DIABETIC DIET MANAGEMENT: A NATIVE INDIAN PERSPECTIVE

by

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B.S.N., the University of British Columbia, 1984

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF

THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE IN NURSING

in

THE FACULTY OF GRADUATE STUDIES

(School of Nursing)

We accept this thesis as conforming

to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

August, 1991
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August 2, 1991
ABSTRACT

Maturity-onset diabetes has become a growing health problem among Canadian Native Indians. Although there is a growing body of literature examining the etiology and cultural meanings of diabetes in this population, there is little knowledge of the Native perspective of diabetic diet management among groups in Western Canada. Therefore, the purpose of this study was to examine the problems perceived by Native Indians in managing a diabetic diet.

Kleinman's conceptual framework guided the formulation of the research question and methodology. In order to elicit and understand the experience of diabetic diet management from the perspective of the Native Indian, the qualitative research method of phenomenology was employed. Data were collected through the use of unstructured tape-recorded interviews that allowed the subjects to describe the phenomenon in their own words according to their own reality. The sample consisted of three men and three women all living on reserve from three Coast Salish bands in the Fraser Valley of British Columbia. Four of the subjects were interviewed twice, the other two were seen three times for a total of fourteen in-depth interviews.

Data were collected and analyzed simultaneously over a period of seven months. After being transcribed verbatim, interview data were examined for common themes that emerged and the raw data were coded accordingly. As themes surfaced during the analysis, they were clarified, validated, and/or discounted during subsequent meetings with the informants. In this process, the nature of diabetic diet management was elucidated.

The problems experienced by the informants were embedded in the larger phenomenon of diabetes management. How the illness was understood and dealt with in the context of daily living shaped the experience of diet management and the nature of the problems that surfaced. Two central interrelated concepts emerged from the data that explained how the subjects lived with their diets on a daily basis. The first concept entailed the evolving
personal understanding of diabetes as it was shaped by the subjective experience of symptoms and the anecdotal stories of the numerous relatives with the same illness. The second concept emerged from the interwoven social environment in which the subjects lived out their daily lives. This was discovered to be both a source of difficulty and a source of strength for the individuals of the study.

A variety of implications for nursing surfaced from the findings. For nursing practice, diabetic education and program development need to be planned and implemented in collaboration with Native leaders and clients. Educators must examine how nursing curricula can focus on the client's perspective of the illness experience to better enhance communication and health care delivery. There also remain many unanswered questions regarding the diabetic experience in this cultural group and how it is tied to the social network of such communities.
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ACKNOWLEDGEMENTS

My sincere gratitude goes out to all six Native participants for extending their honesty, enthusiasm, and generosity towards a better understanding of their experience. The Native communities and resource people were invaluable in the recruitment of participants and unending in their encouragement throughout the study.

Marilyn Dewis (chair) and Carol Jillings are credited for providing consistent guidance and support that reflected their enthusiasm for the research process. Their constructive and meaningful direction was appreciated throughout this project.

This research was supported by research grants from the Canadian Nurses Foundation and the British Columbia Medical Services Foundation. As my first funded project, it has been very encouraging to receive this recognition. Both organizations deserve merit for enhancing the endeavours of graduate students embarking on scholarly research.

My family, friends and colleagues have been unending in their support. And finally, Gordon Glaze deserves special mention for patiently living with this process since the beginning. I thank him for providing me with technical support and fostering my creativity.
CHAPTER 1: INTRODUCTION

Background to the Problem

For the individual living with a chronic disease, day to day management of the condition presents a variety of problems. Strauss (1981) describes such problems as managing regimens, controlling symptoms, organizing one's time efficiently, adjusting to changes in the disease trajectory, and maintaining as normal a life as possible.

One such chronic disease is diabetes mellitus (also known simply as diabetes). The person with this illness must monitor and treat the condition on a daily basis (Oram, 1989). Dietary management is a major part of such a regime. Carbohydrates are restricted to high fibre complex forms, fats and simple sugars limited, and weight loss emphasized (Hollands, 1988). Such management is directed towards avoiding short and long-term complications such as insulin or hyperglycemic reactions and microvascular and macrovascular damage to the eyes, kidneys, feet, blood vessels, and nervous system (Cox, Gonder-Frederick, Pohl & Pennebaker, 1986).

From the viewpoint of health care professionals and diabetic patients, comprehending the diet and applying the knowledge into new daily patterns of living constitute the biggest problem area in diabetes (Lockwood, Frey, Gladish, and Hiss, 1986). Altering previous patterns of dietary intake requires personal skills for the patient such as self-discipline, controlling emotions and attending to the influence of others in the social network (Daschner, 1986). It is little wonder that strict adherence to prescribed diets remains a complex and persistent challenge for both the patient and the health care professional.

In Canada, it is estimated 5% of the general population has diabetes mellitus (Lemay, 1988). However, since the 1940's, type II diabetes mellitus (also known as non-insulin-depentant or maturity-onset diabetes) has become a growing health problem among the Native people in North America (Mohs, Leonard, & Watson, 1985; Gohdes, 1986). A survey of diabetes mellitus in the Canadian Native population was conducted by the Medical Services Branch of National Health and Welfare (1987). A brief summary of these
statistics reveals the prevalence of diabetes among Native people is three to four times the national average in some southern populations, with a pattern of high rates in coastal communities of British Columbia.

The rate of type II diabetes is especially high among Native people over the age of 35 (Medical Services Branch, 1987; Mohes et al., 1985). Montour, Macaulay, & Adelson (1989) report this pattern is accompanied by high rates of diabetic-related complications among the Mohawks of Kahnawake in Quebec. American statistics are also discouraging. Gohdes (1986) found 76% of lower-extremity amputations, 33% of chronic renal failure, and 29% of hospitalizations for ischemic heart disease among Native Indians were related to diabetes. Dietary management, as the cornerstone of diabetes treatment, remains the key in the prevention of such complications (West, 1973).

This researcher's interest in the diabetes experience developed through her work with various Native bands in British Columbia. The preparation and sharing of food is a major component of traditional Native lifestyle. However, the Native person diagnosed with diabetes faces dietary restrictions often involving major life-long changes to previous food behaviours. However, little research exists examining the problems Natives experience in attempting to adhere to such a diet.

The Problem Statement

Diabetes is a growing health problem among Canadian Native Indians. Like others living with diabetes, Native people are expected by health professionals to play a primary role in the daily management of their illness and the long-term prevention of complications. Such ongoing management often involves life-long commitment to a medically prescribed diet. To provide culturally appropriate care and health education, a better understanding is needed concerning the Native experience of following such a regimen.

Purpose

The purpose of this study is to explore the problems perceived by Native people in adhering to a prescribed diabetic diet.
Conceptualization of the Problem

The Health Care System Model (Kleinman, 1978a) guided the conceptualization of the problem and the methodology used to examine the phenomenon. This patient-centered approach concerns how sickness is experienced and reacted to by the various players of the health care system. These players exist in three social domains: the popular, the professional, and the folk arenas. The popular arena consists of the family context of sickness and care and the social network and community activities. Kleinman states the majority of sickness is managed within this domain in both Western and non-Western societies. "Moreover, most decisions regarding when to seek aid in the other arenas, whom to consult, and whether to comply, along with most lay evaluations of the efficacy of treatment, are made in the popular domain" (Kleinman, 1978a, p.86). The folk sector consists of non-professional and/or traditional healing specialists such as herbalists and Native spiritual healers. The professional arena consists of the "Western" or "cosmopolitan" professional scientific practitioners such as physicians and nurses.

Each arena is culturally developed and contains explanatory models (EMs) used in the interpretation of illness. This interpretation includes "explanations of any or all of five issues: etiology; onset of symptoms; pathophysiology; course of sickness (severity and type of sick role); and treatment" (Kleinman, 1978a, p.87-88). Kleinman argues the EMs of patients and professionals often conflict resulting in different clinical realities for the same sickness episode. This can lead to incongruent objectives of care, miscommunication, and poor quality of care.

This conceptualization holds definite implications for nursing practice and research. Anderson (1985) adapted Kleinman's framework to also account for the social, political, and economic processes that shape an individual's subjective experience of illness. She states that "within this framework the nursing profession is viewed as a sociocultural system that possesses its own knowledge, beliefs and values which may be discrepant from those of the client" (1985, p. 238).
In the search for an understanding of the problems of diet adherence, it is crucial to acknowledge the nurse and client may possess differing explanatory models regarding the illness experience. These models can influence the perception and understanding of diet management. If an understanding of the client's perspective of the illness experience is to be one outcome of nursing research, this sociocultural patient-centered approach must be utilized.

Research Question

This research study seeks an answer to the following question: From the perspective of the Native Indian, what is it like to follow a prescribed diabetic diet?

Introduction to the Methodology

The Research Design

Since the early 1980's, nursing research has increasingly utilized the phenomenology approach (Anderson, 1989). This method seeks to discover and understand a phenomenon as it is lived and experienced (Anderson, 1989; Davis, 1978; Oiler, 1982; Omery, 1983). Because it values the perspective of the informant, phenomenology guides the research design for this study.

Anderson (1989) views phenomenology as not just another research method but a fundamental shift from the empirical natural sciences. The social world, as viewed by the natural sciences, contains objective facts which can be discovered and described in a neutral, quantifiable way. According to the empirical sciences, reality and truth exist independently of the researcher and the activity of investigation does not affect that being investigated. The end result is the investigation of pre-determined variables believed by the researcher as relating to the human experience.

The fundamental difference between the natural sciences and the phenomenological perspective is the understanding of truth and knowledge. Anderson (1989) states:

The phenomenological tradition, on the other hand, maintains that meaning is contextually constructed as an intersubjective phenomenon. Human beings create
meaning in interaction with one another....No external referent exists against which various claims to truth can be weighed. Contradictory notions of truth are seen as different ways of constituting reality based on different social and historical conditions (p.20-21).

An individual, therefore, creates meaning socially constructed within his or her subjective reality. Phenomenological research is designed to explicate how such meanings are constituted and to derive from this examination consensually validated knowledge (Lynch-Sauer, 1985).

In this dynamic process of discovery, the researcher is enmeshed in the very phenomenon under study. Empathic and intuitive awareness are modes used deliberately to open up avenues of discovery (Oiler, 1983, 1986). The researcher engages in cooperative dialogue with the subject that communicates interest in understanding the participant's experience and a willingness to suspend moral judgment (Knaack, 1989). By creating an open and accepting atmosphere, the researcher explores the phenomenon as it occurs in the everyday life of the subject.

A key component of the phenomenological research process is known as bracketing, or suspending one's preconceptions and assumptions both prior to and during data collection (Davis, 1978; Knaack, 1989; Oiler, 1982; & Omery, 1983). Swanson-Kauffman and Schonwald (1988) contend bracketing "is an attempt to bridge the gap between the researcher's own experience of the phenomenon studied and the reality that exists outside the investigator's personal world." Hence, there are no implicit or explicit hypotheses directing the researcher regarding what will be discovered in the study.

Phenomenology is a method that directs this researcher to explore and understand the client's personal experience of adhering to a prescribed diabetic diet. Both the research design and Kleinman's Health Care Systems Model (1978a) recognize the importance of the uniqueness and validity of the phenomenon as perceived by the subject. In conclusion, the research design and the conceptual model are consistent for the purpose of this study.
Definition of Terms

In this research study, the following definition of terms are used:

1) Diabetes: (also known as diabetes mellitus) a disorder of carbohydrate metabolism, characterized by hyperglycemia and glycosuria and resulting from inadequate production or utilization of insulin. Treatment varies according to the severity of the disorder and can include diet, insulin or oral hypoglycemic agents, exercise, foot care, and/or blood monitoring (Cox et al. 1986).

2) Native Indian: any person claiming to be of Native ancestry regardless of legal aboriginal status.

3) Problems in diabetic diet management: any problem or shortcoming perceived by the participant as difficult or cumbersome in any way.

4) Illness: the personal, interpersonal, and cultural reactions to disease or discomfort as determined by cultural factors governing perception, labeling, explanation, and valuation of the discomforting experience (Kleinman, 1978b).

Assumptions

The researcher has made the following assumptions:

1) A Native person with diabetes will be able to speak to the phenomenon of managing illness and a diabetic diet.

2) There are problems perceived by individuals in following a diabetic diet.

Limitations

1) According to Swampy (1987), Native people are reluctant to discuss some of their traditional beliefs and customs with non-Native people due to distrust and fear of ridicule. The findings of the study will therefore be limited to those problems that will be discussed with the researcher.

2) The selected communities for subject recruitment are located in rural areas of the Fraser Valley. The researcher recognizes the experiences and life-styles of these subjects could
be very different from those of Native people living in urban areas. The findings of the study cannot be generalized to those Native populations living in larger urban areas. 3) The sample size is small (6 to 8 subjects). The findings can therefore not be generalized to all or most rural Native Indians with diabetes.

Summary

As an introduction to the research study, this chapter defined the problem, purpose and research question. A description of the conceptual framework that guides the study was provided illustrating the relevance of exploring the explanatory models used by the recipients of health care. The phenomenological method was introduced and briefly contrasted to the approach used by the traditional empirical sciences. Key features of the methodology were presented followed by a definition of terms and an exploration of the assumptions and limitations of the study.

The next chapter examines the literature related to the problem and the purpose of the study. Both theoretical and research literature are explored to determine the present state of knowledge.
CHAPTER 2: CRITICAL REVIEW OF THE LITERATURE

Introduction

In the previous chapter, the bracketing process was described as an important component in the research process. Knaack (1989) states it is helpful to clearly examine and state one's assumptions about the phenomenon at the outset. An objective review of pertinent research on the subject and the state of knowledge on the phenomenon is a legitimate initial step in the bracketing of personal biases (Swanson-Kauffman & Schonwald, 1988).

The following review of literature includes both research and theoretical readings. It is organized into three main areas: the enhancement of diabetic diet management, the patient's perspective of diabetic management and the Native experience of the illness. Key themes of the literature are illuminated and gaps in the state of nursing knowledge are identified.

Enhancing Diabetic Diet Management

A vast amount of theoretical and research literature has examined the issue of patient adherence to medical regimens (Anderson, R., 1985; Conrad, 1985; Kurtz, 1990). In his classic analysis of diabetic diet therapy, West (1979) reviewed an exhaustive array of literature published from 1935 to 1973. He argued that although diet is the fundamental therapy for maturity-onset diabetes, patient adherence to prescribed therapy remains abysmally low. Lockwood, Frey, Gladish and Hiss (1986) later confirmed these results in their study examining the most difficult problems perceived by patients and their health care providers in managing and living with diabetes. Using open-ended questions, they discovered both populations strongly agreed that understanding and adhering to the dietary therapy is by far the biggest problem in the overall management of the illness.

Patient Factors as Predictors of Adherence

In the search for a better understanding of adherence problems, many studies have attempted to identify patient characteristics that explain or predict compliance to diabetic
regimens. One such model extensively researched is The Health Belief Model (HBM). It hypothesizes that adherence increases as a function of the patient's perceptions of: (a) greater susceptibility to the illness, (b) greater disease severity, including related complications, (c) more benefits of adherence, (d) fewer costs of adherence, be they emotional, physical, or financial, (e) more social cues or prompts to adherence, and (f) the perceived ability to carry out the various regimen tasks (Becker, 1985). In a review of literature examining adherence to diabetic regimens, published between 1977 and 1989, Kurtz (1990) concluded the HBM has only received modest empirical confirmation. Despite the use of reasonably reliable questionnaires in the five studies reviewed by Kurtz, it appeared none of the HBM components consistently predicted adherence to any aspect of the diabetic regimen. By examining the pattern of study findings, Kurtz concluded "perceived susceptibility and severity are curvilinearly related to adherence, such that too little or too much perceived severity would lead to less adherence; this is different from the HBM prediction that adherence increases linearly with increased perceived severity" (1990, p.53).

The locus-control-theory, formulated by Rotter in 1966, has also received extensive research attention. When applied to diabetic adherence, it is often theorized that internally controlled individuals are self-regulated and are more likely to seek information about their illness (Eckerling & Kohrs, 1984). Externally-controlled individuals on the other hand do not actively seek information and benefit from receiving exact instruction from an authority figure. Although this theory has received exhaustive research attention, findings remain contradictory and largely inconclusive. It is not identified as a useful predictor of treatment outcomes (Edelstein & Linn, 1986).

