# Mount Saint Vincent University Department of Human Ecology

Diabetes Education for the Functionally Illiterate Adult Population
In Central Newfoundland Using a Client-Centered Approach

by

Heather Stevenson Alaverdy

A thesis submitted in partial
fulfilment of the requirements
for the degree of
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# Mount Saint Vincent University Department of Human Ecology

# Illiterate Adult Population in Central Newfoundland Using a Client-Centered Approach

by

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#### ABSTRACT

The traditional provision of health education has promoted an inequity in terms of the comprehension of information provided to members of the Canadian population. Illiteracy is far reaching in Canada and, thus, the provision of ineffective health education to the functionally illiterate population is a waste of valuable resources. Traditional diabetes education has been shown to be ineffective for the education of the functionally illiterate individual with diabetes as these programs are paternalistic and do not take into account the beliefs, knowledge and experiences of the individual. The evaluation of these programs typically involves a quantitative analysis of knowledge, compliance and biomedical indicators. To address the needs of the functionally illiterate population with diabetes, an education program was developed which utilized a client-centered approach and employed methods and materials appropriate for this population. Using convenience sampling and predominately qualitative evaluation methods (interviews and observations), eight functionally illiterate clients with diabetes participated in a four day education program and were assessed on knowledge, behaviour, skills, attitudes, beliefs and quality of life prior to intervention and two months after intervention. Analysis of the data indicated that clients were able to increase knowledge, improve skills and behaviour, improve quality of life and change attitudes and beliefs involving diabetes and education. The most striking findings were 1) an increase in client confidence in their abilities to learn and care for their diabetes, and 2) a shift in the balance of power and control from the educators to the clients. The short term results of this study support the use of clientcentered diabetes education. Conclusions of the long term results of such intervention cannot be made at present, however, the positive outcomes from this study suggest that further research in this area is warranted.

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#### 1.0. THE PROBLEM AND ITS SETTING

Canadians have the luxury of residing in a country which provides universal health care to its citizens and residents. Historically, the provision of health care to Canadian citizens was established as a constitutional right when the Canada Act of 1867 was legislated. (Mhatre and Deber, 1992). The governmental concern with universal health care has prompted such documents as the Medical Care Act, the Established Programs Financing Act and most recently, in 1984, the Canada Health Act (Chrichton, Hsu and Tsang, 1990). The latter act was developed to ensure that five principles; universality, comprehensiveness, portability, public administration and accessibility, were all aspects of the Canadian health care system.

With the historical establishment of numerous acute care health facilities across Canada, it would appear that the governmental interpretation of accessibility in the Canada Health Act originally was one of geographic and financial accessibility to illness care. However, with the recent stress on community-based health and prevention, this interpretation appears to be changing to one of accessibility to health as opposed to accessibility to health care. This change in interpretation, creates a situation in which factors affecting accessibility to the resources necessary for the achievement of health must be examined if all members of the Canadian population are to provided with equal access to health.

One of the factors that requires such examination is that of comprehension of health education programs. An examination of the written materials typically used in health education reveals that health education has traditionally been directed at the literate population. Such materials usually require a high level of literacy for comprehension as witnessed by Doak, Doak and Root (1985) who reviewed 291 health education materials typically used in health care and found that only 32% of the materials were able to be comprehended by the majority of the intended audience.

Directing health education at the functionally literate population is not an appropriate action when the high percentage of Canadians who possess limited reading skills is considered. Nationally it has been estimated that 38% of the Canadian population have some degree of difficulty in comprehending written material used in all facets of daily living (Statistics Canada, 1990). The statistics for Atlantic Canada are even more disturbing as it is estimated that 61% of Newfoundlanders have some degree of difficulty with the comprehension of written materials.

This problem has serious implications when the nature of traditional health care programs is reviewed. Traditional heath care programs are paternalistic, knowledge disseminating and rely heavily on written materials. Clients with limited reading skills may have difficulty comprehending and applying information provided in this manner. The result is that clients may be unable to make behavioural changes necessary to promote optimum health.

This scenario is evident in the field of diabetes education. Education programs have been one of the main mechanisms for providing information about the disease to promote lifestyle changes which will positively affect glycemic control for individuals with diabetes. The importance of such education has been confirmed by the recent Diabetes Complications and Control Trial. This trial overwhelmingly indicated that microvascular complications of diabetes in clients with insulin dependent diabetes are directly related to glycemic control, and that comprehensive diabetes education is necessary for the client with diabetes to manage the disease (Canadian Diabetes Association, 1993). However, traditional diabetes education programs have been shown to be ineffective as a means to adequately provide comprehensible education to the population with diabetes (McNeal, Salisbury, Baumgardner and Wheeler, 1984). This is not to imply that all individuals with diabetes are functionally illiterate, however, the high incidence of illiteracy in Canada gives rise to the idea that a large segment of

the population with diabetes is being provided with information in an inappropriate form.

If clients with limited reading abilities are unable to make necessary changes in diabetes care due to lack of comprehension and application of information provided, then the outcome will be ineffective education. Ineffective education programs waste resources and fail to deliver justifiable outcomes. These programs in turn result in an inequity within the health care system.

The need to address social inequities in the Canadian health care system is identified as one of the three key challenges in Achieving health for all: a framework for health promotion (Epp. 1986), which provides direction for the future of the health care system in Canada. Although Epp's primary emphasis concerns inequities in health between the low income population versus the high income population, a challenge to reduce all inequities affecting health is stressed. In reflecting on social inequities which affect access to health, it is important to discern between inequality and inequity. Rootman (1988) defines inequalities in health as "variations in health status among different groups in a given population" (p.2). Such inequalities may be of biological or social origin. If the inequalities are a function of the lack of optimum social conditions or resources necessary to achieve desired health status, they may be referred to as inequities. It could be argued that inequalities in health status associated with literacy levels are also inequities. Traditional diabetes education programs which do not provide information which can be understood by the functionally illiterate population may contribute to the perpetuation of such inequities. If information is not accessible in terms of a comprehensible format to all people with diabetes, an inequity exists in which clients with low literacy skills are being unfairly discriminated against in the provision of health education.

Developing programs for the low literate population, which effectively provide

education to assist people with diabetes in making lifestyle changes, is one means of addressing the challenge to reduce inequities in the health of Canadians. Providing comprehensible information about diabetes care in a meaningful way to individuals who are functionally illiterate may promote lifestyle changes which will help improve glycemic control and reduce long term complications of diabetes, thus, promoting an improved quality of life. Considering that over one million Canadians have diabetes, the potential impact of poorly controlled diabetes on the health of our nation is enormous.

The program developed for this research was designed to allow individuals who are functionally illiterate access to comprehensible information which could be applied to make lifestyle changes affecting the management of their diabetes. The program was developed using concepts and theories which were directed at, or were adapted for, the functionally illiterate population. This study evaluated an alternative education program for the functionally illiterate adult population with diabetes. This education model could be adopted to reduce inequities in access to health information in Canada.

#### 1.1 Purpose of the Study

The purpose of this study was to assess the effectiveness of a client-centered diabetes education program utilizing problem-solving, activities and materials which were designed for the education of the functionally illiterate adult population in Central Newfoundland.

#### 1.2. The Hypothesis

A diabetes education program utilizing a client-centered approach will be an effective means of improving comprehension of diabetes education among the

functionally illiterate adult population in Central Newfoundland.

#### 1.2.1. The Subhypotheses

an increase in client knowledge of diabetes. This knowledge could include topics such as; the etiology of diabetes, the symptoms of diabetes, an

A diabetes education program utilizing a client-centered approach will result in:

- explanation of diabetes, the functioning of the digestive system, the different aspects of the diabetic meal plan, the role of exercise, the treatment of
- hypoglycemia and hyperglycemia, medications, and diabetic regime
- adjustments for illness and travel;

1)

- an increase in client development of skills utilized in diabetes care. This increase could include skill development in areas such as; blood glucose monitoring, the purchase and preparation of food, and problem-solving;
- a positive change in client attitudes and beliefs involving diabetes and diabetes education. This change could include; a more positive outlook on diabetes and its treatment, an increase in perceived client responsibility in the treatment of diabetes, an increase in perceived client responsibility and confidence in the decision-making process relating to diabetes care, and a positive change in perceived client ability to learn about diabetes;
- 4) an improvement in client quality of life. The improved quality of life could include; a decrease in the stress involved in diabetes care, an increase in client satisfaction with aspects of diabetes care, and an increase in happiness and contentedness regarding aspects of diabetes care; and
- 5) an improvement in behaviour and lifestyle habits which relate to diabetes care. This improvement could include aspects such as exercise and eating habits.

#### 1.3. The Delimitations

This study did not assess the effectiveness of the program and materials for the literate adult population nor were the results generalized to this population. However, this does not imply that this program or materials would not be appropriate for the functionally literate population.

This study also did not assess glycemic control for the following reasons:

- The evaluation of this program was of limited duration, thus, results of glycemic control measures would be of limited validity in predicting a reduction in long term complications associated with diabetes;
- 2) Intervening variables, such as medication and weight changes, could potentially affect glycemic control;
- 3) Clients in this study were followed for a minimum of four months prior to study intervention and appropriate glycemic control was already established.

#### 1.4 Definition of Terms

<u>Diabetes Education Program</u>: A diabetes education program is a learning experience facilitated by health care professionals for the purpose of providing education for clients with diabetes to assist them in making decisions about diabetes care.

<u>Progressive Adult Education</u>: Progressive adult education is a method of teaching which involves the learner in the planning, delivery and evaluation of the education program. This approach utilizes the experiences of the learner and involves problem-solving and practical application of the education material and information (Zinn, 1990).

<u>Functionally Illiterate Population</u>: The functionally illiterate population refers to the group of individuals who are not able to comprehend written materials used in the activities of daily living due to limited reading ability (Doak et al., 1985). Using this

definition, the functionally illiterate population includes Levels One, Two and Three in Statistics Canada's <u>Survey of literacy skills used in daily activities</u> (1990). <u>Reading Ability</u>: Reading ability is the ability to comprehend written material (Doak et al., 1985)

<u>Glycemic Control</u>: Glycemic control refers to the evaluation of blood glucose levels in individuals with diabetes.

#### 1.5. Assumptions

The assumptions were:

- the diabetes education program typically used in hospital clinics is not appropriate for the functionally illiterate adult population;
- the diabetes education program developed for this study was a client-centered education program;
- 3) the education materials developed for this study were appropriate for the functionally illiterate adult population in Central Newfoundland;
- 4) the method of assessing the program's effectiveness was a comprehensive evaluation of the program consistent with the philosophy of client-centered education; and
- 5) the results of this study are applicable to the functionally illiterate Canadian adult population.

#### 2.0. REVIEW OF THE RELATED LITERATURE

#### 2.1. Illiteracy and Health Education

The complex and technological based environment of the 1990's poses many challenges for the individual who is functionally illiterate. A functionally illiterate individual is defined as a person who lacks the basic skills necessary to cope with requirements of adult life (Doak et al., 1985). This inability to cope comprises many aspects of life. For example, the person who is functionally illiterate is the individual who cannot order from a menu in a restaurant. The person who is functionally illiterate is the woman described by Kozol (1985) who bought a large container of Crisco shortening thinking that she was buying the chicken on the label and then did not have any money left to buy food for her children. The person who is functionally illiterate is the person who takes the wrong medication because of an inability to read the writing on the bottle. While these examples of functional illiteracy are obvious, the presentation can also be very subtle. We do not perceive the client who can read the words in a meal plan out loud to the dietitian as being functionally illiterate. In reality, some of these clients are functionally illiterate because they do not comprehend what is being read. Reading is a complex task and not just the ability to perform. As stated in Ontario Public Health Association and Frontier College's (1989) Literacy and health project, "Literacy involves more than simple reading skills (or decoding of words). It involves skills of comprehension, understanding and verbal reasoning ability" (p. 19).

