

THE UNIVERSITY OF CALGARY

“It’s my way of life.”

**Perceptions of Patients with Type 2 Diabetes Regarding
Self-management and Community Resources**

by

Maria Rosario Talavera

A THESIS

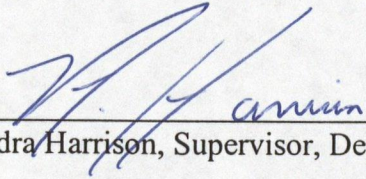
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APPROVAL PAGE

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "*It's my way of life.*" Perceptions of Patients with Type 2 Diabetes Regarding Self-management and Community Resources, submitted by Maria Rosario Talavera in partial fulfillment of the requirements for the degree of Master of Medical Science.



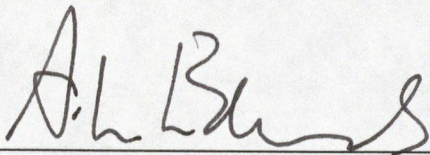
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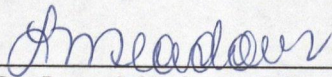
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ABSTRACT

Objective: To explore perceptions of patients with Type 2 diabetes about diabetes self-management and the community resources they need to achieve their management goals.

Methods: This qualitative study included ten patients, each of whom had completed a 6-hour diabetes education program at the Diabetes Education Centre, and had attended at least one session with a nurse and a dietitian to set self-management goals. The open-ended interviews, conducted between Oct 2001 and Feb 2002, were transcribed verbatim. Analysis was carried out through the identification of codes, refining of categories and subcategories, and the building of themes.

Results: Twenty subcategories were grouped into six categories. The overall views of the participants were captured in the quotation, "*It's my way of life.*" Participants identified five main themes of self-management: 1) Personal Care (activities under a patient's control); 2) Co-habitant Support (support from people sharing accommodations); 3) External Support (input from health providers and others); 4) The Balanced Patient (stable care and control); and 5) The Holistic Approach (overall health and wellness). A dynamic model was developed to illustrate the ways in which these components interrelate. The model identifies the following patient stages: Balanced, Neglected, Solitary or Reluctant.

Conclusions: The self-management activities of patients and their use of community resources were found to be key factors in achieving general health as well as diabetes control. Education was a positive influence on these factors. This study demonstrated that in order to provide high quality clinical care, patient views must be considered and intervention strategies must be tailored to their lives, rather than focused on the disease alone. Providers must work to help patients integrate self-management skills and policy makers and providers should promote partnerships with community organizations.

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DEDICATION

This work was done in memory of my parents Maria Luisa & Israel Ugarte-Morales. I have been inspired by their unconditional love and working spirit. Thank you for being my role models, for inspiring me to do my best and for teaching me about God:

God never promised skies always blue,
Flower-pathways our whole lives through;
God never promised the sun without rain,
Joy without sorrow, or peace without pain.

God only promised us strength for the day,
Rest for our labor, and light for the way,
Grace on the path, and help from above,
His unfailing sympathy and undying love.

Author Unknown

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CHAPTER I - INTRODUCTION

I. Introduction

This chapter provides an overview of the thesis. It also introduces and defines key concepts relating to this study including chronic disease, diabetes mellitus, self-management, and community resources.

II. Overview

This thesis is organized into six chapters. In Chapter 1, an overview of the thesis and key concepts related to the research are presented. Chapter 2 summarizes the literature review of self-management, chronic care and community resources and introduces the study objective and the research question. Chapter 3 provides information on the research design and methodology used in this qualitative study. Chapter 4 reviews the participants demographics compared to that of non-participants and to the entire DEC patient population. Also described are the themes, categories, and subcategories that have emerged from the data and patient perceptions about self-management and community resources. Chapter 5 contains a discussion of the results of the study. A self-management model is introduced and is used to illustrate the relationships between the different types of support that form the basis for the balanced patient. The findings are compared with those of previous studies, and the measures taken to maintain rigor in the investigation are detailed. Chapter 6 concludes with suggestions for health care providers and policy makers, propositions for future research, and outlines the significance, strengths and limitations of the study.