Psychological factors of diabetic patients are also regarded as possible determinants of diabetic control and management fluctuations. Dunn and Turtle (1979) conducted an extensive review of such research published from 1935 to 1975. They discovered major methodological problems such as sampling bias invalidated any evidence for the existence
of a specific "diabetic personality." A consistent bias of such studies centered around the selection of diabetic samples solely from patients in poor control or from impoverished or maladjusted home environments. Dunn and Turtle (1979) concluded diabetes merely served to accentuate any psychological problems present before such patients were diagnosed.

Clearly, there is a lack of conclusive evidence regarding patient characteristics that determine or influence adherence to diabetic regimens. The above areas of research are plagued with a pervasive problem; the methodological challenge of measuring adherence. When self-reports are used, accurate information is clouded by social desirability, inaccurate recall, lack of consensus regarding units of measurement, and different interpatient regimens (Eckerling & Kohrs, 1984; Kurtz, 1990). In addition to problems in research design, there is also the conceptual problem of focussing on isolated patient factors. Diabetic diet management occurs within a social context. To focus only on the inner characteristics of the patient artificially constrains the phenomenon and ignores the much larger picture.

**Social Context of Diabetic Management**

To better understand the social environment of diabetic management, research has increasingly acknowledged and studied the influence of the family and the patient-professional relationship. Patients attribute many of their problems in adherence to economic factors as well as interpersonal problems with their peers, family, and health care professionals (Kurtz, 1990). Interestingly, physicians perceive dietary noncompliance to be largely under the patient's internal control, whereas patients maintain adherence is outside of their control (House, Pendleton & Parker, 1986).

Patient-family interactions could be expected to influence diabetic management. Positive, supportive behaviours are generally surmised to enhance adherence whereas negative, judgmental or indifferent behaviour likely hamper adherence. However, research examining the direct relationship between adherence and the frequency of supportive and
nonsupportive behaviours has produced inconclusive results (Kurtz, 1990). This is generally because of significant methodological problems when determining which family behaviours to study, how to measure them, and how to adequately measure adherence. Furthermore, there remains a paucity of research examining the family environment from the perspective of the patient.

The patient-professional relationship is another feature of the social environment influencing diabetic management. Over time, this relationship has shifted from one of prescription and supervision to one of collaboration (Kurtz, 1990; Sims, 1986; Westberg & Jason, 1986). This shift is illustrated by a diabetic education program described by Sulway, Tupling, Webb and Harris (1980). They found that increasing the patient's knowledge base alone does not always result in health behaviour changes. Instead, they designed their program to include more of the affective domain of learning. Essential features of the program included a team approach with a nonthreatening atmosphere, group process to develop sharing of experiences and feelings, family involvement, learning by experience rather than didacticism, and tailoring the information and recommendations to meet individual needs.

Westberg and Jason (1986) discussed the role that collaboration plays in effective patient-professional relationships. They suggested that patients need to achieve a sense of ownership of the changes they make as they assume responsibility for their own care. However, they cautioned that the readiness of the patient to take on an active role in illness management varies with the individual and the stage of the illness and therefore requires careful assessment.

Sims (1986) offered a very relevant view of patient education from the perspective of a person who has lived with diabetes for 30 years. She suggests that professionals need to focus more on the patient's strengths and abilities rather than listing the "patient problems." Sims' statement below clearly stresses the importance of understanding the patient's perspective of daily diabetic management.
Thinking for the pancreas means that people with diabetes have to refigure the variables in their energy equation several times a day. There are many solutions to these equations. We need openness to the many right ways of doing things rather than insistence -- defined as compliance -- on only one way. Emphasis on options in self-care throughout life will encourage us to exercise our Native ingenuity (p.124).

The Patient’s Perspective of Illness Management

People living with diabetes must continually maintain a precarious balance between optimal metabolic control and quality of life. The demanding nature of illness management greatly impacts on the daily living of life and robs the patient of the natural spontaneity others take for granted. Both current theoretical and research literature reflect a growing recognition of the patient’s perspective of the illness.

This shift in thinking is reflected in the manner in which health care professionals are viewing the concept of noncompliance. Anderson (1985) argues that noncompliance does not stem from inappropriate behaviour of the patient but rather inappropriate treatment plans formulated by health care practitioners. From the perspective of the patient, the regimen is not necessarily the solution to the disease but is another part of the problem of having diabetes.

Conrad (1985) offered a relevant alternative approach to the study of compliance. Using data collected from 80 in-depth interviews of people with epilepsy, he used a patient-centered approach to gain an understanding of the meanings of medication in people’s everyday lives. Using this perspective, Conrad argued that for the patient living with a chronic illness, self-regulation is more the issue than compliance. Conrad concludes that self-regulation of medication represented "an attempt to assert some degree of control over a condition that appears at times to be completely beyond control" (1985, p.36). Conrad suggested that the meanings of medication regimens described in the study might be generalized to other chronic conditions such as diabetes. This study illustrates the far-reaching effects that illness management has in the daily lives of individuals with chronic illness.
The issue of quality of life in diabetes management also warrants examination. Oram (1989) interviewed a wide range of people with insulin-dependent diabetes about their experiences of living with the illness. She concluded the goal of optimal metabolic control being advocated by diabetes educators is simply not achievable without seriously compromising the patient's quality of life. She identified key dimensions of quality of life hampered by having diabetes: a) a sense of being normal, b) feelings of inclusion, c) the ability to display competence, and d) being in control of one's life. Because eating is a highly social activity, the dietary management was found to impinge the most on the individual's ability to feel a part of the social environment. At times the need for optimal metabolic control through proper dietary habits conflicted greatly with the need to belong.

It is not surprising that in addition to affecting the social milieu, dietary management requires an enormous amount of self-discipline. To determine the problems perceived by adults in adhering to a prescribed diet, Daschner (1986) used data from semi-structured interviews of 21 adults diagnosed as having diabetes for three months or longer. It was found that the most difficult problem perceived was self-discipline, followed by emotions, events (i.e., eating out, social gatherings and work), other persons, and material resources. Dashner suggested that the major changes in life-style often needed in diabetes management require strong self-discipline on the part of the patient. However, there are limits to the generalizability of her study. For example, 20 of the 21 participants were white. Furthermore, almost all had at least 12 years of education and 13 earned $20,000 or more a year. Such findings, although of interest, may not be generalizable to Native clients. Another weakness of the study was the narrow focus of the questioning technique used. Subjects were asked only two open-ended questions related to dietary management.

Lai's research (1988) illustrated a wealth of information gleaned through a less rigid interviewing process. Her study explored the perspectives of Chinese elderly in living with diabetes, the meanings they assigned to the illness and the ways the disease was managed in the context of their own lives. She stated that the health decisions made every day by the
informants were "based on personal meanings that must be understood in the personal, social, and cultural contexts of their lives. The findings also emphasized that understanding individuals' explanatory models forms the essential building block to establishing a collaborative and meaningful relationship with people" (1988, p.110).

The above discussion illustrates the value of understanding the patient's perspective of diabetic diet management. However, apart from Lai's study, little research could be located by this researcher that examined in depth the experience of living with a diet. If diet therapy represents the major problem faced by individuals living with the illness, better understanding is needed regarding the personal experience of this regimen if collaborative health care is to be realized.

The Native Experience of Diabetes

The etiology of diabetes among North American Native people has received much research attention (Mohs et al. 1985). Such theories include the stresses of Western dietary and life-style acculturation and a "thrifty gene" which predisposes Native people to obesity (Hagey, 1983, 1984; Mohs, et al. 1985). However, only a few studies could be located by this researcher related to the sociocultural aspects of diabetes in Native Indian communities (Garro, 1987; Hagey, 1983; Joos, 1984; Lang, 1989).

Historical Context of Food in Native Culture

To understand the phenomenon of diabetes in the Native population, it is helpful to consider the changes this group has undergone in the last 100 years and understand the place food continues to hold in Native culture. Historically, food played a central role in Native life. In his ethnography of the Kwakiiutl people of British Columbia in the late 1800's, Boaz (1966) observed feasting was a cornerstone of the many events marking life's passage including name-giving, marriage, the religious winter ceremonial and potlatching. Today, the preparation and consumption of food continues to be woven into the social fabric of Native life (Jackson and Broussard, 1987; Joos, 1984; Lang, 1989). Hospitality, which includes preparing and serving food, is a serious obligation. For a guest to refuse
the offered food at such gatherings is socially and culturally unacceptable (Jackson and Broussard, 1987).

However, major alterations in the pattern and type of food consumption occurred as a function of European contact. Joos (1984) examined the influence of the historic background and the contemporary social situation on changes in diet and health status of the Florida Seminole Indians. She stated that "transition from a 'traditional' to a 'modern' lifestyle inevitably results in new dietary patterns, increasing use of modern technology, and declining energy expenditure" (p.217). In the 1930's, the Seminoles were noted to be in excellent physical shape largely due to their vigorous outdoor life. They subsisted by hunting, fishing, gardening, and gathering food. Early ethnographers noted that food consumption among many Native peoples followed a feast or famine pattern where food was consumed when available or when individuals were hungry (Boaz, 1966; Joos, 1984).

However, Joos noted that since the Seminoles began to move onto reservations, the diets have been modified to include more processed, fatty foods that are fried rather than boiled in the traditional way. Carbohydrates and refined sugar in the form of soda drinks and snacks have greatly increased in consumption especially among young people. Concurrently, there has been a decrease in dietary fiber in the form of vegetables and fruit. Based on her examination of medical records, extensive interviews and observations at the Brighton reservation, Joos noted the most outstanding feature of the Seminole diet today is the vast amount of food consumed. Statements such as "We just can't stop eating," and "We Indians just don't know when to stop" illustrated the candid descriptions of large appetites among Native people. Obesity due to a high caloric intake was noted to be a factor common to all diabetics in the community.

Joos' observations are certainly not isolated to the Seminoles. Obesity has become a major health problem among most Native people in North America (Jackson & Broussard, 1987; Lang, 1989; Mohs et al., 1985; Montour et al., 1989). This is attributed to three major life-style changes of modernization: (1) reduced energy expenditure due to sedentary life-
styles, (2) change from a high-fiber, high-unrefined carbohydrate diet to a diet high in refined and simple carbohydrates and low in fiber, and (3) stress due to acculturation. Whatever the cause, obesity poses a grave health danger to Native people as it is considered to be diabetogenic and exacerbates the severity of the diabetic state (Mohs et al., 1985).

The Challenge of Diabetic Diets

The traditional and current foodways and cultural practices of Native people have direct implications for how diabetes is managed. Joos noted a number of aspects of the "social and cultural environment which encourage eating, enhance obesity, and make weight loss and control of diabetes difficult to achieve" (1984, p. 230). The women, as the ones who prepare food in households, found it very difficult to follow weight-loss diets due to complaints from other family members. Also, many Native people do not regard slimness as the ideal. In contrast to the views of the larger North American society, some Native people believe the overweight condition is a reflection of being free of disease and sickness (Jackson & Broussard, 1987).

As in other populations, diabetic diet adherence among Native people is generally quite low (Broussard, Bass & Jackson, 1982; Lang, 1989). Broussard et al. (1982) studied the reasons for noncompliance with diabetic diet prescriptions among Cherokee Indians. Short interviews were conducted with 90 patients visiting a local out-patient diabetes clinic regarding adherence to diets and the reasons for noncompliance. The responses were categorized into three areas: therapeutic and clinician factors; patient factors; and cultural factors. In the therapeutic and clinician category, patients complained that the diet caused hunger, weakness, or dizziness. Others expressed difficulty in using the exchange system, especially when trying to incorporate food preferences and when eating out or on special occasions. Others disagreed with the prescribed weight loss perceiving it as unrealistic. Among the reasons categorized as patient factors, many stated that eating occurred when they were bored or depressed. A lack of supportive family members was also cited. For
example, family and friends would bring tempting food to eat and patients ate more when in a social environment. Among the responses classified as cultural, all related to the desire for Indian foods and local cooking methods. These results point to the importance of client participation when planning diet programs. However, it is noted that the interviews were brief and never repeated. The questions centered on reasons for noncompliance rather than the larger context of living with diabetes. The participants may have been too rushed or simply reluctant to discuss in more detail their experiences and the results therefore may be superficial.

Stegmayer, Lovrien, Smith, Keller, and Gohdes (1988) studied the effectiveness of a nutrition counseling program designed specifically for a Nebraska Native community. Using data on the dietary habits of the participants, the education program was tailored to the available foods and individual preferences. Initial emphasis was on eating more of certain foods versus restriction and elimination of preferred items. The researchers intentionally avoided using the phrase "food exchange" since this concept was not well understood by patients. It is interesting to note that instructors tailored their teaching to the life-styles of the patients rather than aiming for major changes in existing patterns. The sample consisted of 46 patients diagnosed with non-insulin dependent diabetes (NIDDM) who participated in the project for one year. The results showed an average weight loss of 3.3 lbs. However, the average concentration of fasting blood sugar in the patients decreased from 258 mg/dL initially to 179 mg/dL (P<0.01) over the one year period. There are some limitations to the study. First, sampling was not randomized. This limits the extent to which the findings can be generalized to the larger population of Native people with diabetes. It is not clear which statistical test was used to analyze the data. Finally, the study did not control for the fact that some subjects were on oral hypoglycemic agents. This treatment could have been a confounding variable that influenced the fasting blood sugar results. However, if the results are at all reliable, it appears that tailoring nutrition education programs to Native dietary patterns is beneficial.
Both of the latter two studies examined took a focused reductionist approach in the study of diabetic diet adherence. The results illuminate some of the reasons that Native people choose to not follow their diets and suggest ways to make regimens more culturally suitable. However, the studies do not add to our knowledge of the Native diabetic experience from the perspective of those who live it.

**Diabetes as an Imbalance**

Through the study of narratives given by people with diabetes, researchers have gained a better understanding of what the illness means and how it is experienced from the Native perspective. Such studies, although conducted with different Native groups living in various geographic locations, reveal surprising similarities among the general themes of the narratives.

For Native people, health is often perceived as a state in which the spirit, mind, and body are in balance (Jackson & Broussard, 1987). Conversely, diabetes seems to represent a state of imbalance and a failure to adhere to traditional ways. In her study of narratives given by Dakota (Sioux) Natives concerning the experience of living with diabetes, Lang (1989) found that of key concern was the erosion of the traditional Native diet. The modern foods (such as soda pop, canned foods and store-bought meat) were viewed as impure and contributing to the development of diabetes. Traditional food, although in short supply and consumed sparingly, was often held in very high regard as having healthful properties in contrast to modern foods. It was also found that the imbalance of the diabetic state is not an individual experience but is reflected in the larger concerns of community history and cultural identity (Lang, 1989).

Similar findings were made by Garro (1987) in her informal interviews with Ojibwa people living in southern Manitoba. Among this Canadian study population, significant concern was voiced about the use of impure substances injected into livestock and sprayed onto crops. The theme of imbalance included the state of being overweight or abusing
alcohol. Alcohol was viewed as responsible for diabetes development because of the high "sugar" content.

Hagey (1983, 1984) described how the concept of imbalance was used in the Native Diabetes Program in Toronto. The goal of the project was to "facilitate a learning environment within the Native community to promote self help and positive means of coping with diabetes which was derived from the Native culture" (1983, p.29). The Native spiritual story of "Nanabush and the Pale Stranger" was used to present information on food, medicine and exercise. Through the use of this cultural metaphor, diabetes was viewed and discussed by Native people as a problem of imbalance. In order to reduce the feelings of guilt and shame experienced by many Native diabetics, the spiritual leaders used Native rituals such as the "talking stick" ceremony which facilitated free discussion of feelings regarding diabetes. The experience of the Native Diabetes Program points to the importance of health professionals gaining an understanding of the cultural metaphors that are used to understand and cope with illness.

The extent of the use of traditional medicine for illness is not well documented and seems to vary according to the orientation of the individual and the availability of traditional healers and medicine. Through examination of anthropological studies among various North American Native people, Jackson and Broussard (1987) found that traditional healers of the Devil's Lake Sioux and the Papago tribes did not treat diabetes as it was considered a "white man's disease." Furthermore, the Iroquois Indians use fewer herbal remedies for treating diabetes than for diseases having a longer history among Native people. In Garro's study, there was no consensus on whether Indian medicine could cure or control diabetes. Many informants had employed traditional medicine periodically but continued to seek assistance from Western health professionals.