Comprehension is essential to education. Davis, Crouch, Wills, Miller and Abdehou (1990) comment that "of all the literacy skills needed in health care, reading comprehension is the most important" (p. 533). If clients cannot understand the information being presented to them, it will seriously impair their ability to make changes in their health care.

One of the main difficulties in providing effective health education for the person who is functionally illiterate is identifying the individual (Loughrey, 1983).

Traditionally, the person who is functionally illiterate has been depicted as someone with little schooling. This scenario is not always accurate. A study by Belton (1991) indicated that the reading levels of patients in hospital did not correspond with the levels of schooling reported. Thirty-eight percent of the participants in the study tested at a grade eight reading level or less, but only 8% of the participants claimed to have a grade eight or less education. This observation was supported by Davis et al. (1990) in a study in which 60% of the participants were reading three grade levels below the level of schooling reported. In the same study, 31% of high school graduates were reading between a grade two and grade four level. Thus, identifying the person with limited reading skills is not an easy task. This problem is confounded by the fact that many individuals who are functionally illiterate try to hide their lack of reading skills.

As Catano and Breen (1987) comment "illiteracy is not only an enormous hindrance, it is also an embarrassment" (p. 33).

The presence of functional illiteracy in Canada is far reaching. According to Statistics Canada's <u>Survey of literacy skills used in daily activities</u> (1990), 16% of the Canadian adult population do not have the reading skills to comprehend the majority of written materials involved in daily living. The same survey indicates that an additional 22% of the Canadian adult population do not possess reading skills to comprehend materials which require more than "simple reading tasks within familiar contexts with materials that are clearly laid out" (Statistics Canada, 1990). Given the complexity of the majority of health education materials, it is possible that 38% of the Canadian adult population are unable to comprehend the written materials traditionally used in health education. This difficulty with reading skill is especially evident in the Atlantic provinces. The statistics from this survey suggest that 61% of

Newfoundlanders would have difficulty reading and comprehending traditional health education materials.

Education materials traditionally used in health care require high level reading skills. In an assessment of 55 pamphlets used in a family and community clinic, only 14 of the materials were at or below grade nine reading level (Spadero, 1983). Similar results were observed by Glanz and Rudd (1990) when evaluating nutrition education materials used in the education of individuals with elevated serum cholesterol. The analysis of 38 print materials revealed that the average reading level of the resources was approximately grade 11. Failure to develop materials appropriate for the target population is a waste of resources. As stated by Breen and Catano (1988):

Developing health education materials (or material on any topic) which cannot be understood and will not be read by the people for whom they have been written, is a waste of time, energy and resources of both the reader and the writer (p.6).

The use of inappropriate materials for educating the functionally illiterate is only one aspect of the problem. The education process must also be considered. Health care education has traditionally been conducted in a paternalistic manner (Achterberg and Trenkner, 1990). This method is described aptly by Fahlberg, Poulin, Girdano and Dusek (1991) as a method in which the "health educator, just as the physician and the teacher, is often elevated to the role of the expert. Knowledge and skills are thought to be discrete entities passed on to students or clients" (p. 185). The paternalistic method of education is an educator-centered approach which does not take into account the experiences, values, knowledge, attitudes or beliefs of the individual. Paternalistic education does not involve the learner and requires only that they listen. This situation places the control in the hands of the educator and leaves very little power with the

learner. Individuals who have limited reading abilities often feel a loss of control in their lives (Ontario Public Health Association and Frontier College, 1990). This lack of control makes decision-making and the application of such decisions very difficult. A health education program that is paternalistic creates a very negative environment for making lifestyle decisions.

The use of inappropriate materials and methods for educating the person who is functionally illiterate results in ineffective education and failure to convey the intended message. If an individual is not aware of the necessary changes or treatment then it is highly unlikely that the appropriate response will occur. Moreover, Griffin (1987) states that "frustration, fear, guilt, hurt, rejection, confusion, and anger often serve as blocks to learning" (p. 108). As a result, limited reading ability and an inappropriate method of teaching can create a negative picture of health education and the health care system.

2.2. Educational Needs of the Functionally Illiterate Adult Population
Many of the educational needs of the functionally illiterate adult can be
assumed to be the same as literate adults. To assess and address the educational
needs of any population, the educator must first assess his/her own beliefs and
attitudes about adult education. There are many definitions of adult education. For the
purpose of this discussion, adult education is defined as a cognitive process which is
influenced by different aspects such as; the adult learner's knowledge, experiences,
personality, attitudes, beliefs, and physical state at the time of learning (Long, 1990). It
is crucial to recognize that a client is not only a person with a health condition but a
person who has many responsibilities in areas other than health. In addition, each
client perceives education in a different manner. A client may not have knowledge in a
specific area of health but does have knowledge, expertise and experience in other

areas which are valuable to the learning process. A client's perception of his/her health and the corresponding education is affected by beliefs, attitudes, values and abilities which are unique to each individual. These beliefs, attitudes, values and abilities must be recognized and respected if effective education is to occur. It is also relevant to recognize that the client is part of a society which can influence and limit the client's decision-making process.

It is important for the health educator to understand how adults learn most effectively. Freire (1970) states that "Education must begin with the solution of the teacher-student contradiction, by recoiling the poles of contradiction so that both are simultaneously teachers and students" (p. 59). This statement gives rise to the idea that both educator and client should learn from each other and equally contribute to the learning process. The importance of client input in the creation of health education programs can be seen in the study conducted by Duchin and Brown (1990). In this study the learning priorities of diabetes educators and patients with diabetes were assessed. Although there were similarities in the priorities of each group, it was noted that the client group had much more specific educational needs than the diabetes educators who had a more global perspective of the education priorities.

Although these ideas, beliefs and attitudes are generalizations directed at the adult population, these aspects of learning may be even more important in the education of the functionally illiterate population. Due to negative learning experiences and low self esteem, people who are functionally illiterate may respond better to an environment which is open, comfortable and in which the experiences and knowledge of the individual are valued. The active involvement in the learning process would provide an avenue for the client to participate in activities which would not require an extensive reading ability.

The person who is functionally illiterate may have limited problem-solving skills (Doak et al., 1985) which may have serious implications when considering health care decisions. For example, Hussey and Gilliland (1989) describe a man who was admitted to the emergency room for hyperglycemia. When questioned about insulin therapy, he indicated that he was taking his insulin. Further inquiry revealed that he had injected an orange with insulin, as he had been shown when instructed, and then consumed the orange. He understood the concept of insulin injection but was not able to use problem-solving skills to apply the insulin injection example to himself.

Programs which only disseminate information do not address the need to develop problem-solving skills nor do they recognize the lack of problem-solving skills of the clients. Thus, both the materials and the process must be considered in designing effective education for the functionally illiterate population.

#### 2.3. Traditional Diabetes Education

Diabetes is a complex disease and the person who has diabetes needs considerable expertise in the management of the illness in order to survive (Schatz, 1988). Education plays a significant role in the treatment of diabetes, however, the value is diminished if the needs of the population it is serving are not being met. Traditional diabetes education programs, which are representative of typical health education programs, do not meet the needs of the functionally illiterate adult population with diabetes.

This failure to meet these needs is demonstrated in a study conducted by McNeal et al. (1984). In this study, of 30 participants with a grade five reading level participating in a traditional education program, 13% of the participants fully understood the material presented while 23% needed some assistance and 41% did not comprehend the material delivered in the education sessions. The impact on

diabetes care is evident.

Written materials utilized for diabetes education also fail to meet the needs of this population. As an example, the Canadian Diabetes Association's Good Health Eating Guide Poster was designed to meet the needs of the low literate population. However, the reading level of this poster has been assessed to be at a grade 10 level (Shears, 1990).

The practice of information dissemination supports the concept that the attainment of knowledge should be the goal of diabetes education programs. The idea that the person with diabetes who knows the most, lives the longest has been a standard line in diabetes education. This stress on knowledge can be dangerous. As Dunn, Bryson, Hoskins, Alford, Mandelsman and Turtle (1984) state "Knowledge is but one of the important variables involved in diabetes education, and time assessing knowledge is lost to the assessment of other factors" (p.37).

The stress on knowledge can mean that other important aspects such as beliefs, values and attitudes of the clients are not being addressed. Programs which incorporate affective domains including client beliefs, attitudes and values have been shown to be more effective than programs which primarily emphasize knowledge attainment (Travers, Tan, MacCleave, Murphy and Whiting, 1992). Vincent (1991) states "Affective health education is the organization of learning experiences which emphasize beliefs, attitudes and values as integral contributors to the health decision-making process" (p. 272). The need to address these aspects is necessary if a positive learning experience is to occur for the person who is functionally illiterate. The educator must make the effort to deliver a program that takes into account the learner's attitudes, beliefs and values; then, the learner will feel more a part of the learning process. It is much easier to create an environment for change if the learner is involved with the process as opposed to being a silent witness.

In addition to addressing attitudes, beliefs and values, it is important to provide an opportunity for clients to develop skills. Rubin, Peyrot and Saudek (1989) present the idea that self-care skills training, not the attainment of knowledge, should be the focus of diabetes education. Stressing skill attainment requires more client-centered activities which require less reading ability and assist in developing problem-solving skills. The addition of skill development to an affective health education program yields a holistic approach.

The switch from information dissemination to a more holistic education approach requires input from the clients. The clients should determine what they want to learn, after all, it is the client's disease. As McCleod (1990) asks "Why is it that professionals continue to determine what the clients should know, what they should do with this knowledge?" (p. 79). Not only will client involvement in the creation of the program and the delivery of the program result in a program which meets the educational needs of the clients but the program will be more interesting for the client. As Look (1984) so aptly states "Diabetes education can be boring and irrelevant and, therefore, ineffective if the educational topics are not really tailored to the needs of the diabetics" (p. 78). To promote interest in the education process is beneficial when dealing with the functionally illiterate population as many individuals in this population have had negative experiences with education.

One of the problems in using a client-centered approach in the creation and delivery of the diabetes education programs is that this practice makes adherence to traditional standards of diabetes education difficult and not always possible. In <a href="The-standards and guidelines for diabetes education in Canada">The-standards and guidelines for diabetes education in Canada</a> (1985), the Canadian Diabetes Association recommends aspects of diabetes care which should be covered in diabetes education programs. This publication stresses the content aspect of a diabetes education program and does not adequately address the education process.

Adherence to these standards and guidelines requires that the content and the format of the program be determined by the educators to ensure that all the aspects recommended in the publication are covered. To develop a diabetes education program format that does not involve the clients is not indicative of a client-centered approach. While this publication has definite value in diabetes education, its limitations must be recognized.

In addition to the materials, format and educational methods used in traditional diabetes education programs, the learning environment also needs to be examined. The learning environment of traditional diabetes education programs has been a classroom-like setting in a hospital which may be perceived in a negative light by clients. As Griesbach (1985) states "The hospital environment, especially when coupled with the adaptation to a new diagnosis of diabetes mellitus, may be viewed as an anxiety-producing situation" (p. 43). This does not mean that diabetes education should not occur in hospitals, however, efforts should be made to create an environment that is comfortable and relaxing. The negative aspect of the hospital setting is compounded by the frequent blood testing which often occurs in diabetes education programs. Bloodwork is a necessary part of assessing glycemic control but the diabetes education program is not the appropriate nor the optimal time for mandatory client blood testing if a positive learning situation is the goal.