III. Key Concepts

A. Chronic Diseases

Chronic diseases are costly both to the health care system and to the patient. The number of individuals affected by chronic disease is increasing in Canada as the population ages. The Centres for Disease Control (CDC) define chronic diseases as “illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely.”¹ Chronic diseases represent a significant burden to Canadian society, as they are the leading causes of illness, disability, and death, as well as a major factor in the loss of productivity and constraints on lifestyle. Canada also lacks a comprehensive system for the monitoring and management of chronic diseases.² In 1993, \$45 billion was spent in Canada on caring for the 25% of the population who suffer from chronic conditions.³ The Canadian system of care for chronic diseases is deficient in a number of areas that include: limited time for physicians to follow established clinical guidelines, a lack of coordination of care, a lack of timely follow-up, and limited patient education. Chronic illnesses challenge patients and their health care providers with the burdens associated with controlling the disease.⁴ These patients can improve their health status and physical activities through the early identification and treatment of exacerbations and complications, as well as through applying their knowledge and skills learned through self-management education.⁵

B. Diabetes Mellitus

Diabetes mellitus is a chronic condition that affects approximately 6% of the population, which is the equivalent to over two million patients in Canada, although only about half of these are diagnosed cases.⁶ Diabetes ranks as the seventh leading cause of

death in Canada. In economic terms, the burden of diabetes due to health care costs, disability, loss of productivity and premature death is estimated at over 9 billion, annually.⁷ It affects about 50,000 patients within the Calgary Health Region (CHR). Improvements in both early detection of the disease and management strategies are needed for better diabetes care. According to the CDC, diabetes mortality continues to increase, despite an overall decrease in other causes of death.⁸

There are three types of diabetes: Type 1, Type 2 and Gestational Diabetes Mellitus (GDM). Type 1 diabetes, or insulin-dependent diabetes mellitus, is caused by an autoimmune response that destroys pancreatic islet beta cells, resulting in the loss of insulin production in the body. Roughly one half of all new Type 1 cases are young adults. Type 1 diabetes accounts for approximately 10% of the individuals diagnosed with diabetes. Currently, the onset of Type 1 diabetes cannot be prevented, there is no cure, and patients must continue insulin treatment.

Type 2 diabetes, or non-insulin dependent diabetes mellitus, is characterized by a lack of symptoms and accounts for approximately 90% of all diabetics in developed countries. Symptoms may be overlooked for many years, and the disease is often, but not always, associated with obesity, inactivity and poor diet. It is, however, the most common cause of renal failure, lower limb amputation, and blindness in adults. Type 2 diabetes research indicates that lifestyle is a major contributing factor to the development of the disease. It is often mistakenly referred to as 'mild diabetes.'

Diagnosis usually occurs after the age of 40, but has recently been appearing in the younger segment of the population with higher frequency. Recent epidemiological data reports a growing incidence and prevalence of both Type 1 and Type 2 diabetes.

Since the prevalence of diabetes increases with age, it has been suggested that the incidence and prevalence of diabetes is approaching with epidemic proportions.⁹

While chronic diseases cannot be cured, they can be managed. The Diabetes Control and Complications Trial 1993 (DCCT) compared conventional insulin therapy and intensive insulin therapy for Type 1 patients over a period of six years. The U.K. Prospective Diabetes Study 1996 (UKPDS) demonstrated the positive effects of improved glycemic control for Type 2 patients. Both the DCCT and the UKPDS show delayed and slower onset of retinopathy and nephropathy through tight blood-glucose control.^{10, 11}

GDM is a type of diabetes that occurs in mothers during pregnancy and often disappears after giving birth. It occurs in about 4-6% of pregnancies in developing countries and significantly increases the risk of perinatal morbidity and mortality. Strict control of blood sugar levels is required throughout pregnancy to avoid adverse outcomes for either mother or child. GDM also substantially increases the mother's lifetime risk for developing Type 2 diabetes.

