DETERRENTS TO PARTICIPATION IN DIABETES EDUCATION: PERSPECTIVES OF ELDERLY SIKH INDO-CANADIANS

by

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ABSTRACT

Diabetes is a chronic disease which affects approximately 5% of all Canadians and contributes to considerable health care costs. At present diabetes can be controlled but not cured. Increased recognition that the provision of diabetes education is essential in diabetes management has led to the development of education programs in many Canadian hospitals. However, participation surveys done in the United States indicate that only 12 to 35% of individuals with diabetes receive education through formal programs. This study seeks to identify factors deterring participation of elderly Sikh Indo-Canadians with NIDDM in education programs.

In depth interviews were conducted with the research participants. The Adapted Chain of Response Model was used as the framework to develop questions for the interview guide and to collect, organize and analyze the data. Deterrents identified in previous studies and supported by this study include: older age, low self-confidence, questioning the worth of the program, being on oral medications versus insulin, having one's own ways of self-care, having a family doctor for treating diabetes, financial concerns, time constraints and transportation problems, and an underestimation of the seriousness of NIDDM by doctors. Deterrents unique to the study include: viewing self as healthy, desiring anonymity, reliance on religion, not valuing non-doctors, lacking familial support, perceiving health professionals as lacking cultural sensitivity, lacking awareness of program purpose and existence, and not being referred at time of diagnosis. Family doctors not valuing diabetes education and/or services of health professionals and not encouraging individuals to attend were also identified as deterrents. This study makes recommendations for practice and research which may be useful to diabetes educators, health care organizations and researchers in assisting them to fully understand and address challenges involved in making diabetes education a reality for a greater number of individuals with diabetes.
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CHAPTER ONE

INTRODUCTION

Chapter One provides the background of the researcher, the research problem and introduces the research question. A brief review of the study is followed by assumptions underlying the study, significance of the study and organization of the thesis.

Personal Background/Information/Knowledge/Experience

For the past seven years I have been involved in diabetes education, specifically in the area of nutrition counselling for adults with insulin dependent diabetes mellitus (IDDM), non-insulin diabetes mellitus (NIDDM) and gestational diabetes (GDM). I am a member of the Diabetes Educator Section of the Canadian Diabetes Association, have served as a chairperson of the diabetes practice group for dietitians of the Lower Mainland and was among the first group of diabetes educators to be certified for diabetes education in Canada. Frequently, I am called upon as a "resource person" for nutritional management of diabetes in pregnancy and for questions related to nutrition education in Indo-Canadians with diabetes. In 1993 I was awarded the Eli Lilly Graduate Scholarship to assist in pursuing my graduate studies in Adult Education. In March 1996, I submitted the proposal for my Master's thesis to the Diabetes Educator Section of the Canadian Diabetes Association on the basis of which I was awarded the 1996 Bayer Award for Education Research that may benefit persons with diabetes. In May 1996 I received the Coolie Verner Memorial Award through the Department of Educational Studies.

Over the years the field of diabetes education has continued to pique my interest, and was a major factor contributing to my enrollment in the Master's program in Adult Education. Currently, I work as a dietitian at B.C. Women's Hospital's Diabetes and Pregnancy Clinic. Previously, I worked at Shaughnessy Hospital's Diabetes Specialty Centre. Being tertiary referral
centres located in Vancouver, these diabetes clinics receive referrals for patients from varied cultural backgrounds such as Indo-Canadians, Chinese Canadians, Filipinos, Italians etc. The clients also vary in - (1) the length of time they have been residing in Canada, (2) their level of formal education, (3) their literacy skills not only in English but also in their mother tongue, (4) their ability to speak and understand the English language and thus, being able to express themselves and having their concerns addressed and questions answered, (5) their socio-economic status, (6) their degree of "Westernization," (7) their level of exposure to and comfort with the biomedical model of health care delivery employed in Canadian hospitals, (8) the type of diabetes that they have (IDDM, NIDDM or GDM), (9) the length of time that they have had diabetes, (10) the amount of diabetes education they have received, (11) their knowledge level, health beliefs and health practices related to diabetes. For diabetes educators, this diversity in the client population makes the provision of diabetes education interesting and challenging. However, as diabetes educators we often wonder - a) if there is a way that diabetes education could be organized differently to meet their needs or interests more effectively? b) if diabetes education is accessed equally by members of different cultural groups? and c) what factors deter participation of individuals with diabetes in diabetes education programs?

**Background to the Problem**

Diabetes Mellitus is caused by an absolute or relative insulin deficiency which alters carbohydrate, protein and lipid metabolism resulting in hyperglycemia, dyslipidemia and hyperacidonemia (Canadian Diabetes Medical Research Section, 1992). The presence of diabetes in the general Canadian population is 4 to 6% (Canadian Diabetes Medical Research Section, 1992) and it is expected that this statistic will sharply increase as our population ages. In Canada, diabetes ranks among the top five chronic diseases. Thus, diabetes is seen as a public health issue
and education is viewed as an effective means of helping people deal with this problem.

The chronic and acute complications of diabetes account for up to 70% of the morbidity and mortality related to the disease (Sinnock, 1982). Individuals who develop diabetes or its associated complications become potential long term consumers of health care and contribute to considerable health care costs. For example, in the United States diabetes affects at least 5% of the population at a cost for care of about $14 billion annually (Duchin & Brown, 1990) and accounts for 16% of all deaths (Dorman, 1985). A majority of these deaths are caused by diabetes associated complications as patients with diabetes have a much greater risk, compared with individuals without diabetes, of developing retinopathy, cardiovascular disease, microvascular disease, neuropathic disorder, and renal disease (Palumbo, Elveback, Chu-Pin, Connolly & Kurland, 1976).

Epidemiological literature asserts that a large fraction of the considerable morbidity and mortality associated with diabetes is preventable and treatable through correct management of the disorder (Paulozzi, Norman, McMahon & Connel, 1984). Results of the ground breaking Diabetes Control and Complications Trial (DCCT) proved that good glycemic control in diabetes can lead to a major reduction in the risk of developing both microvascular and macrovascular complications in Type I diabetes (DCCT Research Group, 1993). Health experts agree that the incidence and complications of diabetes can be reduced by making healthier choices about how we live. Inherent in prevention and treatment is the notion of self-care and the assumption of responsibility for one's own health through participation in health and patient education programs.

Health education, which is a key component of health promotion, is fast becoming a specialized field of adult education. Health education goes beyond the individual's current illness and focuses on how individual health can be improved or maintained even in the absence of illness.
and disease. Planned educational experiences are provided to enable individuals to take control over their health by adopting and maintaining health promoting practices in their daily lives.

Patient education, which is associated with the primary hospital function of diagnosis and treatment of illness and disease, is considered part of basic patient care and is provided in a number of hospital areas and departments. In Canada, hospitals have recognized their role in this aspect of health care provision and currently many provide patient education programs on acute care hospital wards and/or in ambulatory clinics to their patients with diabetes. Teaching self-management through patient education is, and will continue to be, an essential intervention in the effective clinical management of the patient with diabetes. The Clinical Practice Guidelines for the Treatment of Diabetes Mellitus in Canada were established in 1992 by the Canadian Diabetes Medical Research Section in an attempt to improve the basic health care of all Canadians with diabetes, advocate sound medical care, good diabetes education, complication surveillance and ongoing follow-up.

In the Indo-Canadian population it is estimated that the presence of diabetes is approximately 10 to 15%. However, these numbers are not reflected in the patient statistics collected at different diabetes education centres in the Lower Mainland of British Columbia, leading the researcher to believe that diabetes education may not be accessed as frequently by this cultural group. English as the language of delivery of education was seen as one of the major deterrents to participation in diabetes education by this population sub-group. Recognition of the need for and importance of diabetes education for people with and affected by diabetes led to the establishment of a diabetes education program to deliver diabetes education to Indo-Canadian clients in the Punjabi language. This program was established three years ago and to the researcher's knowledge, it is the first of its kind in Canada, and possibly in North America.
Program planners had expected that the response of Indo-Canadian community to such a program would be overwhelming, however, to date that has not occurred.

The clients seen through the Punjabi Diabetes Education Program (PDEP) are primarily elderly adults (60-70%) who have had NIDDM for many years. Several of these clients are illiterate both in English and their native language and belong to the low or middle socio-economic class. Despite being in Canada for many years, a majority of these individuals have had little or no previous diabetes education. Upon casual inquiry by health professionals involved in program delivery, some reasons given by program participants for their lack of diabetes education include - not having knowledge about the existence of diabetes education programs, lacking awareness of the ability to access diabetes programs, not having the language skills to understand what they would be taught, their fear of being humiliated because of their incompetence in the English language and being dependent on someone not only to take them to the education program but also to act as an interpreter or translator for them. Although some deterrents to participation as expressed by these individuals are addressed by the PDEP, interest, registration and participation in this program continues to be low.

The researcher wishes to explore more thoroughly why this client population does not access and utilize the services of diabetes education programs and diabetes care teams that are available through the major hospitals in the Greater Vancouver Area and through the PDEP.

**Research Question**

What are the factors deterring participation of elderly Sikh Indo-Canadians with NIDDM in diabetes education programs?
Review of the Study

In order to identify and describe the factors that deter participation of elderly Sikh Indo-Canadians in diabetes education programs, eleven members of this cultural group with NIDDM, but without previous diabetes education, were used as the source of data. Research participants were accessed through the Indo-Canadian senior's groups which meet in Vancouver, Burnaby and Surrey and through personal contacts in the community. A qualitative approach was used to study the research problem. An adapted Chain of Response (COR) model was used as the conceptual framework to develop items for the interview guide and to collect, organize and analyze the data. The study was conducted over a five month period, during which time the researcher conducted face to face and one on one interviews with research participants. The interviews were audio taped.

Assumptions

The assumptions underlying the study were as follows:

1) Diabetes education should be accessible and available to all individuals with diabetes. However, the proposed research participants are marginalized in the context of diabetes education as it is currently offered through mainstream programs. These individuals do not have access to information that could affect the quality of their lives and in some instances, their survival (Kirby & McKenna, 1989).

2) Diabetes education should be provided by a health care team that includes a nurse, dietitian, diabetes specialist, and, if possible, a social worker and a physiotherapist.

3) Individuals with diabetes value diabetes education because it provides knowledge, skills and reinforcement to help them make positive decisions about their condition.

4) Diabetes education may lead to improved glycemic control, which in turn prevents or
delays the onset of diabetes complications.

5) There are many factors that influence the participation of individuals with diabetes in diabetes education programs.

6) The validity and reliability of the study are influenced by the skills, integrity, personal values and biases of the researcher.

**Limitations of the Study**

The study acknowledges limitations in the following areas:

1) Many research participants were members of seniors' groups, thus, participating in some sort of organized adult education type activity. Therefore, the results of this study may not be as generalizable to those individuals who do not participate in any form of organized adult education;

2) Even though families, physicians, health professionals and organizations can impact upon participation, this study only represents the perspective of individuals with diabetes on the issue of deterrence to participation in diabetes education;

3) Despite a high illiteracy level in this age and cultural group, all participants with the exception of one were functionally literate. Thus, deterrents to participation as identified by research participants may not include ones faced by those who are illiterate;

4) As distinctions between categories of the adapted COR model were hard to make with the available research data, it made it difficult to suggest significant modification of the model;

5) As most studies examine one aspect for example, health beliefs related to diabetes, an argument can be made by some that the focus of this study was too broad. However, the exploratory nature of this study may serve as a basis for future research in this area; and
6) The personal values and biases the researcher brought to not only the interviewing
table, but also to data analysis and conclusion drawing, exposes the research to the
challenge of critics who hold different values and biases than the researcher.

7) The use of a predetermined conceptual framework may have led to the exclusion of
some relevant data, influenced the development of the interview guide and affected the
interpretation of the participant's responses.

Deterrents to participation identified by these research participants may differ from those
identified by others of this cultural group who are younger, illiterate, and/or do not participate in
any form of educational activity. These differences may limit the generalizability of results of this
study beyond the described context. However, qualitative studies are not aimed at generalizing
results; rather their goal is to extend an understanding of the phenomenon through provision of
detailed descriptions.

**Significance of the Study**

Research contributions relevant to the fields of diabetes and adult education include:

1) contributing to the pre-existing knowledge and literature in the field of adult education
and diabetes education related to participation;

2) involving Sikh Indo-Canadians in identifying and describing deterrents to their
participation in diabetes education programs. To the researcher's knowledge, most
research regarding participation in diabetes education involves English speaking
participants from the mainstream culture;

3) providing further insight into the provision of education that is culturally sensitive and
adaptive for elderly Sikh Indo-Canadians with NIDDM. This information would be of
relevance to educators who work with this population sub-group; and
4) initiating discussions among diabetes health professionals, with a view to modifying approaches to diabetes education as it currently occurs, such that diabetes education may become a reality for a greater number of individuals with diabetes.

**Organization of the Thesis**

The thesis is presented in six chapters. Chapter One introduces the researcher, research problem and the research question, identifies assumptions underlying the study and discusses the limitations and significance of the study. Chapter Two defines health, health promotion, health education, patient education, and multicultural health education. A review of the relevant literature includes: the rationale and support for provision of diabetes education, a discussion on cultural aspects of health education, background information on potential research participants, and studies pertaining to participation of adults in education programs. Chapter Three describes the research methodology including: selection of the theoretical/conceptual framework, research design, site and sample selection, data collection procedures, method for data analysis, issues of validity and reliability and ethical considerations. Chapter Four presents the research findings. Chapter Five provides an in-depth discussion of the findings. Chapter Six presents conclusions that can be drawn from the study, the recommendations of the study for health educators dealing with chronic diseases, in particular diabetes and suggestions for future research. A list of references and an appendix conclude this thesis.
CHAPTER TWO

REVIEW OF THE LITERATURE

Chapter Two provides a review of the literature related to: a) the definition and purpose of health, health promotion, health education, patient education and multicultural health education especially as it relates to diabetes education, b) the role and support for diabetes education c) illness care for the Sikh elderly including aspects of cross cultural caring and pertinent background information on the potential research participants and d) participation of adults in educational programs.

Definitions of Health and Health Promotion

Over the last two centuries the definition of health has undergone changes to coincide with the changes in the types of major health problems facing Canadians. In the early 1800s, when epidemics of acute infectious diseases were the predominant causes of illness and death in Canada, health was defined in terms of absence of disease. By the early 1900s, with a reduction in the incidence of many of the acute infections and a rise in individual infections and accidents, health came to mean more than simply not being ill. This change was later reflected in the 1978 World Health Organization (WHO) definition of health, where health came to be defined as "...a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (p.428). This definition of health encompasses nearly every facet of life; thus, according to this definition very few people could be considered "healthy."

Around the middle of the twentieth century, chronic degenerative diseases such as diabetes, heart disease and cancer surpassed acute and communicable diseases as the leading causes of morbidity and mortality in the developed countries (Green & Kreuter, 1991). High
blood pressure, smoking, high fat and high cholesterol diets have been consistently associated with chronic diseases. Thus, health experts believe that the incidence and effects of many chronic health problems can be influenced by lifestyle choices made daily by individuals affected by the disease. However, associated with the term "lifestyle" are complex lifetime habits and social circumstances surrounding the individual. As such, the persistence of behaviour becomes an increasingly important dimension of health behaviour (Green & Kreuter, 1991).

Jake Epp, then Minister of Health & Welfare Canada, in his 1986 document "Achieving Health for All" outlined the following aspects of health. Health is a part of daily living and an essential component of the quality of our lives. Health is a resource which gives people the ability to manage and even to change their surroundings. Health is influenced by our beliefs, culture, socio-economic and physical environment. Health is a state which individuals and communities strive to achieve, maintain or regain. Viewed from this perspective, health ceases to be measured simply in terms of illness and disease.

The 1986 WHO definition of health reflects this shift in thinking. According to its definition, health is seen as, "a resource for every day living to the extent that an individual or group is able to realize aspirations, satisfy needs, and change or cope with the environment emphasizing social and personal resources, and physical capabilities" (p. 2). Thus, the current view of health recognizes the individual's freedom of choice and lays emphasis on individuals and their communities in defining what health means to them. Health is seen as the responsibility of the individual, family, health care system, community and, ultimately society.

The point to be noted from the preceding discussion is that definitions of health can vary from the simple absence of disease to self-actualization. The manner in which individuals with diabetes define their own health will impact upon their participation in health care activities and
their expectation of health care services. For example, those who define health as the absence of disease will use their resources, such as time and money, to fight diabetes and its symptoms. They may be satisfied with the alleviation of the symptoms of illness as their way of promoting health, as for them, health is defined only in terms of the health problem. Those with a broader view of health will concentrate on many other factors such as educational, social and cultural issues impacting upon their illness.

Health experts believe that many of today's health and illness problems are associated with unhealthy lifestyles can be prevented with simple, inexpensive and effective strategies that encourage lifestyle changes through health promotion and health education activities (Hoffmaster, 1992; Orlandi, 1987). The American Hospital Association (1979), views health promotion as a process of fostering awareness, influencing ideas and identifying alternatives so that individuals can make informed choices and change their behaviour in order to achieve an optimal level of physical and mental health and improve their physical and social environment. The WHO (1984), views health promotion as a process of enabling people to increase control over and improve their health and the factors that influence their health including the physical, social, economic and political environment. Health promotion as defined by Green & Kreuter (1991) is, "any planned combination of educational, political, regulatory, and organizational supports for actions and conditions of living conducive to the health of individuals, groups, or communities" (p. 432). Despite the varying scope of the definitions of health promotion, there is consensus among experts in the field that health promotion is an effective strategy for disease prevention and control. Health promotion provides an avenue for dealing with emerging challenges posed by the chronic diseases of today. Health promotion offers a means of achieving health for all Canadians (Epp, 1986). The concept of health promotion encompasses health education.
Health Education, Patient Education and Multicultural Health Education

Health education is a specific component of the larger concept of health promotion and is seen as a mechanism for bridging the gap between the need for health information and the adoption of health behaviours (Preventive Medicine U.S.A., 1976). The American Public Health Association (1987) refers to health education as, "...learning experiences designed to assist individuals, groups and communities in the voluntary control of their own health as they define it" (p. 89). Green & Kreuter (1991), define health education as, "any planned combination of learning experiences designed to predispose, enable and reinforce voluntary behaviour conducive to health in individuals, groups or communities" (p. 432). In essence, health education aids individuals, groups and communities in making healthy choices about their lifestyle.

Health education has expanded its focus from the individual to a new perspective which recognizes that health issues and problems can be influenced by a number of factors. These factors are as follows: socio-cultural factors such as culture, race, gender, language, age, religion, personality, family/social networks; educational factors such as intelligence and experience, the level of formal, informal and non-formal education and professional sub-culture; economic factors such as income, employment, housing, and access to resources; and political factors such as the amount of power and control within the health care system.

In general, Canadians are changing their views about how health care should be provided and are more willing to learn about and engage in health education activities that may help them achieve better health. Individuals are seeking health information through a variety of resources, in response to which health education programs have been developed in a large number of Canadian hospitals. According to Hawthorne (1995), these health education programs provide:

- a learning experience designed to achieve specific health enhancing outcomes for patients
and their families. The focus is on assisting them in their pursuit of a healthy lifestyle by reducing their risk for disease and improving or maintaining their health. Issues such as stress management, dietary habits, exercise and smoke cessation etc. are frequently addressed. (p.144)

In hospitals, health education becomes synonymous with patient education as it is usually provided as a treatment for patients who have already developed diabetes, heart disease and so on.

Patient education is routinely provided as part of patient care in hospitals. As defined by Bartlett (1985) patient education is:

a planned learning experience using teaching and counselling to influence knowledge and health behaviour. It is provided by health care professionals and is intended to assist patients to: a) actively be informed about their illness, including diagnostic tests, treatments and care, and b) participate actively in the management of their own care. (p.323)

Thus, provision of diabetes education through inpatient and outpatient programs in a hospital setting can be seen as one example of patient education, as its objective is to teach people with diabetes to take care of their illness. However, at some diabetes clinics, not only is information on the patient's current condition provided, but, also information on how to improve general health by making lifestyle changes. In this situation diabetes clinics are fulfilling a broader role than simply one of patient education.

Despite years of research supporting the importance of health education strategies, there has been a slow response from the medical community in recognizing and accepting these strategies as a valuable component of health care (Hoffman, 1992). Instead, the adoption of
the science-based medical model in health care leads to the valuing of technological approaches in patient care with high technology treatments becoming the main emphasis in responding to chronic illness and disease. For instance, lifestyle changes which are the focus of health promotion, health education and patient education programs are simplistic, often invisible, and less prestigious than medical approaches. Thus, they do not command the same attention from physicians (often the leaders of the health care teams) and other health professionals. As gains through expenditure of health care dollars are not immediately apparent, this can lead to cutbacks in health education and patient education programs given the shrinking health care economics of today. However, support for health education and patient education activities is evident in Jake Epp's document "Achieving Health for All," published in 1986, and, now more recently, through the "Closer to Home Report" from the Royal Commission on Health Care and Costs (British Columbia Royal, 1991).

Multiculturalism in health care raises awareness of the fact that cultural beliefs have an impact on the way patients and health care professionals explain illness and disease, how goals are set for clinical management and how therapeutic effectiveness is evaluated. According to Thompson & MacDonald (1989), multiculturalism principles in health care imply that services rendered by agencies be relevant to the needs of the clients they are trying to serve, that all cultural groups have equal opportunities to realize and achieve their health care potential through participation in health education activities and that organizations continually re-examine their mission and vision. Thompson & MacDonald (1989) define multicultural health education as: learning opportunities designed with sensitivity to cultural values, beliefs and practices, carried out in relevant languages, developed and implemented with active participation of members that are truly reflective of the target group, and taking into account the
participating group's definition of health and its cultural diversity. (p. 8)

Multiculturalism principles in health care are being echoed in the mission and value statements of a number of hospitals in the Lower Mainland. However, a question to consider is - How are the organizations and the programs within these organizations changing or re-organizing to implement the multicultural principles found in their mission statements? In addition, from the patient's perspective - What are the beliefs and values of specific sub-cultures within the larger Canadian culture related to health? Does an awareness exist of the presence and purpose of such education programs within these sub-cultures? Are client needs being met through patient education programs as they are currently offered?

**Diabetes Education**

**The Prevalence and Impact of Diabetes**

Diabetes Mellitus affects approximately one in twenty Canadians. In Canada about 1.4 million people have diabetes with 60,000 new cases being diagnosed each year (Bhagia & Bhagia, 1995). Alongside diagnosed cases of diabetes, it is estimated that there are likely an equal number of individuals who have undiagnosed diabetes. The major types of diabetes mellitus are IDDM, NIDDM and GDM. NIDDM accounts for 80 to 90% of cases, and IDDM accounts for most others (Canadian Diabetes Advisory Board, 1992).

Although at present diabetes cannot be cured, it can be controlled. One of the generally accepted goals of clinical care of the patient with diabetes is the control of metabolic abnormalities that predispose the individual with diabetes to acute complications and long-term degenerative complications. A structured diabetes program that emphasizes near-normal glycemic control and provides appropriate patient education and nutrition counselling can result in the reduction of Haemoglobin A1c (a clinical indicator of metabolic control) for a substantial
number of clients with diabetes (Wood, 1989).

Irrespective of their age and gender, patients with diabetes have higher medical expenses, have a higher probability of seeing a doctor and use more medical care than those without diabetes. Thus, the high rate of utilization of hospital services by patients with diabetes is of great concern to health professionals (Kaplan & Davis, 1986). However, the complications of diabetes and their associated personal and economic costs are not inevitable. In the United States, computer projections done by Mazze (1986), suggest the potentially powerful impact of health promotion and health and patient education activities. According to Mazze, if intervention measures were only 25% effective, each year there would be 8000 fewer amputations, 2500 fewer cases of blindness and end-stage renal disease and 10,000 fewer days of hospitalization. All of this would result in significant improvements in health and reductions in health care costs. Thus, education of the patient with diabetes and his/her family makes good economic sense (Smith, 1977).

**Diabetes Education Programs**

Statements about the importance of diabetes education can be traced back to 1924. Joslin, a leading diabetes researcher and educator, in a 1924 speech made many statements about patient education of which the following four were included by Smith in his 1977 article:

Tell them the best and the worst. Have no secrets.

Always make them realize that they have the diabetes, not you, and it is up to them to master it.

It does not take long for the patient to learn that, although he may cheat the doctor, he cannot cheat the disease.

Almost anybody can get a diabetic sugar-free, but the education of the patient to care for
himself upon leaving the hospital constitutes more than 90% of the treatment. (p.275)

Prior to 1970, patients did not generally participate in education programs for the treatment and care of their diabetes. Instead, the physician prescribed the appropriate insulin dose, gave the patient a dietary list and provided the patient with as adequate information about the disease as possible. However, it was subsequently discovered that patients clearly possessed inadequate knowledge about the disease. Thus, in order to increase patient knowledge and adherence to the treatment regimen, a variety of diabetes education programs were developed in the early 1970s (Wikblad, 1991).

The patient with diabetes is his or her own therapist more than 99% of the time (Smith, 1977). Empowerment, a recent approach to diabetes self-management, is directed toward increasing patients' ability to take charge of their own diabetes care, as it assumes that people with diabetes are de facto their own primary health care providers (Pichert, 1990). Providing the individual with diabetes with enough knowledge and skills to make informed decisions about his/her diabetes self-care and encouraging the client to become more involved with his/her diabetes management are recognized as elements of the diabetes management package. In order to manage effectively on a day to day basis at home, patients need to have a firm understanding of diabetes which includes knowledge about the pathophysiology of diabetes, management of hypoglycemia and hyperglycemia, oral hypoglycemic agents or insulin, home blood glucose monitoring, foot care, personal hygiene, exercise and nutrition (CDAB, 1992). The knowledge and skills should be provided by diabetes care teams through pre-assessment, education and regularly scheduled follow-up sessions (DES of the CDA, 1995/96). However, some individuals with diabetes currently receive care from multidisciplinary diabetes health care teams while others do not.
Support for Diabetes Education

Commitment to diabetes education has increased in the last few years. This is evident through the efforts of the Canadian Diabetes Association (CDA) in setting standards of quality in diabetes care, developing a certification program for professionals involved in diabetes education and offering continuing diabetes education for family physicians through programs such as "Diabetes Care Without a Compromise." Furthermore, in its belief statements the Diabetes Educator Section (DES) of the CDA (1994) states, "we respect, value and encourage self-management" (p. 7). The critical role of diabetes education in quality diabetes care is also clearly defined in the Standards of Care for Diabetes Self-Management Education Programs adopted by the American Diabetes Association (National Diabetes Advisory Board, 1995). The 1995 standards state, "individuals affected by diabetes must learn self-management skills and make lifestyle change to effectively manage diabetes and to avoid or delay the complications associated with the disorder. For these reasons, self-management education is the cornerstone of treatment for all people with diabetes" (p. 95).

The DES of the CDA (1995/96) summarizes its position related to diabetes education in its draft belief statements as follows:

We believe diabetes education:

* is a planned, individualized, and evaluated process

* focuses on the individual with diabetes; it includes family and/or friends, and the community

* encourages individuals to modify lifestyle risk factors that may contribute to Diabetes Mellitus.

* takes into consideration physical, psychosocial, spiritual, cultural and socio-economic
needs

* is best provided by an interdisciplinary team of health professionals who collaborate to achieve client-centred goals

* enables individuals with diabetes to manage their diabetes related health to the full extent of their abilities

* enables individuals with diabetes to make choices and take actions based on informed judgement and understanding of possible consequences

* enhances general well being, adaptation, acceptance, and quality of life

* is a continuous process in which needs of the individuals change throughout life (p. 7)

Reflected in these belief statements are some of the key elements in the definitions of health, health promotion, health education, patient education and multicultural health education which were outlined in the earlier sections.

**Research Studies Supporting the Efficacy of Diabetes Education Programs**

The technique of providing diabetes education to patients has and continues to be varied from piecemeal instruction provided by physicians, dietitians, and nurses in physician's offices, hospitals, clinics and health departments to comprehensive patient education programs. Despite there being an increasing amount of evidence to suggest that for people with a chronic disease, patient education is an essential component of effective disease management (Mazze, 1986), studies have shown that fewer than 10% of American hospitals offer formal and acceptable programs for diabetes patient education (Leichter, 1986). In many institutions, patient education consists only of the provision of written materials or is assumed to be an informal responsibility of the primary care nurse (Leichter, 1986). The large hospitals providing systematic education programs for diabetes patients do so through the services of a diabetes team which includes
physicians, nurses and dietitians. Collaboration and consultation services of social workers, physiotherapists and pharmacists are also sought.

In Canada, diabetes educators believe that the suffering, complications (acute and chronic) and the economic burden of diabetes can be reduced through education and the reports of several studies support this belief. For example, the study by Wood (1989), indicates that members of the group attending diabetes education programs experienced greater improvement in compliance and greater retention of self-help behaviours than those who did not attend the class. Muhlhauser et al. (1983), report a reduction in hospital re-admissions for those individuals who attended an educational program. Rubin, Peyrot & Saudek (1989), have shown that diabetes education can promote long term benefits in self-care, metabolic control and emotional status if the program is specifically designed to achieve these benefits. A study by Mazucca et al. (1986) demonstrates that systematic diabetes education can have a demonstrable, prolonged effect on patient self-care skills and behaviours and on intermediate indicators of glucose homeostasis and on chronic vascular complications. Another study by Rubin et al. (1993), indicates that participants improved on all measures including anxiety, self-esteem, diabetes specific knowledge and self-efficacy. The improvements were maintained at one year follow-up. Finally, forty-seven studies on the effect of patient education on knowledge, self-care behaviours, and metabolic control were analyzed using meta-analysis (Brown, 1988). The results of the meta-analysis clearly support the notion that patient teaching has a positive outcome in adults with diabetes.

A criticism aimed at the above studies suggesting beneficial effects because of a decrease in the overall effects of illness is that they do not assess the impact of patient education on diabetes control on a long term basis. An additional criticism is that elements other than education may be more important in producing the improved outcomes. For example, the time
gap between education, changed behaviour and improved medical outcomes can be as substantial as months or years, during which period many other intervening variables such as new treatment modalities may independently affect the outcome. Thus, it is argued that assessments of reduction in morbidity and mortality after educational activities cannot always be directly linked to the educational intervention. A final criticism aimed at these studies is that they evaluate positive outcomes of an educational program not simply on the basis of improved metabolic control but also consider other parameters such as improvements in knowledge, attitude and skills without the accompanying improvement in metabolic control. Some educators believe that gains in knowledge do not really pay dividends until patients can apply that knowledge in the day to day management of their disease and improve some aspect of their lives compromised by diabetes (Graber, Davidson, Brown, McRae & Woolridge, 1977).

The results of studies showing beneficial effects of diabetes education are contradicted by Bloomgarden et al. (1987), who, in their research, demonstrated that improvements in knowledge related to diabetes did not lead to better metabolic control. On the basis of these results, the researchers argue that patient education may not be an efficacious therapeutic intervention for most adults with IDDM. They suggest that before recommending that education as a separate intervention be made part of the treatment of all individuals with diabetes, good clinical research to prove the efficacy of education should be undertaken. A criticism aimed at the findings of these researchers can be that although indices of metabolic control are often treated as the equivalent of measures of knowledge and compliance, such practises are inappropriate and misleading as metabolic control can be influenced by other factors such as health beliefs and the socio-economic status of the individual.
The important point to note is that the assessment of whether diabetes patient education is effective or not has important implications for health care policy.

**Illness Care for the Sikh Elderly**

Culture is defined as, "a set of guidelines (both explicit and implicit) which individuals inherit as members of a particular society, and which tells them how to view the world, experience it emotionally, and how to behave in it in relation to other people, supernatural forces or gods, and to the natural environment" (Helman, 1990, p. 2-3). Culture informs about the standards of behaviour that one acquires as a member of a social group. It is a shared perception of the world. Culture is never homogeneous or static and should not be viewed in a vacuum apart from the broader contexts which influence it.

Canada is frequently referred to as a multicultural society or the "Mosaic." At present, cross cultural encounters in health care are commonplace in Canada as the country's population is made up of people from a variety of cultural groups. In recent years the increase in this cultural diversity has put new demands on the health care system to provide health care that is culturally acceptable as well as effective and economical. As non-mainstream cultures have their particular beliefs and practices about health and illness, it becomes important for health care professionals to explore what these are, what they are based on, their potential benefits if any, and indeed any hazards likely to be associated with them. By freeing themselves of their ethnocentric views, health care professionals may begin to recognize important issues that thus far have been systematically ignored (Kleinman, Eisenbery & Good, 1978).

While diseases are abnormalities in the structure and function of the body organs and systems in the individual (Kleinman et al., 1978), illness affects the kinds of foods one can or cannot eat, restrictions in daily activities and dependence on technology or others. According to
Kleinman et al. (1978), "...illness represents personal, interpersonal, and cultural reactions to and valuation of the discomforting experience, processes embedded in a complex family, social and cultural nexus. Because illness experience is an intimate part of social systems of meanings and rules for behaviour, it is strongly influenced by culture..." (p. 252) as well as by the social and economic circumstances of a person's life. Illness defined as such may occur in the absence of disease; in fact a number of visits to physicians are for reasons which do not have a biologic base. It is important to recognize that the concepts of disease and illness are not two separate entities, instead there is an interplay between the two which requires that a new framework for understanding and treating sickness be developed (Kleinman et al., 1978).