To determine if a positive learning experience has occurred, it is necessary to develop and utilize a comprehensive evaluation of the program. The evaluation of diabetes education programs has been traditionally based on an assessment of factual knowledge learned by the client during the program. According to Dunn et al. (1984) "The knowledge test becomes less a test of knowledge than an assessment of extraneous factors such as intelligence, educational level, test sophistication and simple stamina" (p. 37). The knowledge test assesses what information the client has

learned but does not indicate if the client can or will make necessary changes. These statements are not meant to imply that an assessment of knowledge should not be done. Instead, the suggestion is that an assessment of attitudes, beliefs and skills is also necessary to provide an overall picture of the learning outcome. The other aspect of diabetes education assessment is the client's biomedical data. The assessment of physical health is very important but it also must be recognized that this is not solely indicative of quality of life and is not a direct measure of learning. Rubin et al. (1989) purport that "The quality of an individual's life is determined not only by physical health but by emotional well-being" (p. 678). Philosophically, quality of life is comprised of different components for each individual. The traditional evaluation of diabetes education programs carries the assumption that improved glycemic control promotes quality of life. This assumption may be accurate for some individuals but for others, the lifestyle restrictions necessary to promote the desired glycemic control may have a stronger negative impact than the repercussions of less than ideal glycemic control. This statement is not meant to imply that glycemic control is not important, instead, this statement is meant to give rise to the concept that education programs should be evaluated holistically by using other components of learning outcome in addition to biomedical data and knowledge.

Historically, patient compliance has also been one of the parameters used to assess program effectiveness. If the patients did what the health educator told them to do, then the program was effective. Program effectiveness should not be equated with patient compliance. The goal of education should be to create decision-makers. As Travers (1988) questions "is the purpose of education to develop compliant patients or to assist autonomous persons in their health choices which lead to a commitment to socially responsible action?" (p.8). Learner-centered education requires that the latter be the choice.

This discussion is not to say that traditional diabetes education programs are not useful. Studies show that diabetes education programs can result in an improvement in patient knowledge and self-care behaviours. In addition, metabolic and psychological outcomes indicate that there is merit to these programs (Brown, 1990; Down, 1991; Padgett, Mumford, Hynes and Carter, 1988). Certainly, the value of education does not need to be qualified. However, the design and delivery of these programs can be improved to meet the needs of the functionally illiterate population.

## 2.4. Diabetes Education for the Functionally Illiterate Adult Population 2.4.1. Philosophical Orientation

The basis for any education program should be the philosophical orientation. The combination of two models, progressive adult education (Zinn, 1990) and the compensatory model (Achterberg and Trenkner, 1990), deserves consideration as the philosophical orientation for the education of the functionally illiterate adult population.

The purpose of progressive education is to provide practical knowledge and problem-solving skills in a manner which recognizes and allows the client to see the cultural and societal structures as determinants of behaviour and recognizes that the change is the decision of the client and not the decision of the educator (Zinn, 1990). The progressive adult education approach is a client-centered method which utilizes activities that promote the participation of the client.

In the compensatory model, clients are responsible for solving problems but not responsible for the development of the health condition (Achterberg and Trenkner, 1990). This philosophy demands that the client holds the power for the decisions involving personal health care. The health care professional's role is to provide resources, such as education, to allow the client to make the necessary decisions involving health care. The appropriate application of this model could be very

beneficial for the education of the client who is functionally illiterate. However, extreme use of this model can result in the development of of a stressed, overreactive client. This scenario is most easily imagined in a situation where the client is provided with information but is not assisted and supported during the decision-making process. With proper guidance, this model could promote client empowerment and positive outcomes such as an increase in client confidence. This model also could serve as a means to address client attitudes and beliefs as the client would most likely reflect on the different aspects of daily living in order to make the necessary decisions.

The use of these philosophies to develop and deliver a diabetes education program demands a change from the traditional format. The key difference relates to client responsibility. The use of the progressive adult education and compensatory models demands that the client share responsibility with the diabetes educator for determining the content of the program. The needs, interests, experiences (Zinn, 1990) and the world view of the client are the deciding factors in program development and are determined by the client. The use of these models demands that the client is responsible for the decisions that relate to diabetes care. A diabetes education program can provide information and skill development to assist with client decision-making, however, it is the client's responsibility to make decisions regarding the application of the skills and information.

Using this philosophical approach in diabetes education also changes the traditional role of the diabetes educator. The diabetes educator serves in the capacity of a resource person and not in the capacity of an expert. The diabetes educator's role is to assist the client in making socially responsible decisions and not to hold the position of the decision-maker for the client. This approach benefits the educator, as well as the client, by reducing client dependency.

#### 2.4.2. Theoretical Framework

An appropriate theoretical framework for a diabetes education program for the functionally illiterate adult population is one which is based on the perspectives of holistic education and the ecological systems approach. This framework addresses the needs of the functionally illiterate adult population with diabetes as can be seen in the following descriptions of the two perspectives.

Holistic education is defined by Rinke (1986) as:

A functional, integrated and generalized model of education which focuses on the whole teaching/learning situation, and varies the teaching/learning strategy to meet the needs of the learner, the teacher and the situation, in an effort to attain educational outcomes which are greater than the sum of the parts (p. 15).

The ecological systems perspective takes holistic education a step further. "In using this model, it is assumed that all factors affecting a problem or situation are interrelated and therefore form a system" (Sims and Smiciklas-Wright, 1978, p. 173). This model allows client education to be viewed as a process as opposed to solely an outcome. Most importantly, an ecological systems approach presents a picture which portrays the client as part of an external and internal environment. The external environment is a composite of natural, technological and socio-cultural components while the internal environment is a composite of the individual's knowledge, beliefs, values and attitudes (Sims and Smiciklas-Wright, 1978). The lack of recognition of ability is a limiting factor of the ecological systems perspective. The addition of abilities is imperative when dealing with the functionally illiterate adult population.

Combining the perspectives of holistic education and ecological systems approach offers the diabetes educator an avenue to see the client in the broadest sense. Through the ecological systems and holistic lens the client is seen as an

individual of many dimensions with a life composed of many aspects which all need to be recognized and respected if effective diabetes education is to be promoted and achieved.

#### 2.4.3. Diabetes Education and Client Empowerment

The most significant difference in using this philosophical approach and the theoretical framework is the shift in power which can result. Funnel, Anderson, Arnold, Barr, Johnson, Taylor-Moon and White (1991) state that:

Empowerment is more than an intervention or strategy to help people make behavioural changes to adhere to a treatment plan. Fundamentally, patient empowerment is an outcome. Patients are empowered when they have knowledge, skills, attitudes, and self-awareness necessary to influence their own behaviour and that of others in order to improve the quality of their lives (p. 38).

The role of empowerment in the education of the functionally illiterate adult population is seen as well by Kent's (1988) definition which is that "to be empowered is to increase your capacity to define, analyze, and act on your own problems" (p. 193).

Client empowerment is a recent concept in health education. Historically, the control of a client's health care decisions has been in the hands of the health educator. Traditional diabetes education programs do not encourage client empowerment as these programs do not promote the role of the client as a decision-maker in the program content, program delivery and in the lifestyle adaptations of the information and skills learned during the program.

A client-centered diabetes education program addresses the issues of power and control. Individuals who are functionally illiterate often have a feeling of a lack of control in their lives. The Ontario Public Health Association and Frontier College (1990) state that members of the functionally illiterate population "have limited control"

over their access to health care services. In summary, they have little control over their own health." (p. 24). This aspect is important to address in a diabetes education program for the functionally illiterate adult population. The person who feels in control of their health care decisions will likely have greater confidence in making changes. A diabetes education program which promotes client empowerment is indicative of a program which is attempting to meet the needs of the clients it serves.

#### 2.5. Summary

Traditionally, health education has been conducted in a paternalistic manner. Paternalistic education yields programs which primarily rely on the practice of knowledge dissemination. These programs also rely on the assessment of knowledge as the mechanism for evaluation. This approach is limited when addressing the education of the functionally illiterate population. A large percentage of the Canadian adult population is functionally illiterate. The educational needs of these individuals are not always being met in health education due to inappropriate materials and educational methods.

This situation is evident in diabetes education. Historically, knowledge attainment, biomedical data and patient compliance have been the goals of such programs and the parameters used to assess their effectiveness. Knowledge attainment, biomedical data and patient compliance are not always indicative of positive education and when overly emphasized, aspects such as values, attitudes, and beliefs are ignored. These programs are not appropriate for adults with diabetes who are functionally illiterate. The need for programs which meet the requirements of the adult who is functionally illiterate is apparent. A diabetes education program which uses a client-centered approach and appropriate materials would be invaluable in promoting client comprehension and empowerment. The application of a client-

centered diabetes education program for the functionally illiterate adult population is a definite step forward in the provision of affective and effective health education.

#### 3.0. PROGRAM DESIGN

This program was developed for use with the functionally illiterate adult population with diabetes at the Central Newfoundland Regional Health Center (C.N.R.H.C.) located in Grand Falls-Windsor, Newfoundland.

#### 3.1.Philosophical Orientation

The philosophical orientation of this program was a combination of the progressive adult education model (Zinn, 1990) and the compensatory model (Achterberg and Trenkner, 1990) as summarized in Figure 1.

The main theme which evolved from the application of these two models was the issue of control. The use of these two models demanded that the control shift from the educator to the learner. This shift required that the traditional role of the expert educator make a transition to the role of a facilitator. This change in power was necessary if the loss of control commonly experienced by individuals who are functionally illiterate was to be acknowledged and addressed. Giving clients the control of the education process had the potential to increase confidence in client decision-making. In this diabetes education program, this increase in confidence was crucial if the client with diabetes was to be empowered to make decisions about his/her diabetes care, thus, reducing client dependency on the diabetes educator and benefiting the client.

#### 3.2. Theoretical Framework

The theoretical framework of this program was based on the concepts of the ecological systems (Sims and Smiciklas-Wright, 1978) and holistic education perspectives (Rinke, 1986) as summarized in Figure 1.

#### FIGURE 1

## Model of the Diabetes Education Program for the Functionally Illiterate Population

### Philosophical Orientation

Progressive Adult Education

\*Educator responsible for facilitating problem-solving and providing practical knowledge at client request \*Client responsible for change and decisions Compensatory Model



## Theoretical Application

Ecological Systems
Perspective

\*All aspects of environment recognized; external and internal

\*All aspects of client's life acknowledged as affecting teaching

Holistic Education



#### Program Structure

- \*Clients determine format
- \*Comfortable setting for teaching
- \*No laboratory blood testing during the program
- \*Focus on developing problem-solving skills
- \*Educators are facilitators
- \*Clients' knowledge, beliefs and attitudes are part of program
- \*The process is learner-centered
- \*Practical information as requested by clients
- \*Educational methods and materials are geared to meet the needs of the clients

#### **Program Activities**

- \*Brainstorming
- \*Group Discussion
- \*Role Playing
- \*Problem-solving Activities
- \*Practical Demonstration

Combining these two perspectives provided an avenue to recognize all aspects of the learning environment and all aspects of the individual learner which potentially affected the learning process and learning outcome. This action was necessary if the negative learning experiences common to individuals with low literacy skills were to be recognized. Acknowledging the clients' attitudes, beliefs and knowledge provided a forum for this information to be recognized, addressed and discussed and promoted a much more positive learning experience than that of the traditional information disseminating pedagogical approach. This forum allowed clients to use existing knowledge as a base to acquire further information that could be used in decision-making and the learning process allowed the identification of attitudes and beliefs involving learning and health which was a crucial step to behavioural change.

# 3.3. Program Goals

- 1. To enable the client to acquire skills and knowledge which could be used to make decisions about diabetes care.
- To enable the client to be the decision-maker in his/her diabetes care.
- 3. To enable the client to assess his/her quality of life and its relationship to the diabetic condition.
- 4. To provide a learning environment appropriate for addressing client attitudes, beliefs and behaviour which can affect the diabetic condition.
- 5. To facilitate a learning environment and educational process which meets the needs of the functionally illiterate adult with diabetes.

## 3.4. Program Objectives

- 1. To use learner-centered educational methods.
- 2. To actively involve the client in the content development, delivery and evaluation of

the program.