C. Self-management

The concept of self-management is not a new one. It is widely recognized as an important component of chronic disease management.¹² Since 1920, patient education has been held to be an essential therapeutic tool and has emerged as an integral component of a comprehensive diabetes management program.¹³ Generally, it is anticipated that patients will learn to deal with their diabetes so that the illness will intrude less at the personal level and allow them to function more effectively within their community, home, and work environments. The successful management of a chronic

illness depends heavily on the patient's ability to deal effectively with the self-management challenges presented by the illness and its treatment. The content and consistency of effective interventions tend to:^{5, 14}

- 1) emphasize the acquisition of skills rather than just knowledge;
- 2) encourage patient self-monitoring rather than promote dependency;
- 3) systematically bolster confidence rather than encourage doubt; and
- 4) pay attention to patient demographics, the influences of family, work, and other social factors rather than focus only on patient complaints and symptoms.

Self-management is defined as: "the action or practice of supervision or control of one's self."¹⁵ As point four above emphasizes, resources within the individual's community are an important factor in self-management.

D. Community Resources

Community is defined as specific groups of people, often living in a defined geographical area, who share common culture, common values and norms, and are arranged in a social structure according to relationships that the community has developed over a period of time.¹⁶ The Ottawa Charter's definition of community action for health includes individual participation and organization within an empowered community as providers of social support for health.¹⁷ Through participation, individuals and organizations provide support for health and gain increased influence and control over the determinants of health in these communities. Effective chronic disease management requires that the organized health care system be appropriately linked with the necessary community resources.¹⁸

Informal interpersonal environments such as the patient's physical environment and geographic region form part of the definition of community. The Oxford dictionary defines community as a body of people living in one place, district or country that is considered as a whole. People belong to a number of communities and the meaning hinges on the concepts of togetherness and sharing. For example, aspects that can improve community participation are housing tenure and car access. These factors are also related to morbidity and mortality because of the potential to improve health by increasing access and providing health-promoting resources. They influence community interactions and the relationships that patients have within their communities.¹⁹

IV. Conclusion

The key concepts of this research have been introduced in this chapter. In chapter 2, the relevant literature is presented in more detail followed by the study objective and the research question.

CHAPTER II - LITERATURE

I. Introduction

This chapter provides a summary of the current scientific literature related to self-management, chronic care, and community resources. In addition, it introduces the objective and the research question of this study.

II. Literature Review

The goal of this study is to contribute to the understanding of patient perspectives, particularly those with Type 2 diabetes, on the subject of ‘self-management’ and how it interacts with the use of community resources. In qualitative research, investigators should be discouraged from imposing ideas from published studies on the information that emerges from their own research. To avoid this problem, the investigator should ‘bracket’ the information from the literature. Bracketing means that the information gleaned from previous work is not used to direct the study. A literature review is used to update and guide the investigator in identifying, evaluating and comparing his or her developing knowledge with what is already known.²⁰ In addition, it helps in the development of the questions for the interview guide. In light of this goal, a review of the literature about topics relevant to this study is presented in this chapter.

A. Self-management

The ability of patients to manage their illness is enhanced by support programs designed to increase confidence and skills in self-management. This process is also supported through the development of positive relationships with the health care team, so

that both health-care provider and patient share in decision-making and treatment planning.²¹ The successful management of the disease depends on the patient's ability to deal with its challenges and treatment. Diabetes self-management includes: taking medication regularly, monitoring oneself with the objective of keeping glucose levels within a target range, changing one's lifestyle (especially through healthy eating and adequate levels of physical activity), dealing with emotions, and collaborating with the members of the health care system. The resulting self-management influences both the physical and psychosocial disease-related factors.²²

Management of Type 2 diabetes requires complex, demanding, round-the-clock, self-care behaviours and lifestyle changes. These changes are not limited to taking medications and frequently monitoring blood glucose levels but also require adjustments of diet and physical activity. Failure to follow treatment recommendations is reported as a serious problem in patients with Type 2 diabetes.^{23,24} Disease management is defined as an organized, proactive, approach to health-care delivery. Care is integrated across the spectrum of disease and its focus is on the prevention or delay of complications and co-morbid conditions. Diabetes self-management education interventions are often effective in improving health outcomes.²⁵ Over the years diabetes self-management has evolved to the point where it is now considered an integral component of comprehensive diabetes management.²⁶