The above exploration of Native-based diabetic studies revealed some interesting and relevant findings. Clearly, diet restrictions impinge on customary foodways in a culture where eating is a central part of social gatherings. Diabetes, as a new illness, is viewed as a
state of the imbalance that reflects the many cultural changes that have occurred among Native people. However, only a few descriptive studies could be located that explored the meaning of this illness and its management from the Native perspective.

Summary

The literature review illustrated the challenge that diabetic diet management poses for both the patient and health care professional. Gradually, professional discourse has challenged the concept of noncompliance as a problem with the patient. Theoretical and research literature points to the need for more collaboration and culturally-sensitive care in the design of diabetic regimens. Towards this end, more descriptive research is needed to illustrate the factors relevant to the patient who is faced with the daily management of the illness.

In Native-based research, there remain only a small number of studies examining the experience of diabetic management from the perspective of the patient. Some interesting themes illustrate how diabetes is perceived as an imbalance brought on by the complex cultural changes experienced by indigenous people.

However, the knowledge base of the Native experience of diabetes remains fragmented. All of the research located thus far has involved Native people living in eastern Canada or the United States. There is a marked paucity of research on people living on the west coast of Canada. Such tribes eat a different diet than their eastern counterparts and have their own unique cultural practices. Also, no research could be located examining specifically the problems faced by Native people in following a prescribed diabetic diet. A better understanding of the problems experienced by Native diabetics will further enhance the achievement of effective dietary management.

The population targeted in this study are Coast Salish Native people living in the Central Fraser Valley of British Columbia. It does not appear that this population has been previously studied regarding their experience of following a diabetic diet. A qualitative
research approach is used that allows the participants to spontaneously describe the phenomenon from their perspective and in their own words.
CHAPTER 3: METHODOLOGY

The research design of this study reflects key underpinnings of the phenomenological research method. This chapter describes how this method was implemented including sample selection and criteria, ethical considerations, data collection and analysis and issues of validity and reliability.

Sample Selection and Criteria

Because the purpose of this study was to gain a comprehensive understanding of the meaning of a construct, nonprobability sampling was used. Also, the research design involved the collection of detailed and voluminous verbatim notes which necessitated limiting the size of the sample. This allowed the researcher to "maximize opportunities to obtain the most insightful data possible, ideally selecting informants according to their knowledge base and receptivity" (Morse, 1986, p.183). A theoretical method of sampling was employed which Morse (1986) described as one where the researcher, after becoming familiar with the setting and the actors, chooses potential subjects according to the purpose and direction of the research. For this study, subjects were chosen for their ability to speak to the phenomenon of managing diabetes within the context of their own lives. Sampling and data collection ceased when the researcher obtained enough rich data to serve the purpose of the study. Morse (1986) described this point as saturation when the theory is complete, does not have gaps, makes sense, and has been confirmed with the subjects. Guba and Lincoln (1981) also stated that it is time to terminate data collection when redundancy occurs or a small amount of new information is achieved in return for substantial additional effort. It was difficult to predetermine the number of subjects needed to achieve this saturation, but it was initially estimated 6 to 8 subjects would make the final sample size. In the end, 6 subjects were recruited and interviewed.
Criteria for Selection

Subjects were required to meet the following criteria:

1) to be of Native ancestry between the ages of 40 and 65. As discussed earlier, rates of type II diabetes are especially high among Native people over the age of 35 (Medical Services Branch, 1987; Mohes et al., 1985). Based on such statistics and work-related experience, it was felt by this researcher that this age criterion would capture the highest numbers of diabetics who might also share some common life-style characteristics such as working outside of the home and caring for extended family members.

2) to live on reserve land in the Fraser Valley and understand and speak English. The bands living in this area were familiar to the researcher from her previous employment as a community health nurse. The researcher was also familiar with the Native health workers in the area who expressed interest in participating in subject recruitment.

3) to be diagnosed at least one month prior with diabetes mellitus and to have received a prescribed diabetic diet to follow. This diet could be prescribed by a physician, dietitian, or nurse clinician. It was assumed that subjects would be diagnosed with non insulin-dependant diabetes (NIDDM) because this is the type most prevalent among Native people (Gohdes, 1986). However, the term NIDDM is misleading as many patients require exogenous insulin therapy to reduce hyperglycemia (Morrison, 1988). It has been the personal experience of this researcher and others (Joos, 1984) that most Native people with NIDDM eventually receive insulin therapy. To facilitate the selection and recruitment of subjects and to obtain a realistic view of the Native experience, the selection criteria for this study included both patients who received insulin and those who did not.

Subject Selection Procedures

After approval was obtained from the University of British Columbia Behavioural Sciences Screening Committee and from pertinent band chiefs in the Fraser Valley, selection and recruitment of subjects began. Through assistance from four Native Community
Health Representatives (CHRs), potential subjects meeting the above criteria were chosen and contacted through personal visits from the CHRs. During this visit, an information letter (Appendix B) was given to the potential subjects. People who indicated interest in participating were then contacted by the researcher who further explained the study during a visit to the subject's home. After a written consent was obtained from the subjects, arrangements were made to conduct the interviews. It has been the experience of this researcher that some Native people need time to build a rapport with a non-Native person before free conversation can take place. In a few cases, an informal introductory meeting between the researcher and the participant was necessary for the development of trust.

Characteristics of the Subjects

Interviews were conducted with six Native people from a total of three different bands in the Fraser Valley. They ranged in age from 42 to 67 and were evenly distributed according to sex. Two subjects lived with a spouse only, two lived with a spouse and two children, one with a niece, and one was a widow living alone. One subject had been diagnosed one month prior to being first interviewed, three had had diabetes for two to six years, and two subjects had had diabetes from ten to fifteen years. Three of the subjects took insulin, two others were on oral hypoglycemics, and the remaining subject received diet therapy alone.

Two of the subjects were previously known by the researcher through her work as a community health nurse in 1989. Prior contact with these subjects consisted of brief home or clinic visits. It was believed by the researcher that this prior contact facilitated trust and a willingness to discuss the diabetic experience. All of the participants were on a fixed income which included social assistance, UIC and old age pension. Of particular interest were the number of friends and relatives known by the subjects who also had diabetes. All but one subject had numerous relatives with diabetes either living on or off reserve. This phenomenon was not initially expected but is a reflection of the very high rates of diabetes among Native people. The chart below summarizes this trend.
Table 1:
Prevalence of Diabetes Among Family Members

<table>
<thead>
<tr>
<th>Subject</th>
<th>Parent</th>
<th>Grand-parent</th>
<th>Siblings</th>
<th>Cousins</th>
<th>In-Laws</th>
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<tbody>
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<td>A</td>
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Procedures for the Protection of Human Rights

The rights of the participants were protected in the following manner:

1. Written approval was obtained from the University of British Columbia Office of Research Services.
2. Written consent was obtained from the pertinent band chiefs to conduct the research on three different reserves (Appendix A).
3. Written and informed consent was obtained from participants including permission to tape-record the interviews.
4. Subjects were given information about the nature of the study, what information would be collected, and how the data would be handled.
5. Subjects were informed that participation in the study was completely voluntary.
   Participants were also free to drop out of the study at any time, to refuse to answer any
questions, and to request that any information be deleted from the tape and the data. They were informed that such decisions would in no way affect their medical or nursing care.

6. Subjects were asked to refrain from identifying any provider of care by name. Furthermore, the identity of the subjects, their family members, and the name of the reserve were protected through the use of code names. The coding sheet was destroyed after the tapes were transcribed. Tapes and consent forms were kept in separate locked locations and tapes or portions of the tapes were immediately erased upon request from a subject. All tapes were completely erased after the thesis was completed. The coded transcripts were destroyed after plans were finalized regarding publication of the findings. The raw data were available only to the researcher and her two thesis advisors.

7. Subjects were notified of the intention to publish the findings. The results of the study were shared with the subjects and the CHR’s upon request. The identities of participants, their caregivers, and family members were, and will be, protected in all publications and distributions of the final report.

Data Collection and Analysis

Oiler (1982) contends that data collection must preserve the natural spontaneity of the lived experience. In keeping with this contention, all subjects selected the site of the interviews. Five of the subjects chose to be interviewed in their home, and one subject preferred one interview to occur in a private office at her work site. Data were collected through the use of unstructured interviews that were tape-recorded and later transcribed verbatim. Occasionally trigger questions were used (Appendix C), primarily to initiate conversation or stimulate further exploration of the phenomenon.

An important consideration was the avoidance of leading or suggestive questions. Instead, neutral questions were used to allow the subjects to describe the phenomenon in their own words according to their own reality. Based on the informants' responses, questions were asked to further clarify or broaden exploration of the comments.
The interviews lasted from 30 to 90 minutes. All of the subjects were interviewed twice and two of the participants a third time. Often, other family members would drift in and out of the room in which the interview took place but they did not generally affect the flow of information. Field notes were kept by the researcher that recorded observations of the setting and the interaction. Often, after the tape-recorder was turned off, the subject would continue to discuss the experiences. This was also included in the field notes as appropriate. On four occasions, participants and their families asked the researcher to share the morning or noon meal with them during or after the interview. Because the tape-recorder was turned off during these interactions, the field notes recorded family dynamics and comments pertinent to the study.

It was found by the researcher that the interviews took place in a comfortable and relaxed atmosphere that facilitated free discussion of the diabetic experience. The informants often used humour to describe their experiences. In all of the interviews, periods of silence lasting from five to twenty seconds occurred at various stages of the interaction. Recognizing the importance of such silence in Native communication, no attempt was made to fill the void. It was found that significant comments were often made by the subjects following these periods of reflection.

In this type of research design, data collection and analysis occur concurrently (Lofland, 1971; Morse, 1986). Giorgi's method of data analysis (1975, p.74-75) was used and is outlined below:

1) A naive description of the phenomenon is obtained through the process of unstructured interviewing (as described above).

2) The researcher reads the entire transcript of the data to obtain a sense of the whole.

3) The researcher reads the same description more slowly and notes whenever a change of meaning (meaning units or constituents) occurs. Such discrimination is done while maintaining the context of the whole.
4) The researcher eliminates redundancies, but otherwise keeps all meaning units. These constituents are related to each other and to the sense of the whole to clarify the meaning.

5) The meaning of each unit is transformed from the everyday naive language of the subject into the language of the science.

6) These insights are then integrated into a consistent description of the phenomenon which is communicated to other researchers for confirmation or criticism.

In addition to above the steps, validation and clarification of major themes were also sought with the subjects during data collection and analysis.

Issues of Reliability and Validity

It has been argued that qualitative methods of research, because they seek to discover meaning rather than to test theory, cannot be judged by the same tests of rigor that traditionally pertain to conventional quantitative studies (Sandelowski, 1986). Guba and Lincoln, (1981) contend there are four criteria of rigor against which qualitative studies are judged: credibility, fittingness, auditability and confirmability. These are similar to those criteria used for quantitative studies but more suitably reflect the purpose of naturalistic inquiry.

Credibility

Whereas quantitative research is judged for its internal validity, the truth value of qualitative research is found in the credibility of its findings. Sandelowski (1986) states that the truth value of qualitative research is the discovery of the unique human experience as it is lived by the subject and is not "necessarily accessible to validation through the senses" (1986, p.33). In order to establish credibility in naturalistic research, the researcher must test his findings and interpretations with the various sources from which the data are derived. (Guba & Lincoln, 1981). For this study, the emerging concepts and themes were validated with the subjects during data collection and analysis. For added validity, the
coding categories and emerging constructs were also scrutinized by the researcher's committee members who had access to the raw interview data.

Sandelowski (1986) cautions that the closeness of the investigator-subject relationship can be a major threat to the truth value in qualitative research. To counteract this, this researcher bracketed any preconceived expectations before and during the interviews. The findings as they emerged were also validated with the subjects themselves during the second and third interviews. This served to discount any conclusions that were not viewed as valid by the participants.

**Fittingness**

In quantitative research, assurances of external validity are reflected in the generalizability of findings to cases outside in the natural environment. However, Sandelowski (1986) argues that the more tightly controlled the scientific study, the less likely the findings will truly reflect reality outside of the restraints of the research setting. She further suggests that because qualitative research examines phenomena in their natural settings with few controlling conditions, there are fewer threats to external validity.

Guba and Lincoln (1981) contend that generalizability, as a context-free proposition, cannot be achieved when the inquiry concerns human behaviour as such behaviour can never be entirely context-free. Instead, the criterion for qualitative research is the "degree of fit between the context in which the working hypotheses were generated and the context in which they are to be next applied." In other words, the representativeness of the data is enhanced when the real-life context of the experiences is maintained in the descriptions and the findings are seen as meaningful and applicable. To achieve this end, this researcher has adopted the suggestion below made by Guba and Lincoln when describing the narratives given by subjects and the contexts of the accounts:

Thick description involves literal description of the entity being evaluated, the circumstances under which it is used, the characteristics of the people involved in it, the nature of the community in which it is located, and the like. (p. 119)
In the presentation of the findings in the following chapter, the rich descriptions of the phenomenon are presented in the words of the participants themselves. This serves to illustrate the highly contextual nature of their experiences.

**Auditability**

Guba and Lincoln (1981) argue that consistency, or replicability, is not really applicable to qualitative research. This is because such research seeks to understand the unique human experience rather than identical repetition. Instead, auditability is the criterion of consistency in qualitative research. This quality is achieved through a clear decision trail throughout the study. It can be ensured by using secondary judges who can verify that the coding categories derived by the researcher make sense and appropriately reflect the data base derived from the interviews. Auditability is thus reflected in the final research report in which the reader can clearly understand the conclusions drawn by the researcher and how these were derived from the data (Sandelowski, 1981). For this study, the data analysis and the resulting conclusions were corroborated by the researcher's two thesis committee members for clear evidence of the decision trail.

**Confirmability**

Freedom from researcher bias is a key element of the criterion of neutrality (Sandelowski, 1986). In quantitative research, neutrality is established when a study is believed to be both reliable and valid. This is often achieved through distancing the researcher from the subject and the data. Sandelowski (1986) argues that, realistically, there is no way to study something without in some way altering it; the concept of pure objectivity in research is only a socially constructed phenomenon.

Instead, the relationship between the investigator and the subject is valued as an intrinsic part of the qualitative research process. Furthermore, the subjective reality of the life experience of the subjects is the paramount discovery. Guba and Lincoln (1981) argue that the criterion of neutrality in qualitative research is not the subjective or objective stance
of the researcher or the method, but rather the confirmability of the information once it is obtained, or the truth value as discussed earlier.

Summary

This chapter has examined the phenomenological research design used in this study. The purpose and methodology of the study guided the sampling method, criteria for selection of participants, the collection and analysis of data, and the presentation of the findings. A description was given pertaining to the ethical treatment of the participants and the data they supplied. Issues of reliability and validity, as they pertain specifically to the goals and process of this qualitative research study, were also discussed. In the next chapter, the findings as derived from the interview data are presented.
CHAPTER 4: PRESENTATION OF THE FINDINGS

Introduction

The narratives shared by the informants painted a rich mosaic of the nature of diabetic diet management. It was found that the problems perceived by the subjects were highly contextual and embedded within the larger phenomenon of the illness experience. In order to maintain the integrity of this phenomenon, the problems are discussed below as they emerged within the central themes of the study.

Two central interrelated concepts surfaced from the data that explained how the subjects lived with their diets on a daily basis. The first concept entailed the evolving personal understanding of diabetes. This process was shaped by: (a) the informants' subjective experiences of the illness and (b) the anecdotes of the numerous people in their social world who also had diabetes. It was discovered that this personal knowledge of the illness greatly influenced the motivational factors and the decisions made in regards to eating behaviour.

The second concept emerged from the interwoven social environment within which the subjects lived out their daily lives. Because food preparation and sharing was largely experienced in this context, it strongly shaped the ways in which informants struggled with their diets. The social world around them was both a source of difficulty and a source of strength for the individuals of the study.

