Crossing; therefore, data from these clinics were combined to leave PIMC, Sacaton, Salt River and other as the places of instruction.

8) An organized program of diabetes instruction was initiated in Sacaton in 1975. The Sacaton patients which were identified as receiving the program were labelled as either 0=yes or 1=no.

9) Length of time since diabetes instruction was divided into less than one year and then yearly increments of one to four years or more.

10) Loss of sensation (Question 25) is experienced in both feet and is defined as being either present or absent.

11) Areas of pressure (Question 26) is defined as any break of skin and any infection is labelled as "infection or ulcer" and included in this group.

12) Amputation (Question 27) includes the loss of a foot, any part of a foot or both feet which are not due to accidents.

13) Urine testing skills (Questions 41-43, 48-50). All patients were scored on urine-testing skills. The total score of 6 was divided into high and low. Above 3=high, 3 and below=low.

14) Insulin administration skills (Questions 28-34, 36, 37, 39 and 40) for a total score of 11. Cut-off scores for insulin users were: 4 and below=low, 5-8=medium and 9 and above=high.

15) Cognitive scores for insulin users (Questions 99-129) for a total score of 79. This cognitive score was applied to those patients on insulin. Cut-off scores for the three groups were: 16 and below=low, 27-52=medium, and 53 and above=high.

16) Cognitive scores for patients taking oral hypoglycemic agents or using diet alone to control their disease (Questions 51-98) totaled 48 points. Cut-off scores were: 16 and below=low, 17-32=medium, and 33 and above=high.

# CHAPTER III

## ANALYSIS AND INTERPRETATION OF DATA

Data was analyzed through IBM computer 300 using SAS program. First, the sample of diabetic patients was examined to define the demographic and clinical characteristics of the group. Then the proportions of scores relative to cognitive areas of knowledge of diabetes and clinical skills scores on both urine testing and insulin self-administration were summarized. Finally the hypotheses were tested for relationships in these data.

### A. Description of the Sample.

#### 1) Demographic characteristics.

This sample of 100 cases of diagnosed diabetics represents patients attending clinics in the Phoenix area. Many diabetic patients do not regularly attend clinics even though they have been diagnosed as having diabetes through the National Institutes of Health (NIH) services biannual physical examinations. It is probable that this sample selects for clinic attendees and many cases of diabetes of varying severities are omitted from inclusion.

Demographic information concerning the sample is summarized in Table 2..

Table 2. Description of Sample by Demographic Variables.

| | | | |
|---|---|---|---|
| Age | $\bar{X}$=43.53<br>Md=44.00 | SD=8.8 | Range 38 (21-59 yrs) |
| Sex | Males 27% | Females 73% | |
| Education | Md=8th grade | | |
| Income | Md=$4,500 per year | | |

The youngest diabetic patient was 21 and the oldest 59 years of age. It had originally been planned to exclude people over 50 years; however, the patient group was very cooperative and most anxious to be included in the study. Therefore, patients were not refused entry into the research on account of age. The ratio of male to female, 1:3, possibly is a selection bias due to more females attending clinic than the male population, an observation which had been made by the researcher. Due to the sample being non-random, this may not be typical of the distribution of diabetes by sex. In general this sample reflects a low socio-economic status (SES) group with a median education of grade 8 and a median income of $4,500 a year. The tribal director was included in the sample. His income bracket is highest in the group and he was the only Pima Indian who had completed a college education. The tribal director is obviously atypical of this selected population.

2) Clinical characteristics.

Clinical variables were then extrapolated and quantified in Table 3.

Table 3. Description of Sample by Clinical Variables.

| | | | |
|---|---|---|---|
| Fasting blood sugar (FBS) | $\bar{X}$=203.4 | s.d.=59.5 | range 323 mg% (105-428) |
| Percent ideal body weight | $\bar{X}$=149% | s.d.=27.8% | range 168% (105-273%) |
| Percent with insulin Rx | 43% | | |
| Percent with dietary Rx | 36% | | |
| Percent with Rx for oral hypoglycemic agent. | 21% | | |
| Percent with pathology of lower extremities. | 58% - 2% amputations<br>41% loss of sensation<br>12% ulcers<br>3% both LOS and ulcers | | |

Examination of Table 3 shows a mean level of FBS which is 203 mg% - well above the diagnostic level of 140 mg%. The highest FBS in the study is 428 mg%. Percent ideal body weight (see pg. 25 for definition) mean is 149% indicating that the sample on the average suffers from obesity where even the lowest value is 5% above the ideal body weight. Fifty-seven percent of the cases were independent of insulin administration. Nearly 69 percent of the sample had demonstrable peripheral neuropathy and/or pathology. Two out of the 100 patients had had amputations of the lower extremities which were <u>not</u> due to accidental injury.

Patients in the sample attended four difference clinics where it was possible to receive educational instruction for the disease. The distribution of proportion of patients attending the clinic and years since diabetes instruction had been experienced are shown in Tables 4a and 4b.

Table 4a Clinics Where Patients Received Instruction on Management of Diabetic Condition.

| | | |
|---|---|---|
| 1. | PIMC (central location) | 43% |
| 2. | Salt River (east) | 20% |
| 3. | Sacaton (south) (11% of clinic population had an organized ongoing program of diabetes management, initiated in 1975) | 33% |
| 4. | Other | 4% |

Table 4b Years Since Diabetic Instruction of Any Kind, Individual or Group, was Given to Patients.

| | | |
|---|---|---|
| 1. | One year or less. | 36% |
| 2. | More than one year, but less than two. | 11% |
| 3. | Two and four years. | 8% |
| 4. | Four years. | 26% |

Tables 4a and 4b show that 43% of cases included in this sample attended the centrally located PIMC clinic and 20% attended Salt River. Only seven patients attended other clinics including Gila Crossing. It is clear that over 25% of these patients reported not receiving any individual or group instruction about their condition for over four years. It was questioned if this need for instruction was irrelevant, due to length of duration of disease being so short that 20% of patients had no need of information. Table 5 shows proportion of patients who had suffered from diabetes mellitus for various lengths of time.

Table 5. Proportion of Patients Having Diagnosed Diabetes Mellitus by Years of Duration of Disease in Pima Indians.

| LENGTH OF TIME | PERCENT |
|---|---|
| 3 years and less | 31% |
| More than 3 years and less than 7 | 11% |
| 7 years and over | 58% |
| Md=8 years range=37 (1-38) | |

All cases included in the study had had their diagnosis for over a year and lack of instruction was not due to lack of need. Most patients, 58% percent, had had their disease over four years with a median length of time of 8 years.

3) Description of Patient Scores on Questionnaire.

The questionnaire scores were divided into parts relevant to cognition and application of skills. Cognitive scores were defined as general knowledge of the diabetic condition, cognitive knowledge of the use of insulin (insulin users only), cognitive knowledge of diet (all patients) and scores from demonstration of administration of insulin (insulin users only by definition).

These scoring methods are listed below:

| | | | |
|---|---|---|---|
| a) Cognitive scores: | 1) | General knowledge | n=100 |
| | 2) | Knowledge of insulin action and dosage | n=43 |
| | 3) | Knowledge of diabetic diet | n=100 |
| b) Skills knowledge: | 1) | Scores from testing urine | n=100 |
| | 2) | Scores from administration of insulin | n=43 |

The scores were ranked as high, middle and low, or high/low by dividing the total possible score into thirds or halves as described in data processing (p. 26).