The Alberta Heritage Foundation for Medical Research (AHFMR) conducted a review of literature on the management of Type 2 diabetes in February of 2001. They reported that there is a lack of information concerning the perceptions of patients with Type 2 diabetes regarding self-management. It was determined that there was a need to

conduct research to identify the views of patients regarding the meaning of self-management and their perceptions about how to improve their ability to self-manage their disease.²⁷ Prior self-management research has focused almost wholly on clinical outcomes at the individual level and on effects at the system level. Research is very limited regarding patient perspectives. The AHFMR suggested that formal diabetes self-management should:

- be an ongoing patient-centred process, based on the individual patient's needs and abilities;
- focus on both educational and behavioural strategies;
- be sensitive to the elements of a patient's social and environmental context that support or hinder compliance and adherence to self-management behaviours;
- complement the services provided by other diabetes care members, including services from primary care providers and mental health professionals;
- allow the patient to frequently access expertise for problem solving measures;
- allow a close collaboration between the patient and the health care team;
- allow positive reinforcement of learned skills, healthy behaviours and opportunities for repetition;
- include periodic follow-up components with a re-assessment of barriers to ensure continuity;
- use both individual and group sessions; and
- offer information in multiple formats, to complement, but not replace, human interaction.

Previous studies have suggested that the process of understanding self-management consists of three phases: management-as-rules, management-as-work, and management-as-living. These phases are not primarily about medical issues, but rather take into account an individual's social, cultural, and philosophical nature. Patients identify management as producing good health, with good health as the optimum goal. However, the complexity and unpredictability of the diabetes management process often makes self-management problematic for many patients.²⁸ In addition, it has been pointed out that the approach of patients toward self-management practices is determined largely by their attitude.²⁹

In a previous qualitative study of self-management, M.J. Price suggests that learning self-management can be viewed as a two-phase, five-stage process. The first phase involves the patient's search for an answer to the question, "What works for me?" This phase ends when management becomes routine and the patient moves on to a "good enough phase." In this phase, patients achieve their goals based on personal realities due to the constraints of the disease process. When patients encounter new situations, they are found to have little confidence in their ability to manage and they begin the process again. She concludes that diabetes self-management is learned over time.³⁰

Patient perspectives about the experiences of having Type 2 diabetes have been given some attention in medical research. Hernandez takes a grounded theory approach and reports on the perceptions and experiences of First Nation adults in Canada becoming individuals with diabetes. She examines the process of how they have incorporated diabetes into their lives and lifestyles.³¹ She pushes for a reassessment in the role of the person with diabetes in his or her own care, and she suggests that becoming diabetic is a

process, not an event. Participants in her study looked for a give-and-take relationship with health care professionals. Diabetics are experts in their disease and their particular situation and health care providers are experts in the general science of diabetes.

Hernandez found a three-phase process of integration of the disease. The first phase, 'having diabetes', begins with the patient's diagnosis and is characterized by a lack of knowledge and a disinterest in diabetes. The second phase is heralded by a 'turning point', or a significant life event that happens to the individual. The last phase includes the application of 'the science'. In other words, the patient finds a personalized science of living with diabetes.