This chapter is an in-depth exploration of the above phenomenon that surfaced during the collection and analysis of data. It begins with a presentation of how the informants made sense of diabetes and how this personal understanding shaped diet management. This is followed by an examination of the social context of food preparation and consumption and how such an environment could both hinder and help the subjects in their daily struggle with the diet.
Making Sense of Diabetes

Diabetic Education: Feeling out of Context

In order to grasp how the subjects made sense of diabetes, it is first important to understand their perceptions of the formal patient education classes they attended after confirmation of the initial diagnosis. For many of the subjects, this initial adjustment period was fraught with fear and a sense of being overwhelmed by the complexities of diabetic management. One woman illustrated this as she recalled feeling "frantic" when in hospital shortly after being diagnosed.

So I was there (in hospital) and they started giving me tests and it was two weeks or was it three weeks and I had to practice with an orange. So, I'll tell anybody that an orange is not the same as giving it to yourself!... And I remember the nurse was trying to show me, the first time I tried to give it to myself, and I was bawling so hard, I couldn't even see what I was doing. Oh God, all I could do was cry, I was bawling so hard!

This narrative is one example of the numerous problems and frustrations experienced by the subjects when attending formal diabetic teaching sessions. According to the participants, these experiences did not truly address their learning needs in regards to Native diets and traditional ways of preparing food. The problems encountered were varied but certain themes emerged illustrating the need for culturally-appropriate health education. One such concern involved not having enough time to learn about living with diabetes. This theme emerged during the discussions of the formal classes attended and the one-to-one contact the subjects had with health care professionals. In the narrative below, one woman described the rushed nature of the classes she attended shortly after learning she had diabetes.

When I first became diabetic, they sent me over to _______ for this workshop. And that was fine, but it was a little hard for me. They really didn't give me enough time to ask the nurse questions. It was sort of yes, no, and go on because it was such a large group, you know, you can't answer everyone.
Another man believed that he was not given enough time to get a sense of what diabetes really was. For this man, it would have been more meaningful to talk to others with the illness to fully understand what he was facing.

Like that diabetic clinic, you only go for two days. You only talk to people with diabetes for two days. When I went two years ago, I didn't have any idea what diabetes was. I didn't talk to the people very much, like some of the people have had diabetes for two years or something. I didn't get to talk to them very much.

This man believed that if he had known more about the nature of diabetes in the beginning, he would have known what questions to ask his physician. Informants also talked about the "rushed" nature of one-to-one interactions with health care professionals when they came away feeling that their concerns were not really heard.

There's a lot of times I just want to ask him (physician) questions, cause then like I say, he just talks to me so fast I never get everything in that I want to ask him, unless I talk fast!

Another major theme that emerged from the descriptions of formal diabetic teaching sessions concerned not feeling part of the group. In all cases, the one to two-day teaching programs were provided in hospitals or clinics off reserve and the subjects were asked to attend shortly after being diagnosed with diabetes. One subject felt that because she was the only Native participant in the class she attended, she was too afraid to ask questions and felt intimidated by the other non-Native participants.

It was about 12 (people) in there, some real dressed ladies, men, they kind of talk above you and you don't feel like, I did ask questions, but I know a lot of people who wouldn't feel like, being put down or, that's not the word for it either, intimidated? ....And that's why I say if it was all Native...because, these people that were all there, they were so well dressed, cripes, you know, they can go to the store and buy anything they want, you know. Well maybe they can't but...their husbands were sitting there...and I hate to ask something in case it's really stupid, you know....if you ask a certain question about certain foods....so I think too, if everybody was like me I mean, they wouldn't ask questions. But if we were all alike, well, we all eat the same foods you know. So that's what I'd like to see, all Native groups.

For this woman, feeling out of place in the diabetic class prevented her from participating in the group. Because the classes were held off reserve, people also talked about feeling out of their own territory. One man voiced concern that when such classes are not brought to
the people, a sense of trust is lacking in the relationship between the health educators and
the Native clients. He talked at length about the need to develop such trust by bringing
health education to where people live on the reserves, to allow participants to stay in their
own "comfort zones."

I think if a workshop was put on, on our own territory, instead of going to the hospital,
which we dislike, you would get more participation from our Native people...It is the
comfort of you coming to our territory. It's the comfort and the security that we have
being in our own territory....we know that the person that comes to our territory is
really and truly concerned. I think our people would respect that. You see we have
been put in a certain category all the time and each person has their comfort zone and
this is where it is at. We would be in our comfort zone, we would be more relaxed and
willing to listen, to watch. It's a feeling of trust and comfort, that's what it boils down
to.

This individual had refused to attend the workshops that were offered him when he was
first diagnosed, choosing instead to learn in his own manner about his illness and how to
control it. For him, making sense of diabetes stemmed from his own knowledge of his
body and how it reacted to different foods.

I didn't attend one diabetic workshop. I would like to do the learning of my own. All I
wanted was the guidelines of the food that they use that I couldn't touch, but I wanted
to have my own list....being allergic to certain foods is why I didn't take the workshop.
I know I could learn in my own time more than what I can get in these classes.

The above narratives illustrate how informants found the initial process of learning
about their illness confusing, alienating, and out of context with their own lives. Because
the professional resources were generally viewed as unsatisfactory, the informants instead
struggled to understand their illness in a way that was relevant and personally meaningful
to them. This was achieved using two primary methods: (a) studying their individual
physical responses to the illness and various foods (learning the boundaries), and (b) by
examining how other people with diabetes managed their illness (developing frames of
reference). Creating this personal understanding of diabetes continuously evolved
regardless of the time since initial diagnosis. As it was shaped and validated, it influenced
the many decisions faced by the subjects on a daily basis. These two processes are
described below. Later in the chapter, it is shown how this evolving personal meaning shaped the struggle to live within the boundaries of the diet.

Learning the Boundaries

One method the informants used to make sense of diabetes involved learning how their own bodies reacted to the illness and various dietary transgressions. By using this process, the subjects learned the dietary boundaries within which they had to live out their daily lives. Such an understanding helped the informants to deal with the uncertainties facing them in regards to food choices, amounts, and exercise regimens. This ambiguity was illustrated by one woman who spoke of having to constantly reinterpret her cooking methods and food choices because of the inadequacy of the dietary guidelines: "you never know whether you're eating right or not because our food is so much different than what is on the diet sheet."

This woman used daily blood glucose monitoring to better understand how her body responded to diet and exercise. When asked if the testing helped her know her body better, she responded:

Oh for sure. I know how much I can do. When my blood is low, I know I can't do very much. If the sugar is low, I'm shaking and if it's too high, it's about the same thing....You see if my sugar is high, then I get around and try to work it off (laughs).

By reviewing her log of the test results, this woman concluded that constipation influenced her glucose levels.

Once in a while it (blood sugar) goes right up and I found when it goes right up I have trouble with my bowels moving. And I get a real full stomach and my sugar stays up. I couldn't figure it out before, when I have a hard time I have to take laxatives. So most of the time I take Milk of Magnesia and if it doesn't work too good then I use nature's remedy. But most of the time it's in that range. So long as I keep my bowels moving, those numbers come out almost evenly (laughing).

Later, she described feeling "discouraged" about her health and how the blood testing helped her to understand how her body responded to daily stress.

(The stress) could be some of the up and downs I go through when I'm not feeling good, that's what I think when I'm watching my track record (glucose log). When I see
it was high, I know that I wasn't feeling very good that day...I felt kind of sick or something, or worrying too much and I like to read, it takes my mind off a lot of things, but now I've only one eye.

For this woman, the daily monitoring of blood glucose was a strategy used to test out the nature of her body's responses to diabetes. Other informants would learn their limits by taking note of the physical symptoms they experienced. One subject, who had been noticing changes in his exercise tolerance, asked his wife to validate his reactions.

It just got like that when we (subject and wife) were on the walk because we didn't have a snack before we left. I usually have a fruit. And we went for our walk just now, we got about half way to where we usually go and I noticed how hungry I was and I was hoping I wouldn't start shaking. I told my wife to watch and see what the reaction was when we got back to see how bad I was shaking. It didn't bother me this time. Like, sometimes, I go quite awhile just being hungry and it won't bother me and then sometimes, it gets really bad.

Discovering the boundaries involved continuous trial and error for the informants. One subject noticed many diverse reactions to different foods. When asked who he turned to for information and guidance, he immediately pointed to himself and gave the following account:

I know the food that I try to take. If I have a reaction, I study that reaction, how it affects my body and be it bothering my vision, or I get a rash or how different foods affect my body, I study the reaction after I eat the food and how long it takes. So then I learn all different things about diabetes.

Discovering the boundaries in which they had to live was a central part of understanding the illness and the complex realities and limitations of daily life. As the narratives above illustrate, it was a very personal and individual process. The other method used by the informants to make sense of diabetes occurred largely within the social environment in which they lived.

**Developing Frames of Reference**

Actively seeking out information from other diabetics and comparing and contrasting the experiences of others helped the informants to develop frames of reference. Such frames guided people as they tried to make sense of day-to-day management issues and
what their future health may be like. This process was especially helpful shortly after diagnosis or when facing complications or new treatment regimens.

As mentioned in the previous chapter, diabetes was found to be highly prevalent among the family members of the participants. Most of the informants cited numerous relatives with lived experience of the illness as major sources of support and information. One man, diagnosed six months previously, talked at length of the guidance he received from his family members who had diabetes and with whom he had frequent contact.

When asked what he would do if he did not have family members with diabetes from whom to obtain advice, he gave the following account:

I wouldn't know what I'd do. See mostly every time I talk to (sister-in-law) about it she always mentions something different, heh? Different ways of cooking or different medicines or something like that.

This man had two siblings, one parent (deceased), and three cousins and one in-law who had diabetes. These relatives were his primary sources of information as he had not yet been able to attend a formal diabetic session due to a "back log of people wanting to go."

Because his learning needs had not yet been met, he turned to his sister for information.

My sister has a book for me on all that stuff they take in the hospital. She went to them classes and she's got a leaflet like that and all the stuff that's in there. I'd like to read it....A lot of stuff on diabetes.

Another woman talked extensively of the guidance she received from her sister who had diabetes for over six years. She related the following story of when she was initially in the hospital after learning she had diabetes.

And I started doing exercises in the hospital and my sister was in the hospital at the same time and I kept walking up and down the hall and she said what are you doing? And I said I'm trying to bring my sugar level down! And she said don't be silly!

When this woman was interviewed a second time, she had recently suffered a stroke. She recalled how her sister knew that her diabetic management was poor.

I started eating and last fall I started gaining weight and gaining weight and my sister said 'your blood sugar, it's too high' she says 'go check it', she says 'you're trying to keep up with your insulin...it's just too high'.
Because most relatives were seen on a frequent basis, they were highly utilized as frames of reference. Two of the subjects, who had lived with diabetes the longest among the study sample, talked of often providing such guidance to their relatives who came to them for advice. One woman described the encounters she had with her brother-in-law shortly after he learned of his disease.

He'd sit around and he'd hint around for me to talk about it. He'd say 'yeah, I was doing this and I started getting sweaty and I didn't know what was the matter but I guess I forgot to eat. You get dizzy if you don't eat, heh?' I said 'yeah, you're supposed to eat between meals, have your fruit.' He'd hint around for me to give him advice. Seems like he wanted me to tell him what to do....When he was drinking he wouldn't talk to me or nothing and when he became diabetic he would start visiting me, come ride over here on the bike.

The other woman related how she advised other family members to follow their diet in order to avoid having to take insulin.

Like my daughter-in-law, when she was first diagnosed, she was just on a diet and I kept telling her if she stayed on her diet and watched herself she wouldn't have to go on the needle. But I think she's on the needle now.

For both of these women, providing information was a role they spoke of often and with great pride. It is important to note that not all of the subjects based their frames of reference solely on family members. Two subjects sought out guidance from people who were either not related or who were not Native. The important consideration for these informants was the opportunity to learn from those with lived experience of diabetes. One subject, diagnosed two years previously, had become concerned about some early signs of complications and the possibility of having to use insulin. He occasionally talked to his brother and cousin about their experiences but he also wished to attend self-help groups off reserve as a means of further understanding how to live with the illness. He related the following story of a chance encounter he had with a non-Native man who had lived with diabetes over 20 years.

Like they have a meeting, I think it's once a month or something. When all the diabetics get together on their own. And just to help people who have not had diabetes for a long time, talking to older people who have had diabetes for 20 or 30
years...I think I will start going to their meetings. I think I learned more from him (person with diabetes) than the doctor or the diabetes centre. Whenever I talked to (man with experience) about any symptom or anything, like my lips going numb or something and he'd say yeah and he'd keep going on about the symptoms. I'd just mention something and he'd explain the whole thing.

For this man, the advice he received from those with experience of living with diabetes was seen as more valid than the information received from health care professionals. When encountering conflicting information, more weight was placed on the advice gained from experience. Such frames of reference helped this man to make sense of the symptoms he was experiencing.

I notice that some of the things that my doctor told me or the diabetic clinic saying stuff like I shouldn't get any reactions like the shaking or the numb fingers because I'm not on medication. I can't remember if it was my doctor told me that or the nurses at the diabetic clinic but I was telling him (physician) about all the symptoms and he said I shouldn't get it cause I'm not on any medication, my blood sugar is doing ok. I was talking to (person with diabetes) and he was saying that, uh, he figures it is all the symptoms of diabetes, because I get the shaking, and the numbness, weak....That's why I want to go to this guy's meeting. Talk to all the guys that have had diabetes about 20 years.

Another man talked about how he compared his eating habits with those of other diabetics at social gatherings. This man was the only subject who did not have any blood relatives with diabetes. He talked about the uncertainty he encountered regarding various foods he could no longer tolerate. Comparing what others did helped him to make sense of what the "limits" were.

I guess there's quite a few different diabetics 'cause when I go to different functions, someone tells me they are diabetic and I'm looking at them, eyeing what they have (on their plate).

Later in the interview, this same subject gave the following account:

You see, that is what I don't get, why other people that are on something stronger than Tolbutamide, which I am on, and yet they can eat the different foods. Some of them they can have a chocolate bar for energy and I can't touch it. I can't touch one!

When asked what he talked about with other diabetics in the community, he stated the different reactions to food was, in fact, the central topic of conversation.
We want to know more about why we can't have certain foods. How come a lot of us have different reactions.

People who had extensive experience living with diabetes were therefore viewed as valuable resources. Such people were sought out to provide practical advice and to share their experiences of living with the illness. One area of concern that the subjects often explored with relatives involved the various treatment regimes used to control diabetes. For all of the subjects not taking insulin, the prospect of having to receive such treatment greatly concerned them. For these individuals, the experiences of others helped them to make sense of what such a regimen might be like for them on a daily basis. The following individual wondered if, like his other relatives, he would have to take insulin in the very near future.

Once in a while I sit down and wondering if, like they (physicians) said I'm going to have to take the needle eventually, probably. I talked to a lot of people too and they started out without taking anything....But my two sisters and brother-in-law they just right off they had to take the needle as soon as they got it. I don't know if they waited too long or what. But it sure hit me awful quick, seem like it. It just came. Going right up and went right back down and stayed there.

Based on the anecdotal stories of others, the general consensus was to avoid ever having to take insulin or pills. Convinced by what he had learned from relatives using such a regimen, one man described his understanding of insulin therapy as "a real pain."

But all those other diabetics you talk to and that they're on insulin or pills and they say that if it is at all possible never go on insulin or pills....One of my cousins, he said, when he first started on that insulin, I was talking to him about the reactions and it was so bad that he keeps warning me don't go on insulin. He was trying to warn me.

The experiences of those around them provided people with frames of reference which helped them to understand the precarious nature of medication administration in the event of dietary transgressions. In the narrative below, one man related how his brother-in-law had been on and off medication because of "cheating."

I was hoping I didn't have to take the needle or anything like that. I have another brother-in-law, he was taking pills. And they took him off the pills and he started cheating so they had to put him back on the pills. I guess he was cheating on his diet or something. And his blood sugar went back up.
People also compared anecdotes of successful and unsuccessful diabetic management. The subject quoted below had talked at length about his dislike of having to take oral hypoglycemics. By comparing two different cases and relating them with information he had received from health care professionals, he gained a sense of how other people had avoided having to take additional medications for the illness.