Canada's official health care system and the training of its health care workers is rooted in Western biomedical principles. In the West, medicine has traditionally been oriented toward the effective diagnosis, treatment and/or curing of diseases, and in the development of technology to facilitate this process. Until recently, the tendency of health professionals has been to attribute most illness to a biological cause to the exclusion of social dimensions of illness, which may be partially responsible for patient non-adherence to treatment, patient and family dissatisfaction with health care and the criticism aimed at medicine (Kleinman et al., 1978). It is only recently that the focus is shifting to a more holistic view of health which recognizes that the economic, social and psychological factors can all have an impact on people's health and well-being.

The illness experience begins with a personal awareness of a change in body feeling and continues with the labelling of the sufferer as "ill" by family or self (Wright & Leahy, 1987). Often the illness must have a visible impact on the individual before it is labelled as such. Occasionally, the symptom of the disease may be perceived as the disease. In such a model, the disease is believed to be cured if and when the symptoms disappear. This model has important
implications for a chronic, intermittently active illness such as diabetes. For example, the absence of classical symptoms of diabetes such as polyuria, polydipsia, fatigue and weight loss may lead the individual with diabetes to believe that his/her diabetes is controlled or even cured, which may in turn affect the decision to seek medical care. Another important point to note is that the symptoms may be tolerated until they reach a point of individual crisis before medical help is sought. For many individuals the point of impact is reached when the symptom interferes with customary social or personal activities including housework and household maintenance (Wright & Leahey, 1987).

Once the illness is identified and recognized, personal and family action is undertaken to bring about recovery. It is important to recognize the individual and families as interacting, dynamic wholes because while the illness affects the family, the family affects the individual's response to illness (Wright & Leahy, 1987). Family's role in the process depends on the nature of the condition (acute, chronic or terminal), its perceived severity, the degree of familial concern and the member affected. The family participates in every stage of a member's illness, from diagnosis through to treatment, rehabilitation and death. The family is frequently involved in confirming the member's illness, selecting lay consultants or professional practitioners, ensuring compliance with prescribed therapy, and determining whether chronic illness care can be provided at home. Decisions around what treatment regimen to follow may rest with the family and not necessarily with the patient. Thus, it may be necessary to identify the power structures in the family and it should not be taken for granted that relationships in Western society necessarily parallel those of other cultures. Finally, there is wide cultural variation in how individuals with chronic disorders are perceived and treated by family members and others in their social networks.
Pertinent Background Information on the Potential Research Participants

Demographics and Trends

The first Sikh immigrants to arrive in British Columbia, Canada in 1897 were men from the state of Punjab. With an almost complete ban on immigration until 1947, there were only a limited number of people who came to Canada between 1909 and 1947. The lifting of the ban in 1947 lead to an increase in immigration, especially after 1961 (Assanand, Dias, Richardson & Waxler-Morrison, 1990). As a result of Canada's 1976 immigration policy, there was an increase in the number of people from different countries migrating to and settling in Canada. In the past twenty years, South and South East Asians have made up a large proportion of the newcomers to Canada, and the Sikhs from the rural state of Punjab represent the largest group of migrants from India into Canada (Assanand et al., 1990). As reported in the 1986 Census of Canada, Punjabi is the third most frequently reported non-official mother tongue for British Columbia.

As Canada enters the 21st century, the number of individuals sixty five and over will number nearly four million. By the year 2021 and 2031, the elderly population of Canada is projected to increase to six and seven and a half million respectively. It is estimated that in the next forty-five years the population of elderly will triple in size (Stone & Fletcher, 1986). For these reasons, the Sikh elderly will also be a growing population. Increasing sponsorship of elderly parents by young Indo-Canadians will also contribute to an increase in the number of Sikh elderly in Canada.

As the stringent medical examination of immigrants prior to their arrival in Canada ensures that only healthy persons are admitted (Sharma, 1986), the current health profile of elderly Sikh immigrants to Canada is different than that of mainstream elderly. This trend is likely to continue especially if the recommendations of the Closer to Home Report (1991) which state that any
immigrant who tests positive for an infectious, incurable disease should be refused entry into Canada, are adopted by the Federal and Provincial Governments.

**Village Life of the Sikh Elderly**

India is a land of villages and 70% of its population lives in villages. Punjab is a mainly rural and agricultural state and 75% of the population of Punjab lives in rural areas, and 95% of the inhabitants of rural areas are engaged in agricultural or allied occupations while 5% are involved in teaching, clerical or other service oriented occupations (Yearbook of India, 1988). A large percentage of the elderly Sikh immigrants to Canada in the last twenty years have been skilled farmers or landowners from India with relatively little formal education and/or knowledge of English. By Indian standards many of these elderly immigrants were relatively well off, active and well functioning in India. They were aware of the social structure, knew how to act and react in different social situations and thus, were in command of and comfortable in their social setting.

**Culture Shock after Immigration**

Reasons for emigration to Canada by the Sikh elderly include a desire to be with their children, Canada's riches, good medical system, political stability and abundance of consumer goods. Emigrating to Canada is viewed as being prestigious and is considered "good fortune." Immediately following the arrival of the elderly into Canada, their family and relatives visit them often to try and make the newly arrived elderly feel at home in their new and unfamiliar surroundings. They are invited for dinners by family and friends. However, after some time the "honeymoon" period ends. These newcomers then begin to face the trauma of the uprooting experience, and the personal and economic hardships that come with such an experience.

Some of the new elderly immigrants go through culture shock. According to Foster (1973), immigrants go through a process in which "during the first incubation stage, the
immigrants feel euphoric - it is clear that a wonderful experience lies ahead - then language trouble, house trouble, transportation trouble, shopping trouble - trouble everywhere" (p. 192-193). These elderly Sikhs have come to a new and strange place, and they feel alienated in the beginning. Initially, they share no feelings with their new community of Vancouver and miss the familiar. The act of immigration becomes one of learning new things. Gradually, they pick up some cues which orientate them. They start to become familiar with others in their cultural group, religious institution and so on. "Little by little the problems of living are worked out and it becomes apparent that the situation, although difficult, is not as hopeless as it seemed a short time earlier" (Foster, 1973, p. 193-194). The culture shock helps the new elderly migrants understand the importance of cultural supports and networks.

**Extended/Joint family**

Filial piety demands care of the elders by their children. A son is expected to take care of his parents. There is a well known saying in Punjabi which states, "If you serve your parents, you serve God." Thus, the joint family system with three or four generations living together in one household is still prevalent in Sikh Indo-Canadian families residing in Canada and it is only a small and insignificant number of Punjabi elderly who end up in extended care facilities. The existence of the joint family system has implications for illness, as most health care occurs in the family context (Wright & Leahy, 1987). In the modern world, the joint family system is generally undergoing changes because of changing values, growing individualism, rising aspirations for material gains and the "new generation" favouring a small family (Goode, 1970; Gore, 1968).

**Financial Status of the Sikh Elderly**

As indicated earlier, a large number of Sikh elderly were farm and land owners in India and, by Indian standards, relatively well off. Other elderly may have received a handsome
government pension and may have had substantial cash. Owning land and/or cash, they commanded respect and had power and status in the society. However, their arrival in Canada often alters this situation. In Canada, most seniors do not have sufficient monetary resources of their own, as whatever money they had in India cannot be transferred out of India due to the Laws of the Indian Government. While some elderly receive old age or retirement pensions, most are dependent on their sponsors for their financial needs which encompass fulfilment of personal needs, medical insurance, medication, transportation costs and so on.

Sometimes due to changes in family circumstances or relationship breakdowns, the elderly can find themselves in precarious and problematic financial situations. In such situations some may try to earn money by doing seasonal agriculture or odd jobs such as distributing flyers, while some may manage to get welfare from the Ministry of Social Services.

**Loneliness**

Despite living in an extended family and participating in household chores, some elderly may feel lonely at times. Loneliness that the elderly may experience is not necessarily physical separation from people, but rather a feeling of being apart from one's heritage, village and known resources at home (Lynam, 1985).

**Language Barriers**

Even though the Sikh elderly may have been in Canada for a number of years, few are particularly fluent in English. Language barriers restrict the communication of the Sikh elderly with non-Punjabi speaking individuals, participation in the neighbourhood community life and the usage of public transportation. In addition, language barriers contribute to the Sikh elderly feeling barred from utilizing and accessing the health care, social and community services available to them. As frequently happens, they gravitate towards an Indo-Canadian enclave within the larger
Canadian community where they are immune to many of the outside influences and new ideas to
which the general public is routinely exposed (Mellor & Hoskin, 1986). For instance, twenty
years ago when the elderly would have moved from India to Canada, dietitians were not well
known in India. Consequently, the elderly may lack confidence in the nutrition information given
to them by someone who is not a doctor. Similarly, they may not value diabetes education
programs and the information provided in these programs by those health professionals who are
"non-physicians."

**Issues of Timeliness**

In the rural society of Punjab the work day begins with daylight and ends when the task is
completed or when darkness falls. Thus, in that society attention to time or the clock/watch is not
viewed as important. This concept of time may be brought into Canada by the elderly Sikh
immigrants. This "inattention to time" (according to the Western Standards), rather than lack of
motivation on the part of the Sikh elderly, may be partially responsible for being late for medical
or other appointments or missing them altogether.

**Trust of Strangers/Authority**

Outsiders and strangers, especially authority figures, are not easily trusted by the Sikh
elderly. There is a great amount of value placed on family honour by the elderly. In face of a
threat to the family honour, the Sikh elderly will keep family problems, tensions and conflicts in
the privacy of their minds. They are willing to suffer for the family honour. They believe in the
dictum that "family problems should be kept within the family." If any assistance is needed to help
them cope they will seek it from their extended family, relatives, close friends and only rarely from
a confidential and trustworthy outsider.
Traditional Remedies

An estimated 70 to 90% of all illness episodes are managed outside the perimeter of the formal health care system. A small change in the boundary between cases managed solely in the popular sector and those cared for by health care professionals could overwhelm the professional institutions (Zola, 1972). Thus, there needs to be recognition by health care professionals that alternate healers and traditional remedies may be used in positive ways to help patients.

The use of traditional remedies is popular in India. For example, in India there exists a belief in such agents of disease as "sorcery," "evil eye," "spells," "spirit possession" and "sins of the past." Help may be sought from "Veds" who specialize in Ayurvedic medicine (the ancient Indian medicinal system which is based on herbal medicine) simultaneously while being under the care of a medical physician. Services of an astrologer may also be sought for health purposes. Pilgrimages to holy places, saints or holy persons may be made in search of a cure or better health. For Sikhs, religion is pervasive (directly or indirectly) in all walks of life. As a result, when a person is ill, God's blessings are sought for better health. Advice may be sought from members of the extended family and/or the community, and "marginal" practitioners may be consulted especially if the symptoms are perceived as minor and treatable within the home.

Administration of home remedies by family or friends mobilizes the patient's social support system and validates the trustworthiness of home therapies (Wright & Leahy, 1987).

The tendency, particularly in rural areas and among the poor, is to try traditional remedies first and to wait until an illness is serious before seeking professional medical care. The reasons for this are: 1) that time and money are in short supply and not because people are fatalistic and believe that nothing can be done, 2) that there exists a belief that traditional medicine is more natural, slower acting, not as strong, and has fewer side-effects than biomedicine and 3) that for
certain diseases traditional remedies are more effective than biomedicine (Assanand, Dias, Richardson & Waxler-Morrison, 1990). The beliefs related to the efficacy of traditional and home remedies are carried over into Canada by the immigrants. Thus, the use of traditional remedies by the Sikh elderly may lead to the exclusion of individuals from the "legitimate" health system.

Seniors' Groups

In the Lower Mainland area, some of the Sikh elderly belong to seniors' groups which serve as a social network and a source of obtaining information on topics such as health care, community and social services. These groups also serve as a means of combating and overcoming some of the disadvantages faced by the elderly. For example, the ability to meet and socialize with others from a similar cultural background helps decrease the feeling of isolation experienced by some elderly and serves as an effective bonding force. These elderly develop an attachment with their groups as they provide a sense of equality, security and sympathy.

Experience with Diabetes Education in India

Diabetes education in India presents several challenges such as the existence of a multilingual society with different cultures, large numbers of adults with low levels of literacy, and lack of sufficient resources to organize really purposeful education and plan delivery of sufficient health care. For example, in a city hospital in India, hundreds of patients line up to see a handful of doctors for a three or four hour clinic. Nursing staff may be busy stamping files, processing patients, and collecting and analyzing urine samples. Patients who are lucky enough to have a few minutes with a doctor barely have enough time to get a prescription. No dietitians are usually present (Mellor & Hoskin, 1986).

The Diabetes Research Centre organizes diabetes education camps in selected rural areas to create and increase awareness about diabetes. In sessions that may last a total of one to two
days, the patients, their relatives and the community in general are given education through lectures, demonstrations and so on. It is estimated that 25-50% of individuals with diabetes attend these camps (Vishwanathan, 1986). For persons with diabetes this may be a chance of a lifetime to amass a wealth of information about diabetes that would otherwise be denied to them. However, there is no lengthy history taking by diabetes health professionals, no individualization of diabetes education and no formalized diabetes patient education or self-management programs (Mellor & Hoskin, 1986). So, where does diabetes education as known in the Western world "fit into" the above picture?

The pertinent background information on potential research participants as discussed above can have an impact on the acquisition of health care and adherence to a prescribed regimen. For provision of care to be effective, it may be imperative for health care professionals and medical practitioners to consider these factors in their delivery of health care.

**Participation**

There are several reasons why so much effort is placed by researchers on the topic of participation in adult education activities. Knowles' theory (1988) suggests that when an adult feels a need for knowledge related to a social role, he/she will seek information, and in the case of diabetes education the information will be related to the individual's new role as a manager of chronic illness. Thus, planned adult education activities and programs must meet the individual and unique needs of the clientele it is trying to serve such that attendance can be promoted. The more that is known about adult learning needs, the more that can be done to meet these needs, thereby, increasing the possibilities of participation. Participation research is also important for public policy reasons. If equality of educational opportunity for all persons is to become a reality
then an understanding of the forces that deter participation of adults in adult education activities is essential for designing effective policies and programs (Darkenwald & Merriam, 1982). By seeking to increase participation, adult educators do not simply seek to increase participation for participation's sake and thereby increase their own employment opportunities; instead they seek to contribute to the well-being of individuals and ultimately of society (Selman & Dampier, 1991). This section will clarify what is meant by participation, especially in the context of this research study. Research on barriers to participation and reasons for drop out in adult education and, specifically, diabetes education will also be examined.

**Definition of Participation**

The term used to describe adults who are active learners is "participants." The behaviour of adults who are active in their learning quest is described as "participation." Thus, participation in adult education is the act of joining some form of adult learning (Selman & Dampier, 1991). The word participation emphasizes the voluntary nature of learning. There are two approaches to understanding participation in adult education. One is to have the act of entering and being counted as one attends at a certain time and place denote participation. The term enrollment can be used to describe this approach where the focus is on initial participation. This form of participation has also been termed "presence" (Bagnall, 1989). The second approach emphasizes learning as construed by the learner, whenever and however it occurs. For example, this learning may occur through enrolment in an education program or through the assistance of a book or a manual. The term "engagement" (Bagnall, 1989) is also used to describe this approach.

For the purpose of this research study, participation will be defined as enrolling in a diabetes education program and undergoing an initial assessment which provides individualized assessment and education to the individual with diabetes, followed by attending a teaching
program where some or all of the following broad subject categories are included - explanation of what diabetes is, goals of control, monitoring and interpretation of blood glucose and urinary ketones, identification and treatment of hypoglycemia, meal planning, activity, sick days, foot care and travelling. The rationale for using this definition of participation is based on belief statements related to diabetes education which emphasize that diabetes education, "is best provided by an interdisciplinary team of health professionals who collaborate to achieve client-centred goals" (Diabetes Educator Section, 1994, p. 1). In addition, as discussed in earlier sections, despite their methodological differences studies looking at the outcomes of diabetes education, have shown that participation of individuals with diabetes in such programs is important and effective and should be encouraged.

**Participation Research in Adult Education and Diabetes Education**

Reasons why adults participate in educational activities are usually multiple and interrelated in complex ways. After studying the reasons given by adult learners, Burgess (1971) concludes that reasons chosen by adults for participating in educational activities factor into at least eight groups - the desire to know for the sake of knowing, the desire to gain knowledge in order to achieve a personal goal, the desire to gain knowledge in order to achieve a social goal, the desire to take part in a social activity, the desire to escape, the desire to comply with formal requirements, the desire to comply with general social pressures exerted by acquaintances, friends, relatives or society as a whole, and the desire to study alone or just to be alone. After reviewing the literature on motivation to participate in adult education Rubenson (1984) concludes that reasons for participation can be divided into two major categories of work related and personal satisfaction reasons. Work related reasons include - making practical use of the knowledge acquired, preparing for a new job, job related goals and advancement in the present job. Personal
satisfaction reasons include - adjusting to new roles in society, getting out of the rut and seeing new faces and recreation. Boshier & Collins (1985) came up with a six factor model for participation. Factors for participation based on their research study include - social contact, social stimulation, professional advancement, community service, external expectation and cognitive learning.

Common elements to much of the work on participation and dropouts in adult education include the following assumptions. There is a belief that there are many complex forces and motivations operating between an individual and the environment with a multiplicity of interactions occurring and that participation can be understood from an analysis of these interactions. The strength of the individual to participate is the result of the individual's perception of positive and negative forces in the situation. There is also a belief that the individual has some control over his/her destiny. Maslow's hierarchy of needs is seen to have an impact on participation and the types of programs individual's participate in. Finally, the expectation of a reward is also viewed as an important variable in motivation to participate. These elements are present in the adapted Chain of Response Model which is the conceptual framework used to guide this research study.

With respect to diabetes education, little research has been conducted on the topic of participation in programs that teach diabetes self-management skills. Few studies have examined the factors related to participation in diabetes education programs (Coonrod, Betschart & Harris, 1994). Furthermore, not only is the data reported on participation rates in diabetes education programs minimal, but of the studies reviewed by Glasgow, Toobert & Hampson (1991), only one provides information on the characteristics of those who participated and those who did not.

Despite evidence that participation of individuals with diabetes in diabetes education
programs is beneficial, the study by Duchin & Brown (1990), indicates that only 12% of the patient participants have received diabetes education through formal programs. A household survey of adults in Michigan conducted by Halpern in 1989, provides the only population based estimate of the percentage of individuals with diabetes receiving classroom instruction. The survey estimates that only 32% of those with diabetes have had formal classroom diabetes education. The findings of the study done by Halpern is supported by the data of Coonrod et al. (1994) which indicates that only 35.1% of individuals with diabetes have attended a class or a program about diabetes at some time during the course of their illness.

The Clinical Practice Guidelines for Treatment of Diabetes Mellitus in Canada (Canadian Diabetes Advisory Board, 1992) state that, "education is fundamental in self-management for patients with diabetes. All patients should be referred to a qualified diabetes health care team" (p. 793). An objective of Healthy People 2000: National Health Promotion and Disease Prevention Objectives (1991) is to have 75% of the people receiving diabetes education by the year 2000. These appear to be formidable goals, especially in the face of the evidence presented by Duchin & Brown (1990), Halpern (1989), and Coonrod et al. (1994).

**Deterrents to Participation in Adult Education and Diabetes Education**

In recent years, the term deterrent has come to replace the traditional term barrier as the latter connotes a blockage while the former suggests a more dynamic and less conclusive force (Valentine & Darkenwald, 1990). There are a number of deterrents to participation in adult education. A deterrent or a barrier is a reason contributing to an adult's decision not to engage in learning activities. One concern of adult educators has been to identify and remove these deterrents to participation and, therefore, considerable effort has gone into this.

Categories of deterrents to participation in adult education as defined by Scanlan (1986)
include - individual, family or home related problems, cost concerns, questionable worth or relevance of educational opportunities, negative perceptions of the value of education, lack of motivation or indifference to learning and lack of self-confidence. Another study by Darkenwald & Valentine (1985) identifies types of middle class adults as defined by their perceived deterrents to participation in organized adult education - people deterred by personal problems, people deterred by lack of confidence, people deterred by educational costs, people not interested in organized adult education and people not interested in available courses. According to Darkenwald & Valentine (1990), deterrents to participation for the general public include lack of confidence, lack of course relevance, time constraints, low personal priority, cost and personal problems.

In studies done on deterrents to participation in diabetes education, one can identify some deterrents similar to those outlined above. For example, Irvine & Mitchell (1992) in their study report that non-participants have lower socioeconomic status, poorer attitudes toward diabetes and diabetes education, lower education and income levels than program participants. Non-participants are also younger in age, have had diabetes for twice as long, and report greater barriers to self care and poorer health than participants. The data collected by Coonrod et al. (1994) indicates that for people with NIDDM, young age, black race, residence in the Midwest region of the United States, having a higher level of education and the presence of diabetes complications were associated with having had diabetes education. Their data also indicates that higher income level, living alone, and not having a diabetes physician or not visiting one in the past year, is associated with a higher likelihood of patient education for patients with NIDDM not treated with insulin.

In 1987, a study was initiated by Chapko, Norman, Bellhart, Nagusky & Connell to
determine reasons for under-utilization of outpatient diabetes education programs so that marketing strategies could be developed to increase attendance. The perception of both patients and physicians was seen as being important as it was hypothesized that both must know of the availability of diabetes education programs, perceive that attendance in such programs will be beneficial, and believe that advantages of participation outweigh the barriers. The reason most commonly given for non-attendance by the patients was, "I know most of what is taught." Other reasons given paralleled the concerns expressed in the physician survey which included access problems, scheduling, costs and lack of individualization of treatment. A reason for non-referral by physicians to the program was a perceived weakness of the local program, underestimation of the seriousness of NIDDM, and a belief that the patients were adequately treated in their offices.

It becomes imperative that deterrents to participation in diabetes education programs be ascertained so that individuals who are less likely to receive diabetes education can be identified and targeted more intensively for participation in diabetes education.

**Dropout in Diabetes Education**

Despite the acknowledged value of patient education, many individuals recruited into educational programs drop out before completing the program. Data on program drop outs can help educators design interventions that increase accessibility, and decrease dropout of program participants. Unfortunately, little is known about who drops out of diabetes education programs (Irvine & Mitchell, 1992) because when attrition rates are reported in published studies, the information is restricted to the percentage of the study group that dropped out. Only infrequently are drop outs described or compared with program attenders.

The study by Graber, Christman, Algona & Davidson (1992), examines factors associated with drop out and relapse during chronic diabetes care. Their data indicates that patients were
less likely to return for follow-up if they lived far from the clinic, were on oral hypoglycemic medicine or diet alone and experienced negative outcomes. Interpersonal factors in the patient-provider relationship, financial considerations and lack of health insurance reimbursements for outpatient diabetes care can also influence drop out and seeking of alternative treatment. Another study by Whitehouse, Whitehouse & Hohl (1979) provides the following reasons for dropping out - "can't get off work," "not interested," "too far to come" and "family problems."

The Elderly and Participation/Deterrents Research in Diabetes Education

Two factors have accelerated increased attention to diabetes among older adults: the prevalence of diabetes increases with age and that more people are living longer. In their study, Norton, Breitmer, Welsh & Wyse (1994) sought to identify predictors of non-response in a community survey of the elderly. Their data suggests that individuals who did not participate in this study had lower levels of cognitive function, less formal education, were more impaired in their activities of daily living, and were more prone to endorsing other health related problems. Older adults with diabetes report higher rates of selected chronic illnesses, lower self-rated physical health, and higher levels of depression than do comparison samples of older adults without diabetes (Connell, 1991). Compared with younger adults with NIDDM, older adults perceive fewer impacts of diabetes including symptoms of poor metabolic control, emotional impact and barriers to adherence. Older adults report wanting minimal help from their family and friends with self-management activities and receiving more help than desired with following a meal plan and taking medications (Connell, 1991). Such factors may limit participation or increase dropout of the elderly from diabetes education programs.

Deterrents as identified by Glasgow et al. (1991) in their study on older adults were similar to those identified by Darkenwald & Valentine (1990). These deterrents include - financial
barriers, timing or scheduling of education sessions, program accessibility, physical surroundings of the facility, other health related concerns, having their own way of managing self-care, and decreased valuing of self-care activities related to diabetes. None of the diabetes related variables (duration of diabetes, type of medication, history or other diabetes education) were significant as determinants of participation. Two variables significantly related to participation were - age (inversely related to participation), and the method of recruitment (those contacted through passive means were only half as likely to participate than those who initiated contact with the program offerers). Data of these researchers further indicated that although this older group may have more time to participate, it has generally not been offered diabetes education.

**Summary of the Literature Review**

Health care experts believe that the morbidity, mortality and health care costs associated with diabetes can be reduced through the adoption of healthier life-styles by those affected by diabetes. As diabetes education is seen to play an integral role in this process, a number of major hospitals in the Greater Vancouver area offer diabetes education programs. However, research on participation in diabetes education shows that approximately two-thirds of patients with diabetes have never attended an education program and are not seen by health professionals on a regular basis (Basa & McLeod, 1995). The researcher's experience indicates that an even smaller percentage of Sikh Indo-Canadians access diabetes education services.

The Closer to Home Report: Summary of the Report of the British Columbia Royal Commission on Health Care and Costs (1991) states, "twenty-two percent of British Columbians are now foreign born, compared to a national average of fifteen percent" (p. 24). The number of foreign born British Columbians is expected to increase. The presence of a variety of cultural groups in Canada often leads to language barriers, unfamiliarity of health professionals with
cultural practices of different groups and lack of knowledge of existing health care services by minority group members. Even when health care providers and patients share the same cultural background, they may not share common meanings surrounding a particular event. These factors decrease access to the health care system by individuals of minority groups and make the task of meeting needs of these individuals a challenging one for health care practitioners. The disparity in health care services for multi-cultural groups is not simply a Canadian phenomenon but is also identified in the United States as indicated in the report Health People 2000: National Health Promotion and Disease Prevention Objective (Department of Health and Human Services, 1991).

Fundamental to any plan for achieving or maintaining health and equal access to health is reliance on both health professionals and grass roots people to address the expressed health needs of the community. "We need to determine how to increase access to services, how to facilitate compliance, how to facilitate greater valuing of healthy behaviour while not eroding a sense of ethnicity, and methodologically, how researchers can better access populations at greatest risk" (Powell, 1991, p. 9). Besides paying attention to the culturally different, this literature review has shown that special attention should be directed to the sub-groups of individuals such as older individuals, those not taking insulin, those of a lower socioeconomic status, and those living outside the urban areas in which the frequency of diabetes patient education is particularly low. A number of these factors can be identified in the potential participants of the research study.

In this research study the beliefs, attitudes, knowledge and perceptions regarding diabetes and diabetes education of elderly Sikh Indo-Canadians living with diabetes were explored. The rationale behind doing so was that while diabetes is a disease that can affect all aspects of an individual's life, aspects mentioned above can impact upon the acquisition of diabetes education. In turn, this may affect the individual's self-management of diabetes and ultimately his or her
health. Deterrents to participation in diabetes education programs as perceived by and encountered by these individuals were also explored. An exploration of the above key variables may: 1) enable health care professionals in delivering culturally sensitive care and 2) provide an insight into how participation of elderly Sikhs with NIDDM in diabetes education programs can be increased to help make diabetes education a reality for a greater number. While some of the reasons for non-participation in diabetes education by the elderly Sikhs with NIDDM may have been similar to those as indicated in the literature review, of interest to the researcher were also reasons for non-participation which may be unique to this cultural group.

The review of the literature conducted and presented was by no means exhaustive. Rather, the purpose of the literature review was to identify a gap in previous research and show how the current study hoped to fill that gap. The literature review also assisted in establishing the significance of this study and in the formulation and re-definition of the research question. Finally, literature review identified elements which aided in understanding participation and lead to the selection of the framework of participation theory and qualitative methodology to guide this research study. The rationale behind the selection of the conceptual framework and the choice of qualitative methodology are explored in detail in Chapter Three.
CHAPTER THREE

METHODOLOGY

Chapter Three describes the methodology that was used in the study to identify deterrents to participation in diabetes patient education program as perceived by the elderly Sikh Indo-Canadian patients with NIDDM. It begins with an exploration of the conceptual frameworks which were considered and the choice of a conceptual framework to guide this study. The study design, site and sample selection, and a review of data collection and analysis method that were used for the study are also covered. The chapter concludes with a discussion on issues of reliability, validity and ethics.

Conceptual Frameworks

The research question posed earlier was a practical one that emerged from the researcher's involvement in diabetes education programs. Although the use of a conceptual framework may have lead to the exclusion of some information, the use of a model was seen as being beneficial in selection of particular information related to participation and in reporting findings on the complex research issue of participation. Three models were examined to identify an appropriate framework for this study, namely the Health Belief Model (Rosenstock, 1974), the PRECEDE-PROCEED Model\(^1\) (Green & Kreuter, 1991) and the Chain of Response Model (Cross, 1981).

\(^1\)PRECEDE is an acronym for the diagnostic planning and evaluation model emphasizing predisposing, reinforcing, and enabling constructs in educational and environmental diagnosis and evaluation. PROCEED is an acronym for policy, regulatory, and organizational constructs in educational and environmental development, the phases of resource mobilization, implementation, and evaluation following the diagnostic planning phases of PRECEDE (Greene & Kreuter, 1991, p. 433-434).
The Health Belief Model

The Health Belief Model is one of the most widely used models in health care. It explains health-related behaviours in individuals based on certain attitudes and beliefs. The model is derived from a "...body of psychological and behavioral theory which hypothesizes that behaviour mainly depends upon two variables: 1) the value placed by an individual on a particular goal; and 2) the individual's estimate of the likelihood that a given action will achieve that goal" (Becker & Janz, 1985, p. 42). In the context of diabetes education this could correspond with the value the individual places on diabetes management and, ultimately, on health as well as the individual's belief that participation in a diabetes education program will aid the achievement of this goal.

The Health Belief Model consists of the following dimensions:

a) perceived susceptibility dimension pertains to an individual's perception of contracting a particular condition and includes estimates of beliefs in the diagnosis of the condition and susceptibility to illness in general;

b) perceived severity includes evaluations of both clinical consequences (such as death, complications and pain) and social consequences (such as effects on family and social life);

c) perceived benefits relates to the effectiveness of various actions available in reducing the disease threat; and

d) perceived barriers involves a cost benefit analysis whereby an individual weighs the action's effectiveness against perceptions that it may be unpleasant, inconvenient and time consuming.

According to Rosenstock (1974), the dimensions central to the Health Belief Model are: i) the individual's readiness to take action as determined by perceptions of susceptibility to a health problem and perceptions of severity of the health problem, and ii) the individual's evaluation of the
recommended health action in terms of its benefits and feasibility weighed against perceived barriers to this action.

Research using this model in the diabetes context has generally focused on studies of adherence and compliance with the diabetes regimen and with the modifications of diabetes related health beliefs. Only a limited number of studies were done using this model as the framework to examine the participation of individuals in health care programs (Leavitt, 1979). A criticism against the use of the Health Belief Model to study deterrents to participation is that as a psychosocial model it may explain the phenomenon of participation only as it relates to individual attitudes and beliefs. Other factors such as economic, environmental and habitual factors that influence health action, namely participation are not accounted for by this model. Furthermore, health related actions may be taken for non-health related reasons and this is not considered by the Health Belief Model (Janz & Becker, 1984).

The PRECEDE-PROCEED Model

The PRECEDE-PROCEED Model of health promotion was also considered as a framework to study deterrence to participation. According to Houle (1992), the strength of the model is that it has application for many forms of adult education. The PRECEDE phase of the model deals with social diagnosis, epidemiological diagnosis, behavioral and environmental diagnosis, educational and organizational diagnosis, and administrative and policy diagnosis. The PRECEDE phase concerns itself with the planning of health education programs. The PROCEED component of the model focuses on the analysis and diagnosis of factors relating to administrative issues and policy development for implementation and evaluation of health education programs. The PRECEDE and PROCEED frameworks are seen to work in tandem for the purposes of program planning, implementation and evaluation.
Of interest to the researcher was the "educational and organizational diagnosis" of the PRECEDE component of the model which looks at predisposing, enabling and reinforcing factors that influence health practices such as participation in patient education programs:

a) Predisposing factors are seen to provide motivation for behaviour such as participation in health education programs and include aspects such as knowledge, beliefs, values, attitudes and confidence. According to Green & Kreuter (1991), a "...threshold level of knowledge may be necessary for some action to occur...; but after that level of knowledge is attained, additional information does not necessarily promote additional behaviour change" (p. 155). The Health Belief Model operates within the "belief" aspect of the predisposing factors in the model. Personal values that individuals hold are influenced by culture/ethnicity and are linked to behaviour. Attitudes are defined by Green & Kreuter (1991) as a collection of beliefs that always include an evaluative aspect. Self-confidence pertains to an individual's anticipated success in implementing a new behaviour based on experience with similar action or circumstances in the past and on existing skills.

b) Enabling factors are seen to be facilitators of individual or organizational action. Included under this aspect are factors such as cost, distance, transportation available, hours of operation and so on which can affect the availability, accessibility and affordability of health care.

c) Reinforcing factors include social support, peer influence, advice and feedback provided by health care providers. Social benefits such as recognition, physical benefits such as relief of pain or discomfort, tangible rewards such as economic benefits, and imagined or vicarious rewards such as self-respect or association with a role model demonstrating that behaviour can also reinforce behaviour (Green & Kreuter, 1991). Finally, reinforcing
factors determine positive or negative feedback for the individual undertaking the health behaviour.