The scores on cognitive knowledge are shown in Table 6.

Table 6. Cognitive Ranked Scores of Diabetic Pima Indians from Questionnaire Concerning Their Disease.

| | SCORES | | |
|---|---|---|---|
| | Low | Middle | High |
| 1. General knowledge of diabetes mellitus - n=100 | 33% | 37% | 30% |
| 2. Knowledge of insulin action and dosage - n=43 | 30% | 33% | 37% |
| 3. Knowledge of diabetic diet n=100 | 37% | 20% | 43% |

In general the scores are equally divided between the low, middle and high group in all cognitive areas. There seems to be a higher percentage, 43%, for dietary knowledge than for other areas. Proportional scores for skills are shown in Table 7.

Table 7. Ranked Scores on Urine Testing Skills and Insulin Administration Skills of Diabetic Pima Indians.

| | RANKED SCORES | | |
|---|---|---|---|
| | Low | Middle | High |
| Urine testing skills scores n=100 | 73% | 12% | 15% |
| Insulin administration skills scores (insulin users) n=43 | 33% | 28% | 40% |

The proportion of patients scoring low (less than two-thirds of total possible score) on urine testing skills is 73%. This is due in part to the large numbers of zero scores included in this ranking, a score which reflects total inability to test the urine for sugar. No one knew how to test urine for the presence of ketones, including those patients taking insulin. Through clinical observation it has been noted that the Pima Indian can tolerate excessive blood sugar levels and not suffer from diabetic coma. This is in contrast to Caucasian groups who more easily show signs of impending coma at lower levels of blood sugar. Accordingly, emphasis on urine testing as a method of control has been considered less important for the Pima diabetic. This seems to be reflected in these data.

B. Testing Relationships of Knowledge Scores to Selected Variables.

1) Demographic Variables: Main Effects.

In order to test the main effect of knowledge in demographic variables of age, sex, level of education and income, several correlation coefficients were generated through the SAS program which are summarized in Table 8.

Table 8. Correlation of Cognitive Scores with Demographic characteristics of diabetic Pimas.

| | SCORES | | |
|---|---|---|---|
| Demographics | General Knowledge n=100 | Dietary Knowledge n=100 | Knowledge of Insulin n=43 |
| Age | r=0.01 (p=0.85) | r=0.05 (p=0.61) | r=0.09 (p=0.32) |
| Education | r=.14 (p=0.16) | r=.17 (p=0.09) | r=-0.07 (p=0.48) |
| Insulin | r=.17 (p=0.10) | r=.18 (p=0.07) | r=-.02 (p=0.85) |

The variable of sex and relationship to knowledge scores was also non-significant as shown in Tables 9a and 9b.

Tables 9a and 9b. The relationship of sex to knowledge scores of diabetic Pimas.

9a. Dietary Knowledge.

| | SCORES | | | |
|---|---|---|---|---|
| | Low | Mid | High | |
| Sex | | | | |
| M | 6 | 11 | 10 | 27 |
| F | 33 | 34 | 33 | 73 |
| Total | 39 | 46 | 43 | 100 |

$X^2=1.98$
df=2
p=0.3718 ns

9b. Insulin Knowledge.

| | SCORES | | | |
|---|---|---|---|---|
| | Low | Mid | High | |
| Sex | | | | |
| M | 3 | 5 | 3 | 11 |
| F | 11 | 7 | 14 | 32 |
| Total | 12 | 12 | 17 | 43 |

$X^2=2.32$
df=2
p=o.52 ns

2) Clinical Variables: Main Effects.

To list the main effect of knowledge in clinical variables of FBS, duration of diagnosis, percent ideal body weight (IBW) and years since receiving diabetes instruction, several correlation coefficients were obtained and are compared in Table 10.

Table 10. Correlation between clinical variables and knowledge scores in diabetic Pima Indians.

| | SCORES | | |
|---|---|---|---|
| Clinical Variables | General Knowledge n=100 | Dietary Knowledge n=100 | Knowledge of Insulin n=43 |
| FBS | r=0.22 (p=0.03*) | r=.23 (p=0.02*) | r=0.04 (p=0.78) |
| Duration of Disease | r=0.27 (p=0.006**) | r=0.17 (p=0.09) | r=-0.08 (p=0.42) |
| Percent IBW | r=0.06 (p=0.54) | r=0.04 (p=.68) | r=-0.12 (p=0.23) |
| Yrs since Diabetes Instruction | r=0.21 (p=0.04*) | r=-0.023 (p=0.02*) | r=-0.05 (p=0.59) |

There is a positive correlation between general knowledge of diabetes, knowledge of diet and the FBS levels at $\alpha=0.05$. General knowledge scores reflect the facts known by patients concerning general characteristics of their diabetic disease, its non-curable status, its sequelae, its heritable tendencies, and influence of life style. Dietary information includes selection of food stuffs especially in relationship to cultural mores. It would seem reasonable to expect dietary knowledge to influence blood sugar levels. This study indicates that knowledge of diet is not being applied, in fact, that knowledge is not being translated into behavioral activities. It will be recalled that this population is obese. Also, lack of application of knowledge to behavior is substantiated by the significance and correlation between FBS and general knowledge ($r=0.22$, $p=0.03$*); however, these data do not support Watkins' observations that improved knowledge lowers FBS levels and so improves control of the disease.

Insulin knowledge and FBS have no significant effects. The relationship of FBS to type of prescription was questioned in order to substantiate that FBS levels were the same regardless of the need for insulin therapy and that general and dietary knowledge scores were not influenced only by the patients on insulin. The following Table was generated.

Table 11. Association between levels of fasting blood sugar and prescription for control of diabetes.

| FBS | PRESCRIPTION: Dietary Rx | Oral Rx | Insulin Rx | |
|---|---|---|---|---|
| Low 140 | 2 | 2 | 4 | 8 |
| Mid 140-180 | 18 | 10 | 18 | 46 |
| High 200 | 17 | 8 | 21 | 46 |
| Total | 37 | 20 | 43 | 100 |

$X^2=1.020$
df=4
p=0.9087 ns

There is no significant difference in blood sugar levels of insulin users and non-insulin users. This could mean that patients on either prescription were equally well (or poorly) controlled and knowledge was indeed influencing the FBS levels but adversely i.e., high scores mean high FBS.

Nickerson (1972) had described the relationship to increased duration of the disease with the occurrence of less knowledge. In this study, knowledge of diet and insulin action is non-significant but the direction of the relationship is negative as Nickerson reported. In the Pima people general knowledge increases with duration of diagnosis which is antagonistic to Nickerson's research; but it must be recalled that general knowledge does not have much emphasis on skills in management of the disease. Among these Indian people, when years pass without receiving instruction about diabetes, then general knowledge is seriously jeopardized ($r=0.21$, $p=0.04$).

3) Testing of the specific hypotheses.

Hypothesis #1 tests the relationship between the main effect of knowledge on disease severity as defined by levels of management of diabetes, 1) by prescription of diet, 2) oral hypoglycemics, or 3) insulin medication in Table 12.