I got a neighbour, he's got diabetes too. He's in his 50's I guess. Like, he never uses a diet or anything but he's on uh, Diabeta comes to mind and his vision is going. He said he just started taking more pills. The nurses at the hospital said that four is probably maximum. Four Diabeta pills a day. It's too much.....There's an old guy, he wasn't on anything. Just his diet and exercise. He seemed to be, guess he's in his 70's and he's one of those exercises everyday, walking, he's on a good diet, he wasn't on any pills. His blood sugar's right normal....I guess just the foods he eats. I guess he's sticking close to it, the food list they gave him. I guess he sticks to that.

Based on such frames of reference in the social world around them, informants talked extensively of the desire to avoid taking daily pills or needles. The intention to stay off such medication often surfaced when the informants spoke of the value of adhering to the diet. This contention was supported by numerous stories the informants had heard of relatives or friends not managing well. These accounts were candid and rich in detail. One subject talked to his brother, who had diabetes, about the nature of insulin therapy and learned the following story.

And he (subject's brother) said one of his friends was a diabetic and he was going out drinking one night and he knew he was going to get quite a bit of sugar and he figured he'd better get more insulin and so he gave himself a double shot of insulin and went out drinking and didn't drink as much as he usually does and then he ended up passing out with an insulin reaction, low blood sugar, didn't really drink as much as he thought he was. (chuckles) Ended up in a coma.

Another man talked about the deteriorating condition of his brother-in-law.

Well she (subject's sister) was more or less telling me about the way (brother-in-law) like he I guess, when his diabetes acts up, he gets real crabby like you know and stuff like that. I just go by stuff like they do, more or less. I guess he had to take some kind of a pill, doctor told him, for his circulation. He was not walking and stuff like that, I guess or exercising. I haven't been exercising, I've been on the go. Last time I seen you I was exercising half an hour a day, I haven't been doing that....And he was getting these dizzy spells, they figured it was his circulation that would do that. Like he'd get
up and walk or something like that he'd get a dizzy spell if he got up too fast. They figured it might have been his circulation, so they gave him pills.

When asked if such health problems might happen to him, this man compared his situation with that of his relative and made the following conclusion:

It has possibilities. It's never bothered me, nothing...Dizzy spells or anything like that. I go out for, not even, small walks sometimes, just out to the corner and back. I have to get out for fresh air or something.

Examining the experiences of others was also a tool used to understand how some people achieved strict control over their diet. One woman related the following account of a man who demonstrated her belief in the value of education.

I know someone who measures right down to the amount. I don't know how he is now but he was just on the diet so far. He does his exercises. His daughter was telling me he measured his food and he eats only what he was supposed to eat. I'm telling you, that comes with education I think. Well as long as you had more education I think, you understand those things more. ...I think you have to really get into it and find out just what you have to do to keep it under control.

Later this same woman related how others, who did not have such an interest in learning, did not fare as well.

They don't know, I think, know how to look for that information. If they don't do like I do, read all I can and ask all the questions I can, they don't do that they might just go along and get worse...They lose their toes or something like that you know and some have even lost their feet and all, at the ankle. I think about all that and you know if you know these things happen you're going to try your best to do better.

The topic of complications only came up in the interviews if the subjects were directly asked questions about such future possibilities. It was discovered that five of the informants had either a parent or a grandparent who had diabetes while they were growing up. In all cases, these close relatives experienced severe diabetic-related complications. When relating these events, the subjects all spoke in a calm matter-of-fact tone. One woman related how her mother lost both of her feet to gangrene when the subject was still a child.

And I like to soak my feet. And then I use all kinds of rubs. Since I'm a diabetic, my toenails. I really have to watch them. Because, I know, my mother had to have her feet cut off. Right from here (motions to mid-calf). Just started from her big toe. Got
ingrown, then the other one caught and the legs went all purple and she got blood poisoning.

When asked if she worried about the possibility of experiencing such problems herself, she said: "Yeah. If my feet start getting infected and then I get worried. I have to really watch my feet." Another woman was experiencing gradual vision loss similar to what her own mother had gone through. This woman tried to closely watch her diet and stated that "if you know these things happen, you're going to try your best to do better." However, there was also a degree of acceptance of what fate had to offer her, as illustrated in the narrative below:

Well, I keep thinking if (vision) keeps on like this, keeps hemorrhaging, I could go blind. So I have to see him (physician) once a month and if it starts hemorrhaging then I might have to go down to New Westminster and have a laser beam....I've never been afraid of death....I sure wouldn't want to be blind. My mother didn't go really blind but she had the same thing I have. It was hemorrhaging and it wasn't looked after. And she went blind. She did have some work done on it but she would, like, only see partly. But everything was blurry. But blindness is something my family has always had. I was really afraid of it before but I sort of think now if it is gonna happen it's gonna happen. (laughs).

Another man, who did not have any blood relatives with complications, was asked if the topic ever came up when he talked to other diabetics. He replied: "No. Um, we just learn to accept it that's all. You know, we know we don't have a choice, actually it's something that we don't talk about." The above narratives illustrate that future complications were viewed differently among the subjects but that they were largely seen as part of life's natural course. It was often the immediate day-to-day management concerns that the participants discussed at length as being their primary concerns.

As seen in the above narratives, the process of understanding the diabetic experience did not occur in a vacuum. For the participants, a major part of learning about their illness involved comparing and contrasting the experiences of others with their own. Coupled with their understanding of where the boundaries lay, these frames of reference helped the subjects to develop and validate their own conclusions within the social context of their
lives. This personal understanding of diabetes shaped the nature of diabetic diet management on a daily basis.

Applying the Personal Understanding of Diabetes

The evolving personal conception of the illness greatly influenced how individuals struggled within the boundaries of the diet. The nature of this interrelationship was particularly evident in the strategies chosen by the informants and their underlying motivation to change life-long habits. It is recognized that as each individual meaning of the illness was unique, so was the nature of dietary management.

Using the Boundaries

As the informants discovered the boundaries of the diet and the consequences of such transgressions, they used this understanding to guide them in the many complex decisions related to daily food choices. One woman, described earlier, used blood glucose monitoring daily to clearly delineate the boundaries of her diet. She described a daily systematic routine in which her body's responses to diabetes influenced the decisions she made to stay within the limits of the diet.

What helped me is if my blood is too high, then I will have a cup of tea or coffee and then about eleven I will have my lunch....Now so when it's low, then I know that I have to eat something. If I didn't have that testing thing, I don't know what I'd do!

This information, used to maintain strict diabetic control, also guided her when preparing traditional food. Because the diet sheet she had been given provided little guidance on how to include such foods, she discovered through many years of trial and error how to cook traditional foods and still remain within normal blood glucose levels. In the narrative below, she described this selective decision-making process used to achieve blood glucose control while minimizing the sacrifices she made.

Well, I have the diet sheet. I've had that for years and I don't follow it exactly, I just pick out the things where it says the kinds of foods you can eat and the amount....I just play by my blood test....I've found that the different ways you prepare your fish that makes an awful lot of difference, how much you can eat. I use Crisco a lot when I cook and that helped keep my blood sugar normal. If I want anything fried, I use a little of
the shortening ....Tenderflake (was bringing up blood sugar) uh, that's lard. And any other kind of fat. I've tried other kinds of shortening but Crisco is the better.

Another woman used blood glucose monitoring very selectively for times when she knew she had transgressed the dietary restrictions. In the narrative below, she described a large family gathering on Thanksgiving weekend during which she gave in to temptation.

Oh, I do try them! (food not on diet) I was surprised. At my brother's, I thought I'd have to walk and walk and walk the next day. But I tried my blood sugar and it was fine. And I thought it would be really high 'cause I said 'I don't care, I'm going to have that second piece of pumpkin pie' you know 'cause it was Thanksgiving, you know. And I thought that would really raise it but it didn't....I try to test every other day but I don't do it every day. And if I feel it might be high, like say, if I ate too much, I'll try it the next day....If it's high, I cut right down on eating and exercises....I know when I ate too much then it'll go up, but never really high, never so high that I'd have to worry about it.

For this woman, the low results obtained through the process of testing her blood sugar gave her permission to transgress the boundaries. Other informants used a more subjective testing process. This was well illustrated by one man who used the physical reactions he noticed from various foods to identify where the limits were and how far he could push the boundaries. This man had more faith in what he could learn through trial and error than in the formal diabetic education programs. Like the other informants, the sense he developed from this process coloured the manner in which he followed the prescribed diet.

It's hard to really stick close to it (diet) like I cheat maybe twice a month, like I like to have pork chops but I know I have to stay away from the pork chops and stuff....But there's only certain foods that I can cheat with, I know by my reaction that uh, doing my own study.

He found that the traditional foods such as fish and wild meat were tolerable, whereas the commercially-prepared foods caused physical reactions. This personal understanding of the boundaries influenced this man to choose a diet rich in traditional foods where "the quantity isn't limited." He spoke with pride when describing this diet and saw himself as "one of the lucky ones."

Because you see, the salmon, like I can take smoked salmon, salted salmon, wind-dried salmon, you know, all the wild meat and I can have a great quantity of it and it won't affect me, so this is what we're going back to....I just experiment with my body. It's the only way I want to learn, hey. And once I made up my mind I knew I was going to go
back to my traditional foods where I know that I wouldn't have problems. That's why we got canned fish, frozen fish, we got deer meat. But I'm sticking to my traditional foods....It's just experimenting with a lot of stuff that I know.

The subjects also talked about knowing first hand what would happen if these boundaries were widely transgressed. One woman, diagnosed 16 years earlier, told the researcher that she knew exactly what she could and could not eat based on the numerous reactions she had experienced over the years. She identified her desire to keep her weight down as a major motivator in staying on her diet.

I'm supposed to watch my weight....I did have reactions when I first got diabetes....I was really heavy, I was 235 pounds when I first became diabetic. So that's why I want to keep my weight down. Oh, I never want to be that weight again. Oh, I used to suffer! I was really nauseated, really dizzy. Seemed like quite an effort just to get up to go to the bathroom. You learn as the days go by. Sometimes I wish for things but if you are going to go over, you know you are going to suffer for it, so you just rather go without.

This woman's personal experience of transgressing the boundaries had become a central part of how she understood the illness and greatly influenced her daily struggle to stay within the limits of the diet. All the narratives above illustrate how the evolving validation of the boundaries helped the informants to make the many daily decisions regarding their dietary choices.

Using Frames of Reference

The development of frames of reference, as described earlier, occurred within the social framework of daily life. The information gleaned from other persons with lived experience of diabetes was often used to guide the informants and greatly influenced the motivation to alter life-long habits. One subject talked extensively of the advice he received in relation to losing weight, changing his diet, and starting regular exercise. This man identified scheduling and keeping a diary as central strategies he was using to maintain some predictability and routine.

So we (subject and wife) are going to try to get a schedule where we exercise at the same time every day now...My wife and I both have a diary and we write down every day, like exercising, and we are going to write down why we didn't exercise. Read it back to each other sometime, look at our excuses why we didn't go for a walk. 'Cause
some of our excuses on the last one, the last year's, were pretty stupid, why we didn't do it (laughs).

This man's strategies of maintaining a schedule were influenced by the advice he received from a man with extensive experience of living with diabetes.

The old guy I was talking to, he was about 68 and he says he has it down to a schedule that he's followed for about 20 years where he eats at a certain time, exercises at a certain time. He said just things like that you know, being a diabetic for 20 years, he says he has helped a lot of people, probably more than your doctor.

He also talked about his desire to obtain a glucometer machine so that he could more clearly understand how his body responded to food and exercise. Again, this decision stemmed from the advice received from those with lived experience.

The old guy in the mall was telling me that if I keep a journal and write down your blood tests, find out what it is after you eat, before you eat, when you exercise. He said you have to get a good schedule, when to test it. I told him I didn't have a blood testing thing and he said I should get one.

The informants also used role-modeling of others as a way to know how much to eat while staying within the confines of the diet. One subject described the difficulty he had in changing past eating habits consisting largely of foods high in fat and carbohydrates. For this man, the information he received from his diabetic sister guided his daily cooking methods and portion sizes.

Yeah, it's been pretty hard to stick to that diet. A lot of times I fry up a burger, but I take and squeeze the fat and stuff out of it, 'cause that's what I'm supposed to do. My sister said that's what I was supposed to do. You know, with paper? Stuff that I wish for a lot of times....I don't eat bacon or nothing like that no more, just when I go to my sister's place. (laughs) But she has the portions, she knows the portions and everything.

As mentioned earlier, the information learned from the social frames of reference and the identification of the boundaries was a continuous process. And as the sense of diabetes changed so did the way in which the diet was managed. This was clearly illustrated by one man who had been diagnosed two years earlier and who believed his blood sugar to be normal based on his selective use of urine testing.

I used to do the urine (testing) every day when I first went to the diabetic clinic. I got some of those strips to test the urine every day and it would come back positive. And
then it was normal, and I did it for a week or so and it was always normal so I gave all them strips to my brother. After that I never bothered again, just get the blood tests from the doctor.

When asked how he managed his diet, this man frankly described his selective decision-making in regards to the choices he made.

Well, I'm supposed to go on a diet. And like the diet that the diabetic clinic gave me but I didn't follow it. I just quit sweets. Like I used to eat quite a bit of sweets. Like I like to have two big bottles of Coke at super or something. And then I like cake and stuff like that. I just quit eating sweets, that's all. I still eat just as much as I've always eaten.

This decision was based on not only his negative urine results but also his past experience of "shakes" when not eating enough.

Most of my life I guess, whenever I get hungry, like (if) I don't eat at a certain time, I get too hungry, and I guess the blood sugar drops right down to pretty low and I start to shake and I get weak. That's the only complication I've ever had.

Based on these symptoms and negative urine testing results, this man made the decision not to follow his diet completely but instead to limit only the intake of food high in sugar. By the time he was interviewed a second time, his physician had prescribed oral hypoglycemics. The degree to which he transgressed the boundaries of the diet had changed considerably. He attributed this change to a heightened concern of medication-related side-effects and diabetic complications. Much of his understanding was based on information from other diabetics and health care workers at a recent clinic he had attended.

I got to be a little more serious about the diet now....I worry more about diabetes now. Like, I paid a little more attention to all the stuff, like the complications, from diabetes, eyes going, the tingling in the feet. Losing feelings in the toes and stuff like that.

He also related a story of his grandmother who had several episodes of "insulin reactions" and lost most of her vision before she died.

She was gettin' sicker more and more. We used to think it was because of how she used to eat like she'd have chips all the time and crackers. Pop, not diet pop. She'd drink soft drinks all the time. She was thirsty all the time.

When asked if he was concerned that such experiences might happen to him, he gave the following response:
It does now. I just didn't pay any attention to it...because it was never, um, I guess you think you would never get it or something like that. Now that I have it, I'm learning more about the complications that could happen, start looking after it more.

For this man, the understanding of diabetes had changed as a result of new exposure to information and a heightened concern over long-term complications. This changed sense of the diabetic experience prompted him to alter his dietary transgressions. However, the extent to which he followed the diet was influenced by the physical effects he noticed on a daily basis. These effects formed part of his evolving understanding of how his body responded and resulted in his conscious decision to alter the prescribed dietary guidelines.

Now, if I stuck right to their diet, I'd probably lose about 2 pounds a day. Saturday and that are real bad. Blood sugar lowers down and I'm kinda gettin' scared of that so I've been eatin' more. Uh, it went right down there. I would start shakin' sweat. Like the back of my head just started sweatin' just pourin' sweat off. And that's just before I started shakin' the whole body. It had really worried me so I keep eatin' more and more. Fruit, fruit juices.

For all of the subjects described above, the personal understanding shaped by testing boundaries and examining frames of reference largely influenced the nature of dietary management. As different reactions were experienced in response to the illness, selective decisions regarding dietary management were made. Concurrently, information from other diabetics molded the personal meaning of the illness and and greatly influenced motivational factors shaping dietary control.

The nature of diet management was not exclusively shaped by the evolving personal understanding of the informants. Because food preparation and consumption largely occurred in a social environment, this daily context of day-to-day living also influenced the way subjects struggled to remain within the boundaries of the diet. The following section explores this relationship and illustrates how the many decisions facing the informants were coloured by the social world around them.

Struggling within the Boundaries: The Social Context

The struggle to live within the boundaries of the diet was ongoing and multifaceted. To fully grasp the nature of this process, it is important to first get a glimpse of how the
informants described this daily fight with temptation and change. This sets the stage for a further exploration of the social nature of the struggle and how this same social context shaped the way that temptations were dealt with.