This framework not only considers the interaction between health education and individual characteristics including behavioral, psychological and social forces, but it also accounts for environmental characteristics in the educational and organizational diagnosis. This model was seen as being more comprehensive and inclusive than the Health Belief Model for studying participation in patient education. As will become evident by the discussion in the following section, components of the PRECEDE-PROCEED Model which were viewed as being essential for studying participation were also included in the Chain of Response Model, a model of educational participation.

The Chain of Response (COR) Model

The assumption underlying the COR model is that participation in a learning activity is not a single act but the result of a chain of responses. Figure 1 represents the conceptual framework designed to identify the relevant variables impacting upon participation and their interrelationships.
Figure 1. Chain of Response (COR) Model for Understanding Participation in Adult Learning Activities

The key elements of the model include:

**Point A** - self-evaluation by the potential learner is seen as a motivation for participation.

The notion of self-evaluation presented in the COR Model relates to the self-efficacy/self-confidence aspect of the predisposing factors of the PRECEDE-PROCEED model. Self-efficacy is defined as a perception of one's own capacity to take on a new behaviour based on experience with a similar action or circumstance encountered or observed in the past (Greene & Kreuter, 1991). Thus, an individual may conduct a situation specific self-evaluation which may make him/her more or less confident in taking on a new behaviour in a novel, stressful or unpredictable situation. According to Cross, self-evaluation is where the chain of responses leading to participation begins.

**Point B** - individual attitudes regarding education may arise directly from the learner's own past experience or from the attitudes and experiences of family, friends and significant others.

A certain amount of knowledge and skills regarding diabetes are required by the individual prior to development of attitudes towards diabetes and diabetes education. As outlined earlier, the predisposing factors of the PRECEDE-PROCEED model recognize this value of knowledge.

As attitudes are a collection of beliefs, the belief of individuals with diabetes regarding the severity of the disease and their susceptibility to poor blood glucose control and/or to the complications of the disease can affect their motivation towards self-management. Furthermore, an individual's belief that benefits of self-management can outweigh the barriers may also influence their diabetes self-care. The Health Belief Model and predisposing factors of the PRECEDE-PROCEED model also reflect this emphasis on
attitudes and beliefs in determining behaviour.

Factors such as the recognition, support, feedback and reward given to and received by individuals (reinforcing factors of the PRECEDE-PROCEED model) with diabetes and as related to diabetes care can act as external motivators and influence attitudes toward diabetes self-management. Reinforcement and support can also come from sources internal to the individual. Support for participation in patient education usually comes from health professionals, fellow patients and family members. For example, the support given to individuals with diabetes by their family members, peers and social network for learning self-management through participation in education programs may act as a promoter of participation. In addition, the attitudes of health care providers, in particular those of family physicians and medical specialists, regarding the efficacy of diabetes education programs may impact upon the referrals made to diabetes education programs and also influence the attitudes of and the participation of their patients in education programs.

According to Cross, investigations related to deterrents to participation need to begin with the examination of attitudes towards self and education.

**Point C** - viewing the goals as important and the expectation that goals will be met through participation in education will increase motivation toward learning and, perhaps, interest in education programs. For example, the desire to achieve better blood glucose control through participation in education programs and thereby realize a) physical benefits such as decreased fatigue, urination and thirst, b) economic benefits such as obtaining of a license to operate public transport and c) social benefits such as approval of doctors and family members may act as motivators to participation. The ideas represented
at this point in the model are reminiscent of the reinforcing factors of the PRECEDE-PROCEED model.

According to Cross, expectancy is related to self-esteem, as individuals with increased self-esteem expect to be successful in learning situations.

**Point D** - life transitions are seen as periods of learning. Moving from one stage of life into another requires learning of new knowledge, skills, attitudes or values. A transition is defined as a change in status which makes learning necessary. This definition of transition allows for life changes smaller and less significant than those suggested by Erickson, Neugarten, Sheehy and others (Aslanian & Brickell, 1980). A little transition requires little learning while a large transition requires a large amount of learning. In the context of diabetes a transition is a change in the health status of the individual from healthy to not healthy. In other words, as good health is the only desirable status, individuals who have lost their good health will learn to move into good health.

**Point E** - once the individual is motivated to participate in some form of learning activity, (i.e., gets to this point of the model) then the barriers or opportunities for learning are thought to play an important role. These opportunities and barriers are external to the individual and often beyond the control of the individual. The policies, regulations, guidelines, organizational arrangements and the behaviour of those controlling the resources can create conditions or an atmosphere that either supports or deters an individual's participation in health education programs. For example, the condition imposed by certain diabetes centres that an individual who is referred to the education program must also be seen by a diabetes specialist affiliated with the program may deter access of those individuals to the program who have a diabetes specialist in the
community. Additional examples include direct financial cost associated with participation in the program such as registration fees, indirect financial costs incurred through missed work as a result of participation in the program, distance to the centre, transportation to and from the education centre and hours of operation of the centre.

Most efforts to attract learners to educational opportunities start at this point. However, the removal of these external barriers will do nothing for the individual who has no motivation to participate in education. Concepts represented at this point of the model are similar to those of the enabling factors of the PRECEDE-PROCEED model.

**Point F** - provides the motivated learner with information about appropriate opportunities so that deterrents can be reduced. For example, as knowledge is seen to influence behaviour, individuals with diabetes who have knowledge of the existence and benefits of diabetes education programs may be more likely to participate in diabetes programs.

**Point G** - participation is likely to occur if the opportunities for participation are viewed as outweighing the deterrents to participation.

According to Cross (1981), "the purpose of a theoretical model as broad as the COR model is not so much to explain and predict adult participation at this stage in the development of knowledge, as it is to organize thinking and research" (p. 130-131). The COR model is comprehensive as it considers internal and external variables as deterrents to participation. Psychosocial, cultural and environmental factors are also recognized by this model as deterrents to participation. However, it becomes evident from the discussion of the models in the previous sections that there is much overlapping between the models and that the models inform each other. Thus, the models were combined (see Figure 2) to develop an adapted Chain of Response Model to be used as the conceptual framework for this research study.
Figure 1. Chain of Response (COR) Model for Understanding Participation in Adult Learning Activities

Research Design

A qualitative approach was seen as being appropriate to study deterrents to participation for a number of reasons. Firstly, the traditional quantitative methods did not seem to offer the complexity, flexibility and abstractness required to obtain and interpret reasons for non-participation of this particular cultural group. Secondly, past research done on participation in diabetes education employing quantitative or survey methodology had focused on demographic features of non-participants and on aspects of differences in blood glucose control, knowledge and skills between participants and non-participants. Although as a result of these research studies some general deterrents to participation had been uncovered, these studies had not explored the deeper meaning behind what it means for individuals to have diabetes and what "their" reasons for non-participation in diabetes education programs were. Thus, it was postulated that a qualitative inquiry would aid in understanding the phenomenon from the participant's perspective. Thirdly, members of this cultural background are not accustomed to answering questionnaires, especially closed response questionnaires, and this may have limited vocalization of their responses. Finally, the researcher surmised that a qualitative approach would produce a wealth of detailed information about a small number of people in a particular situation, thereby increasing the understanding of the situation.

The interactive interview technique was used. As Patton (1990) states, one "...cannot observe feelings, thoughts and intentions...cannot observe behaviour that took place at some previous time...cannot observe how people have organized the world and the meanings that they attach to what goes on in the world..." (p. 278). According to Thompson & MacDonald (1989) an effective, although time consuming way of finding out how a particular group views health and illness is to interview its members, preferably in their own homes, through the use of interviewers
who are fluent in the language of the interviewee. In addition to these factors, some anticipated characteristics of research participants influenced selection of the interview method. These included - 1) the presence of a high illiteracy rate in individuals that the researcher wished to do research with which would make it difficult if not impossible to use a questionnaire, and 2) form filling, although common in North America, is not something members of the proposed research group are familiar or comfortable with.

As elaborated upon in later sections and chapters of this thesis, the adapted Chain of Response model was the conceptual framework used to help collect, organize and report the findings on this research topic.

Site Selection

Interviews were conducted with elderly Sikh Indo-Canadians who, despite having had diabetes for a number of years, had not participated in diabetes education. Because they were likely to be scattered throughout the population, multiple sites were used to access research participants. Originally, the plan had been to access research participants through senior mens’ and womens’ groups that meet regularly in Vancouver, Surrey and Burnaby. However, following discussions with the thesis committee a decision was made to also try and include as research participants, individuals who were not members of seniors’ groups in order to add richness and, possibly, another dimension to the data collected. These latter individuals were accessed through personal contacts in the community. Formal approval, participant names and telephone numbers were obtained through senior group leaders and personal contacts.

Initially, the researcher planned to access research participants through those general practitioner’s (GPs) whose major client base included members of this cultural group. However, it was ultimately decided that GPs may resist providing information on, or names of individuals with
diabetes who have not participated in diabetes education programs for the following reasons: 1) issues of confidentiality in a doctor-patient relationship, 2) family doctor may be a source of deterrence to participation of his/her client in diabetes education programs through non-referral of these patients, and 3) lack of co-operation on the part of the family doctor for fear that he/she may be criticized by the patient with diabetes or their family for non-referral, once the patient became aware of the existence of and the purpose of diabetes education programs through participation in the study.

Sample Selection

The selection of participants for this study was based on the following criteria: a) that individuals be diagnosed with NIDDM for a minimum of five years; b) that individuals be of Sikh Indo-Canadian cultural background; c) that individuals be a minimum of sixty years of age; and d) that individuals have not participated in any diabetes education program offered in an inpatient or outpatient setting.

At the outset of the study it was decided that a minimum of ten participants would be included in the study. A decision was also made that the sample size may be added to as the fieldwork unfolded and if the information that emerged indicates the value of a change. At the termination of the study, eleven participants had been interviewed. The rationale for limiting the sample size to this number was - the availability of only one interviewer, the need to first translate the interviews from Punjabi into English and then transcribe the interviews, the preference of the researcher to seek in-depth information from a small number of information rich participants and, finally, the exhaustion of research categories or information such that the researcher was "hearing more of the same."

Purposeful sampling, specifically reputational-case selection was used for selecting
research participants. Knowledgable community workers and program leaders who were active in the seniors' groups and personal contacts in the community were contacted by the researcher and requested to recommend individuals who met the pre-defined research participation criteria and who, in their opinion, would be knowledgable and informative about the research topic.

The researcher requested group leaders and personal contacts in the community to contact potential participants using the "script for the coordinators to make initial contact with the potential research participants" (See Appendix C). The names and phone numbers of individuals who exhibited an interest in participating in the research study were obtained by the researcher from the coordinators and personal contacts. The researcher then made telephone contact with individuals who had exhibited an interest in participation using the "script for the researcher to obtain verbal consent from research participants" (See Appendix D).

Some of the individuals contacted by the researcher expressed reluctance to and/or fear of participation in the research study and declined participation in the study. One individual stated, "I don't have much diabetes. I only take a pill, and I don't know how to talk much" and another voiced, "whatever two or four questions you have, you can ask me on the phone." Another individual, upon being informed of the interview length, nature of research questions and the need for audio taping the interview declined participation. The reasons given for non-participation by this individual included not knowing a lot about the Indo-Canadian community or diabetes, uncertainty on his part that he would be able to answer the questions and, therefore, contribute to the research.

Verbal consent to participate in the study was obtained over the phone. One individual verbally consented to participate over the phone but at the time of the interview appeared reluctant. When all measures taken by the researcher to make her feel comfortable failed, the
researcher decided to refrain from interviewing her so as not to put any undue pressure on her. Prior to conducting the face to face and one on one interviews, written consent was sought from research participants (See Appendix A and B). For those individuals who were unable to read either language, the researcher read out the information on the consent form to the individual [sometimes in the presence of a family member who could read the language(s)] and obtained their signed consent. Verbal consent was obtained from the select few who appeared reluctant to sign the consent form. It was made clear to all research participants that participation in the research study was voluntary.

Data Collection

To identify and describe deterrents to participation in diabetes programs as perceived by elderly Sikhs with NIDDM, an open-ended, semi-structured, informal, and an in-depth interviewing method using an interview guide was employed with individuals meeting the inclusion criteria for the research study. Patton (1990), states that the purpose of interviewing is to find out what is on someone's mind and the open-ended interview aims to do this. According to Lofland & Lofland (1984), an interview guide is, "not a tightly structured set of questions to be asked verbatim as written, accompanied by an associated range of pre-worded likely answers. Rather, it is a list of things to be sure to ask about when talking to the person being interviewed" (p. 59). These views of Lofland & Lofland and Patton are re-enforced by Bauman & Adair (1992) who state that while structuring the interview content, an interview guide tries to capitalize on the richness of qualitative open-ended responses. Bauman & Adair (1992) state that an:

- interview is not free flowing or determined by the respondent's interests; it is focused on a specific issue or set of issues, and the guide specifies the topics that must be covered during the interview. Although this interview requires specific data from all respondents,
it is flexible in the order of interview topics and the wording of questions or probes" (p. 10-11).

In fact, the wording and sequence of the questions can be adapted to: a) the specific respondent (Patton, 1990); and b) facilitate a flow of conversation such that the interview may be called a "guided conversation."

The COR model was the basis for developing the interview guide. A review of the literature identified that pre-existing measurement instruments used to assess the various components of the COR model had been developed. For example, the Diabetes Care Profile (DCP) had been developed to measure aspects related to diabetes including diabetes control, social and personal factors, attitudes toward diabetes, self-care and social support (Michigan Diabetes Research and Training Centre, 1990). The researcher contacted this centre by telephone and requested a copy of the DCP. In addition, the Health Belief Scale (Given, Given & Gallin, 1983), which measures the beliefs of individuals with diabetes, the Diabetes Attitude Scale (Anderson, Donnelly & Dedrick, 1990) which measures the attitudes of patients on a variety of diabetes related issues, the Diabetes Knowledge Scale (Dunn et al. 1984) and the ATT39 attitude scale (Dunn, Smart, Beeney & Turtle, 1986) which measures the emotional adjustment of individuals with diabetes were reviewed. The DPS-G developed by Darkenwald & Valentine (1985) to measure deterrents to participation such as lack of confidence, lack of course relevance, time constraints, low personal priority, cost and personal problems was also considered in the development of the interview guide. The questions included in these scales were modified to make them open ended and culturally relevant.

Experts (i.e., members of the thesis committee) and diabetes educators were also asked to provide feedback on the interview guide. Socio demographic data was also obtained to build a
participant profile. A high degree of flexibility was built into the interview process to allow the researcher to revise questions and/or probes, to get not only the essential questions answered but, also, to be able to follow more promising leads offered by the cultural informants (Jermain, 1986). Not only was the information that the interviewee provides on his/her own seen as important, but also what was not mentioned by the interviewee. To elicit in-depth responses interview probes were also included in the interview guide. However, for those participants bound by time constraints or desiring structure to their interviews, the questions were more structured.

As the researcher was an unknown entity to the participants, it was believed that the researcher's appearance, attitude and general disposition would likely influence the quality of data obtained. Thus, the interviewer/researcher attempted to enter the interview setting with an open, non-judgemental and a self-aware perspective as the researcher's personal biases, values and beliefs could influence the perception and interpretation of the setting and how the researcher interacted with the participants. In addition, the interviewer paid attention to key strategies of effective interviewing which included - trust and rapport building and appearance management (Measor, 1985).

Trust, confidence and acceptance in this relationship are essential ingredients to gaining access to the important realities of the participant's private information. The similarity in the cultural background of the researcher and that of the participants invoked feelings of trust and rapport in research participants. Sharing of some personal information by the researcher with the participants such as - village of origin, area of work and names of parents and in-laws, and the personal knowledge held by participants regarding some members of the researcher's extended family also invoked trust in the participants. This strategy may be criticized by some researchers who advocate that the interviewer remain objective and limit exchanges of information to
objective events to minimize the interviewee biasing his/her answers to please the interviewer. Trust and rapport were also established by the researcher through the use of open ended questions which conveyed the researcher's interest in the participants as a person such as asking them about their village of origin, their life in India and so on, and also through addressing participants in a culturally appropriate way (i.e., "uncle ji or auntie ji"). In addition, the language used in the interview questions was particular to the social environment to allow for a connection to develop between the informant and the interviewer so as to facilitate extraction of information (Becker & Geer, 1970). Sensitive issues such as the support available for diabetes or health management were reserved for later, that is after rapport and comfort had been established.

Appearance management, a strategy seen as being important in building stronger relationships with research informants, was also utilized by the researcher Measor (1985). By dressing selectively that is not wearing traditional Indian clothes nor the Western skirts or shorts the researcher attempted to identify with the research participants' image expectations and ideological perspectives of a professional who could relate to them. In essence with this the researcher tried to create a sense of similarity with the participants in the hopes that they would talk without inhibition about their own perspectives, thoughts and feelings regarding the issue at hand.

The researcher is a diabetes educator who frequently does interviewing at the workplace and is therefore familiar with interviewing technique. Throughout the interview, both verbal and non-verbal methods were utilized by the researcher to convey to the participants that their information was valuable. Good listening skills with frequent reflections (paraphrasing and summarizing) and clarification of meaning were used. Throughout the data gathering process, research participants were allowed the opportunity to ask questions of the researcher.
Participants were contacted by the researcher by telephone to arrange a time and location for the interview that was mutually convenient. All interviews occurred in the participant's homes, sometimes in the presence of family members. In most cases where family members were present through the interview, they added to the richness of the data collected by offering their input, validating the views expressed by the research participant and making the participant feel more at ease with the interview process. Only in the case of one participant did the researcher perceive that the presence of a family member may have inhibited the participant from opening up and expressing his honest opinion on some issues. The interviews were two to three hours long and were completed over a four month period. Codes were used to protect the identity of each participant and to guarantee their confidentiality. The interviews were audio taped to increase the accuracy of data collection, to allow the researcher to be more attentive to the interviewee, to ensure that the interview maintained its "conversational nature," to ensure the capturing of the completeness of the interaction, to provide material for reliability checks and to search for deeper meaning after the interview. Notes were taken by the researcher during the interview process to provide details relative to the non-verbal aspects of the interview and features of the physical surrounding.

According to Patton (1990), the period after the interview is critical to the rigor and the validity of the qualitative inquiry since this is the time to guarantee the quality of the data. Thus, immediately following the interview, the interviewer wrote down or dictated notes into the recorder about the interview such as non-verbal communication, setting or context of statements and activities, and activities of other persons present during the interview (Lincoln & Guba, 1985), which later helped in interpreting and making sense of the data. Any asides such as things said at the end of the interview after the recorder was turned off were also noted. Changes in
data collection, re-ordering or omitting of questions, good probes and new questions which were more successful in eliciting responses were also recorded. Data from each interview was first translated verbally from Punjabi to English and dictated into the dictaphone by the researcher who is fluent in both Punjabi and English. Throughout the translation process, a consistent effort was undertaken so as to yield a literal translation rather than the researcher's interpretation of the information obtained from each of the research participants. Total amount of ambiguity or uncertainty in the interviews was approximately an hour of the taped interviews. Ambiguity was clarified by consulting and utilizing the expertise of professional translators, and/or by contacting the appropriate research participant by telephone. The translated information was then transcribed into an interview log using a computer program called Ethnograph (v. 4.0). Following this, the researcher reviewed the transcribed interview notes to ensure that they made sense and to review the quality of data received.

**Data Analysis**

Data analysis is the systematic examination of data to determine its parts, the relationship among the parts and their relationship to the whole. In qualitative studies, data collection and analysis are seen to go hand in hand (Hammersley & Atkinson, 1983). According to Kirby & McKenna (1989), data analysis involves living with and making sense of the large amounts of data available through engaging in qualitative studies. To answer the research question, the adapted Chain of Response model was used as a guide to analyze the data using a systematic qualitative approach as described by Miles & Huberman (1984). According to Miles & Huberman (1984), "analysis consists of three concurrent (and interwoven) themes of activity: data reduction, data display and conclusion drawing/verification" (p. 21).

To begin with, each transcribed interview was carefully read and re-read so as to become
familiar with the data and to gain a holistic picture from the information or data collected. The raw data generated by qualitative interviews was voluminous (on average each interview yielded fifty pages of transcribed data), thus the process of data reduction was necessary. Analysis is inherent in this process of data reduction. Careful attention as to how data was being reduced was paid (Hammersley & Atkinson, 1983). This form of analysis "sharpens, sorts, focuses, discards, and organizes data in such a way that 'final' conclusions can be drawn and verified" (Miles & Huberman, 1984, p. 21).

Raw data from each interview was coded soon after the completion of each interview. This allowed the researcher to get into data analysis during data collection so that data collected in later interviews could be more focused. Initially, data was coded based on the seven categories identified in the Chain of Response Model using the computer program Ethnograph (v.4.0). This allowed for first level coding. Each category was identified by a unique name or code, examples being "attitude," "support," "self-eval" and so on. Every instance of each category located in the data was coded by the name based on the identified category. Care was taken not to strip the coded data from its context. Instances that fit more than one category were coded and assigned to both categories. As data were coded, patterns and themes emerged that related to the research question. At this stage data that did not appear to contribute to understanding of the research question was not coded. Once all interviews had been coded an output using first level identifiers was generated using the Ethnograph (v.4.0). For example, all segments, chunks or instances coded as "support" in all eleven interviews were collated, scanned and printed using the program.

The categories were re-examined for sub-categories based on the questions identified in the interview guide. Other sub-categories were also identified based on recurring themes or concepts. The sub-categories lead to the formulation of second level codes. Examples of second
level code names included "sup-fam" (support family), "know-bld" (knowledge blood), "perc sever" (perceived severity) and so on. Every instance of each sub-category located in the data was coded by the name based on the identified sub-category. Once again after all interviews had been coded with sub-categories, an output using second level identifiers was generated using the Ethnograph (v. 4.0). The uncoded data was then reviewed to find any additional information that may have been prematurely discarded and which may aid in furthering the understanding of participation. The sub-categories were individually examined and summarized to reduce redundancy and to make the data more manageable.

Miles & Huberman (1984) define data display as "an organized assembly of information that permits conclusion drawing and action taking" (p. 21). Using a chart format, the summarized coded responses obtained from research participants were cut and pasted in the appropriate categories and sub-categories as identified in the adapted Chain of Response model. Each category and sub-category initially represented a neutral position, such that it could be considered a facilitator or a deterrent to participation depending upon the supporting data gathered through participant interviews. The data was also compared with existing theory so as to reflect on interrelationships and/or missed contributions. Some modifications to the model were suggested based on the data gathered through this research process.

Conclusion drawing/verification involves deciding what things mean, and commences at the beginning of data collection, through to the process of data reduction and display. In order to confirm the validity of conclusions made, once final conclusions were drawn, they were verified in two ways, that is by reference back to the data and by reviewing them with research participants.
Issues of Validity and Reliability

As a researcher, it is important to establish trustworthiness of the study. According to Lincoln & Guba (1985), the basic issue related to trustworthiness is how the researcher persuades the reader of the research that findings of the study are worthy of attention. In doing so, the researcher speaks to the internal validity, external validity and reliability of the study. The qualitative researcher conceptualizes validity and reliability differently than quantitative researchers; in the qualitative paradigms these are named truth value, transferability, and dependability (Lincoln & Guba, 1985). According to Patton (1990), the validity and reliability of data in qualitative research depends upon the methodological skill, sensitivity and integrity of the researcher. The definitions of the terms "internal validity," "external validity" and "reliability," and the threats and strategies for controlling them are explored in this section.

Internal Validity (truth value)

The truth value of qualitative research addresses the question - Do the researchers actually observe what they think they observe? How truthful are the findings of the study? According to Lincoln & Guba (1985), the naturalist must show that the multiple constructions have been adequately represented, that is reconstructions arrived at via the research are credible to the constructors of the original multiple realities.

According to McMillan & Schumaker (1989), high internal validity rests on the data collection and analysis technique which were explicitly outlined earlier by the researcher. As these are affected by the personal perspective of the researcher, this too was indicated. For example, inherent in each researcher is a unique perspective of the world which is formed by values, culture and gender. As indicated in Chapter One, the researcher has a background in diabetes education and is involved in the provision of diabetes education for patients of this cultural background.
Furthermore, the researcher is a member of the same cultural group as the research participants. Both of these factors may have led to some biases some of which are explicitly stated in Chapter One and others which the researcher is unaware of. These may have influenced study design, data collection, analysis and interpretation.

Other strategies which assisted in increasing the internal validity of the research study were matching research based categories to participant reality, conducting interviews in a setting that was comfortable and natural for the research participant, and employing self-monitoring techniques, that is submitting all phases of the research process to continuous and rigorous questioning and re-evaluation.

Even considering these types of controls, the researcher is cautious in claiming that the results of the study are applicable beyond the context of the explored area. However, within the parameters of the setting, population and theoretical framework, the research is valid (Marshall & Rossman, 1989). Thus, these parameters are adequately stated by the researcher.

**External Validity (transferability)**

The transferability of qualitative research addresses the question - How applicable are the findings of this research study to another setting or group of people? The aim is not generalization of results, but an extension of understanding. According to Lincoln & Guba (1985), naturalists cannot specify the external validity of the inquiry, instead the burden of demonstrating the applicability of one set of findings to another context rests more with the reader who would make this transferability than with the original investigator.

On the basis of recommendations made by these authors, thick descriptions were provided about the strategies, methods, settings, participant characteristics, analysis techniques, and theoretical framework of this study in the write-up of the project, so that it may enable those
interested in making a transfer to a) understand similar situations, b) extend this understanding in subsequent research and c) reach a conclusion about whether transfer can be contemplated as a possibility depending on whether the contexts are similar. To aid in the establishment of transferability, the typicality of the phenomenon under study was also reported.

**Reliability (dependability)**

The reliability of the qualitative research study addresses the question - How can we be reasonably sure that findings would be replicated if the study were conducted with similar participants in a similar context? The positivist notion of reliability which assumes an unchanging universe, where inquiry could be quite logically replicated, is in direct contrast to the qualitative assumption that the social world is always changing, thereby making the notion of replication problematic.

According to McMillan & Schumaker (1989), the reliability of this research study is enhanced by: 1) making explicit the researcher's role and status within the group, 2) informant description and the decision process used in making their selection (replicability requires a researcher to contact individuals similar to those who were informants in the previous study), 3) describing the social context which can influence the data, 4) description of data collection and analysis - the interview method used, the method of recording the data, a retrospective account of how data were synthesized and the general strategies of data analysis and interpretation, and 5) making explicit the conceptual framework informing the study and with which research findings were integrated. Mechanical recording of data (e.g., through the use of a tape recorder), use of direct quotes and peer examination through publication of results were and will be used to minimize threats to reliability. All of the above will allow other researchers to follow the thinking of the researcher of this study and structure their study in a similar way.
Ethical Considerations

Ethical concerns are relevant in many aspects of life including educational research. Spradley (1980) indicates that a single set of standards are difficult to adopt for varied and complex research settings. However, Spradley cites several important areas of consideration: 1) a researcher's "paramount responsibility is to those he studies" (p. 21), 2) the rights and interests of the informants must be safeguarded, 3) the objectives of the research should be communicated to the informants, and 4) the anonymity respondents must be protected. McMillan & Schumaker (1989) add that i) informed consent of participants must be obtained, ii) for research conducted through an institution, approval for conducting the research should be sought from the institution prior to data collection, and iii) efforts should be made by the researcher to consider the potential for misinterpretation and misuse of the research.

Through the submission of a written proposal, approval for the research study was sought from the Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Rights and Subjects, University of British Columbia.

Prior to the interviews, written or verbal consent was sought from each of the research participant (See Appendix A and B). The consent form included: a) the purpose of the study, b) the interview protocol including the confidentiality aspect of the research study, c) the informant's right to refuse participation in the study, and d) the informants right to refuse answering any question or withdrawing from the study. Procedures were also in place to protect the identity of the informants in all phases of the research.

Chapter Four presents findings of the research study by identifying and describing those factors which influence participation of elderly Sikh Indo-Canadians in diabetes education programs.
Chapter Four outlines and describes factors which were identified as influencing the participation of elderly Sikh Indo-Canadians in diabetes education programs. Data used to develop this section was derived from two to three hour long, semi-structured, one on one and face to face interviews conducted with eleven research participants.

The adapted COR model as outlined and discussed in Chapter Three was used as the conceptual framework to present the findings of this research study. The interviews revealed several themes or topics which were classified into broad analytic categories and sub-categories as identified in the adapted COR model. The categories and sub-categories were not mutually exclusive. Rather considerable overlap was identified.

**Socio-Demographic Characteristics of Research Participants**

The following table provides a partial summary of the socio-demographic characteristics of the research participants. The purpose of the table is not to aid the reader in drawing statistical inferences; instead, it is intended to provide the reader with some sense of who the participants were.
<table>
<thead>
<tr>
<th>Table I: Socio Demographic Characteristics of Research Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age of participants (years)</strong></td>
</tr>
<tr>
<td>60-65</td>
</tr>
<tr>
<td>65-70</td>
</tr>
<tr>
<td>70+</td>
</tr>
<tr>
<td><strong>Place of birth</strong></td>
</tr>
<tr>
<td>village</td>
</tr>
<tr>
<td>city</td>
</tr>
<tr>
<td><strong>Education completed (grade)</strong></td>
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</tr>
<tr>
<td>5-10</td>
</tr>
<tr>
<td>Bachelor's/Master's</td>
</tr>
<tr>
<td><strong>Age at time of marriage (years)</strong></td>
</tr>
<tr>
<td>&lt;18</td>
</tr>
<tr>
<td>&gt;18</td>
</tr>
<tr>
<td><strong>Current marital status</strong></td>
</tr>
<tr>
<td>married with partner</td>
</tr>
<tr>
<td>widowed</td>
</tr>
<tr>
<td><strong>Length of time in Canada (years)</strong></td>
</tr>
<tr>
<td>0-5</td>
</tr>
<tr>
<td>5-10</td>
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<td>10-20</td>
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<td>20-30</td>
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<tr>
<td>30-40</td>
</tr>
<tr>
<td>40+</td>
</tr>
<tr>
<td><strong>Languages spoken</strong></td>
</tr>
<tr>
<td>Punjabi</td>
</tr>
<tr>
<td>English</td>
</tr>
<tr>
<td>fluent</td>
</tr>
<tr>
<td>moderate</td>
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<tr>
<td>minimal</td>
</tr>
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Table 2 (continued):

<table>
<thead>
<tr>
<th>Languages read and written</th>
<th>Males n=8</th>
<th>Females n=3</th>
<th>Total n=11</th>
</tr>
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<td>Punjabi</td>
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<td>3</td>
<td>10</td>
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<td>2</td>
</tr>
<tr>
<td>nil</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time since diagnosis of diabetes (years)</th>
<th>Males n=8</th>
<th>Females n=3</th>
<th>Total n=11</th>
</tr>
</thead>
<tbody>
<tr>
<td>5-10</td>
<td>6</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>10-20</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>20+</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

**Background Information on Research Participants**

Owing to the sample selection criteria, participants interviewed were all greater than sixty years of age. Those who had been in Canada for more than twenty years had come at an employable age and had found employment doing manual or physical labour such as mill work or construction work.

*After I came here I started working in the mills.* (3)

***

*After coming here we, that is my four sons and I, got involved with construction. We worked in the factory and did finishing of basements as a side business. We used to go to the factory, come home and eat in ten minutes and then go and do our construction work. Eventually we started building new homes and selling them. We used to work 12 to 16 hours a day, 7 days a week.* (5)

Although these individuals had come with the intention of making money and returning to their country of origin, they eventually sponsored their families and made the decision to make Canada their permanent home.
I came to Canada when I was twenty years old. My purpose of coming to Canada was to spend four or five years working and earning money to take back to India. My past three generations had lived abroad and had sent money to India for property improvement and/or land purchase in the village. Thus, I came with the same intention. I planned to return to India and live there. When I came to Canada there were 1200 or 1300 men of Indian origin here and only forty-two families. The elders used to tell us that this was a foreign land and we were not to stay here permanently. The elders said that if we sponsored our families then we would settle and die here. (3)

***

I came to Canada in 1959. I was sponsored by a very wealthy uncle in Vancouver. When I came here, I did not like it here and had full intentions of returning to India. I wanted to take money back to India with me. You see, we were three brothers and once my father's land would have been divided between us, not a lot would have come to me. When I came here I used to pine the loss of the familiar and missed India. However, after being here for a year or two my feelings changed. Now I don't even want to go to India for a visit even though we have property and a house there. (6)

Others who arrived in Canada at an older age had come because of family reasons. Some had come with the intention of being re-united with family members in Canada, while others came with the intention of trying to get their children out of India. These individuals, too, had come to Canada with plans of eventually returning to India, but, this did not materialize.