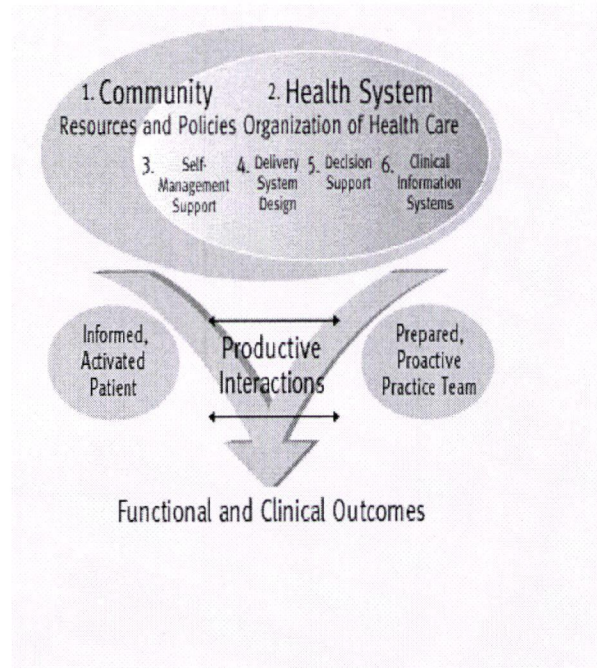
The patient's perception of the content of a diabetes educational program is important. Some studies found that patients believe that diabetes education emphasizes the dangers of diabetes without providing relevant information on solutions. In addition, studies indicated that patients do not accept the term "diabetes control" and only use it to communicate with health care providers. It is essential that health care providers be involved for patient self-management education to be effective. Patients stated that physicians often did not have enough time to answer all their questions or to talk to them about all their feelings.³²

B. Chronic Care Model

The Chronic Care Model, developed by Dr. Ed Wagner of the Sandy MacColl Institute for Healthcare Innovation, provides one approach to chronic care. His model has been supported by both research and practice. The model promotes cooperative programs that work towards reducing disability and improving the care of patients with diabetes. The collaboration between the health care system and community partners is

the foundation of the model. Central to the model are the proactive interactions that take place between patients and health care providers. These interactions are supported by the following four components: 1) self-management intervention; 2) a delivery system with current practices reorganized to meet patient needs; 3) decision support ensuring that health care providers have the necessary expertise and training; and 4) a clinical information system that supports population-based care.³³

The chronic care model identifies the fundamental elements of a system that encourages high-quality chronic disease management. Concentration on the four components mentioned above should foster productive interactions between patients who take an active role in their care and proactive providers who offer expert advice, constant encouragement and guidance. These elements combine to augment interactions between health care providers and patients in order to improve outcomes.³⁴ These “Productive Interactions” include methodical assessments of functional and clinical status, treatment planning, effective treatment implementation, and the sustainability of patient self-management tasks, as well as planned patient follow-up. These interactions are shaped by factors such as occupation, ethnicity, age, along with co-workers, family, friends and personal relationships.³⁵

Figure I. Wagner's Chronic Care Model ^{36, 37}

The model represents the views of health care providers and has been used to effectively manage chronic illnesses. It works toward decreasing complications and enhancing the quality of life. Although the focus of this study is diabetes, it is important to note that diabetes has been used as a prototype of care for other chronic conditions because of its clinical, epidemiological, and economic impact. The collaboration between the health care system and community organizations could enhance the ability of many patients to function, expand their knowledge of the disease and gain insight into self-care and self-management behaviours.³⁸ The only community resource identified in Wagner's chronic care model is the practice of having medical diabetes specialists visit family physician's offices to provide specialized care in the community.

C. Community Resources

Health-promoting capability for effective community participation in health includes the availability of accurate information and the possibility of timely revision to existing systems and practices.³⁹ In addition to promoting individual participation, the Ottawa Charter recognizes that health determinants are prerequisites for health and access to these prerequisites cannot be ensured by the health care sector alone.¹⁷ The main areas of action related to community action and self-management are as follows:¹³

- Create supportive environments to ensure a positive impact on individuals' health.
- Develop personal skills to enable people to have the knowledge and skills to meet life's challenges and to contribute to society.
- Strengthen Community Action so that the community has the capacity to set priorities and make decision on issues that affect their health.