- 3. To use activities and methods which recognize and respect the beliefs, knowledge, attitudes, experiences, needs and abilities of the client.
- 4. To use materials and methods appropriate for the functionally illiterate adult population.

# 3.5. Client-Centered Objectives

- 1. The client will acquire information and skills for diabetes care which reflect client interest.
- 2. The client will be empowered in dealing with health care matters involving diabetes.
- 3. The client will gain confidence in his/her ability to learn.

# 3.6. Clients

The clients in this program were members of the functionally illiterate adult population with diabetes in Central Newfoundland.

## 3.7. Education Strategies

The education strategies employed were client-centered. All activities were those requiring client input and educator facilitation. Activities such as brainstorming, role playing and practical demonstration were utilized. These activities all demanded that clients use some degree of problem-solving skills to participate. For example, in discussing hypoglycemia, clients brainstormed in groups of two or three to outline causes and symptoms of hypoglycemia. Then, as one group, clients used problem-solving skills to determine ways to avoid hypoglycemia. Exercises such as this one allowed clients to acquire knowledge which they translated into practical application.

This method aids in the development of problem-solving skills which has been previously identified as a difficulty frequently experienced by the individual with low literacy skills. This educational approach differed significantly from the paternalistic, knowledge disseminating approach as clients were provided with a forum to obtain and apply information and skills to their lives.

Sample descriptions of education methods used are located in Appendix A.

# 3.7.1. The Education Sessions

Clients attended two education sessions. The first session was a three day seminar and the second session was a one day seminar held one month following the three day seminar. Each session lasted from 9am to 3pm with a one hour lunch break. Clients were encouraged to bring a significant other or family member for support.

The education sessions were facilitated by the dietitian and the diabetes nurse.

Both educators are Certified Diabetes Educators familiar with group teaching.

Consistent with the client-centered approach, clients were responsible for determining the program format based on information on diabetes care provided to the clients verbally and in simplified written form prior to the program. At the beginning of the three day program, topics for the education sessions were determined through group discussion of possible topics suggested by the educators. Topics which were not of interest to the clients were eliminated. Topics which were not suggested by the educators but were proposed by the clients were added to the format. Clients were encouraged to suggest other topics of interest at any time during the program. The topics covered in the program are identified in Appendix B.

Once the topics were determined, a flexible schedule was created by the educators and the clients. Topics not covered during the first seminar were scheduled for the second seminar. Clients were encouraged to make suggestions concerning scheduling at any time during the program.

Clients were encouraged by the educators to participate during any component the program. After each session, the educational tools and methods were informally evaluated through group discussion. This information was used for program adjustment and evaluation.

Scheduled clients who missed the initial three day program were eliminated from the study due to the lack of other scheduled education programs for this research.

## 3.8. Resources

# 3.8.1. Learning Sites

The learning sites included a grocery store, a cafeteria and the main learning site at the hospital. The main learning site was designed to provide familiarity and comfort. The classroom-like setting traditionally utilized in diabetes education was replaced with a structure which resembled a living room.

# 3.8.2. Materials

Materials providing concrete examples of the ideas and concepts presented were used. These materials included items such as food models, actual foods, food containers and labels, boards displaying the fat and sugar content of various foods, recipes, menus, medications, glucose meters and supplies, posters and games such as diabetic bingo and jeopardy.

## 3.9. Formative Evaluation

During the education program feedback was obtained from participants at the end of each day using an exercise, "head, heart and feet" (Arnold, Burke, James, Martin and Thomas, 1991). Subjects were presented with a poster size outline of a person which emphasized the person's head, heart and feet and were asked to comment on what they learned (head), what they felt (heart), and what action they

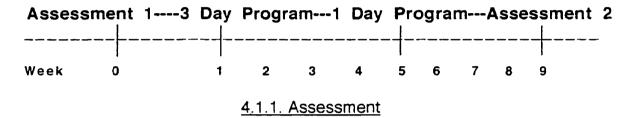
were going to take (feet). The comments were recorded on the outline of the person. This method of evaluation allowed the clients and the educators to see what learning had occurred and also allowed for program adaptation if necessary. This method also provided clients with an informal forum to discuss their feelings and offer their opinions about the education methods and process, thus, promoting client empowerment and an opportunity to reflect on attitudes and beliefs associated with learning about diabetes. Using formative evaluation is an essential component of the client-centered approach if the clients are to have control in the development and delivery of the education program.

The summative evaluation of the program is described in the next chapter.

# 4.0. EXPERIMENTAL DESIGN AND METHODS

# 4.1. The Research Design

A one-group pretest-posttest quasi-experimental design was utilized in this study. The diagram for this design is as follows:



The participants were assessed on specific variables before and after the introduction of the diabetes education program. One week prior to the education program, an assessment session was conducted by the dietitian and nurse to determine:

\*The reading level of group members.

\*Client quality of life, attitudes, beliefs, knowledge, skills and behaviour relating to diabetes care.

An explanation of the program goals, objectives and possible education topics was provided to the clients and the consent form (Appendix C) was reviewed.

Information concerning the consent form was provided verbally and in written form appropriate to client reading ability.

# 4.1.2. Sample Selection and Recruitment

The clients for this study were chosen through convenience sampling (Touliatos and Compton, 1988). The Diabetes Education Clinic (DEC) at the C.N.R.H.C. accepts physician referrals for clients with diabetes. Of the referrals received from October 1992 through December 1993, eight clients who were interested in group diabetes education and who were functionally illiterate agreed to participate in the study. Originally, the intent was that eight clients would participate in one education program

as the diabetes nurse and dietitian had discovered through previous education attempts that a maximum number of eight clients with significant others was an appropriate group size using the client-centered approach. However, it was decided to use two groups of four clients when eight clients were not available for the first education program due to a lack of client interest in participating in group education.

# 4.1.3. Eligibility Requirements

Clients with diabetes who were referred to the clinic by a physician and who tested at Level One, Two or Three of Statistics Canada's <u>Survey of literacy skills used in daily activities</u> (1990) were included in this sample. A description of these literacy levels is included in Appendix D. Prior to the formal evaluation of literacy levels, clients were screened for literacy level during the standard assessment conducted at the DEC. Clients who presented with limited literacy abilities and who were interested in participating in the study were then formally evaluated to establish eligibility.

## 4.2. The Research Methodology

The effectiveness of the diabetes education program was assessed using quantitative and qualitative methods. The results of the interview guide, client assessment sessions and client program evaluations provided qualitative and quantitative data concerning client attitudes, beliefs, skills, knowledge and behaviour regarding diabetes care and client quality of life (Figure 2).

Traditionally, in the review of health care programs, quantitative research has been the standard approach. The use of quantitative methods corresponds with the traditional emphasis on knowledge attainment, compliance and biomedical indicators as the primary evaluation mechanism of diabetes education programs. Quantitative methods were used in this study to obtain and to analyze some of the parameters evaluated. However, the main focus of the research conducted in this study was

# FIGURE 2

# PARAMETERS USED FOR THE RESEARCH EVALUATION

**KNOWLEDGE** 15 true/false questions

BEHAVIOUR Exercise

Home glucose monitoring

Medications Foot care Food habits Diet history

ATTITUDES AND BELIEFS Learning about diabetes

Diabetes care responsibilities

Diabetes medications Blood glucose monitoring

Shopping

Meal preparation

Family life

Social situations

Exercise

QUALITY OF LIFE

FOCUS GROUP Information

Methods Materials Environment

Time

EDUCATOR EVALUATION Information

Methods Materials Environment

Time

OTHER DATA Educator reflection and observations

Summative program evaluation

qualitative evaluation. Client-centered education is not an outcome, it is a process; thus, it was necessary to evaluate the educational experience in a manner which provided insight into all aspects of the pedagogical journey. The need to evaluate process and not just outcome necessitates the need for qualitative research evaluation (Achterberg, 1988). Quantitative research has value is assessing some of the educational components, however, its value must be recognized as being limited in providing in-depth data necessary to understand feelings, attitudes and beliefs (Patton, 1987). Qualitative research methods were chosen for this study primarily due to the educational approach used in the program, however, the literacy level of the participants also dictated the need to employ research methods which did not require participants to have extensive reading ability. Using focus groups (Patton, 1987) and semi-structured interviews (Achterberg, 1988) provided a forum to extract data in a manner which would not be perceived as threatening as methods which required literacy abilities. Overall, considering the many different aspects of the education of the learner with limited reading skills, qualitative research was truly needed to bring the richness and depth of the education process and its process to surface level.

#### 4.2.1. Instruments and Data Collection Procedures

The instruments utilized in this study are as follows:

# 4.2.1.1. Survey of Literacy Skills Used In Daily Activities

This instrument was used to assess the literacy skills of the members of the test groups. This instrument was developed by Statistics Canada and has been tested for reliability and validity through a national testing held by Statistics Canada in 1989. Permission from Statistics Canada to use this instrument was obtained. This instrument is not included in the Appendix as per guidelines of Statistics Canada.

# 4.2.1.2.Knowledge Relating to Diabetes Care Test

This instrument (Appendix E) was used to assess knowledge of test group

members. This instrument was verbally administered and consisted of 15 true/false questions. Due to client participation in determining the education topics, information relating to all of the questions was not presented in the education seminars. One question was eliminated from this section for each group for this reason. This section was scored by giving one point for each correct answer. The reliability of this instrument was evaluated for test-retest reliability (Touliatos and Comptom, 1988) by administration on two separate occasions to thirteen functionally literate staff of the C.N.R.H.C. who were not directly involved with diabetes care. Not using a functionally illiterate population to test the reliability of this instrument is noted as a limitation, however, such a population was not readily available. Face validity (Leeds, 1989) was established by review by experts in nutrition education, research methods and adult education.

## 4.2.1.3. Behaviour and Skills Questionnaire

This instrument (Appendix F) was delivered verbally and consisted of six parts which examined exercise, home glucose monitoring, medications, foot care, food habits and diet history. If a section was not applicable for a client, it was eliminated as part of the assessment. The section was scored by noting improvement in a behaviour or skill. For example, if a client did not exercise prior to the program but initiated an exercise program after the program, this was seen as an improvement. Improvement was noted for each area, however, the quality of the improvement within each area was not noted. For example, no difference was noted between a client who made many changes in one area and a client who only made one. Face validity was established by review by experts in nutrition, research methods and adult education. Reliability was not assessed for this instrument.

## 4.2.1.4. Attitudes, Beliefs and Quality of Life Interview Guide

Participants were asked to comment on different aspects of life relating to

diabetes care. These aspects included areas such as family life, ability to learn, social events and control of health care decisions. This was obtained qualitatively using a general interview guide approach (Patton, 1980). Due to the ambiguity of a definition for quality of life, clients were asked to provide their own meaning and its components. The interview guide is located in Appendix G.

# 4.2.1.5. Focus Groups

A focus group was employed at the conclusion of each program to derive data regarding clients' feelings about the learning process and components of the education programs. The main areas addressed included information provided during the education sessions, education materials, methods, environment and the time involved in the program. Informal discussions concerning each of these areas were conducted, however, in keeping with naturalistic approach, digressions from these areas relating to diabetes, health care and learning abilities were also encouraged by the educators. The use of focus groups has not been a standard approach in the evaluation of health education programs, primarily due to the quantitative data typically used in health related research. However, the use of focus groups has been previously identified as an effective program planning tool for diabetes education programs (Fox, 1993) and as an appropriate method used in the development of nutrition education materials for the low literate population (Ruud, Betts and Dirkx, 1993). The use of focus groups provided a forum for clients to express views in a manner which did not require literacy skills. This evaluation tool also allowed clients to have control of the evaluation process and is consistent with the client-centered approach.

## 4.2.1.6. Head, Heart and Feet

As previously described in Chapter Three, this tool (Arnold et al.,1991) was used to qualitatively obtain formative evaluation data.