My older son came to Canada and sponsored us. We (husband and I) only came for three or four months and had the intention of going back. Now we have been in Canada for sixteen years. (10)

***

I came to Canada because of my son who had sponsored us. My wife and my two children came with me. My youngest son followed us a few years later. The real purpose of our coming here was to get the children well settled as there was lots of trouble in Punjab at that time. Also, there were very few job opportunities for the children in India. I had only taken a leave from my job and had full intentions of returning to it. (7)

***

I came here with my family. My eldest son who had come first sponsored my wife, my younger son and I. I had not resigned from my job and had the intention of going back but later I changed my mind. (8)
After coming to Canada, a number of these older immigrants found it necessary to seek employment.

I came to Canada and worked as a security guard in Toronto....I had to work to make ends meet....Migration is very difficult...our elders worked and because of them we have something in India. It is the same here. Punjabis are hard workers and, wherever we go, we acquire things through hard work. Unlike the Chinese community which has come here (Canada) with lots of money and established businesses, lots of Punjabis have come here with very little money. When we (family and I) moved to Vancouver, I had trouble finding work. (7)

Most found employment as farm workers. Despite belonging to farming families in India, most were not used to doing hard physical labour themselves and found it difficult to get accustomed to such work. Some after meeting eligibility requirements were receiving old age pensions.

I served in the military for five years in India. Then I worked in the transport business doing clerical work in an office and then as a manager. After we came here we worked in the farms until we were 65 years of age. It was hard work. I had worked with a pen and paper for most of my life. My wife found it hard too, as she had been doing used to doing only housework in India...Now we get a pension. (1)

***

I worked as a teacher in India and after coming to Canada worked in the farms. (8)

***

We came here and worked in the farms for four years. In India we had people who worked for us in the house. It was hard to do farm work as we were not used to that kind of work...Now we get a pension. (10)

Only one participant had not worked outside of the home.

I never worked outside of the house since coming to Canada...Now I get a pension. (11)

Approximately, 33% of the research participants lived on their own, with their children and grand children living either in close proximity or at a great distance.

My three sons live in the U.S. and my daughter lives in Richmond. My husband and I live in the house on our own. (10)
I live alone in this house. My husband died fifteen years ago. I suffered a lot after his death. My kids and grandchildren come and visit on a regular basis. (11)

***

We used to live with our older son and then he died in a car accident. We have one daughter in Edmonton, and two sons and two daughters in India. (1)

Others lived with their children as part of an extended family.

I live here with my son, daughter-in-law and grand daughter. My wife died three years ago. I have two sons in India and one here with me. (4)

***

I live here with my oldest son and his family. We have two other houses in this block which are owned by my other two sons. My wife died three years ago. (5)

***

My wife and I live with two of my sons, their wives and kids. The two other sons live in Vancouver and my daughter lives in Germany. (7)

Self-Evaluation (Point A of the Adapted COR Model)

Negative or poor evaluations of oneself as a potential learner are closely tied in with feelings that any learning effort will result in failure and humiliation. Participation in formalized diabetes education programs could be seen as one such learning activity. However, most people, if questioned may not openly ascribe their non-participation to their lack of self-confidence, instead choosing to explain non-participation in terms of lack of available time, not knowing the purpose of the programs, etc. Thus, questions were posed in a non-threatening and indirect manner. As a result, the following sub-categories emerged.

Experiences, Opportunities and Barriers Related to Childhood/Youth Education

Level of formal education acquired by an individual can affect their self-confidence as a learner. Based on past involvement with different diabetes education programs and personal knowledge of seniors of Sikh Indo-Canadian community the researcher's experience indicates that
there are a large number of individuals of this age group who are illiterate. However, this was not the case with a majority of research participants. As indicated in Table I, all participants had attended school, albeit to varying levels ranging from grade three to a Master's in political science. On average, women tended to have a lower level of education than male participants, with the highest level achieved being completion of grade eight. With the exception of one, all participants were able to read and write Punjabi. However, the researcher's experience regarding illiteracy amongst these seniors was validated by these participants.

...there are a large number of our (Indian) people who are illiterate. (3)

***

Although a large number of seniors are illiterate, there are those who have come from India and are very well educated. It is not that all elderly people who have come are uneducated. (4)

***

There were some children who received education. One boy out of three boys in our family went to school. In those days it was the same story in many families, that is one in the family would get an education and the remainder would not. (5)

***

Not only did all my brothers and sisters go to school, but all my cousins went to school too. For those times this was not only excellent but also an exception. (8)

***

In our village there were only seven boys who went to school. (7)

When questioned about their educational experiences as a child or youth these elderly gave a wide range of responses. A few found the school experience unpleasant and something they were made or forced to do.

When I was young my parents wanted me to study and go to school. I stayed in school for nine years and learnt nothing. They (parents) did a number of things to improve my brain and took me to a number of doctors. (6)
I went to school more out of habit than actual liking for it. (8)

***

I had very little opportunity to go to school. I was not interested in school either. Maybe I did not want to go, but my parents did not encourage me either. (5)

However, most participants recalled enjoying learning and the school environment.

I enjoyed school very much and that is why I went to school. It was not that my parents forced me to go. (10)

***

I enjoyed school a lot. I still enjoy reading. I was good in school and even got a certificate upon completion of grade eight. (11)

Aside from the participants' interest in learning, the valuing and provision of support and encouragement by their family was also viewed by them as being important in influencing the participation of these individuals and their siblings in educational activities.

My parents wanted all of us brothers and sisters to go to school. (10)

Families of participants had valued education for a variety of reasons, including facilitating personal growth and enhancing employment opportunities for their children.

My parents valued education as they were educated and they wanted their children to get an education. However, parents of other kids did not know what education was. (7)

***

My parents were educated too. My mum had completed grade 5 and my dad grade 8, which for their time was very good. We had little land and they wanted us to get our education so that we would get good jobs. (8)

***

My father and grand father were both uneducated. However, they wanted their children to receive an education. My father always said to us, "Study and you may find a good job." To enable us to go to school, my father financially supported us as much as he could. (9)
Despite having a great amount of individual interest in education and learning, some research participants were faced with premature termination of education in their childhood or youth. There were several reasons cited by research participants for this which included familial, social and political circumstances of the time.

*At that time they did not allow girls to get out of the house. In addition, the village schools did not go up to high grades. Our village school only went up to grade five. (10)*

***

*Our area was a hilly one and my father did not let us out of the house. We stayed in "purdah" (veil/curtain) so that the men could not see us. A fellow used to come and teach us at home. In my days, teachers did not have good characters and one would have to travel miles to get to school. In addition, my parents got me married off at a young age. Once married I got very busy and hardly had time to do anything. Education got a little easier after the Independence of India, as my sisters and brother who studied after Independence got their MA. (2)*

***

*My father passed away in 1948 and I had to assume responsibility for my family because my sister who was older than me was married and settled in her own house and my younger brother was only thirteen. The agricultural work that the family did fell on my shoulders and I had to quit school. (3)*

***

*In those days, the greed for work was a lot stronger than the desire for education. In our village the people used to say "You are not going to become a revenue or a police officer after you get your education so you may as well work." People paid little attention to education then. In addition, Britishers who ruled India were not interested in making education accessible to people. They could not have cared less whether people studied or not and small villages had no schools....When India became independent schools were started in the smaller villages. Nowadays peoples' attitude about education is different and they encourage their children to get education. (5)*

***

*After partition of India and Pakistan schools were set up in each village, thus making it possible for more people to attend and get education. (8)*
In our times the school situation was different. The closest school to our village was nine miles away. Very few people drove scooters and tongaas (horse drawn carts) and rickshaws for public transport were not common either. We used to walk to and from school. We left home at 7 am with the rising sun and returned home at 7 pm with the setting sun.

**Perceptions of the Elderly Regarding Aging and Learning**

Alongside varying experiences with education in their childhood or youth, the degree of self-confidence in these elderly affecting their participation in formalized educational activities can also be dependent on their personal beliefs regarding aging and learning, that is the dictum an "old dog can't learn new tricks." There is evidence to suggest that these feelings are more common in people who are returning to education after a long hiatus (Darkenwald & Merriam, 1982). When asked about their thoughts on this topic, most participants exhibited an interest in learning and acquiring knowledge and believed that learning could occur at their age.

*I loved learning when I was younger, but that desire never really materialized. At this stage in my life, I don't feel embarrassed about learning. If you try to teach me, the most you may say or think is that I do not know how to read or write. However, that is okay, as long as I learn something.*

***

*Whether young or old, provided the individual's brain is working and they have an interest in learning, they will acquire new knowledge.*

***

*If one needs to do something one will, but if there is no need then they may not. Need is what gets people to learn regardless of their age.*

***

*If there is someone available to teach new things and provided the elderly's brain is working, then they will learn new things. It is not that the elderly cannot learn. Elderly go to school don't they? There is such a thing as adult education. If the elderly want to learn they will. People don't learn simply because someone wants them to. The environment of the person has a lot to do with shaping their character and behaviour.*
However, these elderly were aware of others who did not share their interest in learning.

Old people have a poor memory and forget things easily. Maybe some don't enjoy learning but I still enjoy seeing and doing new things. (11)

***

I enjoy listening and paying attention to new information that is of interest to me. I try and jot things down and implement some of them at a later date. I believe I will live to be a hundred. At present I am only seventy-five, so I still have a quarter of my life left. However, not all old people learn. Take for instance my wife who won't learn. There are all kinds of people in this world. (1)

***

I have never hesitated from acquiring new information. Look at how old I was when I did my MA. I was forty three. I believe old people can learn provided they have the desire and intention of doing so. I am sure there are some elderly who are hesitant about learning new things, but I feel they are few. In general, I believe that elderly want to learn. Here some elderly go to colleges and universities and now more of that is starting to happen in India. At age fifty-five, I wanted to do law in India but then I changed my mind. (4)

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Even though I did not have much interest in studying when I was younger, I now have an interest in learning new things. For me the main reason of getting together in a group is to sit down and chat with people so I can learn something. I agreed to do this interview with you because I thought I would learn something from you. However, each person is unique in their thinking and interests. There are people who come to seniors' group who have no interest in learning new things. (5)

There were a few elderly who did not view learning as important and believed that learning could not occur at this stage of their life. Some gave reasons for their beliefs.

New things... it is hard to learn new things when one gets old. Old people can learn how to lie and gossip but they won't learn much else. I should say that it really depends on the individual's brain. An individual who has an active mind will be able to learn. People who have been exposed to education and know how to read and write from a young age will be able to learn new things. However, there are also people like me whose brain does not work. So it depends on the individual. (6)

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Personally I don't have an interest in learning new things. (9)
A large part of our life is over and done with and maybe we have one, two or three years of our lives left. So my attitude is that what is the big deal. (10)

**Participation or Non-Participation of Elderly in Education Post Arrival in Canada**

Along with the educational experiences of the elderly in their childhood or youth and their perceptions related to aging and learning, the willingness of the elderly to participate in organized educational events and their self-confidence related to education can also be influenced by the nature of their experience with educational opportunities after their arrival in Canada. A common assumption is that language barrier is faced by most new immigrants to Canada and that this may create a desire for learning and participating in organized adult education. When research participants with minimal/poor/non-existent English skills were asked about the kinds of problems they experienced because of their lack of English language skills, they identified difficulty communicating with medical practitioners as the primary problem. To deal with this problem they had chosen family doctors of Indian origin or those of non-Indian origin who spoke some Punjabi.

*Some of the non-Indian family doctors have learnt how to speak Punjabi. I have a Chinese doctor but he does know some Punjabi. For example, he knows words like "does this hurt." However, to go see a special doctor I run into problems and I have to take my son or daughter.* (2)

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*Because of not knowing English, I have had some problems when I have gone in to see the doctors. My family doctor can speak some Punjabi and sometimes when we have trouble communicating we just call in his secretary for translation. It is the English speaking specialist that I have trouble communicating with and have to take someone with me when I go to see him/her.* (10)

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*My doctors have been Punjabi because of convenience with language. However, now some non-Punjabi doctors are also learning Punjabi because of their vast exposure to Punjabi speaking patients...I prefer Indian doctors because of the fact that I cannot express myself well in English. We have wanted to change our family doctor as we know of an English doctor close by who is good. However, he does not want us as he feels that he will have trouble communicating with us. We wanted our boy to accompany us to this*
doctors for the first time so we could provide a detailed history but that has not happened yet. I have been here for forty years and until now I did not recognize the need for English. If I had not got sick now, I still probably would have been okay. (6)

Those who had arrived in Canada many years ago without language skills did not encounter problems related to securing employment or in fulfilling their job duties.

When I came to Canada (forty years ago) work was easily found. In work there was no problem without English and we managed. (3)

However, both the old and newly arrived immigrants recognized that in this day and age this was no longer the case.

The thing is this that when we came to Canada jobs were easy to come by, but now even educated people cannot find jobs. Our time was good and we could survive without English and not knowing how to read and write

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As far as work is concerned not knowing English has posed a problem as one cannot find work without English. (8)

After their arrival in Canada the elderly dealt with the language barrier issue in a variety of ways. The saying "Necessity is the mother of invention," certainly rang true in the case of some seniors who, with encouragement from their family members, participated in English as a second language classes and had positive learning experiences.

When we came into this country, my sons asked me if I wanted to go to English school and I said sure. They used to drop me off at the school which was far away on Victoria Drive. At that time I did not even know A B C and found school hard. Gradually, I started to learn English. (2)

Another participant explained how he improved upon his English language skills with the help of his family.

I learnt English for three years in a school in India. It was very simple English. The way I learnt English in Canada is by starting to read the newspaper. Then I started watching English TV and then later on came my teacher kids. (3)
One participant who had been unsuccessful with learning in India continued to struggle with English language classes in Canada.

When I came here my uncle asked me to attend a school on Broadway to learn English, but I did not even know how to read and write Punjabi so how was I going to learn English... I just feel my brain did not work too well in terms of learning and going to school. I gave up. Another thing is that I was new in the country and there was work to be done and money had to be made. (6)

However, some participants continued to cope with the level of English they had, placing greater priority on paid work.

I could have studied after I came here, but the village misfortune followed me here. We got into the construction business and the work got so busy that I did not have time to go to school. I feel that if out of those years I had spent five or seven years in school, I may not have obtained a degree but at least I would have felt comfortable with speaking the language. (5)

Those elderly who had attained a grade ten level of education in India had an adequate knowledge of written English but encountered some difficulty with spoken English. However, they did not find the language barrier to be an insurmountable problem.

I can read and write English but speaking it and understanding it is difficult. Some English words are hard and the accent can be difficult to understand. (8)

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I can make do and have not felt disadvantaged because of not being fluent in English. In my private business, in going to the doctor's or in going to citizenship office, I have had enough English to cope with. (9)

***

I did my MA in Political Science in English. The problem one faces with Canadian English is that it is sometimes difficult to understand as the accent is different than the Indian English accent. (4)
Knowledge and Skills, Health Beliefs, Attitudes and Support Related to Diabetes and Attitudes Towards Diabetes Education (Point B of the Adapted COR Model)

Along with exploring attitudes towards diabetes education, the knowledge and skills that research participants had acquired to help them manage their condition, their health beliefs regarding diabetes, their attitude towards health and diabetes and, finally, the support available for or needed by these individuals in managing their condition were also explored. It was believed that doing so would provide a more comprehensive understanding of attitudes that these individuals had towards diabetes and diabetes education which could, in turn, influence their participation in diabetes education programs.

Diabetes Related Knowledge and Skills

For some individuals with diabetes, the gap or discrepancy in the level of existing knowledge and skill regarding diabetes management and the desired knowledge and skills may create a desire to participate in educational activities. In addition, the Health Belief Model suggests that for a person to act to prevent or treat a certain condition, they must possess a minimal level of relevant health knowledge. Of interest to the researcher was also the correlation between the self-assessment of knowledge and skills by the individuals with diabetes and their actual knowledge and skill as determined by some key questions. These questions pertained to knowledge about normal blood sugar, home blood glucose monitoring, diagnosis and treatment of hypoglycemia, opthamology visits and foot care.

Self-Assessment of Knowledge

Self-assessment done by participants revealed varying levels of knowledge from poor to adequate. This was expressed in interesting ways by the research participants.

I don't know a lot. I know that if I got diabetes then it is up to me to control it. The diabetes will not go away by itself. (2)
I would consider it poor. I have not read a lot of literature on diabetes. I would like more information on what kinds of precautions I can take for my diabetes. (4)

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Knowledge is something you can never get enough of. You can keep learning all your life, that is how much knowledge there is. Whatever knowledge I have for diabetes, I would like to add to it. I always ask people what their experience related to diabetes is and whatever knowledge I acquire, I try and implement it. (7)

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On a scale of 1 to 10, I would say about 7. (3)

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Whatever knowledge I have I think is enough. If our sugar is high, then what can we do? We have doctors here to help us with that. (5)

Assessment of Knowledge and Skills with Key Diabetes Questions

Awareness of Normal Blood Glucose Levels

It is desirable that individuals with diabetes be aware of what normal blood sugar readings are for them. As is evident from the responses obtained, the knowledge of some participants related to this topic was fair.

I have heard that if it is 6 or 7 it is normal. (1)

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I think 6, 7, 8 or 9 is normal. (11)

***

The doctor tells us that it should be 6%. (7)

However, others were not aware of normal or optimal blood sugar levels.

In my opinion normal blood sugar is 87 or 86. The doctors simply tell me that 85 is okay and if it is 86 or 87, it is high. (2)
In my opinion normal blood sugar is less than 10. (3)

Some participants erroneously continued to base the assessment of their control on the presence or absence of symptoms of diabetes.

Normal sugar is what I have now. I know my sugar is controlled as I don't urinate a lot, get thirsty or feel tired. The doctor also tells me that my sugar is normal. (5)

Home Blood Glucose Monitoring

Home blood glucose monitoring is considered an important component of overall diabetes management and was done routinely by a small minority (two out of the eleven participants). Other participants did not possess a meter. Reasons for not doing home blood glucose monitoring included - lack of encouragement by family doctors, viewing laboratory testing of blood sugars as being adequate, not viewing home monitoring as necessary, cost associated with testing, basing assessment of control on symptoms of hypo or hyperglycemia and fearing that monitoring blood sugars at home on a regular basis would lead to increased mental stress.

No I don't (monitor sugars) and my doctor has not asked me to....I can agree with the rationale of testing one's sugars at home, but if one does not have control over oneself then testing at home will not resolve the problem. If one has control then one will be able to judge how high one's sugar is. I feel that even if I had my machine at home it would be no big deal. If my diet is good and my sugar is controlled then even if I don't test my sugar for six months it is okay. (10)

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I test my urine with a stick that has colour on it. I don't check my blood. The blood is tested by my doctor when I go to see him. The doctor has never asked me to check my blood sugar at home. (5)

***

I never test my sugar at home. I take a paper from the doctor every three months to the lab and have my sugar tested there. I have heard that machines don't tell you a lot. (6)

***

I don't test my sugar but would like to get some financial assistance so I can get the
machine. The tapes for testing blood sugar are expensive. I am not a senior citizen yet so it is expensive for me to buy the tapes. The government should provide some assistance for people with diabetes so they can afford these tapes. (7)

***

I had my sugar checked at the lab three months ago. I am thinking of buying a machine to test my sugar at home. When I was diagnosed with diabetes I used to go to the lab every month for the first two months…since then I only have my sugar tested once every three months. The doctor did not tell me to buy a machine. When my mood is right I will go and get the machine. As long as I am making do without it, I think why bother. I don’t believe in checking the sugar much. I feel that if one checks one’s sugar daily, then it puts pressure on the person’s mind as the person thinks that what is this that has happened to me. This worrying increases the illness. (8)

Symptoms and Treatment of Hypoglycemia

With the exception of one participant who controlled his diabetes with diet and exercise alone, all others used oral hypoglycemic agents to control their blood sugars. Individuals with diabetes who are treated with oral medications or insulin need to be aware of the symptoms and treatment of hypoglycemia (an acute complication of diabetes). Approximately one half of the research participants had experienced hypoglycemia and were familiar with some of the signs and symptoms of hypoglycemia.

All of a sudden my body went cold and I couldn't get up. (10)

***

When my sugar goes too low, I vomit. (11)

***

When my sugar goes down to 5, I start feeling shaky and need to eat something sweet (2)

***

I know right away when my sugar starts to go down. My hands and feet get weak and my heart starts sinking. (9)
Regardless of whether they had experienced hypoglycemia or not, all research participants expressed that they would take a simple sugar source to treat hypoglycemia.

I was at my sister's house when my sugar went low and in a hurry they fed me sugar. (10)

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Once when I went grocery shopping my sugar went low. I started to feel shaky and grabbed some caramel corn and started eating it. My doctor in India told me that I should carry candy with me or biscuits and eat them if my sugar goes down. (2)

***

Even though my sugar has never dropped low, I would know what to do in that situation. I know that I need to put something in my mouth right away. My daughter told me that I should carry some sugar with me in case my sugar goes low. I have had a card made that I carry around in my purse which tells people that I have diabetes and gives my family doctor's name. (3)

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In the evenings when my sugar goes down a lot, instead of sticking around the house and dirtying dishes, I go rushing to the temple and have some parshaad (sweet food items served in the prayer hall). I ask the man at the temple to give me a double helping of parshaad. Then when my sugar goes up high because of that I come home and have some medication. I also carry misri (sugar cubes), almonds and raisins with me as I was advised by my doctor. (11)

In general, there was little difference in the way in which participants who had experienced hypoglycemia treated the condition and those who had not experienced hypoglycemia would do so. From the responses obtained it became apparent that none of the individuals interviewed vocalized the proper treatment of hypoglycemia, that is consuming a simple sugar source followed by a protein and complex carbohydrate.

Eye Examinations

Research participants did not see an opthamologist on a regular basis for eye checks unless they had experienced eye trouble such as cataracts; nor were they aware of the need for doing so.
... for eyesight and not for anything else. I have never heard that you have to have your eyes tested by an eye doctor if you have diabetes. My doctor never told me that. (7)

***

Yes I get my eyes checked through the eye specialist. I had them tested because I saw black spots floating in front of my eyes. (11)

Foot Care

Only one research participant was aware of or knowledgable about the concept of foot care and the rationale and method of proper foot care.

Foot care to me means taking precautions. This means not walking barefoot, not having nails go into the feet and avoiding injury to the feet. I examine my feet on a daily basis when I take a bath. (4)

All others were unaware of foot care.

I check my feet to make sure they are clean. (2)

***

I am not sure what you mean. I have never heard of this before or made a point of doing so. Should I be? Should I just be checking my feet or my whole body? I would say a large number of people with diabetes probably don't know about this. (5)

The preceding discussion makes it evident that responses obtained to key diabetes questions from research participants do not validate their individual self-assessment of diabetes knowledge and skills.

Diabetes Related Health Beliefs

This section of the interview was based on the Health Belief Model which suggests that beliefs of individuals with diabetes regarding their susceptibility and severity of the disease can affect their motivation to participate. Furthermore, an individual's belief that benefits of participation in diabetes education can outweigh the barriers may also influence the decision to participate.
**Perceived Susceptibility**

This dimension refers to the individual with diabetes viewing oneself as being vulnerable to the affects of the condition. This health belief explored the level of blood glucose control of participants, ways in which these individuals determine their level of control including their knowledge and belief related to HbA1c. The affects of poorly controlled diabetes and treatment aspects necessary for preventing complications were also explored with participants.

As is evident from the following statement, a majority of the participants assessed their diabetes control as being fair to good.

*Now my sugar is 7.5.* (3)

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*The sugar usually stays okay. It is when I go to a wedding and eat something sweet that I notice my sugar is a little high. Otherwise it stays around 8 or 9.* (3)

One participant had experienced a recent rise in blood glucose levels.

*Before my sugar always used to be 10 but in the last few months it has gone up to 24.* (6)

Participants based the assessment of their diabetes control on a variety of different sources including verbal information from the doctor, laboratory blood glucose testing and spot checks at home. This variation in sources was alluded to and validates the information obtained from the participants in the "Home Blood Glucose Monitoring" sub-section.

*The doctor tells me my sugar is well controlled based on the lab test. I have my fasting sugar tested every three months.* (7)

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*I just take the paper (lab requisition) he (doctor) gives me and the lab people do what they need to do based on that. He (doctor) never tells me what my sugar was unless I ask him.* (6)
I test my sugar at home and if I have a problem then I tell my doctor and he gives me a prescription to have my sugar tested at the lab. (2)

With the exception of one all participants were oblivious to the meaning and purpose of HbA1c testing.

I have no idea what A1c is or if my doctor does it or not. (6)

He (the doctor) has never felt the need to test my A1c, so that is why he has never sent me for such a test. I also do not believe in such tests so I don't bother getting them done. (9)

Participants had some basic information regarding the complications of diabetes.

Because of its (diabetes') silent nature people may not take the disease seriously. However, they should as it is a bad disease and can affect your kidneys, your eyesight etc. (3)

High sugar will make me feel weak. The higher the sugar the less the effect of food on my body weight. If the sugar is controlled, I will not feel like a dope addict and my head will stop hurting. With the sugar being high, I am tired all the time. I don't feel as energetic as I should. Sugar also affects your eyes. Sugar being high affects the whole body. It is a very bad disease. (6)

Although they cited some of the long-term complications of diabetes as the effects of poorly controlled diabetes, they had a number of misconceptions related to this topic. Their knowledge was based primarily on hearsay and/or personal experiences of others affected by diabetes or its complications.

If diabetes is in your blood then it affects your heart and if it goes into your urine, then it affects the bones and disintegrates them. It can cause heart attacks and make your eye sight weak....I was not aware of its affect on the kidneys as I have not known of anyone who had bad kidneys because of diabetes. I do know that anyone who has diabetes, their wounds do not heal which leads to their hands and feet being cut off. (10)

Diabetes makes your bones weak. That is what people in India told me. They said that it disintegrates your bones which makes a person tired. I can walk and walk but when I get
home, I am very tired. I used to hear that it (diabetes) affected your eyes and brain. I think it affects my memory as sometimes I forget whether I have taken the medication or not. Other than that I don't know much more about the problems associated with diabetes. Sugar can also affects your kidneys if it is in your urine. My dad had failed kidneys because he never controlled his diet and ate everything. (2)

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Diabetes affected my brothers and sister so much so that if they developed a wound it would not heal. However, I have not been affected by it the same way. If sugar is not controlled then it can lead to joint pain. If it is not controlled for a long time then it can affect vision. With uncontrolled sugar I may become upset physically and mentally as I may experience restlessness and fatigue. Thus, if we want to enjoy life we have to control diabetes. It can affect your heart and kidneys as well. (5)

Aspects seen and voiced as being important in achieving good blood glucose by most research participants were diet control, activity and medication. Of these, diet control was mentioned most frequently and was seen as being the most significant.

I need to control my eating, drinking and exercise. I should not feel that my diabetes is okay so I can go ahead and eat what I want. Whatever hunger I have, I should eat less than that. (5)

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Control....control on diet, taking of medicine and walking as much as one can as it helps sugar come down. By control I actually mean precautions. (7)

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Controlling what is eaten and making sure the body gets the proper nourishment. I am not greedy about things, I eat reasonably. The food can be lying besides me but if I know it is not good for me, I won't eat it. I control my diet and eat only what I should. (2)

However, two participants simply stated that they were unsure of what was required for good blood glucose control.

I don't know much but I do know that I have to control my diet, exercise and not get mentally stressed out. (8)

Medications were not always taken by the participants as prescribed. Reasons for this included forgetfulness, basing the dosage of medication on the actual or perceived level of blood
glucose and viewing of Western medicine as having "drying" and other side effects.

I mostly depend on my diet to help me control my sugar. I don't take medication for a normal blood sugar of 6, 7, 8 or 9. I take half a pill if my sugar is 10 and a whole pill if my sugar is more than that. The doctor told me to take my medication based on my blood sugar level. I believe that Western medicines have dry effects. (11)

***

The prescribed medication dose for me is four pills - two Diabeta and two Glucophage in morning and evening. I regularly take the four morning pills, but in the evening I take only two pills. I sometimes forget to take the evening pills or purposely omit them. I believe that taking one medicine will create another illness. For example, if you take one medicine, then because of that medication you have to take another medication which gets a vicious cycle going. (3)

***

I have been told to take two pills in the morning and two in the evening. I am not sure what the pills are called though. However, I take two pills in the morning and take one in the evening. I feel the lower the medication, the better it is for me. If I sense my sugar is high then sometimes I take all four pills for the day. (5)

With the exception of two participants, a majority believed in the efficacy of traditional medicine in aiding with blood sugar control. These two participants gave the following reasons for their non-use of traditional remedies.

I am educated and come from an educated family; how could I use traditional medicine? I don't go to any palm or mind reader and do not believe in magic or witch craft. (11)

***

I drank Karela (bittermelon) water and it made no difference to my blood sugar. (9)

Approximately one half of the participants relied on traditional remedies for their blood sugar control. Some took traditional medicine as an adjunct to their prescribed medication dose while others replaced part of their prescribed medication dose with the traditional remedies.

Daily in the morning I take a spoonful of dried and ground Metthae seeds with a glass of water which helps me with my blood sugar. (10)
When the doctor asked me if I was taking two pills for my diabetes, I told him I was only taking one pill and drinking Karela juice. I have noticed that if I drink Karela juice regularly for a week then my sugar goes down. (1)

***

If I drink 2 or 3 ozs of Karela juice in the morning my sugar goes down. I have noticed that Karela juice has a greater effect on lowering my sugar as compared with the medication. So if I am going to drink the juice then I don't take medication. A teaspoon of ground Jawain with a glass of water also has a positive effect on my blood sugars. I keep trying things like that. Then someone told me that ground Jamun (berry) seeds are good for sugar too. I tried those seeds for four days but suffered with bad gas. (3)

Perceived Severity

This health belief refers to the individual perceiving the condition as being threatening and viewing oneself as being prone to diabetes complications. Aspects related to the perceived seriousness of NIDDM, need for diabetes control in NIDDM managed without insulin and viewing of diabetes management as a short or a long term commitment were explored with research participants.

As indicated earlier, none of the participants had NIDDM which was managed with insulin. Despite this, participants believed that diabetes was an illness which demanded control ("precautions").

No illness is good as it makes one unhealthy. Diabetes is not considered a very bad illness. If one controls it, then one is okay. If there is no control then one's health goes down and the person becomes weak. (10)

***

I have to care for it (diabetes) for only then will I know whether my diabetes is going up or down. If I don't care about it and it goes up then I may develop complications. So I must care and I do care. See if you have a business and you want to run it well, then if you control your business you are okay, but if the business takes control of you then you are in trouble. (9)

They recognized that conscientiousness and awareness on their part regarding their condition was required at all times, as only then could they best care for their diabetes and avoid diabetes related
I would never ignore my diabetes. If I know that something is not good for my diabetes, then why eat it. If something kills you or poisons you, why is it necessary to do it... if you become carefree you may start doing things that are harmful for your diabetes and thereby embrace death. If you avoid these things then you may last ten years, but if you keep doing them, then you may not even last five. I always keep my diabetes in mind. If it (diabetes) goes up, then I am always conscious of what to do to bring it down. (3)

I worry about my diabetes. I know things that are good for me and those that are not... People with diabetes should be aware of things that are poison for them and hence avoid them. See if I am walking along and I encounter a well along the way, then if I don't turn around and go the other way, I will fall into the well. So why should I continue along the path. I believe that if you keep checking yourself then you will know whether your diabetes is controlled or not, but if you don't it is like walking in the dark. (2)

I cannot ignore my diabetes, in actual fact I have to pay attention to it all the time. This is the way I see it, any work that needs to be done cannot be done without giving some thought to it. If something is in your realm of awareness then you will think about whether it is good or bad. If I don't keep diabetes in mind then I may keep eating things that can hurt me in the long run. (5)

Only one participant actually believed that if the ill affects of diabetes were not experienced by him then he did not have diabetes and did not have to be concerned about the disease.

I don't have the illness yet; when I have the illness then I will find out what kinds of problems can occur. I feel I have diabetes in name only as I don't suffer any of the ill affects of diabetes. (8)

For participants the main reason for good control in the absence of symptoms of uncontrolled diabetes and insulin was the fear that poor self-care would ultimately lead to their requiring insulin to control their blood sugar. Participants indicated that they were fearful of insulin injections and did not want their diabetes to progress to that stage.

People who are not taking insulin need to be careful about their diabetes too, as they can go on insulin if they are not careful. It is important to prevent yourself from progressing to that stage. (1)
I tell myself I don't want to get to the stage where I am taking injections. I want to be able to control my diabetes with medications. Some people say that taking a shot is okay, but I say shots are the worst. It is only when medications don't work that one has to take shots. (3)

Some participants hoped and/or had the misconception that at some point in their life their diabetes would be cured and in that event they would not be required to care for their diabetes for the remainder of their lives.