Table 12. Relationship of scores on general knowledge of diabetes and prescription for control of the disease in Pimas.

| Score on General Knowledge | PRESCRIPTION: Dietary Management | Oral Hypoglycemics | Insulin Rx | |
|---|---|---|---|---|
| Low | 22 | 12 | 19 | 53 |
| Mid | 8 | 6 | 18 | 32 |
| High | 7 | 2 | 6 | 15 |
| Total | 37 | 20 | 43 | 100 |

$X^2=4.427$
df=4
p=0.3513 ns

These data suggest that there is no increase in general knowledge scores according to the treatment prescribed to control diabetes. Knowledge of diet and prescription for control showed the same non-significant results, Table 13.

Table 13. Relationship between scores of knowledge of diet and prescription for disease amongst diabetic Pimas.

| Score on Dietary Knowledge | PRESCRIPTION: Dietary Rx | Oral Rx | Insulin Rx | |
|---|---|---|---|---|
| Low | 22 | 12 | 19 | 53 |
| Mid | 8 | 6 | 18 | 32 |
| High | 7 | 2 | 6 | 15 |
| Total | 37 | 20 | 43 | 100 |

$\chi^2 = 4.427$
df=4
p=0.3513 ns

The hypothesis in type of prescription and knowledge of insulin was not tested because non-insulin users had no knowledge of insulin - its dosage, its action or its relevance to the diabetic condition. The difference in insulin knowledge by prescription is therefore extremely wide and the influence on management of this variable requires further investigation.

Hypothesis #2 tests the association between general knowledge scores and the occurrence of peripheral complications defined as LOS (loss of Sensation) and "others", (skin infections, ulcers, abrasions, and amputees). No relationship of general knowledge scores and the occurrence of these types of sequelae can be established, Table 14.

Table 14. Association of scores on general knowledge and peripheral complications.

| General knowledge Score n=100 | Peripheral Complications: None | Los | Other | |
|---|---|---|---|---|
| Low | 20 | 10 | 3 | 33 |
| Middle | 17 | 14 | 6 | 37 |
| High | 16 | 8 | 6 | 30 |
| Total | 53 | 32 | 15 | 100 |

$\chi^2=2.703$
df=4
p=0.61 ns

Peripheral neuropathy had no correlation with the use of insulin ($p=0.18$) compared to other prescriptions.

Association of complications of lower extremities commonly encountered in diabetes with other cognitive areas concerning knowledge of insulin and knowledge of diet were now investigated, Tables 15a and 15b.

Tables 15a & 15b. Association between lower extremity complications and cognitive scores of diabetic Pimas.

Table 15a.

| Scores on Diet Knowledge | PERIPHERAL COMPLICATIONS NONE | LOS | OTHER | |
|---|---|---|---|---|
| Low | 22 | 9 | 2 | 33 |
| Mid | 11 | 16 | 7 | 34 |
| High | 20 | 7 | 6 | 33 |
| Total | 53 | 32 | 15 | 100 |

$X^2 = 10.787$
$df=4$
$p=0.029*$

Table 15b.

| Scores on Insulin Knowledge | PERIPHERAL COMPLICATIONS NONE | LOS | OTHER | |
|---|---|---|---|---|
| Low | 34 | 8 | 11 | 53 |
| Mid | 14 | 4 | 14 | 32 |
| High | 9 | 2 | 4 | 15 |
| Total | 57 | 14 | 29 | 100 |

$X^2=7.636$
df=4
p=0.27

There is a significant association in this population between dietary scores and peripheral complications of the lower extremities, mainly loss of sensation.

Blood sugar levels go up with general knowledge; also dietary knowledge has a negative correlation with years since education. Both these variables of dietary knowledge and FBS may effect the occurrence of sequelae of peripheral complications and this may confound the relationship of this variable with dietary scores.

The following tables show the association of both blood sugar levels and years since education in (lower) peripheral complications (PN).

Table 16. The association of peripheral (lower extremity) complications and fasting blood sugar levels in Pimas.

| | PERIPHERAL COMPLICATIONS | | | |
|---|---|---|---|---|
| FBS | NONE | LOS | OTHER | |
| Low | 5 | 3 | 0 | 8 |
| Mid | 25 | 18 | 3 | 46 |
| High | 23 | 11 | 12 | 46 |
| | 53 | 32 | 15 | 100 |

$X^2=9.151$
df=4
p=0.05*

Table 17. The association of peripheral (lower extremities) complications and years since education for diabetic control in Pima Indians.

| FBS | PERIPHERAL COMPLICATIONS | | | |
|---|---|---|---|---|
| | NONE | LOS | OTHER | |
| Low | 22 | 20 | 8 | 50 |
| Mid | 17 | 10 | 6 | 33 |
| High | 14 | 2 | 1 | 17 |

$X^2=7.945$
df=4
p=0.08

Peripheral complications (PN) of the lower extremities particularly LOS (loss of sensation), is not associated with years since educational instruction, PN is, however, significantly associated ($p=0.05^*$) with FBS. This finding has been supported by other researchers. In this study knowledge of diet is associated with FBS levels as well as peripheral complications.


The effects of dietary knowledge on PN is confounded by FBS. It would seem that dietary knowledge, when effective, should decrease FBS which in turn would decrease the sequalae of diabetes mellitus; small cell sizes would not permit tables to control for these effects.

Hypothesis #3 postulates no association between knowledge scores and clinic placement and this association was tested in Table 18.

Table 18. The association between place of clinic attendance and general knowledge score in diabetic population.

| General Knowledge Score | PLACE OF DIABETES CLINIC | | | |
|---|---|---|---|---|
| | PIMC | SACATON | SALT RIVER | |
| Low | 14 | 6 | 11 | 31 |
| Mid | 14 | 15 | 5 | 34 |
| High | 15 | 12 | 1 | 28 |
| Total | 43 | 33 | 17 | 93 |

$X^2=12.599$
df=4
p=0.0139**

General knowledge scores are highest in PIMC, the central clinic and fairly high in Sacaton which has had an ongoing formal instructional program since 1975. Why the difference in general knowledge exists between the clinics is perplexing. Further analysis showed that the difference persisted between clinics regarding the scores for dietary knowledge (see Table 19) and scores for insulin knowledge. The $X^2$ test in both tables, although significant, must be assessed with caution due to small cell sizes.

Table 19. Relationship of scores on dietary knowledge and place of clinic attendance.

| Scores on Dietary Knowledge | PIMC | SACATON | SALT RIVER | |
|---|---|---|---|---|
| Low | 15 | 5 | 11 | 31 |
| Mid | 9 | 19 | 3 | 31 |
| High | 19 | 9 | 3 | 31 |
| Total | 43 | 33 | 17 | 93 |

$X^2=20.52$
df=4
p=0.0004**

Table 20. Relationship of insulin knowledge group to place of clinic attendance.

| Score on Insulin Knowledge | PLACE OF CLINIC: PIMC | SACATON | SALT RIVER | |
|---|---|---|---|---|
| Low | 5 | 3 | 4 | 12 |
| Mid | 2 | 8 | 1 | 11 |
| High | 13 | 1 | 1 | 15 |
| Total | 20 | 12 | 6 | 38 |

$X^2=18.509$
df=4
p=0.001**

Scores in all areas of knowledge were significantly different in the places where the patients received their diabetic education. Scores are influenced by blood sugar levels, duration of illness, and years since receiving any education. None of these factors showed any significant differences when examined for between clinic associations (FBS, $p=0.34$, duration of illness, $p=0.47$, and years since education, $p=0.23$).

It is interesting that the age of the clinic attendees is slightly different by clinic in table 21. Salt River has a younger (45 years) group of patients. This variable has not been shown to influence knowledge scores in this population.