Data was also collected through educator dialogue and reflection and educator observations during the program.

# 4.2.2. Validity of the Qualitative Data

The debate on the validity of qualitative data versus quantitative data is established in the literature (Patton, 1987) and, thus, does not necessitate an exhaustive discussion. However, in defense of the validity of the data obtained in this research, it is important to discuss the threats to the validity of the data. With the use of qualitative data collection in this study, the potential bias of the participants and the researchers must be acknowledged.

## 4.2.2.1. Participant Bias

Participants were followed for a minimum of four months prior the education program and had considerable contact with the researchers during the program. The positive relationships established between the researchers and the participants may have created a situation in which the participants were reluctant to offer negative opinions about the education program or negative details regarding their behaviour. To decrease the likelihood of this occurrence, the researchers frequently emphasized the need for both positive and negative feedback to properly evaluate the program.

## 4.2.2.2. Researcher Bias

The potential for researcher bias is inherent in any research. However, due to the verbal nature of the data in this study, efforts were taken to ensure optimum validity. These efforts included; tape recording of the assessment sessions and the recording of detailed written records of the observations (to minimize recall distortion). Employing a triangulation method (Patton, 1987) of data collection through the use of various tools such as the interview guide, focus group and educator observation and reflection assisted in promoting validity of the data and of the data analysis.

# 4.2.3. Analysis of Quantitative Data

- 1. The reliability of the knowledge test was assessed using Pearson product-moment correlation (Touliatos and Comptom, 1988) which yielded a correlation coefficient of 0.51.
- 2. The information from the behaviour and skills questionnaire was summarized using the mean, range and standard deviation.
- 3. Demographic information (age and years since diagnosis) was summarized using the mean, the range and standard deviation (Touliatos and Comptom, 1988).

# 4.2.4. Analysis of Qualitative Data

The qualitative data was evaluated initially using content analysis (Patton, 1987). Using this approach the data was categorized into sections consisting of; components of the data from the interview guide, components from the focus group, components from the educator evaluation and observation and components from the "head, heart and feet" evaluation tool. Through inductive analysis (Patton, 1987) these categories were further analyzed and themes were established.

#### 4.2.5. Ethical Considerations

The informed consent documents were designed for the functionally illiterate adult population. Consent was obtained through verbal and written means appropriate to the reading comprehension level of the clients.

The study was approved by the Ethics Committee at C.N.R.H.C. (Appendix H).

#### 5.0. RESULTS AND DISCUSSION

# 5.1. Sample Characteristics

The sample for this study consisted of a relatively older adult population all with limited reading ability and Non Insulin Dependent Diabetes Mellitus (NIDDM). Eight clients participated in the study; four clients were present at each education program. All clients were present for the initial three day program. One client was unable to attend the one day follow up.

The small sample size makes comparison with other study groups difficult as does the limited available research addressing the educational needs of the functionally illiterate adult population with diabetes. However, there are some similarities and differences worth noting.

Recruiting clients for this study was difficult. Twenty clients were asked to participate but only eight clients were willing and able to attend. Nineteen clients accepted an appointment for the initial assessment but only eight kept the appointment. When contacted, the reasons given by clients for not participating in the study included lack of interest, illness, family commitments and shyness. This result is expected considering that the clients being recruited for the education program were individuals with limited reading abilities. It is likely that the majority of these individuals would be intimidated by any type of education program. The eight clients who participated had been followed in the DEC for a minimum of four months prior to the education program and, thus, had established a comfortable relationship with the dietitian and nurse. These findings suggest that group education for clients with literacy difficulties should be initiated once a comfortable relationship is established with the diabetes educators. In addition, it may be more appropriate to initiate an education program for the functionally illiterate population with an introductory half day

session. This action may help to alleviate fears and intimidation concerning group education.

Significant others did not attend the first program, although clients were encouraged to bring them. All four clients' significant others attended the second program. It is interesting to note that all of the male clients were accompanied by their significant other while only one female client's significant other attended. This lack of female significant other participation is similar to findings of other studies which evaluated health education programs with a strong nutrition component (Travers et al., 1992). As diabetes is a chronic disease which can affect many aspects of an individual's life, strong family support is important. Thus, it would be beneficial to stress the importance of female significant other attendance and to investigate methods to promote such attendance.

## 5.2. Demographic Descriptions

Five women and three men participated in the study. The first group was composed of all women and the second group was composed of three men and one woman. The higher percentage (62%) of women in this study is similar to other studies conducted in diabetes education (Padgett et al., 1988). The higher percentage of women is perhaps indicative of the greater number of men, compared to women, who are employed outside of the home and, thus, have less available daytime hours to commit to education programs. This concept gives rise to the idea that the provision of education programs during non-traditional times such as evenings and weekends may have merit.

The age of the clients ranged from 52 years to 70 years with a mean of 60.5  $\pm$  6.1. This age is comparable to other studies of NIDDM clients (Down, 1991) and is expected due to the late onset of NIDDM. Duration of diabetes ranged from three

months to thirteen years; with a mean of 5.25 years ±4.87.

All of the clients lived with a spouse with the exception of one who was a widow and lived alone. Four of the clients had limited financial income, which was derived predominately from governmental support agencies. While only 50% of the participants in this study had limited incomes, the majority of clients who declined to participate in the study were individuals with limited incomes. In general, illiteracy and poverty are strongly related with each having a negative impact on health (Ontario Public Health Association, 1990).

All of the clients were functionally illiterate with six clients reading at Level One of Statistics Canada's <u>Survey of literacy skills used in daily activities</u> and two clients reading at Level Two. No clients with Level Three reading ability participated in the study. This may reflect the difficulty in initially identifying these individuals as many would not appear to have limited reading abilities. The results of the reading assessment indicate that the clients who participated in this study would be predominately classified as non-readers and, thus, would be unable to decipher the simplest of reading materials.

# 5.3. Quantitative Analysis of Intervention Effects

# 5.3.1. Knowledge

Individually, all clients knowledge scores increased; with an overall increase of 28% (Table 1). These findings correspond with other studies which utilize client knowledge as a parameter (Dunn et al., 1984). Clients had the most initial difficulty with nutrition-related questions, specifically with those involving the natural sugar content of foods and beverages. Clients had the least initial difficulty with questions that concerned the etiology of diabetes. On follow up, there was no pattern to the questions which clients did not successfully answer. The noted increase in knowledge

TABLE 1
KNOWLEDGE, BEHAVIOUR AND SKILLS RELATING TO DIABETES

	PRE	POST
Knowledge		
Range Mean Standard Deviation P Value	6.0 - 10.0 8.0 1.31	11.0 - 14.0 12.0 1.2 .0004
Behaviour/Skills		
Range Mean Standard Deviation	0 to .67 0.26 0.24	1.0 to 1.0 1.0 0

indicates that clients with limited reading abilities were able to substantially increase their knowledge base with the intervention of the education program and supports the methods employed as appropriate means of promoting knowledge attainment.

# 5.3.2. Behaviour and Skills Relating to Diabetes

Prior to intervention, clients were not appropriately practising healthy behaviours and lifeskills (Table 1). Dietary habits and exercise were the areas which clients reported the most appropriate behaviour. This finding are not surprising as clients had been followed in the DEC prior to participating in the study and information about diet and exercise had been previously provided and reinforced. On follow up, foot care, home glucose monitoring and dietary habits were the areas of greatest improvement. Using a different measurement scale, Rubin et al. (1989) reported similar improvement in exercise, dietary habits and home glucose monitoring as a result of diabetes education intervention. Such findings support the emphasis of practical behaviour and skill application in diabetes education efforts.

# 5.4. Qualitative Analysis of Intervention Effects5.4.1. Attitudes, Beliefs and Quality of Life Interview Guide

Clients appeared to be comfortable with the interviewing process. Clients who had been followed in the DEC for a longer period of time were more expressive during the initial interview which, perhaps, reflects the greater comfort level of these clients with the educators. On follow up, all clients were equally vocal. The lack of difference in expressiveness witnessed during the follow up interview is not surprising considering the amount of time that clients spent with the educators during the education program.

An analysis of the interview data suggested four main categories (Figure 3).

## FIGURE 3

## INTERVIEW CATEGORIES AND THEMES

**Learning** 

Initial Themes: Incapable of learning

Embarrassment about illiteracy Learning would provide benefits

Follow Up Themes: Increase in confidence

Astonishment about learning abilities

<u>Diabetes Care</u> <u>Responsibilities</u>

Initial Themes: Physician responsible for diabetes care

Client not responsible for diabetes care Spouse responsible for diabetes care Illiteracy has major impact on diabetes care

Follow Up Themes: Client responsible for diabetes care

Increase in confidence

Decision-making

Initial Themes: Cannot make appropriate decisions due to illiteracy

Cannot make appropriate decisions due to lack of

knowledge

Stress involved with decision-making

Follow Up Themes: Increased confidence in decision-making

Clients have knowledge to make decisions Decreased stress noted when making decisions

Quality of Life

Initial Theme: Diabetes negatively affects quality of life

Follow Up Theme: Learning about diabetes improves quality of life

# 5.4.1.1.Learning

Although clients expressed an interest in learning about diabetes, most clients commented that they were unsure what to expect and were nervous about the program. Most clients indicated that they did not believe that they were capable of learning due their lack of formal education and past negative learning experiences. One client stated "I probably won't be able to learn because my eyes aren't too good, I'm old and I can't read". Another client said "I will probably be able to learn a bit but I can't read so I won't learn too much". Some clients did have confidence in their ability to learn as witnessed by one man's comment "I bet I can learn better now then when I was younger". The clients who indicated they believed that they could learn were men who either presently held skilled labour jobs or individuals who had held such jobs before retirement. Most likely, these men had acquired confidence in learning through work situations that required new skill attainment. Although, there were positive comments about learning abilities, it was perceived by the dietitian and nurse through observations during the interviews and the program that the majority of clients lacked confidence in their learning abilities. Many clients appeared uncomfortable when discussing learning abilities and initially awkward in participating in program activities. This concept was supported by the discussions about home glucose monitoring which were held with the participants during the interview. Of the clients who did not test their own blood glucose levels, all indicated reservations about testing. Some clients expressed beliefs that the testing would be uncomfortable and that they would not be able to conduct the testing properly as it was complicated. One client commented "I won't be able to understand how to do it". When questioned about her comment, she stated "I can't read so I won't be able to do that".

In addition to negative attitudes and beliefs about learning, the majority of clients expressed embarrassment about their lack of reading ability. One client was

very emotional during the interview and indicated that she "wouldn't want to go through another 70 years without being able to read". Client embarrassment about reading ability was also witnessed by the dietitian and nurse during the program. As an example, clients complained during the program when the educators wrote down key words to assist with organizing the program. One woman stated that writing down words made her feel sad because she did not know what the words meant. Clients were also noted to be uncomfortable during the reading test.

The negative learning attitudes displayed by the clients prior to intervention of the education program are in keeping with other researchers' findings with this population (Doak et al., 1985). The lack of self confidence in learning abilities witnessed in the majority of clients in this study provides a possible explanation for the difficulty in obtaining clients. The negative attitudes about learning are reflective of the clients' perceptions of themselves as learners and not of their perceived value of the education program as indicated by the common belief held by clients that learning about diabetes would be beneficial. The most common benefit noted was that diabetes education would allow them to take better care of themselves. Other benefits included an increased ability to prepare meals, an improvement in blood sugar control and a better life.

During the follow up interview, all clients expressed surprise and astonishment about their ability to learn. Most clients indicated that they did not realize that they could learn so much without being able to read. One client stated "I was shocked that I could learn so much". Another client commented, "I am much smarter than I thought I was".