It is a long term commitment because if one develops diabetes at a young age then it goes away, but if one develops it an older age then even if the sugar goes away one has to continue on the medication, diet and exercise for one's lifetime. (10)

***

Unless the diabetes went away as in the case of my father, looking after diabetes is a long term commitment. (1)

However, those who believed that diabetes was controllable but not curable saw diabetes care as a long term and life long commitment.

As long as I have my senses, I have to control my sugar. When I no longer have my senses, they tell me that the hospital people will take me away and I will be cared for by the nurses. (11)

***

Diabetes control is a lifetime job. As long as I am alive the diabetes will be with me. It will only go away once I am gone from this world. (2)

***

If I have diabetes for life then I have to care for it for life. This illness does not go away and all one can do is control it. (8)

***

I have three friends who are hakims (doctors of traditional medicine) and they tell me that diabetes is not a curable disease. They say I can control it through homeopathic or allopathic ways but it will not go away. I guess I have it for the rest of my life, so I have to care for it and control it for the rest of my life. (9)
Perceived Benefit

This belief refers to the efficacy of intervention. Although acceptance of vulnerability to diabetes which is believed to be serious by the individual may be sufficient to produce a behaviour change, it does not hypothesize the kind of action that would be taken. The action depends on the belief regarding the effectiveness of various actions available in reducing the disease threat (Becker & Janz, 1985).

The beliefs of participants about whether they felt they could control their illness and whether the control would be beneficial to them were explored. Essentially, participants believed they were capable of controlling their sugar.

At this point I feel I can control my sugar. The future only God can tell. (10)

***

I not only think that I can control my diabetes, but I am controlling my diabetes. (1)

Participants believed that diabetes control measures which were seen to include diet, exercise and taking their medication would be beneficial for them. This belief of the participants is further validated by their expressed views as outlined earlier in the "Perceived Susceptibility" and "Perceived Severity" sub-sections. Participants felt that changes they had made in their life because of diabetes were necessary for diabetes, general living, and health and well being.

I feel that keeping control on your body and not eating junk is a good thing. You may call this a religious belief, but we consider this body to be a temple. Just as one cannot take one's shoes into the temple, similarly, one should not take bad things into the body. I used to drink but I don't now. I used to eat meat but now I don't do that either. These things I do for my religion and my diabetes. (4)

***

I would consider the changes I have made healthy for me. Even if one is healthy, walking and eating good food is beneficial for them. Even people who don't have diabetes can survive without eating sweets. Diabetes has lead to changes in my thinking and diet which keep my body feeling light... So even though diabetes is an illness, it has taught me
control. (5)

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I believe that the benefits of making changes in my life because of diabetes are that I will be healthy, my body will be strong and no part of my body will die. I will hopefully be able to prevent the complications that we were talking about earlier. (7)

**Perceived Barriers**

This health belief refers to the perceived difficulties in undertaking action. The negative aspects of a particular action may act as barriers to undertaking the otherwise beneficial action (Janz & Becker, 1985). A kind of cost-benefit analysis occurs at this stage where the benefits of the recommended action are weighed against feelings such as that it might be unpleasant, time consuming, etc. For most research participants the changes they had implemented for diabetes had not made a huge impact on their daily living.

*Diabetes has not had much of an effect on my lifestyle. (1)*

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Actually my life before developing diabetes was not so dissimilar to what it is now. I used to eat about the same things and my activity level was the same. I was not able to walk much even then. *Diabetes has lead to no major change in my life.* (9)

Participants perceived the changes made by them as being necessary and manageable.

*The diabetes regimen is necessary for my health. I don't think of it as interfering with my daily life. It is a part of my life.* (2)

However, for one participant the impact of changes made because of diabetes was substantial because it affected not only him, but also his family.

*I would say diabetes has made a huge impact on my life. I can't walk fast as I get short of breath. If I did not have diabetes I would be able to eat sweet and fatty things. However, I am educated enough to know that those things can harm me and I try and avoid them. Diabetes has also affected the life of my family as they have to cook things separately for me. The foods that they make, they have to take out a small portion aside for me. They constantly have to consider whether I can be given this item to eat or not. They are concerned about me at all times.* (4)
Nevertheless, all research participants believed that benefits of implementing elements of diabetes control far outweighed the effort involved.

**Attitudes Related to Diabetes**

Belief is defined as "the state of believing; conviction or acceptance that certain things are true or real...even though absolute certainty may be lacking" (Webster's Dictionary, 1986). Attitudes are defined as "a manner of acting, feeling, or thinking that shows one's disposition" (Webster's Dictionary, 1986). Individual attitudes may arise directly from the learner's own past experiences (life and health related), attitudes and experiences of friends, significant others and health care providers. It is possible that attitudes of individuals with diabetes regarding diabetes and diabetes education may be different than those of health professionals.

In this research study aspects such as individual definitions of health, viewing of self as healthy or not by research participants, importance of health in the lives of the participants and reasons ascribed by them to the development of their diabetes were explored with the research participants. These aspects have the potential of jointly or independently affecting individual attitudes towards diabetes management.

**How Individuals Define Health**

According to the health model, the definition of health refers to well being, health status, and health related practices, whereas the definition of health in the medical model refers to absence of disease. When asked to define health in general terms, a majority of research participants defined health in terms of general well being, overt reference to diabetes was missing. Participants laid emphasis on aspects of general living which they perceived would help in maintaining or achieving health. These aspects are similar to those viewed as being necessary for blood glucose control as expressed by participants in the health belief section.
...eat a healthy diet, do exercise and stay happy. (10)

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Being healthy means that your diet should be good, you should exercise daily...By doing so you maintain your health or become healthy. (2)

***

Health basically means there is no problems with an individual’s body. If the individual can eat okay and digest his/her food, is able to eat what he/she wants, is able to come and go as he/she wants and has the strength to walk around, has good vision and does not feel restricted from doing things, that is if he/she wants to work they can, all this is part of being healthy. No one can be better off than the individual who has this. (3)

***

Health means that a person should stay alert and not get lazy. Another thing is that one should control one’s diet, avoid alcohol, smoking and any kind of drugs including tea. It is important to stay busy so one does not think bad thoughts. (7)

In the interview some participants brought up the notion of a balance between physical and mental health as being important for general health.

Physical health is important. When you live in an extended family, a number of things can come up that may make your mental health less than optimal. Mental health can also affect your physical health. You see no matter how happy one is at home, there are always some kind of problems that arise. It is a family you know. (2)

***

For physical health you need diet and exercise and for mental health you need a worry free and happy life. For an older person it is very important that their children be healthy, good and kind. That does a lot in keeping the older person healthy. (10)

***

I don’t dwell on the fact that I am not healthy for hours, because if I constantly think about it then I will develop other health problems. Thinking or dwelling is one of the worst things....Whatever happens I try and keep myself worry free. (6)

***

In order to have good health, the mind has to be settled. For example, just as one cannot stabilize mercury one cannot keep the mind from wandering unless one makes an effort.
Keeping busy is one method of keeping the mind controlled. Keeping busy means that if one does not have physical work to do, then one should keep reading. Also I try and not feel things too much. (7)

Only two of the participants who were interviewed defined health strictly according to the medical model.

Health means being free from illness. (5, 8)

**Viewing of Self as Healthy**

It was interesting that when participants defined health in relation to themselves, the focus shifted from the health model definition of "general health" to include their illness "diabetes" and measures that would keep them healthy in the presence of diabetes. For some, having diabetes meant that they no longer viewed themselves as healthy, while others continued to view themselves as healthy provided their diabetes was in control and they were not experiencing symptoms of poor control.

Even though I have had diabetes for ten years, it is only in the last six months that I don't feel healthy. I used to take one pill in the morning and one in the evening and with that and my diet I could control my diabetes. So I used to consider myself healthy. Now my blood sugar has gone up to 24 and I don't see myself as being healthy. (6)

***

Like I told you earlier, a healthy person is one who is illness free. A person such as me who has heart trouble and diabetes would not be considered healthy. (8)

***

Who would consider themselves healthy despite having sugar. I don't consider myself healthy. When my sugar is out of control, then I don't think of myself as healthy. However, when I am controlled then I feel completely healthy. (3)

***

I would consider myself healthy. I get tired because of my age, but I can still do the things I like to do. I don't suffer any ill affects because of diabetes. (9)

Once again reference was made at several points by research participants regarding importance of
mental health in the overall diabetes control of the individual.

My sugar only goes high when I worry about things. (11)

***

People here are more worried as they have left their country, their houses and so on in India. Sometimes people here are not treated properly by their sons, daughters and daughter-in-laws. So when people worry they develop blood sugar because of it. (10)

***

When one is happy then blood pressure and blood sugar come down but when one is sad or depressed then they go up. Diabetes always increases when one dwells on things. (5)

Importance of Health

Generally, how one defines health can determine the level of importance or value one places on achieving health. What that means is that if one sees health as an absence of disease, that is only in terms of their diabetes, then they will be satisfied with their health status upon the disappearance of the symptoms or upon achievement of good blood sugar control. Those with a broader view of health will concentrate on other issues which can impact upon and can be affected by their health status.

Even though participants included diabetes in defining health in reference to themselves, they viewed health as being important not simply in terms of diabetes control. A great deal of value was placed by all research participants on the achievement or maintenance of health and well being

I think a majority of seniors are concerned about their health. Like all new immigrants they too are struggling to survive. It is not that they are disinterested in their health. Nearly everyone is interested in improving their health. There may be hardly 5% of the people who may think that when it is time to go (die) we will go so why worry about the disease. (4)

Being healthy was perceived as being necessary for enjoying life and as being synonymous with independence from others.
My health is very important to me because if I don't have my health, then I won't be able to get out of the house, won't be able to eat or drink and will become dependent on others. If I have my health I have everything, but if I don't have my health then I have nothing. I pray to God that whether you give me anything else or not, give me good health. I also pray to God and ask for my children's health. (2)

***

My health is important to me because if I have health then I can enjoy all things that the world has to offer like cars, house etc. However, if my health is poor then even if I have a million dollars, I can't enjoy it. The beauty of the world, what the world has to offer in terms of food is all useless to me. It is important for me to look after my health, as that is my biggest asset. I pray that as long as I am alive, I have my health and when I don't have my health then I leave this world. (5)

***

In Punjabi they say that money comes and goes but the most important thing for a person is health. The better my health, the more I can do. Also a healthy person is more physically appealing...When my health is down then neither I nor things around me appeal to me. (6)

***

Health is important to everyone. A person who is sick becomes dependent on others for care and is unable to look after oneself. A healthy person is independent. (8)

***

Health is the most important thing in an individual's life. A person who does not have good health, that person is of no use to anyone. That person cannot fulfil any purpose in life. It is important to remember that health is wealth. (9)

Diagnosis of Diabetes

Owing to the sample selection criteria, all participants had been diagnosed with diabetes for a minimum of five years. Eight of the eleven research participants had lived with diabetes for the last ten years. Despite this none of them had a good understanding of what factors lead to the development of diabetes. Instead, there were a number of misconceptions associated with why they had developed diabetes. Of note was that development of diabetes was ascribed to overindulgence in food and alcohol and to abstinence from activity, the reverse of which
participants had identified as being necessary for achievement or maintenance of health. This subsection can be seen to overlap with the knowledge section in Point B of the adapted COR Model.

I think I developed it (diabetes) because I used to sit around all the time eating ghee (clarified butter) and brown sugar mixed together, pinnis (round balls made with cooked flour, sugar, ghee and nuts) etc. My family both on my in-law's and parents' side fed me well and that led to my sugar going up. (11)

***

I think activity is a big factor. Look at the white Canadians they are very active, they run outdoors but you will never see our Indian people jogging at that age. In India people sweat and work hard physically, when they come here the sweat does not come out of their body and they develop these diseases. I was also very overweight which might have lead to my diabetes. (3)

***

I think I developed diabetes because I started drinking at a young age of fourteen. Drinking alcohol damaged my pancreas which lead to high sugar. (3)

***

It was in 1992 that I found out about my diabetes. Diabetes might have been around for another year previous to that. I developed diabetes because I did not watch my diet. I used to eat sweet things. I actually feel that I developed diabetes because in India we drink a lot of tea with sugar in it, on an average 10 to 15 cups a day. Thus, a lot of sugar goes into our body. Another thing is that in India we eat a lot of fried food, sweet food and all other foods we can lay our hands on and we do not do any exercise. (4)

***

I feel that our Punjabi diet which includes atta (flour) and dals (lentils) has a lot of sugar in it and that makes my blood sugar high. (7)

***

You must have heard the saying that one who eats too much sugar develops diabetes. I used to eat sweets and also drink a lot. I think I developed diabetes because of this. (9)

Support Available for Diabetes

When one thinks of the traditional Indo-Canadian family what comes to mind is the extended family. This conjures up images of members of different generations living
harmoniously under one roof. The living together of grandparents, parents and grand children would lead one to believe that there would be ample emotional, physical and financial support available to the elderly. However, living in an extended family does not automatically translate into support for the elderly and some experience loneliness and family tensions.

When one lives together as husband and wife, the couple's life is very rich. Rich not because they have wealth but because they have love and respect for each other. Husband and wife provide a lot of companionship to each other. My wife died recently and that increased my diabetes. I gradually came to the realization that my wife was not coming back and I would have to learn to cope. Now I don't have much to do, and I go out to meet people. (5)

***

Some of the elderly don't even have the support to walk a few steps outside of the home on their own. They might be scared of what their family might say to them. Probably they cannot and do not want to reveal the problems of their family to anyone. For example, even if I tell you my family problems what will you be able to do for me. That is why they probably think why bother. They have to live with the family as they have no other way. (3)

Occasionally breakdown in family relationships or loss of loved ones in the family leads to the elderly living on their own. These individuals experience loneliness, depression and lack of family support in their lives.

The elderly told me that as the son and daughter-in-law did not get along with them, they had parted ways with them and now the elderly lived alone. Consequently, they (the elderly) were not only burdened financially, but also were mentally stressed out as what they had thought about or envisioned had not turned out between them and their son. (4)

***

We had a dream of building our own house but that dream disappeared when our son died. Now we spend half our time here and half in India. However, we neither fit into the life here nor there. The wife tells me that each day is long and hard to pass time in. I try to keep busy with doing paath (prayers) everyday and going to the gurdwara (Sikh temple) etc. (1)

***

I wanted to and want to die many times as I often think what is the point of going on
living. I know that I would be missed by my grand children. My son's children love me but their mother does not want them to have anything to do with me. (11)

In addition, many Sikh elderly feel lonely in the larger Canadian community because of language barriers, cultural differences and so on.

This is like a golden prison. Here you don't even know your neighbour. In India if you are sitting in your verandah, lots of people will come and say hello to you. If I go into the neighbourhood I can talk comfortably with the neighbours for lengthy periods. The neighbours have time too. Here the problem is that one family may have time but the other family has no time. The life is very busy here. One does not have a lot of friends here. The society is such that there is not a lot of doing stuff together. (4)

When participants experienced problems related to diabetes control, they generally relied first on themselves (i.e., their existing knowledge and experiences) to try and rectify or improve the situation. However, when that was not possible, they turned to their family doctor and then to their family members for support. Limited support as necessary was also sought from members of their social network.

I try and control it myself first. If the situation gets to a stage where I am unable to do so then I go to the doctor. If it goes too high then I will go to the emergency department at the hospital. (5)

***

The doctor is the main person. However, I depend mostly on myself and my mind. I try and find the remedies by trying to figure out what caused the problem and what I should do to rectify the situation. Then I discuss it with my family members. I also ask people as it is only if you ask them that they can help you. (7)

Overall daily care for diabetes was the responsibility of the participants, that is the individual with diabetes. However, familial support was available to some in matters related to diet, emotional support and transportation to and from medical facilities. This support was greatly appreciated by the elderly and viewed as being vital to their health.

The family gives me tea without sugar and if I am accidentally given tea by someone that contains sugar then they (the family) take it away. (10)
I am the only one who can control my diet, eat my medication on time and do my activity. There is nothing more one can do. It can't be that the children take part of my food away from me to help me out. My sons they respect me a lot even now. The older son who sponsored us even though he does not live with us, will never put me off or say no to me. However, I do not put undue demands on my children. If I tell the kids I have to go some place at a certain time, whichever of them is home will drop me off. (3)

***

The family helps a lot. My daughter wrote out the diet for me. She really worries about me a lot. Sometimes she fights with me because I don't care for myself properly. She says to me "We don't want to lose you and you want to leave us and go far away." My wife also helps. For example, when she is not home, she hides the sweets she makes for company so I cannot get to them. It is because of her caring that I have been able to do okay so far. She makes me things that I can eat and drink for my diabetes. (3)

***

My family helps me a lot with my diabetes by making me special things that I want or need to eat for my diabetes. Even though they don't eat meat, they cook me meat. They don't give me too many sweets. (9)

However, one participant indicated that support was not equally and readily available from all family members as provision of support to the elderly could occasionally lead to tensions in the lives of their children.

My daughter helps. My son does not do much as this creates problems in the family. I too do not want that he suffer or that they have family problems because of me. (11)

Some people with diabetes tend to hide their illness and consequently this may limit the support offered or available to them. The sheer fact that participants had volunteered to be a part of the study and, by doing so openly declared their diagnosis of diabetes could lead one to assume that they would automatically be eliminated from the category of those who were secretive about their illness. However, as the following excerpt illustrates, this was not the case for all.

Why should I tell anyone that I have diabetes. They will tell me all kinds of things to help my diabetes and if I follow their advice I may become sick. I will only tell my doctor that I have this problem. I only tell my medical problem to people who are really close to me and care for me or my relatives. (11)
However, most participants were open about their illness and believed that by doing so they would be able to garner support to aid them with their diabetes control.

I don't mind if people find out about my diabetes. Why should I hide it. If I have this problem, then what can I do about it. I don't hide my illness, in fact I tell people that I have sugar so I can't eat this. (2)

***

I feel I should tell. Illness should never be hidden. I don't care what kind of illness it is, one should not keep it a secret. If one keeps it a secret then it is that person that stands to lose. (11)

***

It makes no difference to me if people find out about my illness. In fact, I tell people that I got diabetes so be careful so that you don't get it. One should tell others so that they don't develop it. (3)

***

If I was walking along the road and someone asked me if I have diabetes, I would not tell them. However, I do feel that if someone has a particular problem then others who can help should be told about the problem, as only then do you get information from people that can help you. (5)

***

No, I don't mind if people find out about my diabetes that is why I continued to talk when the lady came in to drop her clothes off. Any medical problem I have I don't mind if people find out. There is a saying in Punjabi that if one has a problem that person should stand on the roof top and yell out the problem so that anyone who listens can respond and give advice. My nature is such that I am an open book. (9)

Research participants were aware of others who would not be so open about their illness and hazarded guesses as to why this might be the case.

Our people hide their illness because they don't want to reveal their pain to anyone. Some people don't want others to know that they are ill. Thus, they hide their problems trying to pretend that there is nothing wrong with them and that they are healthy. (11)

***

Our seniors' group has about ten to fifteen members of which five have diabetes.
However, out of all these people I am the only one who volunteered my name for the study...My habit is such that if I am going somewhere, I ask people to make my tea without sugar. I am not ashamed of saying that I have diabetes. A number of people hide their medical condition. They try and prove to others that they are healthy and strong while they are internally disintegrating. They are embarrassed of their illness as they see it as making them weak and different. (5)

Even though participants had revealed their condition to their family and friends they stated they were not treated differently by them because of their illness.

No, they (friends/family) don't act differently towards me. I don't know much about the disease but I do not know that it is not infectious. It is not catchy like tuberculosis. Eating my germs would not make anyone sick. (2)

Interviews could only be conducted at times when participants were not in attendance at the temple, watching religious programs on television and/or doing private prayers at home. In varying degrees all who were interviewed relied on religion as a source of support in their day to day lives, including their care for diabetes. Praying and asking God for good health once again emphasizes the importance of health in lives of these elderly. Partial credit for possession of good health was given to God. Reliance on religion was not as a cure for diabetes but as an aid for control.

"Dawa le aur dua kar" (take your medication and pray). With prayers a cross becomes a thorn. I place a lot of faith in religion. Religion does not state that one should simply pray and not care for oneself. (1)

***

One has to have faith in God as without him we are nothing. Our scriptures tell us to remember God as it is he who gives us what we need. A person does not have much. He who believes in God has everything. It is all in God's hands and we are nothing in front of God. It is not that we should not make the effort. We should try our best and leave the result to God. For example, we should take medicine for our illness but it is God who will make things better. Our time of death is predetermined by God...but if we look after our health, our health will be good and we won't die sick in bed. (11)

***

Religion tells us to stay healthy, but I don't think it says anything specifically about
health. Religion mostly tells us to take God's name, to help us stay healthy but how can one trouble God all the time. God needs a rest too. (10)

***

Religion does not say that we should simply rely on God and not make an effort. God in fact says that if you don't put the morsel of food in your mouth, the morsel of food will not fly into your mouth. (3)

In addition, concepts of physical, mental and spiritual health and the inter-relationship between them were also mentioned and elaborated upon by the elderly in the following excerpts.

Regarding my health I am blessed by God. To tell you the truth, I am a very religious person. Religion gives me peace of mind. Prayers are such that they take your mind away from bad or evil things and direct you towards positive or good things. When we do "ardaas" (pray), we ask God for good health. However, even if good health is not granted one should still keep faith in God. (3)

***

When we pray for ten, twenty or thirty minutes, at that time we do not have anything else on our minds, we don't think badly about someone, we don't worry about anything and our will power increases. When we take God's name it is as though we are having a conversation with God. The daily prayers we do, are like making a request to God. One day God will listen to what we are saying. (4)

***

I pray daily that I may not get to the stage where I have to go to the hospital long term. It is not that today I feel sick so I should do ardaas (pray). While praying one asks for one's health and the health of the family. Praying also gives one peace of mind which can have a number of positive consequences...If we improve our self and we feel good and happy then we will develop less illness and disease. (5)

***

In Amritsar (in Punjab, India) there is a mental hospital where they use Sukhmani Sahib Paath (religious scriptures) tapes in treating patients. Experiments have been done in India where they have shown that playing the paath (prayer) tapes in Indian parks has lead to the flowers blooming well. It may be that these things only help psychologically. The scriptures say that all illnesses have one treatment or medicine and that is God's name. The religion believes that one should have faith in God. The religion tells us that we should make the effort, share our problems and our wealth and pray. (7)
Religion affects the mind and a lot of illnesses are deeply connected to the mind. In addition, religion prohibits people from using drugs and alcohol which in turn helps us stay healthy. I go to the temple because it brings me peace of mind and that helps my health. In the house of God we hear the preacher giving lecture on religious issues, and going to the temple gets us out and walking. All of this helps us. In addition if we get hungry we eat at the temple. So you see God has ensured that we would have food for soul and body at his house. There is no other religion in the world that does both. (8)

Although research participants were aware that efforts would still be required on their part to control their diabetes and that they could not rely on God exclusively, they were aware of others who did not think the same way they did.

Some say pray to God and that will control your sugar. (11)

***

A number of people feel that their sugar is adequately controlled through the exercising that they are doing and by taking God’s name. They say pray to God and God will take care of it. It is not God that is going to give us medication or test our sugar for us; that is dependent on us. (10)

Attitudes Related to Diabetes Education

As discussed earlier, self-evaluation, health beliefs and attitudes related to diabetes are some of many factors which can have an impact on attitudes related to participation in diabetes education. Prior education that individuals have received from their family, doctor and friends regarding their condition and their assessment of the adequacy of this information can also affect attitudes towards diabetes education. In addition, the anticipated recognition or feedback individuals would receive for participation from their support system, their valuing information provided by someone other than a doctor, their viewing participation in classes as fearful versus challenging, time available for attendance and their concerns related to confidentiality and anonymity were also seen as factors which could affect individual attitudes towards and consequently participation in diabetes education. Thus, these were explored in the study.
Satisfaction with Existing or Available Diabetes Information Sources

Only one participant interviewed relied on written materials as a source of information.

*I found out things about diabetes from the book written by Dr. Minhas. I am really happy that he wrote the book.* (7)

However, all other participants indicated that written education materials did not serve as their information source. This is noteworthy considering that with the exception of one research participant all others were able to read and write a language. The most frequently cited sources for provision of information related to diabetes by research participants were family doctors and informal diabetes networks.

Participants acknowledged that because of time limitations, the information obtained from the family doctors was of a general nature with emphasis on eating a low fat and low sugar diet, doing daily activity and prescribing medications.

*My doctor taught me how to test my sugar. He gave me information about my diabetes. I did not learn about diabetes from the books.* (10)

***

*I got some information from Chandigarh, India. The doctors gave me information about what I should eat. I did not read that much or do too much of what they asked me to do. I know what affects my diabetes as my father had diabetes.* (2)

***

*Here the only thing the doctors have told me is that you must take this medication and control your diet, which means that one must not eat sugar, sweet and fatty things. Other than that they have told me to walk regularly. Besides this I have not received a lot of information. When I went to a diabetes camp here, they gave me some literature but I did not read much of that.* (5)

As the above excerpts point out, participants were generally dissatisfied with the level of information they had obtained from their doctors and had a number of unanswered questions and unaddressed concerns.
My doctor does not explain in much detail what I need to do. (4)

***

The doctors are so busy they don't have much time to give information. Anytime you go to the doctor's office it is packed. The doctor spends a few minutes with you if you are lucky, writes the medication out for you and that is it. (5)

***

The doctors keep such information to themselves and don't share it with their patients. (7)

Dissatisfaction with the level of information provided by family doctors prompted the participants to seek information from their informal diabetes network, that is other individuals with diabetes. The individual experiences of participants living with this condition was also cited by participants as an information source in managing their condition.

The doctor tells me to keep control and not take foods with sugar and not eat mahaan dal (lentils). However, I talk to people more about this issue. (11)

***

The doctor basically tests my sugar and gives me medication and does not give any information. People tell me things and I also find out things through experience. (6)

***

Doctors don't have time to give you the information. They basically write down medications, check you and tell you about blood sugar levels. When friends meet as a group and chat, they discuss that I eat this or that. Generally, they also talk about traditional things that they take to control their diabetes. (7)

***

When one has an illness one likes to talk about it and find out from others what worked or did not work for them. When we get together then the topic of diabetes comes up and that increases my knowledge regarding diabetes. (8)

Once the scope of diabetes education was described to the research participants, most recognized the limitations of the information available to them through their informal networks.

The people I talk to only know about the true, tried and tested methods such as
However, one participant was satisfied with the level of information he had and was not interested in additional information or education related to the issue.

*My mind does not work in that direction (acquiring knowledge about diabetes). I know that I am able to control my sugar with the information I have, so I have no interest in learning more about it by going to anyone. I don't want to waste my two hours or anyone else's two hours. So far as diabetes is concerned, I don't think about it much. I have no interest in such information. Where my interest lies I want to learn new things and where I have no interest I don't want to learn new things.* (9)

For the most part not only were participants unaware of the existence of additional information sources other than their doctors or their informal diabetes networks, they also did not recognize the nature or utility of any additional information other than what they had received in helping them manage their condition.

*I have never tried to get more information than what I have. What kind of information are you talking about.* (10)

**Anticipated Recognition or Feedback for Participation**

The recognition or feedback one receives or anticipates to receive from their family, friends and family doctors as a result of participation in diabetes education may have the potential of affecting individual attitudes toward participation. This is validated by the fact that, as outlined earlier, in a number of cases familial support was a factor supporting participation of seniors in English classes.

For all participants, lack of support from friends was not viewed as a factor influencing their attitudes towards participation in diabetes education.

*Friends, dogs bark anyway and if they said anything negative, I will go anyway if I see it (the program) as beneficial.* (1)

***

*My friends would not say anything.* (5)
That would depend on the society of friends that one moves around in. If it is a good society then they will say it is good and that one should go and if it is not then they will say what is the point of going. Therefore, it depends on who I am talking to. Even after listening to them, I will still do what I want to. I will go for my own need or want. (7)

***

My friends would not say anything. Why should they be bothered with it. Plus, like I told you I don't worry about what people say and I don't usually talk to people about things that only concern me. (6)

Most participants believed that their family would be supportive of their attending diabetes education classes.

My family would support my attending the classes. They tell me that I should go for diabetes education. (4)

***

As far as the family is concerned I am totally free. Never has a child or grand child questioned me on why I want to go where. If they find out that I went for diabetes education, they will never say why did you go there. In fact they will say it was a good thing you went. (5)

***

We never interfere with where anyone wants to go in our family. I go where I want to go and my family goes where they want to go. (8)

Although not personally experienced, some participants did anticipate that other seniors in the community who may wish to participate in diabetes education may encounter lack of support from family members which could potentially affect their desire or decision to participate.

My family would support my going to the classes. They would be happy. Sometimes younger family members do not encourage the elderly to go to classes because they need them at home. However, that is bad. They should consider the health of the elderly and not simply think about what they can gain for them. They should think that if the person was not around, they would have to make do. It is only when the person is gone, that one recognizes the worth of the person. However, one should try to do what they can for the for the person while the person is alive. (3)

The respect and faith that these individuals have for doctors and the reasons behind this
came through very clearly in the interviews. As voiced by participants, the level of respect and reasons behind the awarding of respect were highly variable.

*The family doctor I have is a mind reader....Just as we cannot lie to our mother we cannot lie to our doctors.* (11)

***

*As long as I have been here, I have had the same family doctor. He is also a friend of mine. Just by talking to me, he (doctor) puts my worries and anxiety at ease.* (5)

***

*I feel that just as there is a God up there (heaven), the doctor is the God down here (earth).* (7)

***

*The doctor's word carries a lot of power. If the doctor says to a healthy person you are sick, the person will become sick. It is a well known fact that the medication the doctor prescribes is less effective than the lecture the doctor gives. If the doctor spends five minutes with the patient lecturing, the patient will recover faster.* (8)

***

*Indian people feel that doctors know everything and their knowledge is good. We don't have blind faith in the doctor such that if one doctor cannot help us we look for another. However, we trust the doctor a lot as we don't know much about illness and the human body. Plus, when we have an illness and the doctor is able to treat the illness then our faith also increases. Our people tend to believe in those who can provide treatment which results in positive outcome.* (9)

In addition, individuals have a certain amount of dependence on their doctors as they have limited knowledge or access to other resources to help with their diabetes management.

*The individual with diabetes has to go the doctor. For example, today if you had not called us or come to see us, how would we have known about the diabetes programs. All we can do in that situation is keep going to the doctor and telling him about our troubles in the hopes that he can help us.* (6)

The participants indicated that they saw their family doctor on a fairly regular basis for diabetes care. A large number primarily saw their doctor for having their blood sugar tested.
Some were aware that each time they saw their doctor, the doctor billed the medical system. The following excerpts from the interviews further reinforce the lack of encouragement by family doctors for their patients to do home blood glucose monitoring.

*I go almost weekly to the doctor for diabetes related reasons. Sometimes the doctor just asks me how I am feeling, at other times he may check my sugar or may check my sugar the following week.* (4)

***

*My blood is tested by my doctor when I go to see him. I don't go every week, sometimes I go after a month. I know that the doctor who checks me will also bill the government. My doctor has never strongly encouraged me to buy the machine.* (5)

***

*Over the years, I have kept seeing my doctor regularly. He used to check my blood pressure, blood sugar, etc. and send me to the lab occasionally and with all that I stayed pretty okay.* (3)

***

*I go to my doctor's office once a month for having my blood sugar tested. My doctor has not asked me to buy a machine. He said to me it is up to me, that if I want to I can go ahead and if I don't want that is okay too. He has never forced me to keep the machine at home.* (9)

A large number of individuals indicated that their doctor had not informed them of the existence of diabetes education programs or encouraged their participation in these programs. However, all felt that it should be the family doctor's responsibility to do so.

*The family doctors have a big responsibility in informing their patients about such programs for that is why they have studied and obtained degrees. As people stand to benefit from these programs all doctors should inform their patients and encourage them to attend, however, I wonder if even 5% of doctors tell their patients.* (3)

***

*If I am their (family doctor's) patient then they should be concerned about my health and tell me about things that could be of benefit to me. They should not keep such information from their patients. They should tell their patients that this information is important to you and if you don't follow through, it could be dangerous for you.* (2)
Some believed that their doctors would be supportive of their attending and did not perceive this as a significant factor in affecting their participation in diabetes education.

*My doctor would be supportive of my going.* (1)

***

*My doctor would have no problem with my going.* (8)

Others gave reasons which they perceived could explain the lack of encouragement by their doctor for their participation in education programs. A major reason was the doctors not viewing attendance in diabetes education programs as being necessary for their patients.