Table 21. Relationship of age to clinic attended by diabetic Pimas.

| | CLINIC | | | |
|---|---|---|---|---|
| Age in years | PIMC | SACATON | SALT RIVER | |
| ≤ 45 | 11 | 12 | 11 | 34 |
| 45+ | 32 | 21 | 6 | 59 |
| Total | 43 | 33 | 17 | 93 |

$X^2=8.042$
df=2
p=0.02*

As far as the data can reveal, it would seem that educational opportunities of the Pimas concerning the disease of diabetes mellitus is not equally available at each clinic. The highest scores in all areas of knowledge is found at the PIMC central clinic followed by the Sacaton clinics. Although fewer patients attend Salt River clinics, scores in all cognitive areas were consistently lower where they have a slightly younger population.

The final hypothesis #4 states that the cognitive areas of knowledge concerning general knowledge of diabetes mellitus, knowledge of dosages and action of insulin and knowledge of diet and its effective management will have no correlation with applied skills, i.e., urine testing and administration of insulin. Users of insulin in this sample totaled 43. The association of this group of patients skills with the cognitive scores on insulin use is shown in Table 22.

Table 22. Association between cognitive scores of insulin usage and scores on skills of insulin administration in diabetic Pimas.

| Cognitive scores on knowledge of insulin | SKILLS SCORE ON INSULIN ADMINISTRATION | | | |
|---|---|---|---|---|
| | LOW | MID | HIGH | |
| Low | 5 | 5 | 3 | 13 |
| Mid | 6 | 5 | 3 | 14 |
| High | 4 | 4 | 8 | 16 |
| Total | 15 | 14 | 14 | 43 |

$X^2=3.600$
df=4
p=0.46

It would seem that in this population the knowledge displayed in answering questions about insulin use have little relationship to skills in the administration of insulin injections. Non-insulin users were not exposed to the need to give themselves injections, but both insulin users and non-insulin users were examined on their ability to test their aliquots of urine. Most insulin users on the whole scored low on testing urine (see Table 23).

The researcher observed that patients on the group of non-insulin users were completely unable to test their urine - they had no knowledge of urine testing when their disease was controlled by dietary or oral hypoglycemic agents.

Table 23. Relationship between non-insulin users and insulin users and their skills in urine testing.

| Prescription for diabetic control | SCORES ON URINE TESTING SKILLS | | |
|---|---|---|---|
| | LOW | HIGH | |
| Non-insulin | 57 | 0 | 57 |
| Insulin users | 26 | 17 | 43 |
| Total | 83 | 17 | 100 |

The association of urine testing skills to general knowledge scores is illustrated in Table 24.

Table 24. The relationship between general knowledge scores and scores of urine-testing skills in diabetic Pimas.

| General knowledge scores | SCORES ON URINE TESTING: LOW | HIGH | |
|---|---|---|---|
| Low | 26 | 3 | 29 |
| Mid | 19 | 8 | 27 |
| High | 38 | 6 | 35 |
| Total | 83 | 17 | 100 |

$X^2=0.938$
df=2
p=0.63

# CHAPTER IV

## CONCLUSIONS AND RECOMMENDATIONS

This study of 100 cases of diabetes mellitus in Pima people attending clinics in the Phoenix area, has shown that these patients are obese, and have elevated FBS levels which are far above normal. Forty-three percent of these patients are on prescribed insulin and 57 percent have peripheral complications of the lower extremities. It is clear that medical prescription is not adequately controlling diabetes in this population. Perhaps this is not only a matter of efficiently treating the disease but, from this study appears to be lack of patient compliance - lack of behaviors which are therapeutic. Lack of compliance may be associated with inadequate knowledge about diabetes mellitus and its control. These data show that only about a third of these patients scored high ($\geq$66%) on general knowledge which includes heritable and cultural influences, and only a third scored high in knowledge of insulin action and dosage. One third scored high on dietary knowledge, but less than 20 percent had any knowledge or skills for testing the urine sugar. Most of these patients denied being introduced to the term "ketones" or "acetone" and were unable to test aliquots of urine for this metabolite. This was particularly true when patients were on dietary and oral hypoglycemic medications.

Knowledge scores varied significantly by place of clinic attendance of the Pimas. Salt River had consistently low scores for their comparatively young population whereas Sacaton and particularly PIMC scored highest in all areas of knowledge. It must be emphasized that mean knowledge scores in all clinics were below average, i.e., below 50 percent of total possible scores, but they were highest where fairly consistent instruction was already employed in the clinics at PIMC and Sacaton. These data indicate that the questionnaire is sensitive to the impact of instructional programs for the diabetic Pimas.

Peripheral complications (PN) of the lower extremities were significantly associated with scores on dietary knowledge, patients scoring highest more frequently had no complications. Dietary knowledge was also significantly associated with FBS, fasting blood sugar levels, a variable which was associated with PN (peripheral neuropathy). It is clear that knowledge is not affecting behavior regarding control of the disease through dietary regimes which is also effecting the occurrence of PN. This evidence suggests that dietary knowledge when accompanied by appropriate behavioral changes should decrease blood sugar levels and the concordant peripheral complications.

This study showed no association between knowledge of skills and cognitive knowledge scores. This was particularly obvious between insulin users administration skills and knowledge, and general knowledge and urine testing. Though this may be directly a result of the type of

questions in each section of cognitive knowledge, nevertheless the fact that knowledge and skills do not correlate in this study show inability to associate knowledge with therapeutic activities.

Recommendations for the content and emphasis of future educational programs for the diabetic Indian would be as follows:

1) Dietary knowledge.

This score included knowledge of suitable food stuffs, particularly those foods available to the Pima. Dietary knowledge not only influences FBS and associated peripheral neuropathy, but also influences obesity. Biochemically, insulin stores fat and therefore obesity is more difficult to control when patients use insulin. The importance of dietary regulation can't be overemphasized and this area of concern requires maximum attention.

2) Urine testing is an important method of involving patients in self-care. It provides a daily visual aid to document control of diabetes and can be an important measure of behavioral change which may accompany increased cognitition.

3) Knowledge of insulin action.

This area of cognitive knowledge is an important part of understanding both the disease and the reason for the imperatives for control of the disease.

4) It is important to formalize the educational programs for these patients. This study documents that it is particularly desirable to identify educational knowledge which specifically relates to compliance behaviors.

Future research studies should include the application of education programs emphasizing the recommended content areas to this group of diabetic patients, especially for the attendees at Salt River clinic. Based on data from this study, repeat testing would measure the impact of such programs. These data imply that this questionnaire would be an effective instrument when used for this purpose. The study should also include some new methods to measure behavioral changes which may be associated with knowledge scores. In this population no demographic variables, not even age or educational level (which was mainly 8th grade) influenced knowledge scores. This may indicate that knowledge required by diabetic patients is highly specialized and requires special programming for patients. The data substantiates the desirability of structuring complete educational programs for the Pima patients.

Future research should also consider applying urine testing as a method of assessing nursing skills in patient teaching and as a method of measuring, first, patient compliance and second, the association of urine testing with knowledge scores. This study could be performed in tandem with medical investigation to establish the role of urine testing to patient care. The proposed research would also correlate information

on urine testing with other measures of established validity, such as the FBS and the HgbAlc test for measuring glucose levels in the red cell. Sensitivity and specificity rates could be generated to establish the usefulness of these parameters to measure compliance with both medical and nursing care recommendations.