An increase in client confidence about learning and an overall increase in confidence in all areas of client life was also noted. Three clients had initiated literacy tutoring which they indicated was a result of their new confidence in themselves as

learners. Other clients relayed experiences about how they had begun teaching their friends and family about diabetes. One client stated "I am telling everyone I know about the diabetes". Client confidence in learning ability was supported by the verbalized desire to attend education programs about other topics in the future. Observations made by the dietitian and nurse during the follow up interview supported this concept as clients were visibly pleased with themselves and very excited about vocalizing their learning experiences. These observations were confirmed during the final education day as clients were noticeably eager to participate in activities and comment on their knowledge.

Utilizing learner-centered activities which did not require extensive reading abilities may be the crucial factor in the observed change in the clients attitudes and beliefs about learning. Clients were able to learn information through non-reading activities which promoted practical application of the knowledge as opposed to pure knowledge dissemination used in the paternalistic approach. It was apparent from the interview data that most clients associated the ability to learn with the ability to read. The program activities allowed clients to change this belief and to realize that learning can occur and can be a positive experience. It is evident that clients found the learning experience to be rewarding and positive as witnessed by the comments during the focus group.

The initiation of literacy tutoring by three of the clients in the study is significant and supports the use of educational methods which increase confidence of the learner. Using client-centered methods allows the client to take control of the learning process and fosters confidence-building through the use of activities which build on the client's knowledge and experiences. Although the main focus of the diabetes education program was to allow clients to make appropriate changes in their behaviour and skills relating to diabetes, the role of increasing the clients' confidence

in themselves as learners definitely deserves attention. It is difficult to predict the long term effects from the positive learning experience; however, an increase in a client self esteem would most certainly have positive long term repercussions in many areas of life other than just diabetes.

## 5.4.1.2. Diabetes Care Responsibilities

Data from the initial interview indicated that most clients did not perceive themselves to be responsible for their diabetes care. The majority of clients believed that their physician was the person who made the decisions about their diabetes care as indicated by comments such as "I try to do what I can do but it's really up to my doctor". Some clients believed that the nurse, dietitian or spouse were responsible and made comments such as "My wife is in charge because she can read" and "I guess you two (meaning the dietitian and nurse) are the ones to make the decisions". If clients did express a belief that they had some responsibility in diabetes care, this responsibility was presented as a shared responsibility with the physician or spouse. These beliefs were confirmed when clients were given hypothetical situations about their diabetes care involving advice given from a health care professional about glycemic control. Only two clients indicated that they would challenge the professional if they believed the information to be inaccurate. The other clients made comments such as "I would go along with what the doctor told me. He knows best". The reasons for not taking control of diabetes care revolved around clients' beliefs that they did not know enough and were unable to understand aspects of their diabetes care. One client commented "I would have been able to take better care of myself if I could have read". This belief that lack of reading ability affected ability to take responsibility for diabetes care was supported by comments about grocery shopping and meal preparation. One client commented "I guess it would be hard for me but the wife reads and she picks out the food". Another client stated "I used to make diet foods but my

daughter left so now I don't have anyone to help me".

The lack of control expressed by the majority of clients in the initial interview is typical of the individual with limited reading abilities (Ontario Public Health Association, 1990). Many individuals with limited reading abilities have been forced to rely on others to assist them with basic lifestyle tasks, such as cooking and shopping as witnessed in this study. Thus, it is not surprising that these clients would allow others to take responsibility for their diabetes care. It also must be considered that health care has traditionally operated with a paternalistic philosophy which promotes the physician as the person responsible for health care and treatment and, hence, client views made be partially reflective of societal views.

There was a noticeable shift in perceived responsibility witnessed at the follow up interview as all clients indicated an increased confidence in their abilities to be responsible for their diabetes care. Most clients expressed the view that they were chiefly responsible for their diabetes. The few who acknowledged that the physician was still responsible expressed stronger feelings about their own role. Some clients indicated that since the program they had discussed their diabetes treatment with their physician and had positive feelings about such discussions. One client had explained the program to his doctor and told him that he should send all his patients to the DEC. Other clients expressed a sense of increased control in dealings relating to their diabetes. One client commented "I feel in charge now because I know what to do".

This increased perception of client responsibility was witnessed with the repetition of the hypothetical situation involving glycemic control as all clients indicated that they would challenge the health care professional if the advice was inappropriate. One client, who had initially shown a lack of confidence in her ability to take responsibility for her diabetes care, stated "I would tell him (meaning the doctor) that he was wrong". The increase in client perceived responsibility was also observed by

the dietitian and nurse during the final education day during a brainstorming activity involving complications of diabetes. Clients identified the tests that they needed and showed an acceptance of diabetes care responsibilities by telling the educators which tests they would ask their physician to employ.

The qualitative data indicate that clients were able to change attitudes and beliefs about diabetes care responsibilities. Through intervention, clients showed an increase in their confidence to take responsibility for their diabetes care. This shift in responsibility corresponds with the compensatory model (Achterberg and Trenkner, 1990) employed for the development of the program in this study and confirms the appropriateness of this model for diabetes education. The use of methods consistent with this model promoted client empowerment as witnessed by the data from the interview. This increase in empowerment gives rise to the possible correlation between perceived client responsibility for diabetes care and client confidence in the ability to effectively comprehend and process information. As it cannot be assumed that this correlation exists, further research in this area would be beneficial to establish this correlation.

## 5.4.1.3. Decision-making

Although responsibility for diabetes care and decision-making are closely related, the analysis of the data from the interviews suggested the need for separate categories. One of the main themes which evolved from the data concerned the belief exhibited by most clients that they could not make appropriate decisions about their diabetes care due to an inability to read and/or a lack of knowledge. This belief was clearly seen in discussions about grocery shopping when clients stated that they often avoiding buying foods because they were unsure if the products were appropriate. Such action created feelings of helplessness when discussed with these clients. All of the clients commented that shopping for groceries was very difficult, especially when

they were alone. The clients that expressed the least negative comments about shopping were males whose wives were present for the shopping outings. All clients felt that their inability to read created the negative attitudes towards shopping. One client stated "Shopping makes me sad because I can't figure out all the labels and I don't know what to get". This lack of confidence in decision-making was also witnessed in discussions about eating outside of the home as clients expressed a lack of confidence in the ability to make appropriate food choices. Comments such as "I never know what to get in a restaurant" and "I can't read the menu so I don't go" were common and many avoided restaurants for this reason. Most noted discomfort at weddings and parties due to their inability to choose foods appropriately. Clients also indicated reservations about travelling because of the inability to make decisions relating to diabetes. One client did not travel at all for this reason. Another client stated that she worried constantly when travelling because she was unsure of appropriate diabetes behaviour.

The difficulty with decision-making relating to diabetes was noted by most clients to cause considerable stress. In discussing grocery shopping, one client stated that her blood sugars often increased after shopping as a result of the stress she experienced. Similar comments by other clients expressing feelings of frustration when shopping due to the inability to read labels were also recorded. Clients expressed frustration with their inability to prepare appropriate meals due to their inability to read diabetic cookbooks. One client commented "I would make better meals but I can't understand any of the cookbooks". She indicated that cooking was stressful for her because of her lack of reading ability.

The clients' negative attitudes and beliefs involving food acquisition are understandable. The high level of reading ability required to effectively make decisions in the purchase of groceries and meals in today's society is quite evident

when the amount of new products and new labelling that appears in the market is considered. Clients' discomfort in making appropriate food choices in social situations is understandable considering the strong emphasis on appropriate food choices in the management of diabetes.

The comments made by clients indicating difficulties in making decisions relating to diabetes and the noted stress involved with such decisions is not surprising especially when it is considered that decision-making usually involves problemsolving. The limited problem-solving abilities in the functionally illiterate population has previously been acknowledged (Doak et al., 1985). As information relating to diabetes involving activities such as shopping, meal preparation and travelling often requires problem-solving to translate into practical information, it is highly likely that members of this population would have difficulty and experience stress when making decisions involved in these activities.

On follow up, all clients expressed increased satisfaction with decision-making. As an example, clients expressed an increased confidence in their ability to shop. One client commented "I know what to get now and if I don't, I ask for help". All noted less confusion and a decrease in previously experienced frustration in shopping. The shopping tour was viewed favourably by the clients as the learning format provided concrete examples as witnessed by comments expressed during the focus group. Clients were also able to be actively involved in the learning process which enabled them to identify areas that were most important to them in their purchase of food. Clients increased confidence in the ability to purchase appropriate groceries confirms the importance of using learner-centered activities which provide concrete visual examples which do not require literacy abilities. In addition to shopping, some clients commented that meal preparation decision-making was less stressful and easier. Some had tried new foods and created new meals. Through the education program,

clients were able to learn how to prepare traditional foods in ways appropriate to diabetes. Problem-solving sessions allowed clients to volunteer favourite recipes to gain input from the educators and the other clients. This method was beneficial as clients were able to assist other clients and also have their own needs met. Clients indicated increased confidence in decision-making involving social situations, restaurant outings and travelling. All stated that they would not have reservations about such situations relating to their diabetes in the future. One client commented "We can go anywhere now".

The changes in beliefs and attitudes in decision-making reflect clients' ability to attain information and relate the information to their own life situations. Such changes, again, support the use of learner-centered activities which allow the clients to take information and use the information for practical application. The stress on problem-solving activities, in keeping with the progressive education approach, assists clients in developing problem-solving skills which can be used for decision-making relating to diabetes.

## 5.4.1.4. Quality of Life

During the interview, clients were asked to define their own quality of life. All clients indicated that family was part of their quality of life. The other aspects given by clients varied and included activities such as "going for a drive, going to the cabin and visiting family and friends". Church involvement, financial security, employment and daily activities in their lives such as cleaning and yardwork were also mentioned.

Most clients did not feel that diabetes affected their quality of life. One client indicated that high blood glucose levels did have a negative effect on her quality of life. Overall, clients struggled with this topic. Many expressed difficulty in defining their quality of life and required a great deal of prompting. Although, the vague comments elicited from clients when questioned using the term "quality of life" would appear to

indicate that diabetes did not impact on quality of life, other comments during the interview indicated that quality of life was impacted negatively by diabetes. The previously presented data indicating feelings of frustration in shopping, meal preparation, social situations and the ability to make appropriate decisions involving their diabetes care would indeed indicate a reduction in quality of life. As an example, most clients believed that meals had to be prepared differently for their families. Some expressed beliefs that the family members would refuse to consume diabetic meals which made meal preparation difficult and time consuming. One woman stated "I know my husband won't eat those meals so I don't make them" which she indicated bothered her. The contradiction in responses was also witnessed by one client's comment that diabetes did not affect his quality of life. The same man expressed difficulty in coping with the diagnosis of diabetes which he felt affected his family relationships. He was visibly upset when he asked during the interview "I know that my family worries about my diabetes and what if I get sick, who will take care of them?"

The results in this section of the interview were disappointing and reflect a weakness in the design of this study. Due to the difficulty in obtaining an appropriate tool to assess quality of life for this population combined with the philosophy of the progressive adult approach which promotes learner involvement, clients were asked to define their quality of life. The assumption that clients would have the cognitive skills necessary to provide such a definition was inappropriate. It has already been discussed that individuals with limited reading abilities often have difficulty with problem-solving (Doak et. al, 1985). Thus, the lack of expressiveness witnessed in this section of the interview should have been expected.

On follow up, most clients were more expressive in their responses. All felt that their quality of life had improved because of the education program. Examples such as initiating literacy tutoring and an increased ability to cope with diabetes were

outlined. One client commented "My diabetes is easier to manage and I'm happier". Another client stated ""Life is much easier now". However, the clients still needed a great deal of prompting in this section of the interview. Data throughout the interview indicated that quality of life had improved. For example, some clients indicated that they did not realize how little the preparation of traditional meals had to differ to create diabetic meals. One woman commented about her husband "I stopped frying and he hasn't said a thing about it". She commented that cooking one meal made her life much easier. This increase in quality life was witnessed as well with comments from the client who was having difficulty coping with the diagnosis of diabetes, as he indicated that his negative feelings had dissolved. He had realized that he was not necessarily going to die from diabetes and he now saw the disease as being manageable with positive outcome.