*I don't think he (doctor) felt it was necessary for me to go. Whenever I have had my sugar checked it has been only 1% higher than normal. So why should he want me to go.* (11)

***

*Once he (doctor) was mentioning that there were programs that were run for people with diabetes but since my sugar was controlled he said I may not need to go. Thus, I did not pay too much attention to this whole issue.* (5)

***

*Family doctors can play a strong role in encouraging their patients to attend. My family doctor would send me. He has not sent me because I have not reached the stage where my diabetes is bad. If I had asked her that I wanted to go she would have given me the referral.* (7)

Another reason for lack of physician encouragement for participation was personal financial interests on part of the doctors

*The doctor may be fearful that the number of visits to him may be reduced if patients have other sources that can address their concerns. For example, now that I have bought a machine, I go to him only once a month or less which affects his fees. However, the doctor should not think of his own pocket but should think of the patient's health.* (2)

***

*A family doctor who is greedy will say that one should not attend diabetes programs. However, a doctor who thinks about the patient will say that if the patient gets good information there, then the patient should go and get it.* (5)
My doctor would not tell me to go for diabetes education. Instead, the doctor would say to me I will give you medication, why do you have to go there. Not just my doctor but any doctor would do that. Sometimes one has to do things of benefit to oneself without the doctor's approval or knowledge. (6)

Valuing of Information Given by a Non-Doctor

While physicians are highly respected in India, this same respect may not be transferred to nurses and other health care professionals. Thus, individuals may be suspicious of or not value medical information given by one who is not a doctor. This may also affect their attitude toward participation in programs where teaching is primarily done by other health care professionals.

Since their arrival in Canada, some participants who had positive experiences with nurses and/or other allied health professionals subsequently altered their stereotypes towards the professional capabilities of these health professionals. However, among the research participants these individuals were in the minority.

I spent a week in the hospital and noticed that the doctors here are very good. They are good because they consult the nurses in decision making and don't make decisions unilaterally. If the suggestion of the nurse is good, it is incorporated by the doctor. In India first of all nurses don't give advice or make suggestions to the doctors. If they do then, the doctors get upset as they think am I the doctor or you. The doctors in India are not used to having their authority challenged. The Indian doctors who are trained here or come from India and re-train here, their thinking is different. I would trust a diabetes health professional as he/she is an expert in this area. The family doctor is a generalist and not a specialist. Other than 1 or 2% of seniors, most would feel the same as I do. (4)

One participant stated that a doctor would only send his/her patient to a health professional if they had faith in the knowledge provided by health care professionals.

If my doctor is sending me there (diabetes programs) then that means he has faith in what they tell me. So he will probably tell me to do what they tell me at the centre. (11)

However, contrary to the belief expressed by the above participant, other participants still tended to put their faith and trust in the doctor and stated they would choose his/her advise in the face of conflicting evidence provided by health professionals and doctors.
I would have to depend on my doctor as the family doctor is obliged to tell me the right thing. No family doctor tells you to do the wrong thing. The doctor does not lead you along the wrong path. So I would have to go along with the doctor. (5)

**Fear of Attending**

Learning experiences invoke fear in some while others view them as challenging. This was validated by the research participants who were either themselves fearful of attending and/or knew of others who felt the same way.

*I would be very worried as I don't know what they would ask in these programs.* (11)

***

They (elderly Sikhs with diabetes) are probably scared of what will happen to them there. (2)

***

*I think fear would play a big part in non-attendance for some. People have to be told that classes will be in Punjabi and they should come once and see what they think. They will likely not be scared after they have been once.* (3)

Some expressed excitement at the prospect of attending educational sessions.

*That (attending classes) is no problem for me as I have taken courses in the past and have also written examinations. Going to classes is a fun activity.* (7)

**Time Available for Attendance**

Some seniors have baby sitting responsibilities and/or spend time involved with religious activities while others have relatively few responsibilities around or outside the home. When participants were asked about their daily schedule, a large number indicated that they did have or could make time in their daily routine to avail themselves of educational opportunities.

*I spend five to six hours a day in prayers. I play for a couple of hours with my grandchild and then I spend time making dinner.* (3)

***

*I usually wake up in the morning and do my daily care activities. Then I generally stay*
home with my grand daughter. If the weather is good I usually put her in a stroller and take her with me to the gurdwara (temple). If I am going somewhere further or where it will take me longer, I drop her off with my relatives upstairs. I go daily to the temple. I go to the senior’s group once a week. (4)

***

I try and keep myself occupied. If I don't have a lot to do around the house, I go for a walk, go to someone’s house or just walk around admiring the flowers. (5)

***

I go for walks and go in and out of the house numerous times. I even nap in the afternoon for two hours. I get tired easily. I am not busy, instead I have trouble passing time. (6)

***

Attending the classes would help me pass time, however there are those who don't want to take any time out for themselves or others. (5)

Some indicated that making time for participation in diabetes education was not only possible but also necessary for their health.

We are at a stage in life where we have time to expend in obtaining knowledge. It is not that we are young and have to go to jobs. I don't have much responsibilities such as babysitting either, it is my wife who has some of that responsibility. I guess I am lucky. There are lots of seniors who are in the same situation as my wife as they have to live in a family. They should see it as their responsibility to help their children out but they should also recognize that they are responsible for their own health. They can tell their children that they need time to go to classes that will benefit them. They say work is worship. However, one can still make time to do things of benefit for one's health. (7)

***

Life is busier here, but people still have time. Here the jobs start and finish at a certain time but in India one is busy all the time as when outside work finishes house work starts. Here people have the basic amenities such as dishwashers, dryers etc. to help them out. Also in the villages people who own farms spend long hours on the farms. I can adjust my schedule and have time to attend classes as it is for my health. (8)

Of the participants interviewed there was only one who was working outside of the home. He identified lack of time along with questionable worth of the program as the main reasons for non-
participation.

*I have not attended because of lack of time and because I have not paid too much attention to the topic of diabetes education.* (9)

Participants acknowledged and accepted that non-attendance in diabetes education by other seniors may be partially attributable to work commitments.

*A working person has limited time. Some people may think what is the point of going there, how will I benefit from it. I have been working all this time and now I have to go and sit there.* (4)

***

*Maybe when people committed themselves to coming to class, they were not working and by the time they were called to attend they had found jobs and were working.* (8)

**Issues of Confidentiality/Anonymity**

Fear of having others find out about their condition was not a factor deterring the participation of research participants in diabetes education programs. Keeping in mind how participants were recruited in the research study this was to be expected. However, one research participant did indicate that some people may want to keep their illness a secret, therefore, choosing not to participate in diabetes education programs.

*My experience tells me that people don't go to diabetes education programs as they feel that the news will get around that they are sick as someone they see at the program, such as another program attendee or the health professional will tell others in the community. They are not aware that there are rules governing professional practice.* (5)

**Importance of Goals and Expectations that Participation will Meet Goals**

(Point C of the Adapted COR Model)

Clinical Practice Guidelines for Treatment of Diabetes advocate diabetes education for all individuals with diabetes. However, sometimes when people have lived and coped with an illness for years without education, they become complacent about obtaining education pertaining to the illness/condition. Thus, it was important to explore the opinions of potential participants in this
regard. Once the purpose of diabetes education was explained to research participants, they generally concurred with the view expressed by health professionals.

*I will acquire knowledge by attending. I will consider myself to be better off than others who have not attended as I will have information they do not have. I see these programs as being important and beneficial. I think that the programs are running for our benefit. If I am educated then I can come and directly question the doctor about the aspects of diabetes....This would save the doctor's time....One should get education whether or not they follow through with the information....Education can only benefit, it can't hurt me. Even healthy people should go to the programs so they don't develop diabetes and those whose diabetes is controlled should go so that their blood sugar remains controlled.* (4)

***

*Learning is not a burden for me, instead I consider it to be a gift. If I get an invitation to such a program I will definitely find time to go. I want to obtain such knowledge.* (7)

***

*I agree that people with diabetes should get education about their condition. Like I said before I have never talked at length about my diabetes with anyone. I don't even know what I should discuss with them, what to ask them or what I should know. I only know as much as I have told you. I ask my doctor medication prescriptions and to send me for blood test. I control my diet the best I can and go for walks, but other than that I don't do much for my diabetes or know much about my diabetes.* (6)

***

*It sounds like a very useful thing and it will help the government too. I feel my knowledge will increase in these programs. I will gain something by going not loose anything, I will gain a new experience which is important to do in life.* (8)

Others participants believed that they themselves may not benefit from education as they either had adequate knowledge or could acquire additional information through their informal networks. However, they believed that other seniors with diabetes would benefit from attendance in these programs.

*I have not paid too much attention towards these classes, as I have been getting information from people like my daughter who is a dietitian and the medical doctor who I see regularly and also because I have become accustomed to my routine. I take my medication, eat my diet and do some activity and reading and that is it. I am like a bull with a closed mind who is happy with his limited knowledge. I am happy to share what I*
know with people I know. However, I think people should attend such classes as they stand to benefit from them. (3)

***

I have not needed to go. I am satisfied with the information I have but, if you would like to give me more information then I would be pleased to listen to it and act upon it as long as what you tell me will be beneficial to me. However, people should definitely go, for if they get information and act on the information it could be of benefit to them. (5)

***

I have not considered it necessary for me. See when we go to temple or parties, we find people who have sugar problems and, we can discuss with them there such information as how do you control your sugar. We should go to such programs because if we have certain experiences related to diabetes, then we can share those with the other people there. However, I stay busy all day and there is no time to go. (9)

As alluded to by research participants, a reason for non-participation in diabetes education by others included not viewing self as sick.

My experience tells me that people who don't want to think of themselves as being sick are the ones who don't go to diabetes education programs. (5)

In addition, not recognizing diabetes education as being valuable and a belief that if diabetes was controlled then education was unnecessary was also mentioned.

People need to be convinced that the programs are good and should be attended. (7)

***

Maybe people think what am I going to gain from attending the program. They may think that what they learn from their doctor is adequate to control their disease. (9)

***

They probably think that the classes will not be useful to them. (8)

***

They may think that all they do is talk in these programs so why should they go. (4)
Some say pray to God, eat missi roti or ground methi seeds... Ask people about medications and they will tell you more than the doctor can. Some feel that if they can control their sugar why should they bother going to the programs. (11)

Finally, for some lack of concern for one's health may also contribute to non-participation.

Some people don't even worry about their diabetes. They say what is the big deal it is only sugar. They might think what is the point of going for education, how will I benefit from it. It depends on each individual's thinking. (4)

***

Despite having diabetes some people are too busy drinking and so on. They do not worry about their health and are not interested in obtaining knowledge to improve their health. There are all kinds of people in this world. There are people who are very sick and yet they would rather spend time playing cards all day rather than focusing on ways of trying to get better. (3)

**Life Transitions (Point D of the Adapted COR Model)**

Life transitions are seen as periods of learning in the lives of most people. However, perhaps transitions, readiness and willingness to learn are not quite enough. Perhaps there have to be specific life events called "marker events," "stressors" or "teachable moments" to trigger learning. In the context of diabetes these triggering events may be the diagnosis of diabetes, diagnosis of long-term complications of diabetes, a bad hypoglycemic episode related to diabetes, or when diabetes is no longer controlled through oral medications and a change over to insulin therapy is necessary. These triggering events may make the individual with diabetes recognize that his/her health will continue to deteriorate unless he or she learns new health habits. The time of diagnosis was identified as one of the major triggering events by research participants. They believed that participation in diabetes education to acquire knowledge, skills and information related to diabetes care would be very beneficial at the time of diagnosis.

Information is beneficial at any time but if I had received it six years ago it would have been better because the control I have now, I could have had then. (11)
I should have been given information when I developed diabetes and before my diabetes got bad. Maybe I would have never got to this stage. (6)

***

There is a saying that when one has a problem one tries all within their means and knowledge to get rid of that undesirable situation. So obtaining knowledge is good at any stage but if one gets it at the time of initial diagnosis then one can use the knowledge and do the right thing from the start. There is also a saying that "in life it is only implementation of knowledge and not simply having the knowledge that can make the difference between a smooth versus a stormy life." (7)

Generally, individuals are reactive in their approach to health. Therefore, it is possible that they may be reactive to health education as well. For example, the impetus to obtain diabetes education may arise only when signs and symptoms of uncontrolled diabetes are present, the blood sugar is high or complications related to diabetes develop. The following excerpts from the interviews provide support for this notion.

My sugar has gone up to 12 and my doctor told me that he could not give me any more medication and that I should go for walks to bring my sugar down. If the sugar does not come down I will have to go on injections. I would like to know what else I could do to bring my sugar down. (8)

***

Any information that will help me deal with my diabetes better will be helpful for me. Anything that will help me control my blood sugar and help it drop from 24 to 10 will be appreciated by me. (6)

In addition, certain cataclysmic life events create a desire for changing behaviour and/or learning.

When my wife died, I came to realize that my good life is tied in with my physical health, that is if my body is okay then I may be happy. So I have made positive changes in my life over the past two years. (5)

Only one participant believed in the value of diabetes education for prevention and he acknowledged that he may be one of the select few individuals who believe in prevention.

I think an individual should be taught about diabetes even before they develop the condition. I feel that even though I don't have a particular problem, knowing about it and taking the necessary precautions may save me from developing the problem. I don't
think the general public views this the same way. I think they feel that once they have the problem they will do something about it. For them the most suitable time for providing the education is as soon as they find out about the problem. There are even those who have the attitude that they will go for education only when the problem is bad. (4)

Topics for further knowledge/information as identified by participants were of a general and basic nature. This again validates the fact that despite a high self-assessment of their diabetes knowledge and skills, these individuals in reality had fairly limited knowledge and skills.

Information on how I can further control my blood sugar. I should seek this information before I develop problems related to my condition. (7)

***

When I developed the condition twenty years ago, I would have wanted to know about what things in my diet I should control. At present, I feel that whatever information there is one should try and obtain. For example, there are always new treatments coming up and one should know about them. (3)

***

The information that I would find useful now is one that helps me control my sugar better. I would also like to get information on why this condition develops and what I can do to make it better. We go to the temple as we learn new things which are good for our soul. Going to the program should be a learning experience too. (8)

Opportunities and Barriers (Point E of the Adapted COR Model)

Opportunities and barriers refer to factors that are external to the individual but which often play an important role in the individual's decision to participate in educational programs. Organizational factors explored with or identified by participants were costs related to attendance, location of classes, dependence for rides, timing of classes and language of instruction.

Cost of the Program

Some participants did not perceive a small cost associated with program attendance to be a deterrent and one actually believed that classes offered free of charge would not be valued by seniors. The reason he gave was:
All courses cost if you want to take them. Let us say someone gives us free medication and tells us it would be really beneficial for us. Just because it is free, people will accept the medication but they will not use it. Similarly, if the program is provided free of charge people will not attend as they will think it is not worthwhile. However, if they have to pay they will attend. (8)

Others did state that any cost associated with the program would be a deterrent.

Seniors cannot afford bus fare at times and don't go to seniors' group meetings that are far from their home. However, as far as going to the diabetes centre is concerned, I would go for my personal health and it would not be a problem to pay the bus fare...but it may be difficult to pay for the registration. (7)


Some may feel that they have to pay and this poses a special problem to seniors as a large number of them do not have financial independence. Financial problems are a big problem for people here. A large number of people are struggling to survive. (4)


I would not be able to go even if the cost is as low as $10 to $15. The work that I do at home is limited. My income is so limited that I basically make ends meet. (9)

Location of Classes

The issue of location was interpreted in two different ways by the research participants. Those who interpreted location as proximity to home were overwhelmingly in favour of having classes close to home. The reasons for this are probably tied in with problems of transportation to and from classes, as will be indicated later. Others interpreted location as having classes at the hospital site versus another location. With the exception of one research participant, location of the classes in the hospital was not a barrier. Most individuals were aware of teaching areas versus patient care areas in the hospital and viewed hospitals as institutions which could help individuals achieve or maintain health.

The classes would not be on a hospital ward. There would be a class room set aside for it. Even in India, student doctors attend classes in hospitals. (1)
It would make no difference to me if the classes were held in a hospital. I always pray to God that I don't end up in the hospital... I don't think along the lines that the hospital is only for sick people so I won't go there for education. Hospital is a place of God where sick people are made better, where an unhappy person is made happy so why should we feel bad about going there. We only go to the hospital to gain something. I am sure there are areas for education in the hospital. (5)

***

The hospital is not going to fall on top of us. It is no problem for us to go there. People who are ill go to the hospital and diabetes is an illness. (8)

Only one participant did not favour hospitals as the location for teaching and gave the following reason for this.

Education cannot occur in a hospital. Most people will go if they have to, but some may not go as they are afraid of the hospital. If they go and find out somebody died, then that will create a negative affect in their minds. The best locations for education such as this are community centres and neighbourhood houses. If the environment of the education is suitable then the education provided will be more affective. (4)

Dependence for Rides

Daily routines such as getting around a city, which are taken for granted by mainstream Canadians, were matters of increased concern for these elderly. For example, as a large number of seniors did not own cars or drive, and did not want to or were unable to use public transport, they had to rely on family members or friends to provide transportation to and from places. This can make it difficult for some to participate in educational activities. Transportation was perceived as a barrier by all of the female research participants.

It is hard to go. I can't go at night as my husband does not drive car at night. In addition, we have no children here who could take us to the program. If the hospital could make arrangements to take us there it would be a different thing. (10)

***

When I came to this country with my husband I travelled on buses. However, since his death I have not done so as I am scared I will get lost. Canada is a very scary place. My son told me that there are bad people here who don't care about the person's age and they will take you if they want to....I can only go if someone takes me. I don't drive and I
cannot walk far because of my knees. My daughter takes me around as my son can't as this creates problems in his family....I also wear this bracelet (medic alert) in case I get lost or fall somewhere then at least people will know of my condition. I always carry a card in my purse which has my name and address on it. (11)

***

I don't go on buses. If I have a friend I go with her. My son takes me around. I have never taken a bus. If the kids are home they drop me off. If they are gone to work that is a different thing. I use the handy dart occasionally. My big concern is getting there and back. If the programs are in the neighbourhood then one can say "Oh well let us go." However, if they are in Surrey, then someone like me would be discouraged as I don't even know what buses to take to Surrey. I would be circling the whole day trying to find the place. The children have to go to work and if they don't, then what will we eat. If you said that you would come and pick us up and drop us back, then we could attend the program easily. Most of the seniors here do not own cars nor drive them. Thus, it becomes hard. They don't know about the roads so how will they drive. The seniors may be afraid that if the classes are daily they may not have people to take them and bring them back from classes. (2)

The seniors were also aware of others who would be deterred by lack of transportation to and from diabetes education classes.

They may be dependent on others to bring them to and from the centre. Some cannot come and go on their own. Some are such that they won't even walk ten or twelve blocks on their own even though they have been in the country for fifteen to twenty years. (8)

The opinion of male participants was split. Some perceived transportation and/or the cost associated with it as a deterrent.

It is like a prison here. We can't get out and if we want to go somewhere, we have to go in cars. In India the distances to travel are a lot less and one can walk to places. If the place (diabetes centre) is far then it can be a problem for seniors. If they go on the bus it will cost them and as the distances are great they will not be able to walk. It would be better if classes were held close to where the people live. If not then maybe arrangements can be made by the centres such as partially covering the bus fare or even better providing transportation. (4)

Other male participants were either comfortable with using public transport or drove cars.

I drive my own car. (3)
I have no problem using public transport. As long as we know where the classes are and how to get there, it is no problem. (6)

Timing of Classes

For participants who were generally free from in-home or outside responsibilities, timing of classes was not an issue. They indicated that they would be able to attend daytime or evening classes.

Whether the classes were during the day or at night would make no difference to me. I have no other responsibilities. I am a free bird. (3)

***

As long as I know before hand then it does not matter to me if it is day or night. I can adjust my schedule to that. (7)

Others, however, preferred evening classes primarily because of home responsibilities such as babysitting grandchildren.

My son leaves in the morning and comes back at night. My daughter-in-law leaves at 10 am. Here (Canada) both husband and wife have to work. The old folks get left behind to look after the grandchildren and do cooking etc. The classes should be offered in the evenings after 5 pm as it would be difficult for someone like me to leave my husband alone with the grand children for the whole day. (2)

***

The evening is more appropriate as children of seniors go on jobs to make ends meet. If I wake up in the morning and say to the kids that I have to go and attend camp that day, they will have to make alternate arrangements to leave their child some place. This could create problems for both parties, namely my children and I. Also one has to consider finances. I usually look after my grand daughter and if my kids had to pay for babysitting, you can imagine how much they would have to spend. (4)

Language of Instruction

When travelling in a foreign country where English is not spoken by the majority, one becomes aware of the importance of having a common language of communication. Although more than one half of research participants read and wrote English, a larger number spoke none
or minimal English. Most speaking none or minimal English preferred Punjabi as the language of instruction.

*I would not go to diabetes classes in English as I would not understand what was being said or what was going on. I would like classes in Punjabi.* (11)

***

*The classes (diabetes education) should be in Punjabi so I can understand. If they are in English and I can't understand then there is no point in going. In Punjabi I will be able to understand that this is what I should or should not do.* (3)

***

*It would be better if they were in Punjabi as I don't understand English. If there is no Punjabi speaking person available at the classes, then one does not have to go. If we go and cannot understand anything, then it is not beneficial to us. However, if we go and come away with new information then it is good.* (8)

Those participants who spoke and understood English acknowledged that even for them Punjabi as the language of instruction would be a better choice and would particularly benefit those who did not speak or understand any or much English.

*It is very important that information be given in Punjabi. No matter how much English seniors know, there are certain terms that they cannot explain properly in English to health professionals. A number of things can come up that we may not be able to tell the doctor because of language problems. For example, if I walk 20 or 25 feet, and I have trouble breathing, if I want to explain that to an English doctor, then I may not find the right words to express it. In addition, as the Indian English accent is different than the Canadian accent, it makes it difficult to understand what is being said, thus, creating difficulty for some.* (4)

***

*If classes were in English I would understand, but some words are still hard to comprehend. Therefore, the message or education that one receives does not have the same impact. So if the diabetes classes are in Punjabi then it is better for us.* (8)

***

*I can understand both languages (English and Punjabi) so the language of instruction makes no difference to me. However, classes in English would stop some people from attending. If they start classes in Punjabi then it would be good for these people.* (3)
Some individuals with minimal English language skills were comfortable with attending diabetes classes in English and only partially understanding what was said and done in the classroom.

*Something is better than nothing. It does not matter if the teacher is English or Punjabi speaking...even if I understand 10-20% that is good enough for me. Even if I learn one thing that is okay.* (1)

***

*I can understand a little bit as I have been here (Canada) a little while. Even if I don't understand it all, I will be able to get at least something out of it. Sometimes they (educators) give handouts which I can bring home and have my children read to me.* (5)

**Information (Point F of the Adapted COR Model)**

Since diabetes education services are so widely available in Canada, it could be assumed that individuals would be made aware of the existence and purpose of these services through their doctor, health professionals family and/or friends. However, as the study found out this was not the case.

**Lack of Knowledge Regarding the Existence of the Programs**

A majority of participants had developed diabetes after their arrival in Canada and, thus, were unaware of the existence of diabetes education programs in India.

*In India what is lacking is that there is nothing at the government level or societal level that provides one with education.* (4)

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*I don't think such programs exist in India and even if they did I doubt if people would have time to go to them.* (6)

When research participants were asked to give their main reason for non-participation in diabetes education, a large majority indicated that it was the lack of knowledge regarding their existence.

*I did not know about the programs. If I had known about the programs then I would have gone. It is hard to get yourself excited about things which you don't know about.* (7)
I did not know about the programs. The way you have described the programs, I will be happy to attend such programs. I think that not only seniors but everybody after the age of forty should request a check up and education. Even little children can be given education about diabetes, as diabetes affects them too. I had only attended that one camp. The government does a lot of good things for people, but people don't find out about them and, therefore, they are not able to take advantage of them. (4)

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I did not know the programs were around. Had I known, I would have gone earlier, maybe my sugar would not have gone up as much. I have it under control now, but then I would have had it under control earlier. (11)

There was one participant who stated that he had heard of clinics through his relatives, but had not pursued the matter further.

There are a number of my relatives who have gone to Dr. Minhas' clinic. I think there are also other such clinics but I have not made a lot of enquiries into them because I am very busy on the Gurdwara (temple) side. (7)

Awareness of Program Purpose

Individuals with diabetes need to be aware of the purpose of diabetes education, so that they can assess its importance. However, the knowledge that a majority of research participants had regarding this topic was essentially non-existent and/or erroneous.

I have no idea about the purpose as I did not even know they were around. (11)

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The person who went to the program and gave me information about the program told me that they were for exercising. (2)

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I have never been to the clinic personally. Thus, I have to rely on what people tell me. They tell me that they get tested there. (7)

Two participants exhibited a fair amount of knowledge regarding the program's purpose.

They will probably teach me about diet and educate me on other precautions for diabetes. (4)
In these programs Canadian Diabetes Association or Medical Association people probably teach about what things are good and harmful and that you can control your sugar in this manner. These are probably the things they tell you about. They probably tell you that by eating a certain way and doing jogging etc. individuals can stay healthy. Doctors and dietitians probably give information about diabetes. (3)

Access to Diabetes Education

Once individuals became aware of the existence of diabetes education programs as a consequence of their participation in the research study, they were asked if they would know how to access such programs. A majority of responses obtained indicated that individuals would not know how to access the programs.

Had I even known about the existence of the programs, I would not have known how to access such programs and what they teach in these programs. (2)

Some indicated that if their family doctor was asked for a referral and he/she denied them the referral, then they would question him/her on his/her decision and if still unable to acquire a referral through the family doctor, they would try other ways of accessing education programs. However, these participants were aware that a vast majority of individuals with diabetes would not be so persistent.

The family doctor or other people with the same medical problem can be asked. Different societies such as the Canadian Diabetes Association can be contacted to see where information about diabetes can be obtained...However, as a large number of our people are illiterate, I doubt if they would know about these societies. (3)

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I would ask my doctor for a referral. I think he would give it to me and if he did not give it, I would go to the program anyway. I don't need a referral to all programs, do I? (8)

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I would ask my doctor to send me. He may say no once, but if he says no the second time, then I will approach the director of the diabetes program. If the doctor does not want to do something for your benefit, then you can approach the centre directly and ask them questions about how to access their program. I may consult other people about the issue that my doctor does not refer me so what should I do. That person if they know
what to do in that situation will tell me what to do. They may advise me to go to the diabetes centre and ask their opinion on this situation. However, I do know that many people would not do this. (4)

Potential Sources of Information Regarding Existence, Purpose and Access to Diabetes Education

Research participants indicated that they obtained information about educational opportunities through Sikh temples, seniors' groups, doctors' offices, word of mouth, health fairs (diabetes camps) and the media. They also elaborated on how these sources could be potentially useful in providing learners information about diabetes education opportunities.

Since Sikh temples play a predominant role in the lives of the elderly, they were mentioned by a large number of research participants as a source of information dissemination regarding educational opportunities. To advertise the program, participants suggested that the location of programs and services offered by the programs be included in community service announcements at the prayer hall, in program pamphlets which could be distributed at the temple and in a poster display placed in the eating hall.

Announcements in the temple will benefit people who go to the temple. In the temple notice boards can be placed advertising community events or activities which may benefit the community. Brochures can also be placed at these notice boards so that people can pick them up and read them. Brochures should be in both English and Punjabi. (4) A notice board should be placed in the langar hall (eating hall) where people line up to eat. Then when people come to the temple, they can read the information on the board. Once people get used to the temple as an information source, they may come to the temple specifically for the purpose of getting new information. Right now the temple is only a place of worship but then it can become both. However, the problem is that power and politics play a strong role in decision making at the temple. Thus, before doing that we would have to get the permission of the party elect. In addition, to advertise the program be prepared to speak on the temple stage. (7)

As a large number of research participants were also members of seniors' groups and gleaned a lot of information from their attendance at these groups, it was not surprising that they suggested the use of these groups as a source of dissemination of information about the programs.
However, to ensure participation in diabetes programs these individuals recommended that concrete measures for enrolling participants be employed at seniors' groups.

Come and talk at the seniors' groups and leave pamphlets there. There is also a senior women's group that you can talk to. You should not simply go to the groups, drop your pamphlets and leave, instead you should do what you did for your study. You should get people's names and numbers down so that they are committed to attending. Once you have the names and numbers, you can later call these people and book them for the classes. If the people are convinced by your talk then you will have no trouble booking them when you call them. However, some who commit initially may need more convincing later on when you call them. If you simply talk to the group and then leave, then no one will care afterwards. This way the program will be successful. Once the program gets going then it will spread through word of mouth. It is a matter of getting it going once and when people see the benefits from it they will tell others about it. (7)

Advertising the program through a mail out or as newspaper insert and the advantages of each were also discussed by the participants.

Do a mail out to all households giving information about the programs and encouraging people to attend. I feel the mail out system gives people a greater sense of anonymity. When the announcements go on radio and TV and people are encouraged to call in they feel that their identity would become apparent to all. Some people want to keep their disease anonymous. The brochures need to contain information that diabetes can kill and/or can severely damage your body such that you are neither dead or alive. It might be fear that gets people out to the program. The complication of diabetes definitely need to be emphasized. (9)

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In India what they do is they advertise...if one simply advertises in the paper, then no one reads that advertisement, but if the advertisement is placed as an insert in the paper then one gets curious about it and reads it. (5)

Personal contact such as directly meeting with or talking with potential program participants and their families or making the contact indirectly through community workers was seen as a way of not only providing information about the program, but also as a means of decreasing a barrier to participation, namely the fear of the unknown.

Now that I have met you personally I find it easier to talk to you. Our people are scared and health professionals such as yourself need to work with people and get them feeling comfortable. In addition, health professionals can work through neighbourhood houses
and community workers are great at convincing the public that they come in contact with. You (health professionals) should phone the person with diabetes and their family and tell them that a class on diabetes is going to be offered and they should attend. You as a professional are not the only ones who should be convincing the individual to control their diabetes and attend education classes; the convincing also has to come from the family. The friends should also be supportive.

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If they (individuals with diabetes who were registered for the program) don't show up for classes the first time, then maybe if you explain to them why they need to come, they may come the second time. You may want to seat them in the midst of their family members and explain to them and their family members the importance of diabetes education.

Family doctors and their offices were seen as playing an important role in providing information about the programs and in encouraging their patients to participate in diabetes education programs.

*Family doctors can also play a strong role in convincing these individuals to go.*

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Pamphlets can be left at the MDs' offices which tell about the purpose, time and location of the programs. In addition, MDs can encourage the clients to go. The doctor's word carries a lot of power.

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There should be a rule by which MDs should be obligated to send their patients with diabetes for education. If the MDs don't send these people then there should be a law that punishes them and if the patients don't go then there should be a law that punishes them. The problem right now is that a lot of people don't know about the program to be able to access it.

Media was also seen as a powerful information source for the general public including the potential research participants. Participants stated that targeting of Punjabi speaking individuals needed to occur through multi-cultural channels on TV or radio and through Indian newspapers.

*Talk about the program on the television or radio Rhim Jhim. People watch Sushma's program and listen to her programs so this information can be made available through the media. Tell the people where the programs are and how they can attend them. You can give your program's name and your contact number. Tell Sushma that you want to*
help the older people by making them aware of your program and she will likely assist you. The message should be delivered earlier in the program so that the older people can hear it before they go to sleep. (2)

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Even if I don't watch television, my kids do and they tell me about what is going on. Television is a very strong medium. Radio is the same but not a lot of people have Indian radio channels, as only those with a strong interest subscribe to the radio channels. However, both television and radio would be good advertising mediums. (4)

One participant advocated the use of mass education through diabetes camps to get general information regarding diabetes out to the public and also as a way of enlisting individuals for diabetes education.

There should be mass education. Camps should be organized and should be compulsory to all. After the age of forty everyone should be required to attend. Things such as blood sugar, blood pressure and cholesterol should be checked. It is important for people to have general knowledge about the disease such as how it develops, the affect it has, and the precautions one can take. Once one has got the basic education, then one can form smaller groups and become more specialized. (4)

Word of mouth was another source that was mentioned by some research participants.

It is my responsibility to inform all my relatives and friends about diabetes programs and their existence. However, it is only today that I myself have found out about them. I feel I should tell people just as you have told me. (5)

Chapter Four identified and described those factors that may have an impact on participation of elderly Sikh Indo-Canadians with diabetes in diabetes education programs. Data that emerged from interviews conducted with research participants was categorized according to the adapted COR Model under the different categories and sub-categories of the model.

Chapter Five discusses and interprets findings of the research study as presented in Chapter Four.
Chapter Five discusses and interprets the findings that are seen to influence participation of elderly Sikh Indo-Canadians with diabetes in diabetes education programs. The recurrent themes influencing participation that emerged from the analysis of the data were categorized using the adapted COR Model as the conceptual framework. The use of a predetermined framework in data analysis may have led to the exclusion of some relevant data and influenced the interpretation of the data, as the data were not coded, recoded and analyzed to allow for theory to emerge from the bottom up as described by Glaser & Strauss (1967). Informant data (explicit and implicit) obtained through interviews, findings of the needs assessment survey done by Bhagia & Bhagia (1995) and the literature review conducted on the topic of participation were used to develop each section in this chapter.