Finally, this study of knowledge of diabetes in the Pimas identified some important correlations of knowledge scores to clinical variables. Watkins (1967) had asserted that FBS levels are inversely related to knowledge, but this study does not support her observations.

It is pertinent to reaffirm that the questionnaire appears to be an effective instrument and the data was collected by interview after a pilot study to insure patient understanding. Therefore the discrepancy between these results and Watkins is not due to instrument failure. Rather it is the important inductive leap from knowledge to practical application of the facts which is the important intervening variable which must be considered. These data suggest that in diabetic Pimas, this is an acute problem which must be addressed if instruction is going to be an effective part of care.

In summary, the diabetic Pima would benefit from consistent structured ongoing educational programs which would increase their knowledge and the management of their disease. These programs should stress the importance of behavioral changes which accompany increased

knowledge. At present the change from a cognitive to a behavioral frame of reference often fails to occur. If adequate control of this disease is maintained then the high prevalence of sequelae from diabetes and the accompanying obesity should be reduced. This can be accomplished through involvement of the Pimas in their own self-care. Through education, through interdisciplinary cooperation and theough medical and nursing research, the quality of life for the diabetic Indian can be improved.

# REFERENCES


1. BENNETT, P.H. Epidemiological Studies of Diabetes in the Pima Indians. Recent Progress in Hormone Research. 1976, 32:333-68

2. Disease Trends in Indian Health Service, 1974. Publication Health Education and Welfare USPHS, HSA, IHS, Division of Research Coordination Office of Program Statistics. pp 1-73

3. Ibid., p. 35-38.

4. BENNETT, P.H., 1976, Ibid., p. 335-36.

5. SELIGMAN, A. Level of Medical Information Among Clinic Patients. Journal of Chronic Diseases, 6:504, June, 1957.

6. ROSENBERG, S.G. Patient Education Leads to Better Care for Heart Patients. Health Services and Mental Health Administration. September 1971, Vol. 86, No. 9, 793-804.

7. SELIGMAN, 1957, Ibid., p. 508.

8. BEASER, S.B. Teaching the Diabetic Patient. Diabetes. 5, 146-9, 1956.

9. STONE, D.B. A Study of the Incidence and Causes of Poor Control in Patients with Diabetes Mellitus. American Journal of Medical Science. 241:64-69.

10. WATKINS, J., WILLIAMS, T.F. A Study of Diabetic Patients at Home. American Journal of Public Health. 57:452-57, 1967.

11. NICKERSON, D. Teaching the Hospitalized Diabetic. American Journal of Nursing. May, 1972, 935-938.

12. ETZWILER, D.D. What the Juvenile Diabetic Knows About His Disease. Pediatrics. 29:135-41, 1962.

13. SIMON J., STEWART, S. Assessing Patient Knowledge About Diabetes. The Mt. Sinai Journal of Medicine. Vol. 43:2 March/April 1976

14. WEST, K. Prevention and Therapy of Diabetes Mellitus. Nutrition Reviews. 3317, 193-B, 1975.

15. WILLIAMS, T.F., MARTIN, D.A., HOGAN, M.D., WATKINS, J.D., and ELLIS, J.V. The Clinical Picture of Diabetic Control: Studied in Four Settings. American Journal of Public Health. 57:441-51, 1967a.

REFERENCES (Cont'd)

16. WILLIAMS, T.F., ANDERSON, E., WATKINS, J.D., and COYLE, V. Dietary Errors Made at Home by Patients with Diabetes. Journal of American Dietary Association. 51:19-25, 1965b

17. HOLLAND, W.M. The Diabetes Supplement of the National Health Survey, IV. The Patient's Knowledge of the Food Exchanges. Journal of American Dietary Association. May, 1968, 52:388-99.

18. NICKERSON, 1972, Ibid., p. 937

19. Diabetes Course for Health Professionals. Sponsored by the American Diabetes Association, October, 1978.

20. ELLENBERG, M., RIFKIN, H.M. Diabetes Mellitus: Theory and Practice. McGraw Hill, Inc., 1970.

21. National Research Council American Academy of Science, Conversion Table for Calculation of Desirable Weights for Adults (age 15 and over), 1976.

# BIBLIOGRAPHY

BENNETT, P.H., MILLER, M., BURCH, T.A. Prevalence of Diabetes Mellitus in the American Indians; Results of Glucose Tolerance Tests in the Pima Indians of Arizona. Diabetes, 14:439, 1965.

MILLER, L.V., GOLDSTEIN, J. and NICOLAISEN, G. Evaluation of Patients' Knowledge of Diabetes Self-Care. Diabetes Care. V:5, 275-80, 1978.

MYERS, S.A. Diabetes: Patient Education and Care. The Nursing Clinics of North America. Vol. 2:3, September, 1977.

SKILLMAN, T., TZAGOURNIS, M. Diabetes Mellitus. Upjohn Company, 1973.

SKYLER, J.S., "Control" and Diabetic Complications. Diabetes Care. 1:3;204 1978.

WEST, K. Diabetes in American Indians and Other Native Populations of the New World. Diabetes. 23:841-55, October, 1974.

# APPENDIX A

## CONSENT FORMS

UNITED STATES GOVERNMENT

# memorandum

DATE: 13 March 1979

REPLY TO ATTN OF: Chairman, Phoenix Area IHS Research & Publications Committee

SUBJECT: Proposed Survey

TO: Jean Koopman, R. N., Head Nurse/Clinical Specialist, PCRS (PIMC)

1. I have reviewed your proposal for an assessment of "Knowledge of Diabetes Mellitus in the Pima Indians of Arizona."

2. The proposed evaluation is to be done entirely within the Public Health Service and only PHS personnel are involved. Its purpose is primarily programatic, and is subject to the usual administrative controls. There is no identifiable risk to participants. In essence, information obtained by interviewer will be evaluated for relationships between knowledge of diabetes and the severity of the illness and the occurrence of complications. A stated purpose is to utilize the information for development of an effective instructional program for Pima Indians.

3. On the basis of all the considerations, the survey does not require the approval of the Area Research Committee. However, the customary administrative clearances will be necessary.

[redacted]

Maurice L. Sievers, M. D.

I, _____ herewith agree to serve as a subject in the investigation of Knowledge of Diabetes Among the Pima Indians of Central Arizona by Dr. Katherine Chavigny, faculty advisor of the University of Oregon Health Sciences Center. The investigation aims to find out what the knowledge the Pima Indian patients have about their disease.

It is my understanding that I will be asked to answer questions about diabetes, go through the motions of administering insulin, and test a sample of solution to resemble urine. The time it will take is about forty-five minutes.

All information that I give will be handled confidentially. My name and hospital number will not be used to identify my questionnaire.

I may not receive direct benefit from participating in this study immediately, however, it is my understanding that the results from this study will be used to assist in the development of a diabetes instructional program which may eventually benefit me.

Jean Koopman, R.N., has offered to answer any questions I might have about this study.

I understand I am free to refuse to participate or to withdraw from this study at any time wtihout this decision affecting my receiving medical treatment.

I have read the above explanation and agree to participate as a patient in this study described.

Date_____ Signature_____

Witness_____

# APPENDIX B

# INSTRUMENT

# PATIENT ASSESSMENT

PART I.