**Cravings and Feeling Full: The Daily Struggle**

All of the participants described the many challenges regarding day-to-day self-control. Words such as "frustration," "craving," and "anger" were used by the informants to describe the problems they faced when changing life-long eating habits. When asked to identify the most difficult aspect of dietary adherence, all of the subjects referred to the size of the portions. This was true regardless of how long the informants had been living with diabetes. One man, diagnosed two months previously, and another woman, diagnosed seven years previously, used very similar words to describe their frustrations with the small portions of fish as they both outlined with their fingers small squares a few inches in diameter. For the respondents, the diabetic diet did not satisfy their desire to "feel full" after eating. This experience was richly described by one man who talked about his struggles with controlling the size of his meals.

Even when I'm full I can't stop eating. Figure after supper too have a big mug of tea after supper and I have a sandwich with that (laughs). Still full yet, still don't know why I'm having a sandwich when I'm full.

He later described how his "nerves" played a central role in a cycle of over-eating and frustration.

Probably do it this winter (lose weight). Pretty hard to. I'll follow a diet for two days and then usually when you go off it again it gets worse. It's pretty frustrating....Like if I get depressed or something, I start eating or I get nervous, I start eating. I guess trying to diet too, I get nervous about it too and I notice how fast I eat and how much gas I get from it. Trying to stop the way I eat and how fast I eat and all that. Trying not to wolf down all the time.

Another woman reflected on how much she used to eat before she became ill with diabetes.

Oh, I used to eat everything like pork chops. Big portions. Now that I look at it, it seems like it shrunk so much (laughs). I couldn't believe that I ate that much but I was
really big... Just to go and serve yourself you find that your portions are smaller. And I was thinking about it and I looked at somebody else serving that's not a diabetic. And I think, gosh, are they going to eat all that?

After becoming diabetic, this woman began eating more dried fish and meat jerky because "they don't have sugar and stuff in it... it makes me stay full longer." In this way, she could eat food that was considered "OK" but with which she could still feel satiated. Later in the interview, she claimed that the desire to eat more was still a problem.

Sometimes it gets kind of tempting and I wish for more. Late in the day I get hungry. During the day, it don't really bother me. At night time, I sit there and watch TV and if I can't sleep I start wishing for this and that.

Others talked of having "cravings" or "wishing for" certain foods which were now considered to be "bad foods." Two different subjects are quoted below:

I just crave for pancakes. (laughs) I've been wishing for pancakes for three days now so I made those muffins and I burned them (laughs)

I was a real candy addict. There have been a lot of birthdays in my family, you know, lots of nice cakes and stuff like that... I used to have a lot of stuff like that. I have a sweet tooth.

Changing the types of foods consumed and reducing the size of the meals were identified as two of the major areas of struggle faced by the informants. The subjects also spoke of times when this constant struggle would weaken their resolve and they would make conscious decisions to cross the boundaries of the diet. One woman, who had been in hospital numerous times related to her diabetes and heart disease talked about times when the daily temptations would win over.

Sometimes (when under stress) I can't eat and other times I eat like a horse, like I eat things I'm not supposed to. I say "oh to heck with it. I'm sick all the time anyway, might as well eat what isn't any good for me." It's been hard to stay on my diet.

When asked how she felt after she had eaten foods she knew she was not supposed to, she said, "I just try to forget about it (laughs) Or it makes me (feel) even worse. So why eat it!" Clearly, the struggle to stay within the boundaries of the diet required daily self-control. This daily battle was found to be largely fought in the social environment shaping
the lives of the informants. In the section below, the social context of food preparation and consumption is described by the informants.

The Social Context of Eating

The social nature of food preparation and eating was clearly illustrated when participants talked of large group gatherings such as extended family dinners, pow wows, and winter ceremonial dancing (known as the smoke-house). The generosity and abundance of food was woven throughout the narratives. One woman described a family get-together which involved seven children and seven great-grandchildren. As in many households, it was primarily the women in the house that prepared the food. She gave the following illustration of the large quantities of food available at such gatherings.

On our lunch on Sunday, I didn't know what to prepare for lunch with all the people over. My daughters were busy getting their children ready for church. And my granddaughter said why don't you make some pie. And then I thought, this isn't very much. And then my other daughter said she'd take out some smoked fish and some dried fish. Then I was going to make some salad anyway. Some green salad and some potato salad. Then, it kept getting more! (laughs) So the meal was growing!...My granddaughter was over here too and she said, Grandma, I sure wish for beans. And then when we finished cleaning up I said I'll help you. So we put the beans on. Just plain brown beans. A big pot of beans. And then after that, well, if you're going to have beans you have to have rice! (laughs) Yeah, that's what we had, smoked, canned and dried fish!

This description illustrates the great abundance of food and the generosity of the providers. The informants also talked about the expectation that guests at such gatherings accept the food that is offered. One man related how it can be very difficult for a person to adhere to dietary restrictions when attending large feasts.

You see with our people you have to sit down at the table and eat whatever they offer and it's hard for me to tell them 'no' because there are certain foods that I can't eat and when I tell them I am diabetic they may have bacon and eggs. Like eggs is one of the things I can't eat, I have a terrible reaction when I eat eggs. It's our people's system that you have to accept the food that they offer.

Another man believed that the tendency of Natives to eat large meals was one reason for the high prevalence of diabetes among his people.
I think it's just the diet. Like, there's a lot of pow wows and stuff up here and there's always food all the time. A lot of time we will have dinner here and then go over to the smoke house and have supper again because they put the food on the table. You have to eat again. If you are invited to go and if you refuse their food you are insulting them. So when you are asked to sit down and eat, everyone just sits down and eats. A lot of starches like fried bannock. Almost a delicacy now with Natives. Just that most Indians just like to eat. 'Cause they have all the traditional foods, like the smoked salmon, the deer, or duck. There's also a lot of stew. At these big gatherings, there's big pots of stew. Everybody likes that 'cause everybody fills their plate up with rice and boiled spuds and then pours stew over it. Fish, or smoked salmon.

For these subjects, the generosity and abundance of food were major sources of difficulty when large groups of people came together to share food. Other respondents claimed that such gatherings were not difficult because of the great variety of choice provided them.

It's easy because there's lots of choices, a lot of different foods. You can eat ham, you can eat just a little bit, they always have ham there. They have fish, baked fish. Usually a roast or something and all sliced up and everything and all kinds of vegetables. The pastry is all on one end so you don't go down that end (laughs).

This woman found dietary management much more difficult at home where she lived with her husband, three children, and occasionally up to four grandchildren. Because the food preferences of the family members contrasted with her dietary restrictions, she found herself struggling to balance the two on a daily basis. In the narrative below, she described this process in relation to grocery shopping.

I buy my food, what I need and then I buy theirs so I have a great big cart full (laughs). Sometimes, I go, if I'm really in a hurry I forget about myself and I have nothing to snack on.

When asked what foods in her diet were not preferred by the other family members, she responded:

Vegetables. They don't eat vegetables. She (granddaughter) don't like peas or stuff like that. My other grand kids didn't like cabbage, uh, what do you call that stuff? Bok choy.

Foods high in fat such as pork chops, steak, sausages, and fried potatoes were some of the foods preferred by her family members which she believed to be contraindicated for her diabetes. When a family meal was prepared by herself or another household member, generally the preferences of the family prevailed. The subject would eat the same foods but
would try to eat smaller portions. On one occasion, the woman's husband served a rich breakfast of bacon, eggs, and potatoes for the researcher and the subject.

When he cooks for me, he always cooks potatoes, and I'm not supposed to have too much of them. And when you have bacon, you don't have eggs with it. Or you're supposed to have one egg or one bacon it's alright. But he always serves me so much.

After the meal, the researcher asked if she believed her husband understood her dietary restrictions. She stated that "he knows but it's just the way he serves all the time." Another woman gave a frank description of how her family's preferences shaped the degree to which she followed her dietary guidelines.

They (dieticians) gave me a list of what they call free foods that I can eat a lot of and no greasy foods, and no gravies. And now I've learned that, I do eat that type of food (high in fat) but I don't over indulge....Otherwise, I have to buy all the food that I can eat and the family, well, they could eat it but they wouldn't like it. And uh, when I buy a roast, I'd cut off all the fat and it would come out all dry like a piece of leather.

Both she and her husband shared the tasks of meal preparation. When asked if her husband helped her to follow her diet she said "no, he just cooks away." For both of the women described above, there was a certain degree of resignation to the preferences of their family members. In the social context of day-to-day management of the illness, both chose to honor such group choices over their individual dietary restrictions.

Clearly, the struggle to stay within the boundaries of the diabetic diet occurred within the social environment that shaped the daily lives of the informants. The narratives above illustrate how such a medium could be a source of difficulty for the subjects. Concurrently, this same social environment served as a source of strength used by the informants to restrain their own temptations. This process involved the use of others in the social environment to set and enforce the limits that the subjects had to adhere to.

Using External Controls

Throughout the narratives, people talked of the valuable role others played in the daily struggle to stay within the boundaries of the diet. This limit-setting came in many forms
from gentle humour and "kidding" to direct verbal statements referred to as "bawling out."

One subject described the limits placed on him at family birthday parties and at a local bar.

Oh, well, I'd go pick at the table or something like that they bawl me out. I have lots of nieces and nephews that, you know, like, my brother-in-law's diabetic and they know a lot about this....even the barmaid at the bar, they tease me and stuff too!(laughs)....Well, one of them, her father is diabetic, so she knows all about that too.

When asked how he felt about such interactions, he admitted that it was all part of learning about his condition.

Oh, well, I'm just learning about this really, you know so there's a lot of people know quite a bit about diabetes. Quite a few people have gotten it now I guess.

For this man, the external controls placed on him by others were integral in the process of making sense of where the boundaries were. It also helped him to regain self-control as the temptations became difficult. Another man, who had been "teased" for years about his weight problem, talked at length about his struggles to recognize when he was full and to then stop eating. He described his wife as "the most important one to me now to control it."

This man believed that such outside influence was instrumental in his control over his large appetite.

With the eating like I can't stop myself unless somebody else mentions it while I'm eating....If I get really hungry, then I'll start eating real fast and it keeps going on until somebody notices and then says so and then I can stop.

He went on to describe how limit-setting allowed him to finally cease eating when there was still food available. This was viewed by him as a major milestone in his struggle to live within the boundaries.

Seems the first time I stopped myself was yesterday. My wife and I eat out, eat lunch out and had steak. I finished my steak and baked spud. Had garlic toast, fruit or salad bar. By the time I finished mine, I was pretty full and my wife didn't finish hers, garlic toast, so I started eating it on her. And I said, since she's stuffed, so I said geez, I'm stuffed too but I'm still eating and she told me just to put it down and just stop eating and so I stopped. And that's about the first time I ever stopped when there's still food there. You leave food on your plate for the first time. Probably start doing that more now that everybody, like my daughter, son and wife are more aware of how I eat now. Start helping more.
External controls also took the form of actively limiting choices available to the informants. One woman described how her daughter interpreted the dietary guidelines and enforced the boundaries through external limit-setting.

And she looked at that (diet) list, and she liked to cook, and she'd go in the kitchen and fill my plate with just the right amount. We don't eat at the table, we tend to sit in front of the TV. So she would say 'go sit down' and she'd bring my plate, and my coffee and my fruit. I gradually learned to do it myself (laughs). But it was good, I didn't have to worry about what I'd have for dinner....And she'd look at the list they gave me. And I'd say 'this is free food this one'. And she'd say 'heh! You know you're reading that wrong, it's not a free food!'

Once again, this narrative illustrates the role that others in the social network played in helping the person to determine where the boundaries of the diet lay and to stay within those limits. Clearly, the nature of diabetic diet management was heavily influenced by the social contexts of the lives of the informants.

**Summary**

This chapter has presented the rich narratives elicited from the participants of the study. The process of diabetic diet management was discovered to be based on both personal meanings ascribed to the illness and the social context in which the participants lived out their daily lives. As the perceptions and experiences of the subjects were highly individual and contextual in nature, so was the management of the diabetic diet.

As the findings emerged from the study, it was found that the problems faced by the informants were highly contextual within the larger phenomenon of the illness experience. In summary, the participants found many of their questions and uncertainties not addressed by formal diabetic teaching sessions they attended. Instead, the subjects struggled to interpret their illness within the contexts of their own lives.

When making sense of the diabetic experience, the subjects participated in a trial and error process by which they discovered the boundaries of the diet. This was an on-going and multi-faceted approach that helped the subjects gain a highly personal understanding of how their own bodies responded to the illness. The second method used in making
sense of the diabetic condition was derived from the nature of the social network they belonged to. By listening to the anecdotal accounts of the numerous diabetic relatives, the subjects gained a sense of what it means to live with diabetes. This helped the subjects to develop frames of reference which were especially relevant shortly after the initial diagnosis or in the face of new complications or treatment regimes. It was discovered that as this personal sense of diabetes evolved, so did the nature of diabetic diet management.

The subjects faced numerous problems in their daily struggles to live within the boundaries of the diet. This battle was strongly influenced by the nature of the social environment. The concepts of abundance and generosity were woven throughout the descriptions of family and group gatherings. This only intensified the struggle to change well established life-long eating patterns. The prescribed diets were often difficult to follow because they did not incorporate preferred food items and cooking methods. But while the social pressures in both the home and in cultural events made diet adherence difficult, the social environment also provided the subjects with external controls facilitating their fight against temptation.

By examining the narratives, this chapter has explored the explanatory models used by the subjects in interpreting the nature of diabetic diet management. The nature of this daily struggle was not largely influenced by the advice received from the formal health care system. Instead, actions and motivations stemmed mainly from the social context that shaped the daily lives and experiences of the subjects.

To better understand these findings, it is important to relate them to the theoretical and research-based literature currently available. This is the focus of the next chapter which examines the conclusions of this study in light of the themes evident in various sources of professional discourse.
CHAPTER 5: DISCUSSION OF THE FINDINGS

Introduction

The conceptual framework of this study stressed the value of the explanatory models used by people experiencing illness within the contexts of their own lives. Using this approach, the findings of this study illustrated the individual and highly contextual way in which people struggled to understand and deal with their diabetes. The central themes that were generated from the findings are further explored below in conjunction with theoretical and research-based literature. Some of this literature, previously examined in Chapter 2, is briefly reviewed in light of the study's findings. Other studies and frameworks are introduced and examined here for the contributions they make in understanding the phenomenon in question.

Diabetic Teaching in Native Communities

The subjects who attended formal diabetic teaching sessions sponsored by hospitals and outpatient clinics generally found that the experiences did not truly address their learning needs. Often, the information provided in such sessions failed to encompass the Native experience in relation to food preferences. All of the informants suggested that diabetic workshops be held in Native communities and include all family members.

These perceptions are not unique to this study. A review of relevant literature reveals a common thread stressed in relation to diabetic teaching among Native people. It is emphasized that the approach and content be congruent with Native concepts of health and learning in order to be truly successful. Hagey (1983, 1984) described in detail the landmark Native Diabetes Program in Metropolitan Toronto. This program was a collaborative approach between the Ojibway and Cree leaders of the area and the University of Toronto, Faculty of Nursing. In order to enhance mutual feelings of trust and acceptance, the program encouraged participation of Native people through the use of monthly community events and home-centered interventions. A didactic approach was specifically avoided to facilitate self disclosure and individual problem solving. Native
concepts of health and the use of Ojibway mythology were consistently integrated resulting in a successful program. One such feature involved seating all of the participants in a circle to incorporate the Native concept of nature.

Explanations are given as to the way in which the circle represents the Native community in harmony with nature: birds make their nests in a circle, the earth turns in a circle, the Indian people dance in a circle, the most powerful forces of nature such as cyclones turn in a circle. Childhood, youth, adulthood and old age are the four seasons of life which form a circle. (Hagey, 1984, p.266)

Approaches to health education must also entail the understanding and incorporation of traditional beliefs and patterns. Professional care givers must tailor treatment suggestions to the user rather than expecting the client to conform to a drastic regimen (Broussard et al., 1982; Joos, 1984). Stegmayer and Lovrien (1988) describe an approach which minimizes the complexity of the diet and enhances the incorporation of traditional foods and individual preferences. Jackson and Broussard (1987) further suggest that the therapeutic value of food in traditional Indian medicine be incorporated in discussions about the use of diabetic diets. Food preparation and eating are highly social activities and Joos (1984) suggests that diet counseling include all family or household members wherever possible.