Introduction

NIDDM (Non-Insulin Dependent Diabetes Mellitus) represents a serious medical problem with implications for daily living, long term health risks and significant health care costs. Faced with a chronic illness such as diabetes, individuals have to make changes in their lives to deal with the illness. Despite feeling well on a day-to-day basis, they must assume an active role in the daily management of their health. In order to do this they must incorporate a significant amount of knowledge and skills to maintain health, avoid acute crisis and prevent or slow down the onset of long term complications. Thus, in addition to diet, activity and medication, patient education is now recognized as the fourth cornerstone of diabetes management. However, research on the effects of patient education has produced what appear to be mixed results ranging from positive
results to no effects (Pichert, 1990).

A team approach is the best method of helping people with diabetes acquire the knowledge and skills related to diabetes care (CDAB, 1992). To facilitate this there are more than 200 diabetes education centres in Canada that offer such an approach (Catellier et al., 1992). However, educational research in diabetes has shown that a relatively small number of individuals with diabetes participate in these diabetes education programs. These findings are substantiated by the Indo-Canadians diabetes needs assessment survey conducted in the Greater Vancouver area by Bhagia & Bhagia (1995) which found that only 32% of the one hundred and fifty participants interviewed had utilized diabetes resources. Thus, the care of Canadians continues to be variable with some receiving diabetes care from multi-disciplinary teams while others are not.

As different cultures have their own particular beliefs about health and illness, and with the changing face of Canadian society reflected by an increase in cultural diversity, there is an increasing awareness on the part of health care professionals to provide culturally-sensitive health care. Therefore, it becomes important to determine what these cultural beliefs are, what they may be based on and their potential hazards or benefits if any. However, culturally-sensitive health care does not mean a cataloguing of beliefs of people from different groups and simply basing provision of health care on these assumptions. Instead, beliefs of these individuals and methods that individuals use to cope with their illness must be understood and analyzed within the context of social, economic and political factors affecting their lives so that the phenomenon of participation can be understood. Not considering these influences can lead to blaming individuals for choices made which may be influenced by factors beyond their control.

Analysis of data presented in Chapter Four revealed several deterrents to participation in formalized diabetes education programs faced by elderly Sikh Indo-Canadians with NIDDM.
Deterrents identified by the research study are displayed in Figure 3 using the adapted COR Model as the conceptual framework. Although deterrents to participation are organized under distinct categories and sub-categories according to the model, there exists amongst them a considerable amount of overlap and interrelation. Several times this overlap made it very challenging to make a decision regarding which category and/or sub-category the data "best fitted" into. In addition, it is probable that the use of a predetermined framework and a search for the best fit of the data in a particular category or sub-category may have also impacted upon how the data was interpreted.

**Self-evaluation (Point A of the Adapted COR Model)**

Cross states that investigations of deterrents to participation need to begin with an examination of attitudes towards self (Cross, 1989). The study by Bhagia & Bhagia (1995) indicated that 19% of respondents had elementary education, 35% high school, 28% college or university education and 17% had never attended school. In the current study approximately 25% of participants had less than a Grade Five level of education, while most others had attained up to a Grade Ten level of education; only one of the eleven participants was illiterate. However, comments made by participants did point to a higher level of illiteracy in this population subgroup than evident in both of the above mentioned studies. The amount of formal schooling or previous educational attainment of an individual can affect his/her self-confidence regarding participation in formal education, as research has shown that individuals who are not self-confident in their abilities as learners are less likely to volunteer for, or participate in, learning activities which may pose a threat to their self-esteem (Cross, 1989). Therefore, carrying this notion further, it is probable that those individuals who have a low level of formal education may have decreased self-confidence as learners and, just as they are less likely to participate in
voluntary educational activities, they may not wish to participate in voluntary educational research, as both activities have the potential of presenting a threat to their self-esteem.

Since the presence of illiteracy and low levels of education in individuals of this age and cultural group appears significant, it is important to be aware of why this may be so. For some, besides a lack of interest in education and not enjoying school, their or their family's socio-economic status, and the social and political climates of their time were also responsible factors. For example, lack of schools in Indian villages under the British Raj, families not valuing education and, therefore, not providing encouragement and support to participate in educational activities, more emphasis on and valuing of paid work, and placing the meeting of basic living needs and welfare of the family before education ("we" versus the "I" society) were cited as contributory factors towards lack of or low levels of education. Although, in India in recent years the educational gap between genders is closing because of increasing educational opportunities available for women, the female participants of the research study had a lower education level than the male participants.

Having gone without participation in formal education and, despite that, having lived a fairly productive life, and/or having had poor experiences with educational institution in their youth, some adults may be reluctant to subject themselves to situations which may re-invoke negative feelings and fear. They may operate on the premise that if they did not need schooling to survive in life, why attend diabetes classes to cope with diabetes, especially if their sugar is controlled and, if in their opinion, they are receiving adequate information from their doctor and informal network in order to help manage their diabetes.

A fear of the unknown may also be linked with the individual's self-confidence as a learner. For example, fear of what would be asked of them, said or done to them at these education
sessions was a concern for some research participants. Even when attempts were made to recruit participants for this research study, this fear was expressed by a large number of individuals prior to them consenting to or declining participation. Personal rather than telephone contact, and personal knowledge of individuals or their family by the researcher aided in decreasing the fear level and increasing the comfort level of these individuals. This in turn made it easier to recruit participants for the research study. Similar issues could potentially impact upon participation in patient education programs.

Finally, previous research in adult education has shown that age is a powerful predictor of adult education. Besides attainment of low levels of formal education by the older generation, other factors that may have an impact on their low levels of participation in diabetes education may include their declining energy and mobility, and the belief that learning may not occur at their age. However, this does not necessarily mean that the elderly are not concerned about their diabetes or their health.

**Knowledge and Skills, Health Beliefs, Attitudes and Support Available Regarding Diabetes and Attitudes Towards Diabetes Education**  
**(Point B of the Adapted COR Model)**

It was hypothesized that the knowledge and skills, health beliefs and attitudes of research participants regarding diabetes and the support available to them related to their illness could potentially influence individual attitudes towards diabetes education. When these issues were explored through the research study some interesting findings emerged.

**Knowledge and Skills Regarding Diabetes**

The evidence of poor diabetes-related knowledge and skills exhibited by research participants was present in the study of Bhagia & Bhagia (1995). In the current research study, the interviews made it apparent that despite their high self-assessment, in actual fact participants
had limited knowledge and skills related to diabetes. For example, in this study none of the participants had a solid understanding of why diabetes develops. Although diet control was mentioned frequently by these elderly, they were unable to translate this into healthy food choices they should make. Most of the participants were unaware of the need for or methods to carry out some key skills of diabetes care such as home blood glucose monitoring, foot care and eye care. They were unaware of the proper treatment of hypoglycemia. Furthermore, although they were aware of optimal blood sugar levels, they continued to base the assessment of their blood glucose control on symptoms of hypo or hyperglycemia and laboratory testing of fasting or random blood glucose, but not on results of home blood glucose monitoring or HbA1c. Both methods of blood glucose assessment used by these elderly are unacceptable and unnecessary given today's available technology of home blood glucose testing. The purpose of some of their doctor visits was simply to have their blood glucose level checked, which is in itself a costly venture in the current environment of health care cost containment. Most had a limited understanding of the long term complications of diabetes and a number of misconceptions related to this topic, such as their belief that diabetes led to a "weakening" of the brain and disintegration of the bones.

A majority of research participants perceived their diabetes control as being adequate. This led them to be comfortable with their existing knowledge and skills regarding diabetes. It was only through their participation in this research study that participants became aware of their limited knowledge and skill related to diabetes. This complacency in research participants related to acquisition of diabetes education is supported by Greene & Kreuter (1991), who believe that "...a threshold level of education may be necessary for some action to occur" (p. 155). Thus, in these individuals and others like them, the desire to participate in diabetes education may not develop unless they could be: 1) made aware of the gap or discrepancy in their knowledge level
and the desired level of knowledge and skills; 2) shown why closing of this gap is necessary in order for them to better manage or continue to manage their diabetes; and 3) shown how their participation in diabetes education programs could help them close this gap.

With diabetes of their patients being adequately controlled, family doctors too may believe that through their brief and basic discussion of diabetes management, they have provided their patients with adequate knowledge to control their diabetes. They may not be aware that similar education was provided to patients with diabetes in the 1960s, when it was discovered that patients had inadequate knowledge and skills regarding their condition and this led to the development of diabetes education programs. As outlined earlier, results of this study clearly validate these earlier observations. However, family doctors may be unwilling to acknowledge and/or be unable to accurately assess this because of time limitations imposed by their busy practices. Thus, referrals to diabetes specialists and/or teaching programs are not forthcoming from family physicians which, thereby, contributes to non-participation of this client group in diabetes education programs.

**Health Beliefs Regarding Diabetes**

All research participants controlled their diabetes without insulin. Although a majority were not experiencing complications related to their diabetes control, they regarded diabetes as a serious illness. They believed that life-time control over elements such as diet, exercise and medication was needed to maintain or improve their diabetes and, ultimately their health status. Lack of attention to these elements was believed to have led to the development of their diabetes. Implementation of these elements was not viewed as interfering with their or their family's daily living. Most participants assessed their control as being good and believed that poor control could eventually lead to their requiring insulin, and/or would make them susceptible to the long
term complications of diabetes. Diabetes education as an aid to control was not mentioned by research participants in their health beliefs. This could be attributed to the nature of questions asked (i.e., questions pertained to diabetes related and not diabetes education related health beliefs), the participant's lack of knowledge regarding availability or purpose of diabetes education and the value placed by these individuals on diabetes education.

**Attitudes Regarding Diabetes**

Attitudes individuals hold are influenced by their beliefs. As such, beliefs that individuals have regarding diabetes and diabetes education can affect their outlook towards the illness and potentially influence their participation in diabetes education. Although most participants included a reference to diabetes in their definition of health, they did not define health simply in terms of their illness and the absence of signs and symptoms related to diabetes. Rather, they defined health in terms of general physical and mental well-being and the elements required to achieve or maintain that sense of well-being. These participants viewed health as being essential for personal independence and for enjoying all good things that the world had to offer. As such, they placed a great deal of emphasis on the achievement and maintenance of health. Despite having diabetes, most participants continued to view themselves as healthy unless they were experiencing the effects of poor diabetes control. It is probable that unless these individuals become or are made aware of the role of diabetes education in health maintenance, they may not view diabetes education as being necessary until they experience a decline in their health status.

**Support Available Regarding Diabetes**

Support available to the individual with diabetes can come from a number of different sources such as family, friends, health care professionals, family doctors and individual religious or spiritual beliefs. This support has the potential of affecting individual attitudes towards
A number of research participants lived as part of an extended family or in close proximity to their children. The family unit was a pervasive and an all-encompassing phenomenon in their lives. For example, upon arrival in Canada a number of elderly had attended English as a second language classes because they received support and encouragement from their family. In addition, health care practices of these elderly related to their diet, activity, mental health and visits to health care professionals were influenced by their family situation. In their research Bhagia & Bhagia (1995) found that 54% of respondents with diabetes received help from their family in managing their diabetes and 47% of families of individuals with diabetes were interested in diabetes education.

Filial piety in the Indo-Canadian culture demands that parents be taken care of by their son. This culture also mandates maintenance of the extended family unit despite increasing tensions and strains existing within members. Thus, extended families do not always translate into support for the elderly who live in those families. For the elderly this lack of support can manifest itself as the family verbally not supporting participation in diabetes education, not providing transportation to and from the program, not accompanying them to education programs where the workers are English speaking and/or not making time available for them to attend by freeing them of their home responsibilities. This may result in non-participation of these elderly as they may not wish to speak out in front of their family to assert their needs. Although all research participants believed that their families would support their attendance, they were aware of other elderly who may not receive similar support from their families.

Throughout their lives the elderly had been in a position where they have provided moral and financial support to their children. However, upon their arrival in Canada, the roles are
reversed and most elderly become dependent on their children. They often find it awkward if not outright impossible to seek financial assistance from their children. In India, there is a saying that "What is yours is also your children's but what is theirs only belongs to them." If the elderly live in an extended family where other family members are adequately employed, health care professionals can make an assumption and have the expectation that the elderly are in a position to obtain things required for diabetes management such as proper food, adequate medicine and test strips. However, due to a breakdown in family relationships or family tensions, this may not always be the case. The elderly would rather have health professionals think of them as non-compliant by not showing up for appointments or not following through with recommendations made by health professionals, than reveal problems that they face at home for fear of losing the family "izzat" (honor) or being humiliated in front of their children by having to ask them for money. Thus, lifestyle circumstances can be a deterrent to the participation of individuals with diabetes in education programs (Anderson, Blue & Lau, 1991).

There is a popular saying in Punjabi that, "All Jat Sikhs have a common grandmother." Sikhs form the second largest ethnic community in the Greater Vancouver area but, despite this, they are a closely-knit group. Thus, there is normally a common relative or friend one can find in a room full of strangers. This results from the Sikhs in Vancouver having come from a fairly small geographical area in India, namely Punjab. In addition, a large majority have come to Canada in the family class category of immigrants. As being ill is somehow viewed as being weak or different by some elderly, they may choose to deny their illness or keep it a secret, especially if it is controlled or not causing them any problems. They may even choose not to participate in diabetes education classes where they might encounter an acquaintance or a friend and, therefore, risk the "community" finding out about their illness. This need for anonymity can limit the
support available to the elderly for diabetes management from members of their social circle.

The holistic view of health to which elderly Indo-Canadians subscribe recognizes psychological and social dimensions of illness in addition to biological ones, while some health care practitioners who provide diabetes care have and continue to subscribe to the medical model view of health. An example of this is the difference in health beliefs of the elderly and health professionals regarding the use of traditional medicines. Traditional medicines are used as an adjunct to or replacement for prescription medicine by the elderly as they are viewed as being less expensive, more effective and as having fewer side-effects than prescribed medicines. Strategies of illness management such as the use of traditional medicine by patients may not conform to the expectations that health care professionals have of their patients. This may lead to the patients being labelled as non-compliant or not motivated by health professionals without them recognizing that non-compliance may be a function of the socio-economic factors surrounding the individual. In turn these elderly may view health care professionals as lacking sensitivity towards their health beliefs. This may result in the elderly viewing the health professionals as being non-supportive and non-understanding, thereby preventing the elderly from turning to health professionals for encouragement and support.

When faced with problems related to their condition, these elderly first relied on themselves to try and rectify the problem and only then turned to their family physician for support. Unawareness of the existence, purpose and utility of other diabetes resources besides their informal networks caused research participants to depend on their doctors to help them with their diabetes care. A majority of research participants had a tremendous amount of respect for their family doctors because of their belief in the physician's sound knowledge base and his/her ability to make them "feel" better. However, there were some seniors who were not satisfied with
Physician services as they often had to wait long hours at the physician's office, had limited time to discuss their problem and its solution with their physician and believed that, despite there being no language barrier, they were not understood by their physician (i.e., their health beliefs). For the most part participants believed that their physicians had their best interests at heart, and relied on their physicians for advising them of matters which could be of benefit for their health and their diabetes. This is fairly representative of how other Indo-Canadian seniors view their doctors.

Religion and praying for good health were viewed as providing solace to research participants. Volunteering their services in religious institutions contributed to the elderly's self-worth, helped them pass time, socialize and also enabled them to seek support from others similarly placed. Research participants had a tremendous amount of faith in their religion and in the ability of religion to assist in their diabetes care and general health. Although they did not believe that faith alone was adequate to deal with their illness, they were aware of others who relied heavily, and sometimes solely, on God. These latter individuals would likely channel their energies into devotion of God rather than participation in diabetes self-management or education in the hope that God would repay them for their efforts by endowing good health upon them.

**Attitudes Towards Diabetes Education**

Attitudes of participants towards diabetes education were seen to be affected by their level of satisfaction regarding the medical and diabetes care provided by family practitioners, their access to and utilization of informal networks to help aid in diabetes care and their valuing of information provided by "non-doctors". In addition, the attitude of general practitioners towards the services offered by allied health professionals and diabetes education programs can also influence a participant's attitude towards and participation in diabetes education.

The relationship that patients have with their doctors can influence their decision to attend
patient education programs. Many participants viewed their family doctor as a "mind-reader" and a "friend". Most participants had strong faith in the competence of their physician and they generally believed that the care they were receiving through their family doctor was adequate to help them control their diabetes. Thus, the likelihood of their attending diabetes education programs may be low. The results of this study are supported by that of Cosby & Houlden (1996), who found that in the Native community if a person felt physically well and did not think that they would develop complications of diabetes because of the care provided by their physician they would choose not to attend any form of diabetes education. A similar view was expressed in a study done with Chinese-American patients with diabetes who stated that as long as they saw a "good" doctor for their diabetes, they would stay healthy (Rankin & Huang, 1991).

Not only patients, but their physicians may also believe that they are providing adequate care, education and complication surveillance by regularly seeing patients in their office; thus, not feeling the need to refer these patients to diabetes education programs. Therefore, it is probable that if family doctors told these individuals that their diabetes was adequately controlled and they did not need to participate in diabetes education, then their faith in his/her decision, their inability to question his/her authority combined with their lack of knowledge of the program's existence and purpose may lead to their non-participation.

Besides relying on medical doctors for their medical care, the practice of utilizing informal networks as an information source is common practice in the villages of Punjab, India, where young and middle-aged individuals gather at a common meeting spot in their free time in order to discuss their health beliefs about different ailments and about how to remain healthy by exercising and eating healthy foods. This is an open forum for thought and opinion exchange without any formal curriculum or agenda. The forum is utilized because time and money are in short supply in
rural areas and also because there exists a strong belief in traditional remedies.

In their research study, Bhagia & Bhagia (1995) found that of the 40% of respondents who had knowledge about diabetes, 70% had been to diabetes education classes while the other 30% had obtained information from other sources such as doctors' offices, the media and friends. This reliance on informal networks for diabetes information was also validated by participants of this research study. Dissatisfied with diabetes related information provided by their doctors and not knowing what additional resources were available to them, research participants frequently turned to their informal networks to share or obtain diabetes information. Some participants were satisfied with the level of information they received through participation in these informal networks and did not desire additional information through participation in formal diabetes education programs. Others, through their participation in this research study, came to recognize the limited amount of information made available to them through these networks and, as a consequence, became interested in acquiring additional information through participation in diabetes education. It is important to note that informal networks of these participants did not make them aware of the existence and purpose of diabetes programs, which leaves one wondering if others in these informal networks had also not participated in diabetes programs and/or had not found them useful.

The interview excerpts made it apparent that research participants had a high level of respect for their doctors. Coming from a country where allied health professionals are not accorded the same level of respect as they are in the Western world, these individuals may transport similar attitudes to Canada. Lacking English language skills, these elderly gravitate towards Indo-Canadian enclaves where they may become immune to changes in the larger community and are often excluded from the discourse in society and to the dominant forms of
thought or ideologies that English-speaking people have regular access to through the media, billboard advertisements and so on. Dominant ideologies are reproduced through social interaction and individuals who are not included in the discourse of the dominant society do not have access to these mainstream forms of thought. One example of this would be valuing the knowledge and expertise of non-physicians (i.e., the allied health professionals) and not simply relying on medical doctors. Thus, although some have altered their perception of allied health professionals since their arrival in Canada, those individuals remain a small minority. Consequently, a large majority of individuals may choose to simply implement diabetes control strategies as recommended by their doctor and not participate in health education or patient education programs where teaching is done primarily by allied health professionals.

Since doctors are viewed as authority figures by these patients, they can be very influential in not only promoting participation in diabetes education, but also the valuing and utilization of allied health professionals in helping their patients manage their diabetes, and ultimately, their health. However, this is likely not what happens and the research participants are living proof of this. As identified by research participants, there were a number of reasons why this may be so.

Along with some research participants, some family doctors may not value the information provided by health professionals who are not doctors. Utilization of non-physician diabetes educators may be a bigger step for some physicians than they are willing to admit. This may be especially true of physicians who have been trained in India where allied health professionals are not as valued as in North America. According to Daneman (1994), in many centres throughout Canada and elsewhere, the physicians and diabetes care teams work in separate worlds and often appear to be in competition with the only loser in this process being the individual with diabetes. Thus, the way to promote enhanced care and education for the patient is by appreciating the
unique roles played by different members of the diabetes team. Being part of a team that promotes self-care is more satisfying than enduring sole responsibility for a patient's non-compliance (Connel, 1995).

Furthermore, despite the Clinical Practice Guidelines established by the CDAB (1992), family physicians "... have not bought into the notion that education is necessary in order for patients with diabetes to self-manage their condition and that all patients with diabetes should be referred to qualified diabetes health care teams" (CDAB, 1992, p. 793). There may be several reasons why this may be the case. Some physicians may believe that although DCCT (Diabetes Control and Complications Trial) proved that good glycemic control is important in lowering micro and macro vascular complications, it still did not prove that diabetes education is the key to good glycemic control. It may also be that physicians subscribe to the results presented by those research studies which indicate that diabetes education does not result in improvement of metabolic control. Finally, because of the adoption of the medical model in health care, patient education strategies with emphasis on life-style changes such as eating a healthy diet, exercising, doing home blood glucose monitoring and foot care are often considered simplistic by the physician community, thus, not commanding as much respect as should be due to them. The emphasis of many doctors is on altering medications rather than on promoting lifestyle change to improve glycemic control.

What is important to note is that research participants continued to believe that their doctor would be supportive of them attending diabetes education programs, even though despite them having had diabetes for a number of years, the doctor had not generated a referral to diabetes education or even informed them about the existence or purpose of these programs. It was interesting that participants did not view the above actions of their physician as lack of his/her
Importance of Goals and Expectation that Participation Will Meet Goals
(Point C of the COR MODEL)

India is a developing nation and lacks the resources to provide adequate medical care for
treating illnesses. Thus, health promotion, health education and patient education strategies are
minimal if not non-existent in India. Having lived a large part of their lives in that health care
environment and, because of language barriers and illiteracy, these elderly often do not participate
in dialogue surrounding these issues in Canadian society. Consequently, they often do not
become aware of the purpose of these strategies.

In order for individuals to participate in diabetes education programs there has to be a
belief that such participation is important and will meet their goals. Thus, opinions of potential
participants in this regard were explored since this could influence whether or not they would vote
with their feet. Results of the research study clearly demonstrated that a large number of
participants of the research study had none or erroneous information regarding the program
purpose. It was only once the program's purpose was explained to these individuals that most
recognized diabetes education as being potentially beneficial for them and stated they would be
happy to participate in a program to acquire knowledge and skills which could help them better
manage their diabetes.

Thus, in order to encourage participation of the potential client group in diabetes
education programs, they have to be made aware of the purpose of the program and how they will
personally benefit from attending these programs. For example, if despite having diabetes, the
person has felt well physically and has not developed long-term complications of diabetes, his/her
motivation to participate may be low. This individual may have to be informed about how
through participation in diabetes education programs, he/she can acquire tools to continue to
manage his/her condition and have an alternate resource to call upon in case of need. Individuals with diabetes would also have to be informed that participation in diabetes education is not a "quick fix" for their illness, as lifestyle or behavioral changes take a long time to make and require considerable effort on the part of the individual who is to make them. Furthermore, positive outcomes resulting from these changes are often invisible and may take a long time to materialize.

**Life Transitions (Point D of the Adapted COR Model)**

Life transitions and triggering events are seen as periods of learning in the lives of most people. Thus, if at the time of these trigger events an education program is offered the goals of which coincide with the goals of the individual, and there is an expectation on the part of the individual that through participation in the program the individual's goal may be realized, then the likelihood of participation increases. Participants identified that, in most cases, for individuals with diabetes this event would be the time of diagnosis of diabetes.

There are at least two reasons why the diagnosis period may be crucial for provision and acquisition of diabetes education. Firstly, as diabetes is a chronic intermittently active illness, if individuals have lived without diabetes education for a number of years and have managed to control their diabetes adequately with their existing knowledge and skills and/or are not suffering from the symptoms or consequences of poor control, it may be difficult to convince them of the value of diabetes education. Secondly, having sound diabetes education from the start may lead to a prevention or delay in the onset of acute or chronic complications of diabetes. Generally, as the family doctor is involved in diagnosing an individual with diabetes, he/she is in an ideal position to generate a referral for and encourage the participation of his/her patients' participation in these programs. However, as is evident from the participants of this research study, this is not what occurs.
Opportunities and Barriers (Point E of the adapted COR Model)

As outlined by Cross (1981), most efforts to attract learners to educational opportunities begin at the level of the organization (Point F of the adapted COR Model). Dulai (1996) makes this evident in his newspaper advertisement of a recently started diabetes education program in Vancouver:

Diabetes in the Indo-Canadian community is a growing concern. And to counter the ignorance and lack of interest in dealing with this subtle disease a number of organizations have sponsored the development of a centre that would serve Indo-Canadians in Punjabi. The joint community project was sponsored by Mount Saint Joseph Hospital, Vancouver Health Board, Physicians Interested in South Asia, and Canadian Diabetes Association.

The reasons for starting this program are the same as those expressed by the coordinators of the Punjabi Diabetes Education Program in Surrey. By establishing language-specific programs in a number of locations throughout the city, organizations hope to reach out to and increase the participation of those segments of the population that they believe have been under served by the existing mainstream programs. However, this step only addresses issues of language, availability and proximity and is only one of many steps needed to promote participation.

Organizational deterrents identified by research participants included finances, registration fees, language barriers, time available for and timing of classes, location and transportation problems, personal contact and appointment bookings.

A large number of the Indo-Canadian Sikh elderly have been circumstantially, yet voluntarily, transplanted to Canada which they call a "sweet prison." What this means in their case is that although there are excellent facilities here, they long to return to Punjab. However, they are unable to do so because of familial, financial or political reasons. In India, most of them
were landowners, had money and, as such, they commanded respect. However, their arrival in Canada altered this state of financial independence as: a) the money they had in India could not be transferred out of the country; b) the Indian Rupee is worth little in Canadian currency; c) they may be at a stage in life when they cannot be viably employed; and d) as family class immigrants they may be financially dependent for a period of time on those who sponsored them.

As indicated in Chapter One, 60-70% of the elderly clients of the Punjabi Diabetes Education Program belonged to a low or middle socio-economic group. A majority of participants of this research study, had found it necessary to seek employment upon their arrival in Canada and a large number lived alone or with families in small and often run down basement suites, which raises questions about their or their family's financial status. Canada's health care system removes substantial financial barriers to medical and hospital care and ensures comprehensiveness and universality. In theory, then, both the rich and the poor should have equal access to health care services. However, diabetes management, including aspects of home blood glucose monitoring, urine testing, medications and so on can be expensive for those elderly who are not covered by Pharmacare. Thus, although these individuals may be deeply concerned about their illness, the demands of trying to survive financially in a new country and the social and economic circumstances of their family or self in the family (also outlined earlier in Section B of the Adapted COR Model) are such that survival often takes precedence over illness management.

The same elderly who could not afford bus fare to attend seniors' group meetings were also the ones who stated that a small registration fee for attending programs would not serve as a deterrent. They felt that a program offered without registration costs may not be as valued by some and that a small cost may increase commitment and participation. However, it may turn out that if these individuals are actually asked to attend diabetes education and pay a registration fee,
the registration cost combined with transportation costs may present a significant challenge to them and may become a reason for their non-participation. Some participants clearly stated that because of their financial situation any kind of cost associated with the program would make it difficult for them to attend. Thus, for them the charging of even a nominal fee may be a deterrent, especially if participants perceive that they are successfully managing their condition without education and that the money may be better utilized elsewhere. Therefore, organizations offering services to this client group may need to consider fee waivers to promote participation.

As outlined in Chapter Two, 95% of the Sikh elderly who came to Canada were farm owners or land owners with little education and little knowledge of English. This was verified by the research participants, a large number of whom spoke no or minimal English and had limited understanding of the spoken English language. In this aspect, this group is fairly representative of their counterparts in the Indo-Canadian community at large. Language is seen as a formidable barrier preventing many elderly from learning about, accessing, seeking and receiving assistance from health care services. Owing to their lack of English skills, participants identified communication with medical specialists as a primary problem facing them. Faced with a situation that disadvantages them, people try to find creative ways of coping with it as did these elderly. Participants dealt with this issue by accessing services that were provided to them in Punjabi, by enrolling in English classes with the support and encouragement from their family members, or by trying to learn English on their own through reading the newspaper and watching television.

Only a small number of participants stated that they would feel comfortable attending diabetes programs where English was the language of instruction; most preferred diabetes education classes in Punjabi. As a majority of diabetes education services have thus far been English based, this may have been a deterrent to participation for some. As most health services
do not usually have interpreters available, they require that an English speaking family member or friend accompany the elderly to education programs. In some cases, family members or friends may themselves not be proficient in English, which may lead to a limited understanding of the program content, thereby resulting in low knowledge acquisition and dissatisfaction with the program. In addition, a family member or friend may him/herself be employed in a job where taking a day off results in loss of pay, further compounding the financial problem faced by these elderly or their families. Faced with such a situation and belonging to the "we" versus the "I" culture, these elderly may forego their participation in diabetes education.

The language barrier not only prevents individuals from accessing and utilizing health care services but also inhibits their participation in mainstream Canadian life. A majority of the elderly Sikh Indo-Canadians have had little or no formal education for reasons outlined earlier. Throughout their lives in India, and after their arrival in Canada, most elderly had been and/or became involved with unskilled labour or farming jobs. Owing to the nature of their jobs, lack of English language skills and illiteracy, they have none or limited knowledge about the social structure here and are not aware of doing volunteer work or participating on different boards etc. in the Canadian community at large. Despite being retired, these elderly are active at the family and community level as they do volunteer work such as shopping, babysitting and housework for families, friends and relatives in their own community. Thus, they are not "lazy" and "uncommitted" as thought of by some health care professionals. Some participants of this study believed that just as the elderly could make time available to do paid work, they could also make time available for participation in diabetes education, provided they valued and had an interest in diabetes education and could afford to attend.

Bhagia & Bhagia (1995), identified that while 45% of their respondents stated that any
day would be suitable for classes, 33% preferred weekends, 10% weekdays and the others were indifferent. Regarding the timing of classes 63% of their respondents said that any time was suitable, 10% preferred mornings, 10% evenings and 5% afternoons while 12% were unsure. In the current research study, the preferred timing of classes by the elderly was tied in with their and their family’s commitments. Participants who were free from home responsibilities stated that both daytime or evening classes would be suitable for them. However, those who had jobs or were not free during the daytime because of babysitting responsibilities preferred evening or weekend classes as their children were home then to free them of their responsibilities and, possibly, drive them to education classes. This would suggest that flexibility in scheduling of classes would be required such that a combination of evening, daytime, weekday and weekend classes were offered. As this flexibility does not exist currently in most diabetes programs, it may be a deterrent for some potential participants.

For most research participants, location interpreted as the place of offering education classes (i.e., the hospital versus the Sikh temple) was not a significant issue. This is validated by the results obtained by Bhagia & Bhagia (1995), who found that although 90% of their respondents wanted to learn about diabetes at the Temple, 66% stated they would attend classes at the hospital and 10% said they would go anywhere. However, language barriers, not having a means of transportation, not feeling comfortable using public transport and relying on family members or friends to take them to classes, makes it difficult for these elderly to attend classes which are at a great distance from their places of residence or are offered at times or days on which they do not have access to transportation. The proximity of location issue is addressed to a certain extent through increased attempts made by organizations to make more culturally relevant (or at least language specific) programs available throughout Greater Vancouver. A large number
of elderly did indicate that provision of transportation to and from education classes by the sponsoring organization would greatly facilitate their participation.

Research participants indicated that in order to increase participation in diabetes education programs, health professionals employed in diabetes programs would need to increase personal contacts either directly or indirectly with potential clients through speaking at gatherings such as at the temples and seniors' groups, becoming involved with diabetes camps and doing in-services for community workers who frequently work with the potential clients. These means of recruiting potential clients were seen as being more effective in increasing participation than patients initiating contact with program offerers. These results are contradictory to those presented by Glasgow et al. (1991) in their study. This validates the notion that what works in one culture may not necessarily work in another.

Patience, persistence and clarification of the purpose of this research study was required to encourage participation of individuals in this research. This is what may be needed with potential participants of diabetes programs. In addition, currently, if a patient does not show up for an appointment, organizations generally do not call these patients back or try and re-book them. However, keeping in mind the aforementioned deterrents to participation encountered by this cultural and age group, flexibility in re-booking policies may be required.

**Information (Point F of the adapted COR Model)**

Existence of health education or patient education programs is an important step towards the provision of these services. However, if the target audience is not aware of the existence and purpose of these education services and how to access them, then the acquisition of these services and their potential impact may be reduced.

The study by Bhagia & Bhagia (1995) showed that 54% of the individuals with diabetes
had not consulted a dietitian and 68% had never been to see a diabetes specialist as they lacked awareness of the availability of dietitians or diabetes specialists. Only 41% of the respondents had knowledge about diabetes education resources. However, when they found out about the availability of these classes, 99% of the respondents were interested in learning about their diabetes through participation in diabetes education classes.