## DEMOGRAPHIC DATA

1. Date of birth:

2. Duration of diabetes (years):

3. Sex:

   0=Male
   1=Female

4. Income level:

   0=4,000
   1=5-8,000
   2=9-12,000
   3=13-16,000
   4=16,000 and over

5. Education level:

   0=grades 1-6
   1=grades 7-9
   2=grades 9-12
   3=beyond high school

## LEVEL OF CONTROL

6. Fasting blood sugar:

7. Urine sugar:

   0=Negative
   1=One plus
   2=Two plus
   3=Three plus
   4=Four plus

8. Urine acetone:

   0=None
   1=Small
   2=Moderate
   3=Large

9. Urine protein:

   0=None
   1=Trace
   2=One plus
   3=Two plus
   4=Three plus

10. Height (Cm.):

11. Weight (Kg.):

12. %Desirable weight:

13. Insulin? Dose_____

   0=None
   1=up to 19u/day
   2=up to 39u/day
   3=up to 59u/day
   4=up to 79u/day
   5=up to 99u/day
   6=100u+/day

14. Oral diabetic medication:

   0=None
   1=Tolbutamide (Orinase)
   2=Chlorpropamide (Diabinese)
   3=Acetohexamide (Dymelor)

15. Current medications (specify):

   0=None of the following
   1=Oral contraceptives
   2=Diuretics or other antihypertensives
   3=Corticosteroids
   4=Salicylates
   5=A digitalis preparation

16. Control with diet alone:

0=yes
1=no

17. Diabetes Education:

0=PIMC
1=Sacaton
2=Gila Crosssing
3=Salt River
4=Other

18. Type of instruction:

Patient Status.
0=As inpatient
1=As outpatient
2=Both
3=None of the above

19. Organized program of instruction in Sacaton:

0=yes
1=no

20. Incidental type of instruction:

0=yes
1=no

21. Number of years since diabetes education:

0=Less than one
1=More than one but less than two
2=More than two but less than three
3=More than three but less than four
4=More than 4

22. Planned exercise (one done most frequently):

0=None
1=Walk
2=Jog
3=Bicycle
4=Sports such as baseball etc.

23. Frequency of exercise:

    0=None
    1=Daily
    2=3-6x/wk
    3=1-2/wk

24. Family members who have diabetes:

    0=None
    1=One member
    2=Two members
    3=Three members
    4=Four members or more

ASSESSMENT OF FEET

25. Loss of sensation:

    0=None
    1=Rt foot
    2=Lt foot
    3=Both feet

26. Areas of pressure:

    0=None
    1=Ulcers
    2=Corns
    3=Calluses
    4=Combination of 1, 2 & 3
    5=Combination of 1 & 2
    6=Combination of 1 & 3
    7=Combination of 2 & 3

27. Amputation:

    0=None
    1=Rt foot
    2=Lt foot
    3=Both feet

PART II.

SELF ASSESSMENT SKILLS

SELF ADMINISTRATION OF INSULIN

28. Washes hands well:

    0=Yes
    1=No

29. Handles part of syringe appropriately:

    0=Yes
    1=No

30. Cleanses stopper of bottle:

    0=Yes
    1=No

31. Rotates bottle of insulin:

    0=Yes
    1=No

32. Draws plunger back to the correct number of units, injects this amount of air into syringe:

    0=Yes
    1=No

33. Withdraws correct amount of insulin:

    0=Yes
    1=No

34. Expels all air bubbles:

    0=Yes
    1=No

35. Cleanses site of injection:

    0=Yes
    1=No

36. Pinches skin:

    0=Yes
    1=No

37. Pulls back on plunger to check if blood returns:

    0=Yes
    1=No

38. Gently massages area after injection:

    0=Yes
    1=No

URINE TESTING TECHNIQUE

39. Test urine at home for sugar:

    0=Yes
    1=No

40. Tests according to directions for method:

    0=Yes
    1=No

41. Patients interpretation correct:

    0=Yes
    1=No

42. Patient checked reading with color chart:

    0=Yes
    1=No

43. Tests urine at home for ketones:

    0=Yes
    1=No

44. Understands significance of ketones/acetone:

    0=Yes
    1=No

45. Tests according to directions:

    0=Yes
    1=No

46. Patients reading correct:

    0=Yes
    1=No

47. Checked reading with color chart:

    0=Yes
    1=No

DIABETES MELLITUS GUIDED QUESTIONNAIRE

PART III.