Health care professionals also must be in tune to the communication patterns used in any cultural group (Hagey, 1983; Lang, 1989). As discussed previously, the interviews all contained varying periods of silence. Often, this silence was followed by significant comments by the participants. This phenomenon is discussed by Huttlinger and Wiebe (1989) in their work with Navajo Indians in Arizona.

Navajos are accustomed to long periods of silence during their communications. For the Navajo, the use of silence is one of the accepted rules of communication. A Navajo uses silence to formulate thoughts so that the following spoken work will have significance. A nurse who interrupts during these periods of silence, who interjects or hurries the conversation along may therefore be thought of as rude. This nurse will not be respected and therefore any advice or intervention that is attempted will not be followed. (p. 31)

The literature also suggests that direct questioning, common in the culture of health care professionals, be avoided when interacting with Native people (Huttlinger & Wiebe, 1989;
Hagey, 1983). In describing the diabetic teaching program at the Mohawk Reserve of Kahnawake in Quebec, Macaulay and Hanusai (1987) argue that the quality of the rapport between the educators and the Native clients greatly influenced patient education. Good examples of indirect communication are sentences that start with "It seems to me," "I wonder if", and "Other people say" (p. 135). Hagey (1983) contends that the cultural principle of non-interference is the underlying theme in the use of silence and indirect questioning and answering. She stresses the importance of allowing the Native respondent a choice in how much information to volunteer and the manner in which it is communicated.

Clearly, the off-reserve programs as described by the subjects who attended such formal diabetic teaching sessions were not culturally-appropriate in either the approach or the content. The narratives revealed that this process left the informants confused and often angry. In a search for an understanding of diabetes which was personally meaningful to them, the subjects turned to their own experiences and the social environment in which they lived.

The Subjective Experience of Illness: Knowing the Boundaries

For the subjects in this study, the diabetic experience was highly individualistic and involved a continual process of knowing how the body responded to the illness. Based on the subjective experience of reactions, the boundaries of the diet were established and validated. The informants placed more credence in this process of learning about their illness than the formal guidance they received from health care professionals.

This theme is congruent with the existing literature on the subjective experience of illness. Peyrot, McMurry, and Hedges (1987) described illness states as the interplay of both the personal subjective experience and the public, or professional formalized knowledge. By synthesizing these two realms, ill persons develop an individualized conception of the condition which guides them in day-to-day living. Conflicts often arise because traditionally subjective symptoms have been discounted by professional care
givers as less real and legitimate than the publicly validated medical reality. Instead, Peyrot et al. (1987) argue that symptoms are not merely indicators of disease but form the highly private and personalized knowledge of illness.

In their ethnographic description of adults with diabetes, Peyrot et al. (1987) found that in the initial period shortly after diagnosis, people relied quite heavily on professional knowledge to reduce the uncertainty and ambiguity of the new condition. As they gained more experience with the illness and the subjective symptoms, a personal store of knowledge about their own condition was used more readily to guide the decision-making process. Both realms of knowledge were tested in unique ways. Professional knowledge was judged by how well it worked in the real life situations of the ill person. Personal knowledge underwent continuous testing and mediated the role of professional knowledge. Similar to this study's findings, Peyrot et al. (1987) found a great range of adaptations to living with diabetes which illustrated individualized interpretations of the illness event.

Frames of Reference: Within the Social Environment

In this study, gaining a personal understanding of diabetes was based not only on subjective experiences but also occurred in a social context. Developing frames of reference from the anecdotal stories of their numerous relatives with diabetes was also a key method used to make sense of their illness. To better elucidate this process, literature on social support and self-help groups is explored here.

Social Support

The area of social support has received exhaustive research attention in the past 20 years (Wortman & Conway, 1985; Tilden & Weinert, 1987; Gottlieb, 1985). A thorough discussion of this concept is beyond the scope of this chapter. Instead, the examination focuses on the primary factors of social support as they relate specifically to the findings of this study.

It has long been recognized that the onset of chronic illness and the accompanying daily management can be stressful for both the patient and the family. Hamburg and Inoff (1983)
described the initial diagnosis of diabetes as a life crisis that is often accompanied by anxiety, cognitive confusion and feelings of helplessness. It has been suggested that while a stressful event can have a negative effect on health, social support may serve to buffer the stress and reduce impairment of health (Tilden & Weinert, 1987).

Often, the terms social network and social support are used interchangeably (Ayers, 1989). Tilden and Weinert (1987) attempted to clarify this confusion by defining the former as the structural inter-relationships of family, friends, neighbours, co-workers, and others who provide support. Characteristics of social networks are the size, density (the extent to which members have contact with each other), frequency of contact, durability of the relationships, and homogeneity (the similarity of people in the network). Gottlieb (1985) suggested that the networks which are very dense also tend to be very cohesive and therefore exert more conformity pressures than low density networks.

In this study, the density of the support networks encountered by the subjects was not formally measured in a quantitative manner. However, it is not unreasonable to assume that the networks of the groups are quite dense, large and homogeneous. The subjects spoke of often sharing meals with other family members who were also diabetic or who were very familiar with the illness. Because large family meals and social gatherings were a key part of their daily lives, the subjects had frequent and consistent contact with these members of their social group.

Tilden and Weinert (1987) defined social support as the psychosocial and tangible aid provided by the social network and received by the person. In a review of the vast amount of research in this area, Wortman and Conway (1985) outlined five key purposes that social support serves for an individual experiencing a change in health status. These are: (a) the expression of positive affect; (b) providing information that the person is part of a network or support system of mutual obligation or reciprocity; (c) encouraging open expression of feelings; (d) expressing agreement with or acknowledging the appropriateness of a person's
beliefs and interpretations; and (e) providing information or advice or providing access to new sources of information.

Wortman and Conway (1985) also contend that the nature of how people use social support can vary as the illness trajectory progresses. For example, seeking informational support from those around them is often a key coping mechanism shortly after an illness is diagnosed. Gottlieb (1985) also suggests that during this early adjustment period, information seeking could be supplemented by the very subtle use of social comparisons. This could involve comparing the emotional reactions of those around them to better understand the seriousness of the event. Gottlieb concludes by saying:

Finally, supportive peers buttress the behavioural dimension of coping by redirecting problem-solving strategies, by providing concrete services and tangible aid, and by offering a set of emotionally-sustaining provisions. To the extent that the types of support rendered by peers match the demands and needs imposed by the stressor, they will ameliorate ongoing adjustment strivings. (p. 15)

In this study, subjects spoke extensively of the valuable information and advice they received from family members and friends shortly after diagnosis and during times of illness exacerbation. Such advice was not sought solely from concerned family members but primarily from those in the naturally-occurring social network with extensive experience of living with diabetes. Because the illness was so prevalent among the families of the study participants, this process had many similarities to that found in self-help groups.

Self-help Groups

In recent years, there has been an increasing number of organized peer support groups forming in both the US and Canada (Ayers, 1989). Often, the members of such gatherings are brought together by a common bond or experience and a desire to further meet needs largely not addressed by health care professionals (Getzel, 1986; Kelleher, 1990). Gottlieb (1982) contends that a major component of such groups is the homogeneity of members which allows for empathic understanding and the modeling of successful coping patterns.
There has been a recognition in the professional literature of the use of self-help groups for people with diabetes. Participants of such groups have reported that in addition to improved knowledge, the "interpersonal learning" and "the imparting" of information to other diabetics were the most valued outcomes of group sharing (Jennings, Morgan & Barnett, 1987). Jennings et al. (1987) found that interactions in such groups resulted in improved metabolic control, more so than that found in control groups. Kelleher (1990) studied eight such self-help groups and found that initially the discussion was dominated by the sharing of concrete information and advice on diabetic management. Such discourse often focused on the need to follow medical advice in order to avoid complications. Kelleher concluded that such dialogues served a social control function, stressing the importance of self-restraint to achieve balance. In addition to sharing information, issues involving emotional reactions were addressed in the groups. Often, these two types of support were intermixed from different group members creating a jointly constructed narrative. This phenomenon is summarized below:

At this stage of the analysis the lay term 'sharing' can be seen to include both instrumental and psychological support. What seems to be important about sharing is that, in the act of disclosing their feelings about their own experiences, people are able to reduce their fear by recognizing that their experience is not unique but is shared by others. (Kelleher, 1990, p. 68)

Sharing of information among group participants is also identified among Native people with diabetes. In her review of a variety of programs in Canada, Steckle (1987) cited numerous cases in which the sharing of stories and experiences was incorporated with great success. One such example comes from the Native health centre in Bella Coola, British Columbia. By bringing the diabetics together for foot care clinics, informal discussion among group members is facilitated concerning feelings about having diabetes and how individual problems can be solved. "This kind of informal contact among diabetics can be most reassuring and instill in them a sense of power in resolving their own health problems" (Steckle, 1987, p.145).
Clearly, the current perspectives on informal social support and self-help groups are pertinent to the findings of the present study. However, these two forms of lay-helping are often viewed as being structurally distinct in the literature. Ayers (1989) stated that while informal social support is comprised of family, co-workers and friends, self-help groups are usually made up of strangers formally united strictly on the basis of a common problem or experience. The present study represents a unique departure from this usual configuration of social support systems. The participants, members of a closely knit informal network, had frequent contact with blood relatives who had diabetes. This can be viewed as a dynamic and naturally occurring self-help system interwoven within the larger social network. As the narratives attest, this phenomenon resulted in understanding diabetes and its management on a personal and meaningful level.

The Social Context of Diabetic Diet Management

Generosity and Abundance

Most of the study participants spoke of attending large group gatherings in which refusal of food was considered socially unacceptable. Such cues added to the struggle of adjusting to a diet that limited and drastically altered life-long dietary patterns. This finding is not unique to this study. Joos (1984), in her research with Florida Seminole Indians, concluded that gathering together to share food was a cultural metaphor for generosity and friendliness. Lang (1989) drew similar conclusions in her study of the Sioux Indians in North Dakota. In the excerpt below, she described the numerous places for food in Native culture.

...food plays a central role in many kinds of social interactions and is one of the most important elements of hospitality. Food in the form of a side of beef, prepared dishes, and assorted canned or boxed grocery items in a basket may be raffled off at a school fundraiser, presented in a give-away in honor of someone, or awarded as prizes for bingo games. Reminiscences by older people about the quality and quantity of foods at meals held in times past by other communities indicate the significance of a generous and complete repast. (p. 312)
Abundance of food has been viewed by Native peoples as the symbol of cultural strength and identity. In the words of a Gitskan elder of the Nass River of British Columbia: "Cultures, like armies, march on their stomachs. If there is insufficient food and empty stomachs, the culture marches nowhere; with plenty of food and full stomachs, the culture marches ahead" (People of 'Ksan, 1980).

The concepts of abundance and generosity that emerged in the narratives were not isolated to this sample. Diabetic dietary restrictions clearly represent a major shift in well established cultural foodways.

**Living with Diabetes in the Home**

It was readily apparent in the study that the suggested diet was vastly different from preferred foods and previous sizes of portions consumed. For example, the suggestion that vegetables be included more often and portions of fish reduced was cited by all participants as very difficult to adhere to. This is congruent with a variety of studies on Native diabetic diet management (Stegmayer & Lovrien, 1988; Jackson & Broussard, 1987). In particular, Lang (1989) discovered that among the Dakota Sioux, a common critique was the numerous vegetables suggested that were either too expensive or simply not palatable.

Another similarity pertained to the accommodation of family preferences. All of the women in the group remarked on the difficulty in adhering to the diabetic diet when preparing food for their family members. Often, the diet included food which was disliked by other household inhabitants and the women invariably sacrificed their guidelines to go along with the status quo of the group. This finding was also discovered by Joos (1984) among the women in her study sample. In the Seminole Indian population, the women were primarily in charge of food preparation and often found it difficult to prepare their diabetic meals and then prepare separate meals congruent with family preferences. For example, Joos (1984) described one woman who wanted to boil or roast her foods but faced opposition from her husband who wanted his food fried. In a study by Broussard et al. (1982) both men and women among the Cherokee Indians cited the lack of family support
as one reason for nonadherence to dietary guidelines. For this study, the problems with family preferences were encountered only by the women in the group. Because of the nature of the study design and the research question, it is unrealistic to generalize such findings to all Native women with diabetes.

**Perceived Beliefs of Others: Using External Controls**

The social forces in the environment were not entirely sources of frustration. The external limits set by significant others were discovered to play a central role in helping the subjects maintain self-control. As described in the previous chapter, this process ranged from humorous teasing to "bawling out" and often influenced the behaviour of the subjects.

This phenomenon is similar to that discussed by Ajzen and Fishbein (1980) in their theory of reasoned action. They suggest that human social behaviour is not controlled by unconscious motives but that humans are rational and make systematic use of the information and cues around them. According to this theory, behaviour is largely based on the intention a person has to perform the action. The theory of reasoned action suggests that this intention is derived from two basic determinants. The first factor is personal in nature and is comprised of the individual's positive or negative evaluation of performing the behaviour. This is called the "attitude toward the behaviour" and is influenced by a person's values and judgments. The second factor determining intention and subsequently behaviour is the influence of the social environment in which the person lives. This is labelled the "subjective norm" and is defined as the person's perception "that most people who are important to him think he should or should not perform the behaviour in question" (Ajzen & Fishbein, 1980). These theorists caution that this subjective norm is based solely on the individual's perception of what others desire and may or may not reflect the actual beliefs of others. It is suggested that the more a person perceives that others important to him believe he should perform a behaviour, the greater his intention to do so. This is true conversely; if the person perceives that those same others believe a behaviour should not be performed, the individual will likely not intend to do so.
Miller, Wikoff, Keen, and Norton (1987) applied the theory of reasoned action to their study of the relationship between perceived beliefs of others and diabetic regimen adherence among American Indian diabetics. These authors described the process that would occur if the variables identified in the model could be applied to the diabetic experience. The first stage would be the formation of personal beliefs about the diabetic condition and the medical regimen (diet, medication and exercise). Based on this information, attitudes would be developed about the illness and the required health behaviours. These attitudes would then be coupled with the patient's perceptions of what others believe he should do to manage the illness (normative component) and lead to the development of intentions to perform the prescribed regimen. These intentions then lead to performance of specific regimen prescriptions. Miller et al. (1987, p.34) found that "a subject's beliefs about regimen prescriptions that others important to him think he should perform, were as strong or stronger than the subject's actual adherence, and was predictive of adherence for all prescriptions of the diabetic regimen." This finding supports the contention that health behaviour can be strongly influenced by the perceived beliefs of others.

Unfortunately, the identity of the significant others referred to by the subjects is not clear in the study by Miller et al.. (1987). For example, were they only household or family members or did they also include friends who the subjects perceived as significant and/or knowledgeable about their condition? In the present study, it was clear that key people who influenced the behaviour of the subjects were close family members living in the home, friends they encountered at social gatherings, and others with lived experience of diabetes.

It is also important to consider the manner in which these perceived beliefs are communicated to the person with diabetes. Because Miller et al. (1987) were mainly interested in studying the relationship between the subjective norm and behaviour, the process of belief formation was not elicited. Among this small study population, it
appeared that the consistent use of humour and firm limit-setting ("bawling out") were employed on a regular basis and guided the decisions and behaviour of the participants. It gave a firm message to the diabetic person which foods were acceptable and what quantities to consume. It can be argued that consistent limit-setting provided by significant others could influence the formation and validation of the subjective norms of the subjects.