Awareness of the existence of services is a key factor in service utilization. Lack of awareness of the existence of services was given as a main reason for non-participation by the elderly. Information about services available is not readily available to Punjabi speaking people, especially the elderly (Lynam, 1985). Carter and Peel (1976) state that the poor and the coloured are often unaware of the array of services available and when confronted by the imposing health care organization which is often staffed by professionals whose diagnoses and treatment procedures may be unfamiliar and threatening, they often withdraw and reduce contact with them. Other than their GP's office, there is no health and health care service that Indo-Canadian elderly can call for information. When a health care service is called the language that greets the elderly is English and, as such, they may not be able to find out how to access and use the service.

In Canada, the elderly make an average of 3.7 visits per year to a physician specifically for diabetes care and over 80% of this care is provided by the family physician (Sclater, 1995). Research participants saw their family doctor on a frequent basis for reasons such as having their blood sugar tested and assessed and to ask diet and other diabetes related questions. Participants indicated that their family doctor had neither encouraged them to purchase a meter to do home blood glucose monitoring nor had he/she made them aware of the existence and/or purpose of diabetes education programs. Some felt that a reason for this may be related to a perceived drop in the billings of family physician if the patients learned self-care. They recognized that this was
unethical on the part of the doctor, but, also acknowledged that doctors with a financial self-interest may compromise good patient care.

Research participants cited a number of ways in which information regarding the existence and purpose of diabetes education programs and ways of accessing these programs could be made available to others such as themselves. They indicated that diabetes education programs could be advertised through Sikh Temples, seniors' groups, doctors' offices, newspapers, television and radio shows and through diabetes health fairs.

Although the study did not seek to explore differences in or the degree of differences in deterrents facing men and women, some issues related to this did emerge through the course of the study. It appeared that elderly Indo-Canadian women were more hesitant than men to participate in research studies or diabetes education classes. This may be because deterrents to participation as outlined earlier, may be more intense or aggravated in these women. For example, women who participated in the research study had lower literacy levels, more home responsibilities, decreased exposure to "outside life" (both here and in India) and lead more sheltered lives as compared with their male counterparts. In addition, in the process of trying to recruit women for the research study, it was discovered that women who declined participation in the study did not value their life experiences and did not view what they had to offer as being of benefit to others. As one male participant stated:

*Women probably know less about diabetes programs than men do and it is probably very scary for them to attend. Thus, one needs to be persistent with the women. They should be told that if they were to develop the disease and if they ask someone like me for advice about what to eat for diabetes, if I am not educated then I may give them the wrong advice which if they follow can harm them. However, if they have education, and they listen to what I say, then they have the knowledge to judge if what I have said is right or wrong. Even if the husband has diabetes it is beneficial if his wife is educated about diabetes as then they can become aware of what the good and bad affects of diabetes are*
and can help the husband look after his diet and blood sugar control. Women who are afraid of attending need more encouragement to attend. They may not come once, but if you explain to them why they need to come then they will come the second time. You may want to sit down with the family and explain to them the importance of encouraging attendance. (4)

Chapter Five discussed and interpreted the major deterrents to participation in diabetes education programs facing elderly Sikh Indo-Canadians in diabetes educations programs that emerged from research findings as presented in Chapter Four. Based on the literature review presented in Chapter Two and an analysis of the findings of the current research study, minor modifications to the model as outlined in Figure III were suggested. In addition, while supporting some deterrents to participation as outlined in the literature review in Chapter Two, this study also identified other deterrents which were not included in previous participation research. Research participants, indirectly, also offered some ideas on how diabetes education could become a reality for a greater number of elderly members of the Sikh Indo-Canadian cultural group.

Chapter Six addresses conclusions drawn from the results of the study. It also discusses recommendations for relevant fields that flow from this study and concludes with suggestions for proposed future research.
Figure 3. Deterrents to Participation in Formalized Diabetes Education Based on the Adapted Chain of Response Model.
CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

Chapter Six addresses conclusions that can be drawn from the results of this study. Although the study could not confirm the interrelationships between variables of the adapted Chain of Response Model, the model did serve an important function, namely that of helping to identify deterrents to elderly Sikh Indo-Canadians with NIDDM participating in organized diabetes education programs. These conclusions were reviewed, verified and confirmed by the researcher with research participants by telephone. Minor modifications as suggested by participants are incorporated in the final conclusions presented below. Recommendations flowing from the findings of the research study for the provision of and participation in diabetes education programs by this population sub-group are discussed. This chapter also proposes suggestions for future research.

The goal of enabling as many individuals as possible to take part in organized diabetes education activities cannot be achieved without a better understanding of deterrents to participation and the development of practical strategies to combat these deterrents. The results of this study support results provided by previous studies on the topic of participation. That is, an individual's decision not to participate in organized adult education is because of the combined or synergistic effect of multiple deterrents rather than just one or two deterrents in isolation.

Conclusions

As a result of this study a number of deterrents to participation in diabetes education programs by the elderly Sikh Indo-Canadians can be identified. While some deterrents outlined in this research study are reminiscent of deterrents addressed in previous participation research, others are unique to this study. It is important to note that deterrents were identified or derived
based on opinions or thoughts expressed by "individuals" or "patients" who were the research participants and do not represent the views of physicians, family members or organizations who provide care to these individuals with diabetes.

Deterrents as identified in previous participation studies and supported by the results of the current research study were as follows:

♦ Decreased self-confidence as learners was associated with a low education level and a fear of the unknown. Lack of encouragement or support provided by family, friends and doctor may also indirectly contribute to a decreased self-confidence.

♦ Older age and a belief that knowledge may not be easily acquired or beneficial at this age.

♦ Questionable worth of the program was alluded to in several ways by research participants. For example, their high self-assessment of knowledge and skills related to diabetes, viewing their diabetes as being adequately controlled with their current knowledge and skills, their belief that they already knew what would be taught in the program and their perception that the program would not be relevant to their needs.

♦ Being on oral hypoglycemic treatment or diet alone versus being on insulin for diabetes control.

♦ Having their own ways of managing self-care utilizing informal networks, traditional medicine, family doctors and religion.

♦ Having a physician treating participants for their diabetes.

♦ Underestimation of the seriousness of NIDDM by family physicians and a belief that their patients were adequately treated in their offices.

♦ Financial reasons related to a low or no income level of participants, lack of financial support by the family, combined with anticipated program costs such as registration fees,
transportation costs, missed wages, and an expectation on the part of some health professionals that patients purchase aids for diabetes self-management such as blood glucose meters and strips.

✧ Time constraints because of doing volunteer or paid work, having home or family responsibilities and not being released by the family from home responsibilities (e.g. babysitting) in order to participate in diabetes education.

✧ Distance from the clinic and resulting transportation problems to and from the program.

Additional deterrents unique to this study and as discussed in Chapter Five included:

✧ Physicians believing that their patients already had adequate knowledge and skills to control their diabetes.

✧ Viewing of self as healthy and therefore not seeing the need for diabetes education.

✧ Family not encouraging or supporting participation by not accompanying the elderly to appointments where language barriers existed for the elderly and by not providing transportation to the program.

✧ A need to maintain anonymity and not have others find out about their illness.

✧ Perceived lack of cultural sensitivity of health professionals towards their health beliefs.

✧ Reliance on religion and God to help control or cure diabetes.

✧ Not valuing health related information given by non-doctors.

✧ Physicians not valuing diabetes education and not viewing it as being necessary for self-management by their patients.

✧ Physicians not valuing and utilizing the expertise of allied health professionals.

✧ Lack of encouragement from their family doctor to attend diabetes education programs.

✧ Being satisfied with the level of care provided by their family doctor.
Non-referral or non-participation in diabetes education at the time of diagnosis of diabetes.

Lacking awareness of the existence and purpose of diabetes education programs because of language barrier and a lack of information provision through their informal network and health care providers.

Lack of English language skills which prevented individuals from learning about, seeking, accessing and receiving relevant health care services, and led to decreased participation in mainstream life and non-subscription to dominant ideologies of health care.

Lack of direct or indirect personal contact by health professionals working in these programs with potential program participants; and

Current appointment booking policies and procedures of programs not being conducive to promoting participation of this age and cultural group.

Physicians believing that as a consequence of patients learning self-care, their billings would drop.

Gender issues, as most of the factors deterring participation were intensified in female participants.

**Recommendations of the Study**

Recommendations of this study for practice that is, provision of and participation in diabetes education, and for future research in participation in patient education programs are explored in the following sections.

**Recommendations for Practice**

If health professionals, physicians and organizations which provide care for elderly Sikh Indo-Canadians with NIDDM wish to help them improve or maintain their health status by increasing attendance of these individuals in diabetes education programs, they need to learn more
about factors that deter participation of these individuals in such programs. To operate on the assumption that deterrents to participation are cross-culturally homogenous may be misguided on the part of program planners. At the same time, focusing efforts on removing one deterrent at the expense of others may help some sub-populations while ignoring others. If, in the judgement of program planners or program offerers, the sample on which the current research study is based is similar to the adults to whom they wish to reach out and serve, then the results of this study may help identify specific strategies to overcome deterrents to participation experienced by their target population. Aside from strategies mentioned in Chapter Five, the following measures can also be taken by program planners and offerers.

For those elderly adults who are deterred by a lack of self-confidence in their abilities as learners and who may think that learning is not possible or useful at their age, use of promotional messages such as "You can do it! Have faith in yourself!" may be useful. Along with making learners aware that the program is non-competitive, emphasizing that failure in the program is not an option as it is an information provision/sharing program may also be beneficial (Valentine & Darkenwald, 1990). In addition, creation and development of educational opportunities such as educational videos with low levels of risks and threats attached would also be useful. These videos could provide basic diabetes education and present test questions followed by answers, which may help viewers assess their knowledge and understanding. Through this method, those individuals who have had unpleasant experiences in school may receive a boost to their self-confidence and may become more willing to venture out of their homes into the "higher threat learning situations" such as those presented by formalized diabetes education. Once these adults venture out to educational programs, care must be taken by education providers to create a learning situation that is non-competitive and non-threatening so that they may acquire new
perceptions regarding their learning abilities and the formalized learning environment. This can be accomplished by a modification in the attitude and technique of the educator.

To build positive attitudes towards diabetes education, public awareness campaigns such as diabetes camps or health fairs aimed at targeting the Sikh Indo-Canadian community can be conducted at Sikh temples and community centres. These efforts may also help potential participants and their family members with a language barrier and who do not prescribe to dominant ideologies in health care become more aware of: a) the existence and purpose of the diabetes program, b) the role and expertise of health care professionals, c) the importance of familial support in helping people with diabetes successfully manage their condition, d) the limited, albeit important, role that informal networks and religion plays in helping with diabetes self-manage their condition, and e) the complications and incidence of diabetes. Through these means, efforts can be made to convince individuals and their families that participation in diabetes education is good, and interested individuals can be recruited for participation in diabetes education programs that allow self-referrals. Individuals can also be encouraged to refer a family member or a friend to these programs. These means also serve as an excellent way of increasing personal contact (direct and indirect) with potential clients and thereby decreasing fear of the unknown.

There are some individuals who may believe that the program is not relevant for them. In their case this deterrent can be overcome by ascertaining what their learning interests are so that the program can address their relevant interests and in some cases provide potential participants with information about the program through awareness-oriented promotion. Brochures which clearly describe services and benefits offered by the program can be dropped off at neighbourhood houses, temples, seniors' groups and physicians' offices. Health care providers working in these
programs should become involved in doing public service announcements on local multicultural radio, television programs and in community papers. Program providers can contact multicultural media programmers and offer to do an interview. The Director of the program and diabetes educators can convince family physicians of the utility of program by speaking at meetings of Physician's with an Interest in South Asians (PISA), so that physicians can in turn convince their patients. Programs services can be explained to community health workers such as public health nurses and neighbourhood house multicultural workers so that they can also promote the program with potential clients and provide referrals. Finally, to interest potential participants and make them aware of their lack of knowledge, brief self-assessment quizzes can be delivered in written or verbal form through the media by program providers.

Research on life cycle and life changes has shown that at some periods in life (trigger events/teachable moments) the motivation for learning is exceptionally high. Although health professionals cannot do much about influencing transitions directly, they can be prepared to respond to the motivational changes generated by these events. For example, in the case of diabetes these trigger events occur at the time of diagnosis. Since it is family physicians who are usually involved in diagnosing diabetes, they should be encouraged to play a role in integrating the overall care of the individual with diabetes with a diabetes health care team consisting of a physician, diabetes nurse and dietitian (Daneman, 1994). Family physicians must learn to see themselves as one member of a team promoting knowledge and self-determination in the individuals with diabetes.

Several strategies can be employed by program providers to encourage referrals from family physicians. Program providers may consider offering patient education versus treatment programs for some patients in whom the GP insists on providing medical care without
intervention from a diabetes specialist. Reassurance should be provided to the effect that patients will always be returned to the medical care of their family doctor so as to allay any fears on the part of the general practitioners that they will lose patients as a consequence of the patient's participation in diabetes education. Regular consultations between program providers and family practitioners should occur concerning the patient's medical condition(s) and prescribed treatment. Written reports should be sent by program providers to family practitioners outlining the patient's existing knowledge and skills related to diabetes, the education provided and the self-management strategies recommended.

Time constraints and transportation difficulties are identified fairly frequently in studies on participation. To help overcome these deterrents and to make diabetes education more accessible to potential learners, organizations need to offer varied and flexible scheduling of education classes. Along with this, provision of opportunities for distance learning through the media and use of educational videos also need to be considered. Patients can be encouraged to car pool whenever possible. Organizations would further benefit from breaking away from the mode of thinking that programs should be offered only within their own physical setting and in a traditional classroom format. Health professionals employed by these organizations should be encouraged to get involved with organizing and offering diabetes camps, speaking at seniors' groups, Sikh temples and on multicultural radio and television shows. Additional options include offering of decentralized or satellite programs in other locations such as at neighbourhood houses, physicians' offices and community centres. These means should also be viewed as ways of providing education to this cultural group.

For those elderly deterred by cost factors, the waiving of registration fees, making programs available on days and times that the elderly or their family members are not working,
providing culture and language specific programs or interpretation facilities if the programs are offered in English are some options of cost saving measures for these individuals. Rather than focusing on how they can generate revenue through charging registration fees, these organizations and the health care system should consider the larger cost savings which can result through decreased hospitalizations related to diabetes if the patient is better self-managing his/her diabetes.

Deterrents to participation in diabetes education may be somewhat overcome by having an individual who speaks the language of the potential participant book program appointments. This individual could also politely, but firmly, explain the purpose and importance of the program to the potential participants, address their fears, answer their questions and generally encourage their participation in the education program. In addition, flexibility in re-booking of no-show appointments may be required such that if patients do not come for their first appointment, they are contacted and the reason for their non-attendance ascertained and addressed if possible. Finally, confirming appointments ahead of time was vital to doing interviews with research participants and would likely be required for potential program attenders. The rationale behind this is that because of long wait lists, appointments for potential participants are sometimes booked weeks or months ahead. Unlike Chron's or ulcerative colitis, diabetes is a silent illness and may not serve as a significant reminder to individuals for their education or follow-up appointments.

Several studies have shown that illness education programs must be culturally-relevant to the participants (Cosby & Houlden, 1996) and principles of multiculturalism are mentioned in the mission statements of most hospitals. However, this should not simply mean offering language specific programs. Instead, a culturally relevant program should meet the criteria for multicultural health education as defined by Thompson & MacDonald (1989). This should translate into the
program being responsive and relevant to the needs, values and beliefs of the clients and the culture it is attempting to serve. The program should also be implemented with active participation of its potential members, taking into account their definition of health. Frequently, organizations try to transpose the model of education that succeeded with one community on to another community and, then, are surprised when it does not work.

Health professionals need to become more culturally sensitive in planning and delivering patient education services. This can be achieved by including courses on multiculturalism as part of the regular curriculum for health professionals in colleges and universities. Cultural sensitivity or awareness can also be facilitated through conducting, publishing and reading of additional research studies such as this one, through health professionals receiving and obtaining on the job in-service training in multiculturalism and cross cultural communication by health care organizations inviting speakers to discuss the cultural definition of health, and the health beliefs, practises and concerns of the elderly Sikh Indo-Canadians with diabetes.

However, while it is important to recognize and address these deterrents to participation, it must be recognized that there will be some individuals for whom such efforts will not be effective. These individuals may choose not to participate because of the low personal priority of these programs to them. As Darkenwald & Valentine (1990) state:

In their zeal..., adult educators might persuade themselves that such individuals are suffering from misinformation about the importance of our enterprise. Such a paternalistic argument, however, would reveal at once a mistrust of the judgement of the adult population and a denial of individual's fundamental right of freedom of choice. Nothing short of engineering attitudes through manipulative promotion can reasonably induce...adults to participate in adult education; we should recognize this and leave them
alone." (p. 41)

**Recommendations for Future Research**

As indicated earlier, there is limited research available on participation and deterrents to participation in diabetes education programs. Thus, numerous implications for future research in this area exist, some of which are discussed below.

If one believes that adult education can be a way to personal advancement and increased social equity, then there is a need to study those adults who are not the "haves" of Canadian society (Valentine & Darkenwald, 1990). Research is needed to replicate this study with similar populations. In these studies it may be useful to use a Grounded Theory approach so as not to influence data collection and analysis with a predetermined conceptual framework. Studies are needed which not only obtain the perspective of the individual with diabetes about deterrents to participation, but also the perspectives of families, family physicians and health care organizations on this issue. This strategy will provide a well-rounded and comprehensive view of the phenomenon of deterrence. Finally, it would also be interesting to explore what the reasons for non-participation are for those individuals who, despite referral to a program by their family doctor, choose not to participate in diabetes education or who drop out without completing the programs.

Research can also be conducted to determine whether deterrents to participation as identified in this study exist in members of different age groups but belonging to the same cultural group. Research also needs to be conducted to determine whether there is a significant difference in issues of deterrents to participation facing males than those facing females of this cultural group. In addition, it would be interesting to explore similarities and differences in deterrent to participation faced by elderly Sikh Indo-Canadians with NIDDM and similar individuals belonging
to other dominant cultural groups in Greater Vancouver.

While American data on the number of individuals with diabetes who have participated in diabetes education programs is scarce, Canadian data addressing this issue is non-existent. As the Canadian health care system is based on universality of health care, it would be interesting to see how the two populations compare. In addition, studies on deterrents to participation that are available in the literature are American studies. Owing to cultural differences in the two countries, more Canadian studies are needed to understand and address deterrents to participation in the Canadian context.

It is not enough to say that diabetes education is a fourth cornerstone of diabetes management. As studies looking at the efficacy of diabetes education have been non-conclusive to date, diabetes programs and diabetes educators need to become more actively involved in conducting research studies to unequivocally establish the efficacy of diabetes education in improving glycemic control and the outcomes of diabetes. In addition, as health care resources become more scarce, these programs may have to produce such data to justify their existence.

**Summary**

In summary, this study led to the identification of deterrents to participation in diabetes education for this client population. These findings add to the results of previous studies on the topic of participation and offer practical strategies for increasing participation of non-participants in diabetes education. However, it is essential that research in this area continue to help make diabetes education a reality for a greater number of individuals with diabetes.

The results of the DCCT and the demonstrated relationship between improved blood sugar control and diabetes complication development in Type I and possibly in Type II diabetes should spur all professionals and organizations caring for persons with diabetes to re-evaluate the
type of care they provide, update their own knowledge base and facilitate patient access to
additional resources (Connel, 1995). Accessing the system is the first barrier to obtaining state of
the art diabetes health care. As such, physicians, along with every other health care provider,
have a role to play in ensuring that each and every person with diabetes gets a fair shake
(Daneman, 1994). In terms of patient satisfaction and the toll of long-term complications, the
"good enough" myth about adequacy of care does not hold up (Connel, 1995). Before offering
intensive diabetes care, efforts should be directed at meeting the basic care needs of all Canadians
with diabetes which include sound medical care, good diabetes education, complication
surveillance and ongoing follow-up through partnerships between patients, family physicians and
diabetes health care teams.
References


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Appendix A

CONSENT FORM FOR RESEARCH PARTICIPANTS

RESEARCH TITLE: Deterrents to participation in diabetes education: Perspectives of elderly Sikh Indo-Canadians

UBC FACULTY ADVISOR: Dr. Thomas J. Sork

UBC STUDENT: Rema Rajeeta Sanghera

I am a Master's student in Adult Education at the University of British Columbia. My Bachelor's degree was in Human Nutrition and Dietetics. Currently, I am also working part-time as a dietitian at BC Women's Hospital in Vancouver providing nutrition counselling for women with diabetes in pregnancy. I have been working in diabetes education for the past six years and during this time my interest in diabetes education has continued to increase. This increase in interest was the factor which led me to pursue my Master's degree. I am particularly interested in the education of patients and their families related to living with a chronic health problem such as diabetes.

I would like to request your participation in a research study which is aimed at identifying factors which are deterrents to the participation of elderly Sikh Indo-Canadians with non-insulin dependent diabetes mellitus in diabetes education programs. I am interested in finding out what information you have received about living with diabetes, changes you have made in your lifestyle because of the diagnosis of diabetes, your beliefs about health and diabetes, your perceptions of the value of diabetes education, and the support you receive in managing your diabetes.

An examination of the above issues will help health educators as follows:
1) Increase their understanding of the information and support needed by patients with diabetes and their families to help manage diabetes.
2) Suggest concrete ways of improving the effectiveness of diabetes education as it is currently offered.
3) Suggest new/innovative and cost effective ways of making diabetes education a reality for a larger number of individuals with diabetes.

You are asked to participate in an interview at a place and a time that would be mutually
पेन रा प्रिंसेस लैट प्लेसियन सली उन्नतपती ड्रामा

पेन रा प्रिंसेस:— ड्रेस ड्राम एवं एंटीक रिंग प्लेसियन सली संवाद देने वाले सातवानी धृष्टि बनते दिनसारा बनकर पावटीया ड्रामा।

पृथ्वी. विद्वान परामर्शक:— (Faculty Advisor) डॉ. प्ररम्भ ने संवाद
पृथ्वी. ली विद्वान परामर्शक:— डॉ. प्ररम्भ संबोध

में वित्तीय वेंबजीया दुर्गीधरिती दिवि अंबास विश्वविद्यालय (संस्था विद्वान) दिवि अंबास. ची विद्वान परामर्शक ते। घी.मे. ची विज्ञान विद्वान देने में वित्तीय देनल लाइफ संबोध अनुभव लाटे चेले मथ। अंत चलू मे ची.मे. विविध अंबास दे) वातवक दिवि बुवर ट्रेकर विम बनली तृं, तिचे मे मूल विविध ट्रेकर अंबास तृं वेंबजीया देनल लाध मथ-अंबास दिवि तृं। अंबी वित्तीय दिवि दिवि देनल ते वि मे संवाद देने दुर्गीधरिती प्रतिनिधि देने दुर्गीधरिती देश मे ची भरत बनव चेले वित्तीय ने नीमां तृं तिम देन बनवे सातवानी देश।

भेदी आप भुं दिम पेन दिवि दिवि लैट सली बेकरी ते वि उमी भृं दिम दों वि संवाद देनल तें नुमुने संवाद देने बिती बु सातवानी ते। अंबे दिम विद्वान बनवे उमी अपटे देंसल नीति दिवि विविध-विविध उपरान्ती दिवि देनल। दिम विद्वान बनवे सातवानी धृष्टि बनव बनवे री चित्र देन।

दिम पेन राज तुमा, उफित अअ डिफेंसियॉन (मुखप दे अवश्य) तृं बेंटव दिंटव तुलिया अनुभाव मारिज लिखेती:

* दिम उपन धृष्टि बेकरी मुख तद दिट्य मुकाबल देने वेंबजीया तृं धृष्टि मारिज-अंबास दे सहक।
* उपने दिंटव बेकरी तृं बुवर तद देनल बेकरी विद्वान विविध घट साधेती।
* संबोध देने एक भुवन साधे वेंबजीया तृं दिम देन बनवे दुर्गीधरिती सातवानी धृष्टि बोली न साधेती।

अप नी बेंट भेडी दिवि बेकरी ते वि उमी भृं अपटे तल भोक्ताबाद बनव दे में देन दिंटव। दिम नी बोक्ताबाद (दिंटवलिंटव) तृं बेकरी देने एक दे मारिज संबोध। दिम बोक्ताबाद तृं मे टेंट तीमलबाद बनव लाईवें, दिम दे दे बफल वाल; बिधे दिम बि ने मे अप दी बेकी नी बोक्ताबाद दिखण उं मारिज भुवन निचाना संबोध, दूसरा दिंटव बि ने मे दिखण उं अप दी बेकी नी बोक्ता दिंटव दिंटव दिंटव टोड ला साधेन।

उन्में मे मार तृं तल धृष्टि मारिज-अंबास दे में दिंटव देकी देन मे एक्स बु मारी अप भुं मारिज, उं बि मे अपटे पेन असे दिम दे लालिमा यरे उपने तल भोक्ताबाद बनव मारी।
Appendix C

SCRIPT FOR THE LEADERS TO MAKE INITIAL CONTACT WITH POTENTIAL RESEARCH PARTICIPANTS

I was approached by Rema Sanghera who is a Master's student in Adult Education at the University of British Columbia. While going to UBC Rema is also working part-time as a dietitian at BC Women's Hospital in Vancouver providing nutrition counselling for women with diabetes in pregnancy. Rema has worked with individuals who have diabetes for the past six years. Her work in diabetes got Rema very interested in the education of patients and their families related to living with a chronic health problem such as diabetes. In 1993 Rema was awarded a scholarship for her proposed research topic relating to the field of diabetes and adult education.

Rema has asked me to talk to this group (you) to see if anyone (you) would be interested in helping Rema out with her research. The aim of the research is to help identify factors which prevent the participation of elderly Sikh Indo-Canadians with diabetes in diabetes education programs. Rema is interested in finding out what information you have received about living with diabetes, changes you have made in your lifestyle because of the diagnosis of diabetes, your beliefs about health and diabetes, your perceptions of the value of diabetes education, and the support you receive in managing your diabetes. She will get this information from you by talking with you. The time that would be required from you for this research study would be two to three hours. This is a way for our community to get involved with the larger Canadian culture and an opportunity to have our voices heard. The findings of the research could help other individuals such as yourself who are living with diabetes.

Rema will really appreciate your participation in the research study. If you think you would be interested in being a part of this research study and/or would like to help Rema out with her research study, then please let me know. I can give her your name and telephone number. She will then call you and explain her research to you in greater detail.
SCRIPT FOR THE RESEARCHER TO OBTAIN VERBAL CONSENT FROM RESEARCH PARTICIPANTS

Hello, my name is Rema Sanghera. Your name was given to me by the co-ordinator of your senior's group Mr./Mrs. ____________. Thank you for your initial interest in my research study. I wanted to call you and explain in greater detail who I am and the purpose of my research study. I am a Master's student in Adult Education at the University of British Columbia. My Bachelor's degree was in Human Nutrition and Dietetics. Currently, I am also working part-time as a dietitian at BC Women's Hospital in Vancouver providing nutrition counselling for women with diabetes in pregnancy. I have been working in diabetes education for the past six years and during this time my interest in diabetes education has continued to increase. This increase in interest was the factor which led me to pursue my Master's degree.

I am particularly interested in the education of patients and their families related to living with a chronic health problem such as diabetes. I would like to request your participation in a research study which is aimed at identifying factors which are deterrents to the participation of elderly Sikh Indo-Canadians with non-insulin dependent diabetes mellitus in diabetes education programs. I am interested in finding out what information you have received about living with diabetes, changes you have made in your lifestyle because of the diagnosis of diabetes, your beliefs about health and diabetes, your perceptions of the value of diabetes education, and the support you receive in managing your diabetes.

The above information will help health educators such as myself increase our understanding of the information and support needed by patients with diabetes and their families to help manage diabetes. It may suggest concrete ways of improving the effectiveness of diabetes education as it is currently offered. Finally, it may help inform new/innovative and cost effective ways of making diabetes education a reality for a larger number of individuals with diabetes.

I am seeking to talk with individuals who are more than sixty years of age, who have had diabetes for a minimum of five years, and have not participated in any diabetes education program. If you meet the above criteria then I will be interested in meeting with you and having you be a part of my research. We will meet to talk at a place and a time that is mutually
Appendix E

THE INTERVIEW GUIDE

Section I - Demographic/ Background information

Gender and Birthdate

Tell me a little about your life in India. (Prompt: birth place, school, work, village/city life, family members, friends)

How long have you lived in Canada?

How is your life here similar or different as compared with your life in India? (Prompt: friends, things you do on a daily basis, freedom to go out)

Who else lives with you at home? (Prompt: spouse, extended family)

Section II - General information about health and diabetes

What does being healthy mean to you?

How important is health to you? and why?

Who in your opinion can help you become healthy or stay healthy?

When did you first find out that you had diabetes?

Why do you think you developed diabetes?

Despite having diabetes, do you view yourself as being healthy?

How is your diabetes currently being treated? (Prompt: diet alone, oral medication, insulin, traditional remedies).

Section III - Self-evaluation (Point A)

When you were in India, did you have the opportunity to go to school when you were younger?

What was your school experience like?

Have you attended any education classes or programs since your arrival in Canada? When? What
was your experience like?

A common Indian belief is that an old dog can't learn new tricks. What are your thoughts on this?

Do you read and write Punjabi?

Do you speak, read and write English?

If no, have you encountered any difficulties because of language barrier (Prompt: getting around, obtaining health care, knowing what is going on in the community)

**Section IV - Diabetes knowledge and skills**

How would you assess your knowledge and skills related to diabetes?

In your opinion what is the normal range of blood sugars?

Have you ever had a low blood sugar reaction? What were the symptoms you experienced? How did you treat the low blood sugar?

Do you do blood sugar testing at home? urine testing? What are your thoughts on this topic?

How often do you have your eyes checked? (not for vision but to detect changes in your eyes)

How often do you check or care for your feet?

**Section V - Health beliefs related to diabetes, attitudes about and support available for diabetes and diabetes education (Point B)**

Health beliefs about diabetes

**Perceived susceptibility**

How would you assess your diabetes control? How do you know that? Have you ever had your three month blood sugar level checked through your doctor?

What do you think are the effects of poorly controlled diabetes on an individual?

What do you think can help prevent complications related to diabetes?
**Perceived severity**

If someone said to you that as long as you are feeling all right (i.e., symptom free) you don't have to worry about diabetes, would you agree or disagree with the individual and why?

Do you think that people whose diabetes is controlled without insulin do not have to worry about getting long term complications of diabetes?

For you, is caring for your diabetes a short or a long term commitment?

**Perceived benefits**

Do you believe that you can control your diabetes?

What kind of benefits will result from changes in your lifestyle related to diabetes?

**Perceived barriers**

How does following the diabetes regimen affect or impact upon your daily activities?

**Attitudes about diabetes education**

Have you ever received any education related to diabetes? (Prompt: doctor, family, friends, alternate healers, hospital). Who do you think should be providing this diabetes education? (Prompt: doctors, diabetes nurses, dietitians, diabetes specialists)

How do you keep current in your knowledge and skills related to diabetes?

In Canada, diabetes programs have been set up for individuals with diabetes. Are you aware of the existence of these programs? If yes, who made you aware of this? *(Point F)*

What in your opinion is the purpose of these programs? *(Point F)*

Do you think such diabetes programs exist in India?

What recognition/reward/feedback would you receive for participation in diabetes education? (Prompt: from your family doctor, your family, your friends)

If a dietitian told you something about nutrition and your doctor told you something else, what
would you do?

Support for diabetes and diabetes education

How do you feel about people finding out that you have diabetes?

How do people react when they find out that you have diabetes?

If your diabetes gives you trouble who do you talk to about it?

Who encourages/helps you manage your diabetes? (Prompt in blood sugar testing, meal planning, taking medications)

Has your having diabetes affected your life and the life of your family? How?

Are you currently employed? If yes what do you do? If not, what is your source of income?

Does belief in God or religion aid in caring for your diabetes? If yes, how?

Section VI - Importance of goals and expectation that participation will meet goals

(Point C)

Can you describe a typical day in your life to me. There are many demands on your time in the course of a day. Would you be able to take some time out to participate in diabetes education?

Do you think you would find it beneficial to obtain diabetes education?

Section VII - Life transitions (Point D)

Is there any point since your diagnosis of diabetes that you feel you would have benefited most from participation in diabetes education?

What kind of information about diabetes would you like to gain at this point in your life? How would you like to get this information?
Section VIII - Opportunities and barriers to participation (Point E)

What are some barriers that you perceive in your attendance of the diabetes education programs? (Prompt: cost, questionable worth, fearful of attending classes, not valuing diabetes education, dependence on someone for rides, timing of the classes, language, location, time available, family, friends, not knowing about the programs)

What in your opinion are the reasons for low attendance by Punjabi seniors in a program that provides education in Punjabi, is scheduled during the day and is free of charge?

Do you see the hospital as a place for diabetes education?

Section IX - Learner information about educational opportunities (Point F)

If you were interested in attending the diabetes education programs, would you know how to access them?

Section X - Participation (Point G)

What is the most effective way you see of obtaining information or education about diabetes?

Is this a way that in your opinion can benefit other members in the community?