It has been previously discussed that quality of life is a philosophical issue. Clients' limited responses on quality of life make it difficult to conclude direct findings concerning quality of life. In can be elucidated from clients' comments in other sections of the interview that quality of life did improve due to the education program. Perhaps, it would be productive to discuss quality of life during an education program to allow reflection on this philosophical issue which would assist in program evaluation.

## 5.4.2. Program Evaluation

# 5.4.2.1. Head, Heart and Feet

The comments from the use of "head, heart and feet" (Figure 4) primarily concerned content of the program and the clients' predictions of what behavioural changes would occur as a result of the program. Clients indicated that the learning experience was positive and the specific behavioural comments, such as; "look after feet" and "test blood sugars", promote the concept that clients were able to incorporate

the information and skills learned into application in their day to day lives.

# 5.4.2.2 Focus Groups

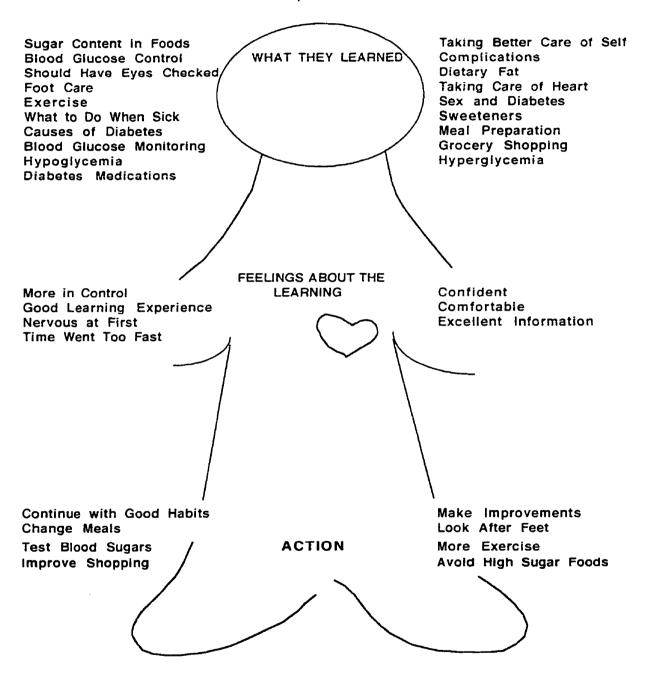
Clients' comments (Figure 5) about the program were positive overall. Clients indicated that they all had learned a great deal and were very pleased with information and skills that they had been able to acquire. They all indicated an increase in confidence in learning as the program developed. Client comments such as "I can't get over how much I learned" and "I never knew that there was so much to diabetes" were typical. These data were supported by client comments during the formative evaluations indicating that the information and skills learned were excellent and that the program was a good learning experience.

Clients enjoyed participating in the learning process. They commented positively about activities such as: role playing, brainstorming, drawing and games such as diabetic jeopardy and bingo. One client stated "I really liked participating, it was fun". Another client commented "It wasn't what I expected; I thought it would be like school".

Client feedback indicated that the methods employed in the education program were appropriate. The positive comments in the formative evaluation indicating that clients felt comfortable and that "time went too fast" supports client enjoyment of the methods employed. The positive learning experience indicated by the clients endorses the use of client-centered approach in the functionally illiterate population. The noted increase in clients confidence as learners also supports the use of this approach.

The numerous positive comments concerning the educational tools in the program suggest the need to use a variety of concrete educational materials which require limited reading ability to comprehend. Clients with limited reading abilities need information provided in ways which do not involve any great amount of problem-

FIGURE 4
HEAD, HEART AND FEET



Adopted from Educating for a Change (Arnold, Burke, James, Martin and Thomas, 1991)

## FIGURE 5

# FOCUS GROUP EVALUATION

## Information

- \*Excellent topics
- \*Everything covered was desired
- \*Easy to understand
- \*Interesting
- \*Useful

#### Methods

- \*Comfortable with participating
- \*Fun way to learn
- \*Liked the informal style
- \*Did not like when key words were written down
- \*Liked concrete examples (ie. drawing outline of shoe and foot to assess appropriateness of footwear)
- \*Easy to understand

# Materials and Activities

- \*Enjoyed going to the grocery store
- \*Videos were excellent
- \*Really liked the sugar and fat boards
- \*Posters were easy to understand
- \*Had fun with jeopardy and bingo
- \*Enjoyed role playing
- \*Liked drawing

#### Environment

- \*Comfortable
- \*Living room style was better than a classroom

#### Time

- \*Six hours per day was good
- \*Four days was appropriate
- \*Liked having the last day one month later
- \*Need a break every hour

## Other

- \*Would come back again
- \*Initially embarrassed about lack of reading ability
- \*Initially nervous

solving abilities (Doak et al., 1985). Concrete educational materials such as food models, sugar boards and grocery items, allow clients to incorporate ideas about aspects of diabetes into their lives and, thus, make appropriate changes.

The environment of the education program had a positive influence in creating a comfortable learning setting for the clients and the educators. The deviation from a traditional classroom-like setting was appropriate as indicated by the clients responses in the focus interview. These data are supported by previously outlined comments made during the formative evaluation indicating that clients were comfortable during the program. These data suggest that the program developed in this study was able to overcome the previously discussed negative hospital environment employed in traditional teaching methods (Griesbach, 1989). However, the potential in delivering education program outside of the hospital environment certainly deserves attention.

Overall, clients' comments about the learning process and outcomes were positive. The ability of the clients to make appropriate lifestyle changes through the intervention of the education program supports that the program was able to deliver appropriate outcomes. As previously noted, long term follow up is required to assess if these changes are able to be incorporated into long term behaviour.

## 5.4.2.3.Educator Evaluation

The educators comments are summarized in Figure 6. The educators both felt that the program was highly successful based on the positive comments by the clients and the noted increase in client quality of life, knowledge, skills and behaviour and the change in client attitudes and beliefs. The teaching methods employed were also very rewarding as the educators derived satisfaction in witnessing the clients' enjoyment and positive learning experiences. Both educators had previously used the paternalistic approach and had witnessed client boredom and dissatisfaction with the

#### FIGURE 6

## PROGRAM EVALUATION FORM: EDUCATOR INPUT

## Information

- \*Having the clients choose topics was important
- \*Information requested by the clients was relevant
- \*Having the educators participate in the topic choosing was important
- \*Knowing that the information was desired increased the educators' teaching satisfaction
- \*5 to 6 topics per day was an appropriate amount to cover

## Methods

- \*Clients responded well to group activities
- \*Asking for client input regarding the timing of topics was helpful to avoid overloading the clients
- \*The evaluation tool "Head, Heart and Feet" was an excellent tool
- \* Analogies were an excellent way of teaching
- \*Writing down key words was not appropriate
- \*Reviewing information and summarizing was very important
- \*Teaching method was tiring for the educators
- \*Decreased learner dependency was beneficial
- \*Teaching method was more time consuming then lecture style

## Materials and Activities

- \*Videos which summarized the previously covered topics were useful
- \*Videos should not be used directly after a meal due to tiredness
- \*More AV materials would have been helpful
- \*Going to the grocery store was time consuming but was an excellent activity
- \*Brainstorming, role playing and games were the most useful

# Environment

- \*Living room environment was excellent
- \*Informal atmosphere allowed educators to be more relaxed

## Time

- \*More breaks were needed
- \*Asking clients if they were tired towards the end of the day allowed appropriate adjustment of the schedule

#### Other

\*Extremely rewarding way of teaching

lecture format. Facilitation provided an opportunity for the educators to enjoy the education process as opposed to solely disseminating information. The adoption of this approach in the DEC for all client groups certainly supports these views.

One of the noted areas of concern in using this approach was the element of time as the educators found this approach to be very time consuming. However, effective education that takes a great deal of effort to perform is much more desirable than using ineffective educational methods which do not deliver positive outcomes.

# 5.4.3. Predominant Themes from the Qualitative Data

The analysis of the qualitative data suggests two main themes. The strongest theme involved the issue of client and educator confidence. There was a consistent increase in confidence expressed by clients in their abilities to learn and in their abilities to make decisions. This theme was witnessed in all areas of the qualitative data collection.

Increasing client confidence is essential in the promotion of client empowerment. For clients to make decisions and to be willing to learn new information and skills, it is necessary that confidence in these abilities exist, as witnessed in the results of this study. The vast amount of information and skills that are required for individuals with diabetes to cope with the day to day management of their disease make it necessary that clients have confidence in their abilities to comprehend new information and to make decisions involving this information. Clients who have limited reading abilities are presented with this challenge which is compounded by the challenge of existing in a literate society.

The theme of increased confidence was also strongly witnessed in the data from the educators' evaluation of the program. Using a new teaching method may be intimidating to many educators, especially when it deviates from traditional methods. Positive program experiences and outcomes confirmed the educators' beliefs that

client-centered education is a valuable method of teaching and increased the educators' confidence in themselves as diabetes educators.

The other main theme involved the issue of control. This theme was clearly witnessed when clients showed an increase in control in making decisions relating to diabetes care. Hussey et al., (1989) discusses this concept and uses the expression "locus of control" in the explanation of control in decision making. "Locus of control, a behavioural concept, concerns how a person perceives his/her (sic) ability to control and influence his/her life" (p. 608). Using this definition for discussion, clients were able to change their attitudes and beliefs concerning their perception of their control of diabetes care decisions. This change in client perception of control benefits the client as well as the diabetes care professional by reducing client dependency.

Empowering clients with limited reading abilities is an invaluable outcome of diabetes education program, especially when the lack of control commonly experienced by this population is considered (Ontario Frontier College, 1990). As well, in keeping with the progressive education approach, decisions made by the client are more valuable to the client as these decisions have more meaning.

The issue of power was also witnessed in the education program as there was a shift in power from the educators to the clients. This shift required a philosophical change in the educators' attitudes and beliefs in health education. The educators initially struggled with this concept due to fears that the clients would not be able to take on the role of educators and that information and skills perceived by the educators as being valuable would not be relayed. As the data suggest, these fears were ungrounded, however, the educators' experience with the transition to client-centered teaching has value for other educators who are seeking to adopt client-centered methods.

#### 5.5. Limitations

The attempt to develop and assess a non-traditional health education program resulted in research limitations which must be discussed. The lack of a control group in this study is a limitation as results from these research efforts were not able to be directly compared to other research efforts. However, the literature review and educational experiences of the researcher strongly indicated that the paternalistic approach typically employed in diabetes education programs is not effective. The primary aim of this study was not to compare results of this research with other research outcomes. Instead, the primary aim of this research was to assess if client-centered teaching was valuable in the education of functionally illiterate clients with diabetes.

In addition to the lack of a control group, the small sample size may be construed to be a limitation as the limited numbers presented difficulties in making generalizations. However, the significant amount of qualitative data generated by the participants allowed for a comprehensive evaluation of the program.

The greatest limitation of this study was the lack of long term follow up. The two month follow up did not allow any significant conclusions concerning long term implications of the intervention. As diabetes is a chronic disease with the potential of long term complications, a longer follow up period would have been valuable.

#### 5.6. Conclusions and Recommendations

The findings of this study indicate that client-centered education is an effective means of providing comprehensible information to functionally illiterate individuals with diabetes which can be used for practical application in the management of diabetes. The use of client-centered education not only provides comprehensible information to these individuals, it also promotes an increase in client confidence in

learning abilities and decision-making. Results of this study suggest that client-centered education benefits the client by improving quality of life and promoting client empowerment and benefits the educator by reducing client dependency and increasing educator satisfaction in diabetes education efforts. The results of this study are encouraging, however, further research is needed to conclude if the education program outlined in this study is effective in achieving similar long term results. Future research evaluating client-centered education of the literate population is also an area which merits attention.