GENERAL KNOWLEDGE OF DIABETES

PERSONS WHO HAVE DIABETES

48. Don't make enough insulin:

0=Yes
1=No
2=Don't know

49. Don't make enough sugar:

0=Yes
1=No
2=Don't know

DIABETES IS GENERALLY THOUGHT TO BE

50. A disease you can catch from someone else:

0=Yes
1=No
2=Don't know

51. A disease passed on by your parents/grandparents:

0=Yes
1=No
2=Don't know

THOSE PERSONS MORE LIKELY TO HAVE DIABETES ARE

52. American Indians

0=Yes
1=No
2=Don't know

53. People who are overweight and over 40 years of age.

0=Yes
1=No
2=Don't know

PERSONS WITH DIABETES

54. Can be cured by losing weight:

0=Yes
1=No
2=Don't know

55. Can get better by losing weight:

0=Yes
1=No
2=Don't know

THE POSSIBLE COMPLICATIONS OR THINGS THAT CAN GO WRONG WITH YOUR BODY WITH DIABETES ARE

56. Poor eyesight.

0=Yes
1=No
2=Don't know

57. Bad kidneys:

0=Yes
1=No
2=Don't know

58. Gangrene and possible loss of a foot or leg:

0=Yes
1=No
2=Dont' know

PERSONS WITH DIABETES SHOULD WORK

59. The same as people without diabetes:

0=Yes
1=No
2=Don't know

60. Only at jobs that require "sitting at the desk."

0=Yes
1=No
2=Don't know

EXERCISE FOR PERSONS WITH DIABETES

61. Should be hard enough to work up a sweat:

0=Yes
1=No
2=Don't know

62. Is good and should be done every day:

0=Yes
1=No
2=Don't know

DIABETICS SHOULD TAKE GOOD CARE OF THEIR FEET BECAUSE

63. Diabetics may have poor circulation to their feet:

0=Yes
1=No
2=Don't know

64. Diabetics may have loss of feeling in their feet:

0=Yes
1=No
2=Don't know

65. Their doctor tells them it is important:

0=Yes
1=No
2=Don't know

LARGE AMOUNTS OF SUGAR IN THE URINE OF A DIABETIC MAY MEAN

66. Not enough insulin:

0=Yes
1=No
2=Don't know

67. An illness or infection:

0=Yes
1=No
2=Don't know

68. Eating too much food:

0=Yes
1=No
2=Don't know

KETONES MAY BE FOUND IN THE URINE WHEN

69. There is not enough insulin:

0=Yes
1=No
2=Don't know

70. There is starvation-not enough food:

0=Yes
1=No
2=Don't know

71. There is an infection present:

0=Yes
1=No
2=Don't know

72. There is too much insulin:

0=Yes
1=No
2=Don't know

A DIABETIC TESTS HIS URINE FOR SUGAR BECAUSE

73. It tells them the level of sugar in their blood.

0=Yes
1=No
2=Don't know

74. It tells them if their body has enough insulin:

0=Yes
1=No
2=Don't know

KNOWLEDGE OF DIET

FOODS A DIABETIC SHOULD EAT ARE

75. Special foods for diabetics only:

0=Yes
1=No
2=Don't know

76. Foods the whole family can eat:

0=Yes
1=No
2=Don't know

PERSONS WITH DIABETES SHOULD

77. Have their food cooked separate from the rest of the family:

0=Yes
1=No
2=Don't know

78. Never eat the food they really like:

0=Yes
1=No
2=Don't know

79. Eat the same foods every day:

0=Yes
1=No
2=Don't know

80. Only eat foods labelled "low in sugar" or "no sugar":

0=Yes
1=No
2=Don't know

BEANS AND TORTILLAS

81. Are nutritious foods:

0=Yes
1=No
2=Don't know

82. Are high in starch:

0=Yes
1=No
2=Don't know

83. Are high in fat:

0=Yes
1=No
2=Don't know

WATERMELON IS

84. High in vitamins:

0=Yes
1=No
2=Don't know

85. High in sugar:

0=Yes
1=No
2=Don't know

THE COMBINATION OF CHEESE AND BEANS CAN FULFILL YOUR NEEDS FOR

86. Meat:

0=Yes
1=No
2=Don't know

87. Starch:

0=Yes
1=No
2=Don't know

88. Fat:

0=Yes
1=No
2=Dont' know

PERSONS WITH DIABETES SHOULD AVOID FRIED FOODS BECAUSE

89. They are high in fat:

0=Yes
1=No
2=Don't know

90. They are high in calories:

0=Yes
1=No
2=Don't know

91. They coat the stomach walls:

0=Yes
1=No
2=Don't know

HONEY IS A NATURAL SWEETNER AND IS

92. Safe for diabetics:

0=Yes
1=No
2=Don't know

93. High in calories:

0=Yes
1=No
2=Don't know

ALCOHOL DRINKS SUCH AS BEER, WINE, WHISKEY AND ALL OTHERS

94. Are high in calories:

0=Yes
1=No
2=Don't know

95. Can cause you to gain weight.

0=Yes
1=No
2=Don't know

KNOWLEDGE OF INSULIN

WHAT DOES INSULIN DO TO THE AMOUNT OF SUGAR IN YOUR BLOOD?

96. Increase:

0=Yes
1=No
2=Don't know

97. Decrease:

0=Yes
1=No
2=Don't know

IF YOU DIDN'T TAKE YOUR INSULIN WHAT WOULD HAPPEN TO THE AMOUNT OF SUGAR IN YOUR BLOOD?

98. Increase:

0=Yes
1=No
2=Don't know

99. Decrease:

0=Yes
1=No
2=Don't know

REGULAR INSULIN ACTS

100. Fast and lasts from 6-8 hours:

0=Yes
1=No
2=Don't know

101. Slowly and lasts up to 24 hours:

0=Yes
1=No
2=Don't know

NPH INSULIN ACTS

102. Slowly and lasts up to 24 hours:

0=Yes
1=No
2=Don't know

103. Fast and lasts from 6-8 hours:

0=Yes
1=No
2=Don't know

NPH INSULIN REACHES ITS PEAK ACTION (WORKS THE MOST)

104. In the late afternoon:

0=Yes
1=No
2=Don't know

105. In the late morning:

0=Yes
1=No
2=Don't know

WHEN IS IT POSSIBLE TO HAVE TOO MUCH INSULIN IN YOUR BODY?

106. By skipping your insulin:

0=Yes
1=No
2=Don't know

107. By eating too little food:

0=Yes
1=No
2=Don't know

108. By hard exercise:

0=Yes
1=No
2=Don't know

HOW WOULD YOU FEEL IF YOUR BODY HAD TOO MUCH INSULIN?

109. Weak:

0=Yes
1=No
2=Don't know

110. Sweaty:

0=Yes
1=No
2=Don't know

110. Hungry
0=Yes
1=No
2=Don't know

112. Nervous:

0=Yes
1=No
2=Don't know

AN INSULIN REACTION OR SHOCK IS CAUSED BY:

113. Too much insulin:

0=Yes
1=No
2=Don't know

114. Not enough food:

0=Yes
1=No
2=Don't know

EXCESS ALCOHOL INTAKE (BEER, WINE, WHISKY, ETC.):

115. Could cause a severe insulin reaction with a loss of consciousness:

0=Yes
1=No
2=Don't know

116. Could make you forget to eat:

0=Yes
1=No
2=Don't know

117. Is harmful and should be avoided:

0=Yes
1=No
2-Don't know

WHEN A DIABETIC BEGINS TO HAVE A REACTION, THEY SHOULD:

118. Immediately take some insulin:

0=Yes
1=No
2=Don't know

119. Immediately lie down and rest:

0=Yes
1=No
2=Don't know

120. Immediately eat something sweet:

0=Yes
1=No
2=Don't know

121. Begin to exercise:

0=Yes
1=No
2=Don't know

WHEN DIABETICS WHO TAKE INSULIN EVERYDAY SUDDENLY INCREASE THEIR EXERCISE, THEY WILL NEED:

122. To carry something sweet with them like a candy bar in case they feel an insulin reaction coming on.

0=Yes
1=No
2=Don't know

123. To remember that exercise may lower blood sugar:

0=Yes
1=No
2=Don't know

THINGS THAT CAN CAUSE THE SUGAR IN THE BLOOD TO INCREASE ARE:

124. Too much exercise.

0=Yes
1=No
2=Don't know

125. An illness or infection such as a cold, sore throat, boil, bad cut, and sore on your foot:

0=Yes
1=No
2=Don't know

126. Skipping your insulin:

0=Yes
1=No
2=Don't know

129. Identification number:

AN ABSTRACT OF THE CLINICAL INVESTIGATION OF

ELNA J. KOOPMAN

FOR THE MASTER OF NURSING

Date of receiving this degree: June 8, 1979

TITLE: KNOWLEDGE OF DIABETES MELLITUS IN THE PIMA INDIAN OF ARIZONA

Approved: _____

Katherine Chavigny, Associate Professor, Advisor

# ABSTRACT

For this research 100 cases of maturity onset Pima Indian diabetics were interviewed regarding their knowledge of diabetes mellitus. Mean age for the sample was 43 years. The sampling was non-random selected out for patients attending three diabetes clinics.

The results show that only about a third of these patients scored high ($\geq$66%) on general knowledge of the disease, insulin, its action and dosage and dietary knowledge; but less than 20 percent had any knowledge or skills for testing urine for sugar and ketones. Knowledge scores by clinic showed that these patients exposed to diabetes instruction already employed at two clinics scored higher in contrast to a clinic where diabetes instruction was almost non-existent. Peripheral complications (PN) of the lower extremities were significantly associated with scores on dietary knowledge. Dietary knowledge was also significantly associated with fasting blood sugar levels, a variable which was associated with PN. No association was shown between knowledge of skills and cognitive knowledge scores which show inability to associate knowledge with therapeutic activities.

These data suggest that for the diabetic Pimas, lack of knowledge of the disease is an acute problem which must be addressed through more effective organized programs of instruction which are vital to patient understanding and management of the disease.

# APPENDIX C

## ERRATA

IMPORTANT: Questionnaire must be typed.