Summary

This chapter has explored the findings of the study in the context of current literature. A variety of sources were reviewed from different fields of academic study and involving both Native and non-Native populations. Although this research concerned the personal experiences of a small group of people from three different villages, the conclusions are congruent with much of the literature reviewed. There were also some unique departures found in this study from traditional views. This reflects the individuality of both the individual subjects and the study population as a whole. Clearly, the issue of diabetic diet management represents a very subjective experience largely shaped by the social environment surrounding the individual. Such an environment, being highly contextual in nature, is bound to the unique cultural underpinnings of any population. This points to the importance of understanding the illness experience not solely from the professional perspective but also from the individual explanatory models used by the very people living with the condition.
CHAPTER 6: SUMMARY, CONCLUSIONS, AND IMPLICATIONS FOR NURSING

Summary and Conclusions

This study was designed to describe and explore how Native Indians manage prescribed diabetic diets. Type II or maturity-onset diabetes is a growing health problem among various Native groups in Canada and its treatment usually involves major changes in lifelong eating habits. There is a growing body of excellent research exploring the Native perspective of diabetes. However, this knowledge base remains fragmented as most of the study groups have involved Native tribes in Eastern Canada or the United States. No related research could be located that specifically examined the phenomenon among the coastal people of British Columbia. It was recognized that as the diet and cultural practices of such groups are different from those of the tribes in Eastern Canada, so might be the nature of diabetic diet management. This study recruited subjects from three Coast Salish bands of British Columbia and it is hoped that the findings will enrich the current perspective of the nature of diabetic diet management among Native peoples. Such an understanding is essential if culturally-relevant diabetic teaching and interventions are to be realized.

Kleinman's Health Care System Model (1978a) guided the development of the research question and methodology. In this model, the medical system is viewed as a cultural system consisting of three distinct but interrelated social domains: the popular, the professional, and the folk arenas. In each domain, sickness is experienced and reacted to in a unique way and the interpretation of the same sickness event can differ from one arena to the next. The professional domain involves the "Western" professional scientific practitioners whereas the folk sector consists of non-professional and/or traditional specialists such as Native spiritual healers. The popular domain is of particular interest as it is the primary sphere in which sickness is experienced. It is comprised of the family context of sickness and care as well as the social network and community activities.
According to Kleinman, explanatory models are used by individuals to understand the etiology, symptoms, pathophysiology, and treatment of an illness event. To better understand each domain, Kleinman argues it is essential to elicit the explanatory models (EMs) used by individuals in each arena. For the popular domain, the EMs of the patient can be explored to better understand how the illness is experienced, understood and dealt with by the person living with the condition. Kleinman contends that as each arena is culturally developed, the EMs used by individuals in different domains may not agree with each other. As patients interact with nurses, for example, each individual may have different interpretations of the same illness event. The result is different clinical realities for the same sickness episode which can lead to incongruent objectives of treatment, miscommunication, and poor quality of care. A better understanding of the illness experience from the perspective of the person who lives with the condition can enhance patient-professional relationships and promote the delivery of effective care. In conclusion, Kleinman's conceptual framework guided this researcher to elicit and explore the explanatory models used by Native Indians in managing their diabetic diets.

To achieve this end, the qualitative method of phenomenology was employed as the research design. In congruence with Kleinman's model, the phenomenological perspective emphasizes the importance of understanding the subjective world of the person who lives with a phenomenon. To achieve this end, the researcher recruited six subjects who had lived experience of managing a prescribed diabetic diet. All of the informants were from one of three bands in the Fraser Valley of British Columbia and all lived on reserve. Although not part of the selection criteria, it was found that five of the six people had frequent contact with numerous blood relatives who also had diabetes.

Data were collected through the use of unstructured tape-recorded interviews that generally took place in the homes of the informants. Four of the subjects were interviewed twice, the other two were seen three times for a total of fourteen in-depth interviews. Eight trigger questions (Appendix C) were initially formulated to facilitate the collection of
pertinent data. Additional questions were generated from the responses of the informants and the common themes that emerged. All interviews were transcribed verbatim to capture the phenomenon as described in the words of the participants. Data were analyzed as they were collected and after all interviews were completed. Using Giorgi's method of data analysis (1975), the interviews were examined for common themes that emerged and the raw data were coded accordingly. As themes were generated from the analysis, they were clarified, validated, and/or discounted during subsequent meetings with the informants. In this process, the nature of diabetic diet management was elucidated from the data. Although each experience was as individual as the informants themselves, the way in which diets were understood and dealt with was found to be tied to the socio-cultural context that shaped the lives of the study population.

It was found that the problems experienced by the informants were embedded in the larger phenomenon of diabetic diet management. How the illness was understood and dealt with in the context of daily living shaped the experience of diet management and the nature of the problems that surfaced. To best summarize these findings, the conclusions are listed below and illustrate the complex and interrelated nature of the common problems that emerged.

1. The formal diabetic teaching sessions were found by the informants to be out of context with their own lives. Often, traditional diets and cooking methods were not addressed in the classes that were held off reserve. Contact with health professionals was perceived as rushed and unsatisfactory. The experience left many of the subjects with little pertinent information on which to base their daily decisions.

2. In a search for a personally relevant understanding of their illness, the informants used two interrelated processes stemming from their own daily lives. The first method involved examining the subjective experience of the illness. This helped to establish and validate the boundaries of the diet within which they had to live. The second process was tied to the social environment surrounding them. Because all of the subjects either knew friends or
had numerous close relatives with diabetes, the information gleaned from these frames of reference helped the informants better understand the nature of the illness and how it is managed. This phenomenon can be viewed as a dense naturally-occurring self-help system within the larger social network. Both the subjective and the socially-derived understanding of diabetes was found to offset the uncertainty of the illness and guided the daily management of the diabetic diet.

3. The social environment not only shaped the understanding of diabetes but also created difficulties for many of the subjects. The generosity and abundance of food in the Native culture resulted in many life-long eating habits and social rules that made the adherence to the confining diabetic regimen extremely difficult for the subjects.

4. The presence of others in the social network was also a source of strength for most of the subjects. Often, relatives and friends would set and enforce dietary limits which the subjects invariably found effective in the daily struggle to remain within the boundaries of the diet.

The exploration of the explanatory models used by the six Native informants has enriched the understanding of how diabetic diet management is understood and dealt with among this study population. There is an obvious and immediate need to recognize the implications that such an understanding has for nursing practice, education, and research.

Implications for Nursing Practice

As the nature of diabetic diet management unfolded during the research process, a variety of implications for nursing practice emerged. The suggestions noted in this section are certainly not new for nursing practitioners but point once again to the urgent need for culturally-appropriate patient education and program planning.

As noted in Chapters 3 and 5, patient teaching needs to incorporate the interests and the realities of the target group. However, for this small group of subjects, this need was not fulfilled by the diabetic teaching sessions sponsored by local hospitals and outpatient clinics. For educators to effectively reach the Native population, it is apparent that these
sessions should be designed in collaboration with community health representatives and the patients themselves. Such an approach allows the client group to participate in determining the learning needs and teaching strategies (McLeod, 1990). Informal design of such sessions can facilitate the sharing of information among diabetics and the professional resource person.

In this study, gaining a meaningful understanding of diabetes was achieved by listening to the anecdotes of those with lived experience of the illness. If this finding is at all generalizable to other Native communities, it points to the important role informal support can play in client educational programs. Professional nurses can enhance this phenomenon by holding open foot care clinics, nutrition workshops and random blood-testing services on reserve. Such contact among diabetics can facilitate the sharing of advice and experiences offsetting feelings of isolation and uncertainty. Clearly, didactic methods involving only passive participation of clients is not appropriate. The open sharing of information based on lived experience needs to be recognized as a valuable component of the learning process.

Another problem faced by the participants was living with diet regimens which did not acknowledge the foods eaten in the Native community. Stegmayer and Lovrien (1988) argue that regimens need to be tailored to the audience by including available foods and individual preferences. Emphasis needs to be placed on increasing some foods already in the diet rather than restricting favorite items completely. The regimen also needs to be low on complexity. For example, expecting clients to weigh foods and follow elaborate exchange programs does little to enhance diet management in day-to-day living (Stogmeyer & Lovrien, 1988; Broussard et al., 1982; Peyrot, McMurry & Hedges, 1987). Diabetic diet regimes clearly need to acknowledge the cultural ways in which food is prepared and consumed and offer realistic choices.

The findings of this study emphasize the need to recognize the personal and subjective understanding of the diabetic experience. Because this meaning is culturally derived
within the social context, it shapes not only the interpretation of the illness event but also the way in which regimes are managed. Health professionals need to abandon rigid nutritionally-perfect regimes and didactic approaches of the past and instead present user-friendly diets in a collaborative and open manner.

Implications for Nursing Education

If nursing is to provide culturally-appropriate care to all groups of clients, the education of future professionals must be examined. Nursing school curricula need to acknowledge the diverse cultural makeup of Canadian society. This cannot be achieved by only focussing on the cultural stereotypes of different ethnic groups. Mardiros (1987) argues health care patterns used by various cultures need to be examined not in isolation but in context of the larger culture such as kinship patterns, spirituality, and the historical evolution of the practice. To achieve this end, the cultural context of the illness experience needs to be incorporated throughout nursing curricula.

Related to this suggestion, innovative ways are needed to enhance the education of Canada's indigenous people as health care professionals. Currently, very few physicians and nurses are of Native ancestry which only compounds the need for culturally-appropriate health care (Mardiros, 1987). This complex issue involves many factors including (a) the remoteness of most native villages, (b) the educational bridging needed from high school to community and university programs, and (c) the heavy domination of western medicine at the expense of traditional views of health and healing. However, if Native people are to have an active voice in the planning and delivery of health care programs, their access to professional training is imperative.

This study also underscored the importance of understanding illness from the client's perspective. In order to uncover such meanings, nursing students need strong communication skills. Nursing educators need to not only stress the therapeutic response but also the use of silence. For the subjects of this study, the poor listening skills of their care-givers was often a source of aggravation and frustration. Among Native people,
silence during conversation needs to be recognized as not awkward but an integral part of the cultural use of communication. This researcher found that invariably significant comments followed periods of silence and reflection. Clearly, the art of listening is an important skill to be fostered.

Understanding the client's perspective is only one step in the delivery of quality nursing care. Future practitioners must also examine their own beliefs and assumptions and how these may conflict with those of the recipient of nursing care. Because health care interactions are very complex and contextual in nature, differing explanatory models can result in poor communication and treatment conflicts. Although nursing strives to deliver care that is sensitive and culturally-appropriate, it does not always meet this goal. Hagey (1983) contends that nursing gives only lip-service to individual self-care promotion. Instead, the profession maintains the power and authority in a relationship not unlike that of overzealous missionaries with their converts. "As recipients of health care, individuals are coerced into sharing the beliefs of the caregivers and given the model of a supposedly mature personality or lifestyle to emulate -- the equivalent of the saved Christian" (Hagey, 1983, p.28). Future practitioners need to recognize the inherent danger of subscribing to narrow and inflexible views.

The education of future nursing professionals needs to promote culturally-appropriate care that recognizes the individual experience of the illness event. In the field of diabetic diet management, there still exist gaps in the knowledge base which must be addressed if sound educational preparation and nursing care delivery are to be realized.

Implications for Nursing Research

As the knowledge of the illness experience grows, further questions arise which need to be addressed by the nursing profession. This study uncovered the complex and highly contextual nature of diabetic diet management among a group of Coast Salish Native people. It is not known if this phenomenon is true for other groups of Natives living in different geographical locations who have different cultural practices and kinship
relationships. Four areas of investigation are suggested below which could add to the understanding of how diabetes is managed among this cultural group.

1. Among the six subjects, it was found that often it was the woman of the household who shopped for groceries and prepared meals. A further exploration is needed of how the experience of diabetic diet management is different for women and men given their different roles in the Native society.

2. In this study group, the incidence of diabetes was found to be very high among related groups of individuals. Further study is warranted concerning the familial prevalence of this illness in the Native community. Related to this theme, research is also needed regarding how social support is utilized by Native people with diabetes. For example, it is not known if people with extensive experience of the illness are sought out for different types of support than those individuals who have either less lived experience or are perceived as not managing adequately. It is also not known how the illness trajectory influences the nature of support provided and received. Such research is needed to better understand how the high incidence of diabetes among Native people can influence the understanding and management of the illness.

3. External limit-setting by family members was found to be a major aid in the daily management of diabetes. It is not known how such "bawling-out" is perceived when such limits are set and enforced by non-relatives or non-Native health care workers.

4. The study population were all living on reserve in rural areas. It would be of interest to examine the same phenomenon among Native people living off reserve in urban areas. Because the social network and resources are vastly different among this group, the experiences could be very different from those uncovered in this study.

The answers to such questions would greatly enhance the understanding of the nature of diabetes diet management among Native people. This study has explored this phenomenon from the perspective of those that live with the illness. It was found that the process of understanding and dealing with diet restrictions was highly contextual in nature
and imbedded within the social environment of the participants. It is hoped that these conclusions will contribute to the evolving understanding of the Native experience of diabetes. As this field of research grows, the nursing profession must continue its efforts to deliver culturally-sensitive care to all Canadians.
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Dear

You may remember me as a community health nurse who worked in the Fraser Valley in 1988/89. Recently, I have gone back to school to study for a graduate degree in Nursing. As part of my studies, I am planning to do a small research study concerning the experiences of Native adults in following a diabetic diet. My interest in this area developed during my work with various Native communities in the Fraser Valley and Bella Bella. I noticed that all too often people were asked to follow very complex diabetic diets to control their symptoms and prevent serious complications. However, very little research has been done to examine what it is like from the patient's perspective to make life-long alterations in dietary habits. I believe that an understanding of that personal experience would help health care workers to better meet the needs of their clients. It is my plan that after the study findings are complete, the report will be distributed to all CHR's. The findings will also facilitate the development of a diabetic nutrition information package that could be used by CHR's when working with diabetic clients.

Before I can proceed, I need written consent from you allowing me to proceed with this research in the community. The entire research will require 6 to 8 participants. Their involvement will entail 2 to 3 one-hour informal interviews with me about their experiences of managing a diabetic diet. I have included a sample of the information letter that all participants will receive. This letter clearly outlines the study and ensures that participation is voluntary and confidentiality is protected. I have also included a brief summary of the research proposal for your perusal. Please call me at the above number if you have any questions or concerns about this research. If you decide to consent to the research in your community, please sign the consent below and return it as soon as possible to me in the envelop provided. Thank you for your interest.
Appendix B: Information Letter and Consent Form

My name is Anne Fuller. I am a registered nurse and am a student in the graduate program at the School of Nursing at UBC. If my name sounds familiar, it is because I worked as a community health nurse for Medical Services in 1988-1989.

I am presently conducting a study to learn more about the problems experienced by Native Indians in following a diabetic diet. I believe that in order to meet the needs of people with diabetes, health professionals need to have a good understanding of what it is like to have to follow a diabetic diet. As nurses learn more about the individual experiences of this chronic illness, we can help people live with and manage their diabetes in a realistic and effective manner.

I would like to invite you to participate in this study if you so wish. To recruit participants, I have asked the Community Health Representative that works on your reserve to give this letter to you. The study will involve two to three informal interviews with me in your home at times that are convenient to you. Each interview will be about one hour in length. I will ask you about your experiences with following a diabetic diet and any problems that you perceive.

YOU ARE UNDER NO OBLIGATION TO PARTICIPATE IN THIS STUDY, AND ARE FREE TO WITHDRAW FROM THE STUDY AT ANY TIME. YOUR WITHDRAWAL WILL IN NO WAY AFFECT YOUR TREATMENT AND ACCESS TO MEDICAL AND NURSING CARE. YOU MAY ALSO REFUSE TO ANSWER ANY QUESTIONS AND/OR STOP THE INTERVIEWS WHEN YOU FEEL NECESSARY. AGAIN, THIS WILL IN NO WAY JEOPARDIZE THE MEDICAL AND NURSING TREATMENT OR CARE YOU RECEIVE.

The interviews will be tape-recorded, with your permission, and will be transcribed into a script of what was said verbatim. Your name will not appear on the transcripts or in any written report about the study. Only myself and my two nursing professors will have access to the tapes and written transcripts. Any part of the tape or transcript will be erased and destroyed at any point in the study if you so wish. I may include excerpts of the transcripts in the study when I write the report, but your name and any other identifying information will be withheld. If you wish, I will contact you after the study is completed and share the results with you. I hope that this study will enhance our knowledge of chronic illness management and promote the delivery of culturally sensitive and appropriate health care.
Appendix C: Sample of Interview Trigger Questions

1) Before you had diabetes, what kind of foods did you eat?
2) How has your diet changed since you have had diabetes?
3) What have you been told to eat to manage your diabetes?
4) Do you have any problems in following this diet? What are they?
5) What is the most difficult problem in following this diet?
6) What would make it easier for you to manage your diabetic diet?
7) What problems do you see in the future in respect to your diabetic diet?

Note: these questions are not listed in order of presentation or priority.