In addition to providing effective education to individuals who are functionally illiterate, the client-centered approach demanded a transition from the traditional quantitative evaluation of diabetes education programs to a predominately qualitative approach. Through the use of qualitative methods, in-depth insight into clients' attitudes and beliefs was experienced. Through qualitative methods, valuable information was also obtained for the use of program evaluation. The findings of this research indicate the merit of qualitative evaluation in health education programs and future research attempts utilizing such methods are recommended.

The results of this study indicate that a learner-centered education program which addresses the attitudes and beliefs of clients is a successful and effective means of educating the functionally illiterate adult population with diabetes.

Considering the high level of illiteracy in Canada and the difficulty in assessing literacy levels in the health care setting, developing programs which are geared for the functionally illiterate client would be advisable. Providing such programs would promote accessibility of comprehensible information relating to diabetes to the majority of the population and would address one of the inequities which presently exists in the provision of diabetes education.

#### 5.7. Final Reflections

Client-centered education has been discussed as being a process as opposed to being an outcome. In reality, client-centered is much more than this abstract definition. Client-centered education is an attitude which requires that the educator not only change methods of teaching, in addition, the educator must make a conceptual transition from the traditional philosophical framework of paternalism to a philosophical framework which promotes the client as decision-maker in health-related matters and in health education. This transition is the greatest challenge for the educator who wishes to adopt client-centered methods.

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#### APPENDIX A

## SAMPLE DESCRIPTION OF EDUCATION METHODS

Topic:

Introduction to the program

Place:

Main diabetes education room

Methods:

Group discussion

Brainstorming

Materials:

Flipboard

Goals:

- 1. To create an atmosphere in which all participants are relaxed and comfortable.
- 2. To have clients realize their role in the education process.
- 3. To have clients realize that the decisions relating to their diabetes care belong to them.

Objectives:

- 1. To review the goals and objectives of the program.
- 2. To review methods which can be utilized during the program.
- 3. To allow clients and educators to become familiar with individual backgrounds, experiences and ideas.
- 4. To determine the format of the program.

Content Outline	Activities
Goals, objectives and methods of the program are reviewed.	Educators present the goals, objectives and methods of the program.
Idea, experience and background sharing.	Group discussion
3. Education format created.	Brainstorming

Topic:

What is diabetes?

Place:

Main diabetes education room

Methods:

Group discussion Brainstorming Team project

Materials:

Flipchart

Digestion poster

Handouts about diabetes

Goals:

- 1. To allow clients to understand diabetes as it relates to them and in general.
- To have clients realize their existing knowledge about diabetes.
   To have clients realize what aspects of diabetes they wish to learn.
- 4. To educate clients about diabetes.

Objectives:

- 1. To gather a composite of the group's knowledge about diabetes.
- 2. To have the group decide upon a working definition and explanation of diabetes.

	Content Outline	Activities
1.	A composite of the group's knowledge about diabetes.	Brainstorming Group discussion
2.	Creation of a working definition and explanation of diabetes.	The group will divide into pairs. Each pair will create an explanation and definition of diabetes. The pairs will present the concepts. The group will use the concepts to develop a group explanation and definition of diabetes

Topic: Treatment of hypoglycemia

Place: Main diabetes education room

Methods: Group discussion

Brainstorming Problem-solving

Materials: Flipchart

Goal: For clients to understand hypoglycemia and its treatment

Objectives: 1. To have clients recognize the symptoms of hypoglycemia.

2. To have clients determine the causes of hypoglycemia.

3. To have clients determine the proper treatment of hypoglycemia.

_	Content Outline	Activities
1.	Determination of the symptoms of hypoglycemia.	Group discussion
2.	Determination of the causes of hypoglycemia.	Brainstorming
3.	Determination of the proper treatment for hypoglycemia.	Problem-solving. The group will divide into two groups and report their conclusions to the group. The group will decide on an appropriate overall conclusion.

#### APPENDIX B

## **PROGRAM TOPICS**

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- 2. Hyperglycemia
- 3. Hypoglycemia
- 4. Blood glucose monitoring
- \* 5. Alcohol
  - 6. Diabetic meal planning
  - 7. Sugar content in foods
  - 8. Stress
  - 9. Long term complications of diabetes
  - 10. Grocery shopping
  - 11. High blood pressure
  - 12. Foot care
  - 13. Exercise
  - 14. Cholesterol
  - 15. Eating out
  - 16. Travelling
  - 17. Guidelines for iliness
- 18. Coping with diabetes
- +19. Reducing body weight
- \* 20. Sexuality and diabetes
- 21. Diabetes medications
- \* 22. Insulin
  - 23. Cooking
  - Topics not chosen by Group 1
  - + Topics not chosen by Group 2

### APPENDIX C

### CONSENT FORM

name:	Date:
	Meeting the Needs of the Functionally Illiterate Adult Population in Newfoundland: A Diabetes Education Program
know al	ction: You are asked to be part of a study. It is important that you bout the information in this paper. If the information does not make you, tell us.
	up to you to decide if you want to be part of this study. If you do not,

2. You can stop being part of the study at any time.

The Reason for the Study: This study is to see if the diabetes program used at this hospital is good for people who do not read well.

The Way the Study Works: You will come to the hospital in Grand Falls-Windsor for this study on six different days.

- 1. The first time will be to talk to the nurse and dietitian about your diabetes. We will send you to the lab for a blood test on this day.
- 2. The second, third and fourth days will be the teaching days. These days will be July 6,7 and 8, 1993.
- 3. The fifth day will be on August 4, 1993. This is a teaching day.
- 4. The sixth day is on September 2, 1993. On this day, the nurse and dietitian will talk to you about your diabetes again. We will send you to the lab for a blood test on this day.

**Risks:** -There are no risks.

- -You may find some discomfort with the blood testing.
- -You may have a difference in your blood sugars.
- -Coming to the hospital so much may be hard for you.

<u>Benefits</u>: You will learn more about diabetes. Learning about diabetes should help you to make decisions about your diabetes care. Learning about diabetes should make it easier for you to take care of your diabetes. Learning about diabetes should help improve your life.

<u>Confidentiality</u>: If the results of this study or published or discussed at meetings, your name will not be used. This study will follow the rules of confidentiality of The Central Newfoundland Regional Health Center.

## Please Fill Out

have been given a chance to disc part in this study.	cuss it and ask questions. I agree to take
Signature of Participant	
Witness	Heather Stevenson, R.Dt., CDE

Debbie Byme, R.N.,B.N.,CDE

I have read and/or listened to the reading of the explanation of this study. I

#### APPENDIX D

#### LITERACY LEVELS

- LEVEL 1 Canadians at this level have difficulty with printed materials.

  They most likely identify themselves as people who do not read.
- LEVEL 2 Canadians at this level can use printed materials for limited purposes only, such as, finding a familiar word in a simple text. They would likely recognize themselves as having difficulty with common reading levels.
- LEVEL 3 Canadians at this level can use reading materials in a variety of situations, provided the material is simple, clearly laid out and the tasks involved are not too complicated. While these people generally do not see themselves as having significant reading difficulties, they tend to avoid situations which require reading.
- LEVEL 4 Canadians at this level meet most everyday demands. This is a diverse group which exhibits a wide range of reading skills.

#### APPENDIX E

### KNOWLEDGE RELATING TO DIABETES CARE TEST

Please listen to each statement. Tell me if you think it is True or False.

- 1. Exercise usually increases blood sugar.
- 2. If you have diabetes, it is best to eat only one meal a day.
- 3. A good bedtime snack for someone taking insulin is a piece of fruit.
- 4. If a person has diabetes, drinking alcohol usually decreases blood sugars.
- 5. The best times for someone with diabetes to test their blood is before meals.
- 6. People with diabetes should soak their feet in hot water every day.
- 7. When a person with diabetes is having a low blood sugar reaction, they should eat a candy bar.
- 8. Insulin is made by your liver.
- 9. Kidney disease can happen to people who have diabetes for a long time.
- 10. Stress can increase blood sugar levels.
- 11. Butter has a lot of sugar in it.
- 12. When someone who has diabetes is sick, they should stop taking their insulin or diabetes pills.
- 13. Symptoms of diabetes can include: being thirsty, having to pee a lot and blurred vision.
- 14. When someone has diabetes, they can drink unsweetened juice whenever they want.
- 15. People with diabetes should avoid eating out.

## Answer Key

- 1. False 2. False 3. False 4. True 5. True 6. False 7. False 8. False 9. True 10. True 11. False 12. False
- 13. True 14. False 15. False

## APPENDIX F

## BEHAVIOUR AND SKILLS QUESTIONNAIRE

Exercise  Do you exercise?  What do you do for exercise?  How Often?  For How Long?	
Home Glucose Monitoring Do you test your blood? How often? When? What do you do with the results?	
Medications (if applicable) What time(s) of day do you take your insulin/diabetes pills? Do you ever not take your diabetes pills/insulin? Where do you give your insulin?	
Foot Care Do you check your feet? How often? How often do you wash your feet? Do you soak your feet in hot water? How often? Do you cut your own toenails? How do you cut them? What kinds of shoes do you wear? What kinds of socks do you wear?	
Food Habits How often do you eat fried food? How often do you eat sweets? What do you drink when thirsty? Do you skip meals? Do you skip snacks? Do you follow a special diet for your diabetes?	

Page 2
Diet History: Please tell me what you usually have in a day to eat and drink.
Breakfast
Dinner
Supper

Snacks

#### APPENDIX G

## ATTITUDES, BELIEFS AND QUALITY OF LIFE INTERVIEW GUIDE

<u>Topic 1</u>: Learning about diabetes Feelings about learning

Ability to learn

Perceived benefits from learning

Topic 2: Diabetes care responsibilities

Prompts: Who is responsible?

Client's role

Feelings about decision making involving diabetes care

<u>Topic 3</u>: Insulin and diabetes medications (if applicable) Prompts: Feelings about taking insulin and diabetes pills

Ability to give insulin

Effect of insulin or diabetes pills on lifestyle

Topic 4: Blood glucose monitoring Prompts: Feetings about testing

Ability to test Effect on lifestyle

Topic 5: Shopping

Prompts: Feelings about shopping

Ability to read labels and choose appropriate food items

Effect on lifestyle

<u>Topic 6</u>: Meal Preparation

Prompts: Feelings about cooking for diabetes

Ability to prepare appropriate meals

Effect of diabetes meal preparation on family life

<u>Topic 7</u>: Family Life Prompts: Support?

Effect on family relationships Effect on family lifestyle

Topic 8: Social Situations

Prompts: Eating Out

Parties, weddings etc.

Travelling

# Page 2

Topic 9: Exercise

Prompts: Feelings about exercise

Ability to exercise

Topic 10: Prompts: Overall effect of diabetes on life

Client definition of what composes his/her quality of life Effect of diabetes on different aspects given

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REGIONAL CLINICS AT: ST ALBAN'S, LEWISPORTE MOSE AMBROSE, HERMITAGE

4 March 1993

Miss Heather Stevenson Regional Dietitian\Diabetes Educator Central Newfoundland Regional Health Center

Dear Miss Stevenson:

At its meeting March 3, 1993, the Board's Ethics Committee considered your research proposal entitled "Meeting the Needs of the Functionally Illiterate Adult Population in Central Newfoundland: A Diabetes Education Program".

We find your proposal to be in keeping with the requirements of the committee with respect to human investigations.

We wish you well with your study and look forward to reading your findings.

Yours sincerely,

A.N. LUDLOW

Secretary

Board of Trustees

ANL\lb

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