Date Rec'd. _____

ORS I.D. No. _____

UNIVERSITY OF OREGON HEALTH SCIENCES CENTER
Committee on Human Research

# PROTECTION OF HUMAN SUBJECTS
# INITIAL REVIEW QUESTIONNAIRE

This information is needed to determine the human risks and potential benefits of the proposed research. The questionnaire is based on DHEW requirements for the protection of human subjects, UOHSC policy, and legal considerations. All research involving humans, regardless of funding, must be reviewed. NOTE: Current NIH regulations require that applications involving humans be reviewed by this institution within 60 days after the grant deadline. Please allow 6-8 weeks for the review process.

| Principal Investigator: (Last Name) | (First Name) | (Initial) | (Degree/Other) |
|---|---|---|---|
| Chavigny | Katherine | H. | Ph.D./R.N. |

| Department/Division | Rank/Academic Standing | School | Telephone | Building/Room # |
|---|---|---|---|---|
| Nursing | Associate Professor | SON | 225-7709 | EJH - 333 |

Research Project Title

KNOWLEDGE OF DIABETES AMONG THE PIMA INDIANS OF CENTRAL ARIZONA

| Funding Source or Sponsor, if any | I.D. No. assigned by funding source, if any |
|---|---|
| | |

## 1. DECLARATION THAT HUMAN SUBJECTS EITHER WOULD OR WOULD NOT BE INVOLVED:

Does the proposed research involve human subjects, including human organs, tissues, fluids, or other materials; or the collection of potentially confidential information?

XX Yes ___ No

If NO, no further information is needed. Sign (page 4) and attach the questionnaire to the front of your proposal.

2. Has the SAME project been reviewed before?

___ Yes XX No

If YES, give ORS I.D. No.: _____ Title of Project: _____

Principal Investigator: _____ Review Date: _____

Please note on separate attachment(s) any changes in the current proposal which differ from the previously approved protocol with regard to procedures involving human subjects (e.g., duration of study, age of subjects, study population, frequency of tests or visits, volume of blood, etc.). IMPORTANT: Federal and state regulations require that the committee be informed of any changes. OR, I certify that there are no changes in this prot[redacted]

3. Study subjects will include (please check): ___ Minors; ___ Fetuses; ___ Abortuses; ___ Prisoners; ___ Pregnant Women; ___ Mentally Retarded; ___ Mentally Disabled; XX None of the above.

4. If this study may involve any of the above special subject groups, check one:
___ Use of such subjects is a necessary part of the project.
___ Such subjects may be included incidentally as members of a more general population.

5. Will this work be done if the project is not funded? XX Yes ___ No

Indicate date on which you expect to start this research: January 1979

Funding date: _____ Other: _____

6. Research will be conducted through or in collaboration with: PLEASE CHECK:

School of Nursing XX
School of Dentistry ___
Clinical Research Center ___
VA Hospital ___
Primate Center ___
Other PIMA Reservation*
Not Applicable ___

If one of the above is checked, this questionnaire and a copy of the protocol and consent form should be submitted to the Human Research subcommittee of that school or activity, as well as the UOHSC Committee on Human Research.

*This research has been reviewed at the Research Center, Phoenix, Ariz. by the Committee on Human Subjects

7. DRUG USAGE: Will an investigational (unapproved) new drug be used? ___ Yes XX No

OR

Will an approved drug be used for an unapproved indication? ___ Yes ___ No

If YES, 1) Name the drug(s) and uses _____

2) Attach the data on previous human experience, animal studies and lab tests.
3) Give the name of person/firm that holds IND and the date of IND filing:
Name: _____ Date: _____
Address: _____
4) Sign the separate investigator's assurance below.
5) Obtain a copy of the official consent form from the State Board of Pharmacy, 1400 S.W. 5th Avenue, Portland, Oregon 97201, (503) 229-5849.

TO BE SIGNED ONLY IF SUBJECTS ARE TO RECEIVE FDA-REGULATED INVESTIGATIONAL NEW DRUGS OR DEVICES. I will obtain each subject's written informed consent on the official State Board of Pharmacy consent form, filled in as approved by the institution's Committee on Human Research, maintain one copy of each completed and signed form in my files, and send another copy to the State Board of Pharmacy as required by Oregon law.

_____ _____
PRINCIPAL INVESTIGATOR DATE

8. RADIATION: Will subjects be exposed to radiation or radioisotopes? ___ Yes XX No

If YES, the investigator MUST contact the Radiation Safety Office. The Committee on Human Research will withhold final approval until written approval by the Radiation Safety Committee has been received.

Total dosage in rems: _____ Date submitted to Rad. Safety Committee: _____

9. CHARACTERISTICS OF STUDY SUBJECTS:

a. Patients XX Volunteers ____

b. Age range: 21 to 50

c. Estimated number: ____

d. Affiliation or source of subjects, e.g., hospitals, outpatient clinics, general public, UOHSC students, etc.: Hospitals and clinic of the Pima Indians in Phoenix, Arizona

10. CONFIDENTIALITY OF SUBJECT DATA:

a. If research records which identify subjects will be kept, describe measures for maintaining confidentiality: Records will be coded, names of patients deleted and then data will be processed

b. Will records which contain personal identification (i.e., name, address, Social Security number of subject) be transmitted outside this institution? ____ Yes XX No

If YES, (1) Include a statement in the consent form that such data will be transmitted and to whom.

(2) Give name and address of recipient(s):

Name ____

Address ____

11. RISKS TO SUBJECTS:

a. Describe any physical, psychological, social, economic, or other risks to subjects, including discomfort or inconvenience:

| NATURE OF RISK | SERIOUSNESS | INCIDENCE/PROBABILITY |
|---|---|---|
| None | | |

b. Precautionary measures to be taken to eliminate or reduce the risks:

c. Measures to be taken if complications occur:

12. Describe the benefits that may be reasonably expected from the proposed activity to:

a. The subjects: Improvement of Diabetic management in the Pima Indians and reduction of physical complications arising from this disease

b. The advancement of scientific-medical knowledge: Yes

13. If the study involves treatment, describe alternative treatment, including the benefits and risks:

14. The attached "FORMAT FOR INFORMED CONSENT" is offered as a guide in preparing an acceptable informed consent form. NIH requires, and therefore, the University of Oregon Health Sciences Center requires, that WRITTEN informed consent be obtained for ALL research procedures involving humans.

15. Are you a physician or dentist? ___ Yes XX No

If NO, attach written assurance from the physician or dentist who assumes medical responsibility for the subjects, if applicable.

16. PROTOCOL: Describe the proposed research. Define abbreviations and symbols. The Committee on Human Research reviewers need:

a. ABSTRACT: Briefly outline objectives, methods and procedures.
b. SUMMARY OF PREVIOUS RELATED WORK: Include human and/or animal studies.
c. METHODS AND PROCEDURES: Describe in sufficient detail so that reviewers unfamiliar with the field may clearly understand what will be done with or to the subjects. If complete grant application is submitted, please list pages on which procedures involving human subjects are described.
d. INFORMED CONSENT FORM.

17. LIST ATTACHMENTS (please number):

18. INVESTIGATOR'S ASSURANCES:

a. I will promptly report proposed changes in the activity and any unanticipated problems involving risks to subjects, including adverse reactions, to the Committee on Human Research; and, in the case of DHEW-supported activities, to the Department of Health, Education, and Welfare (through the respective granting office).
b. I assure that documentary evidence of informed consent will be included in the medical files of the subjects after the proposed activity has been completed or discontinued.
c. Since the Committee on Human Research is obligated to periodically review this activity, I will furnish it with relevant information when requested.
d. I, the undersigned, will be responsible for the ethical conduct of this project, and for protecting

[redacted]

December 15th 1978
Date



rel