Enhanced access to services and the desire to improve performance and quality lead to greater intersectoral cooperation, problem solving, analysis and revision of provisions. People should be progressively more involved as full partners in the health process, in the identification of needs and, in planning and implementing programs.⁴⁰

Community control means that the decision-making processes and organizational configuration within a community are specifically intended to give all community members the power to manage their own affairs. A prerequisite for a community's ability to meet the needs of its people is the proper management of allocation and community improvement resources.⁴¹

Macintyre states that partnerships with organizations outside the health care system should be established by identifying community organizations that patients perceive as important. In addition, it is essential to ensure that extra resources are

allocated towards the promotion of partnerships between the health care system, local government and other agencies.⁴² It is anticipated that the effective use of community resources may enhance the care of the patients in their communities and thereby improve health outcomes.⁴³ Community resources may be able to influence chronic illness care by providing services that help patients achieve their management goals. Strong support links with appropriate community resources for services such as support groups, transportation, and exercise programs are likely to increase the use of such services.

III. Study Objectives

The objectives for this study were to explore patient perceptions about:

- 1) the meaning of diabetes self-management; and
- 2) the community services and support they need to achieve self-management goals.

This study builds on the Wagner's Model, but assumes a broader view of community.

IV. Research Question

Previous self-management studies looked at the views of patients regarding the process and attitudes of learning diabetes management. A review of the available literature identified a lack of information concerning the perceptions of patients with diabetes regarding self-management. From this review, it was determined that there was a need to conduct research to determine patient views on this subject.

The literature on chronic care advocates collaboration between the health care system and community resources. A void exists when examining the utilization of community resources beyond the health care system. Consequently, this study attempts

to identify which community resources, outside of the health care system, patients are using to achieve their self-management goals and to understand how patients use these resources. The research question of this study is: What are the perspectives of patients regarding diabetes self-management and the community resources necessary to fulfill their self-management goals?

V. Conclusion

This chapter provided information about the relevant literature regarding self-management, the Wagner's Chronic Care Model and community resources. The study objectives and research question are presented. The purpose of this study is to contribute to the body of knowledge about self-management from patient perspectives. Self-management is viewed as one of the central tasks confronting patients as they cope with their illness and understanding a patient's view of this task would be invaluable. The research design and methodology of the study is presented in the next chapter.

CHAPTER III - METHODOLOGY

I. Introduction

This chapter presents an overview of the study design and includes descriptions of the study sample, method of data collection, and data analysis as well as the ethical considerations taken into account when conducting this study.

II. Research Design

A qualitative design was chosen for this exploratory study. Qualitative inquiry often entails the collection and synthesis of text data. Qualitative methods are particularly appropriate for studies in which the context is important, variables are unknown, and there are no established theories from which to generate hypotheses that can be tested quantitatively. The process is characterized by the search for meaning in a particular setting in which informants are considered active forces.⁴⁴ Qualitative methodology is especially useful when there is limited information available on the topic under study.⁴⁵ A qualitative design was used for this study because of the limited information currently available regarding the perspectives of patients with diabetes regarding self-management and need for community resources.

Qualitative research is a systematic inquiry that occurs in a natural setting with minimal manipulation by the researcher. The primary principles of qualitative research are the familiarity, meaning and perceptions which are revealed by the participants and the researcher's insights and understanding of the phenomena.⁴⁶ This kind of design allows for greater depth of understanding and enriches collected information as a result of the intensive contact with the participant's natural setting, an interactive process between

the researcher and the participant, flexibility in data collection, and the weight given to the views of the participants.

This study is based on the following three fundamental concepts described by Morse:⁴⁷

1) perspectives, 2) contexts and 3) approaches or processes. It applies the following:

1. *The emic perspective* - obtained from the views, understanding or experience of the informants rather than from the researcher's perspectives. Using this perspective requires identifying the beliefs and values of the participants that are relevant to the phenomenon under study.
2. *The holistic perspective* – includes the fundamental values of the context as part of the phenomenon. It examines multiple viewpoints in a natural setting.
3. *The inductive and interactive processes of inquiry* – require that both the researcher and the informant understand the phenomena.

“Research is to see what everybody has seen and to think what nobody has thought.”

Albert Szent-Gyorg^a

Qualitative research depends on descriptive text data, so the researcher leads the reader to an understanding of the phenomena under study. Morse suggests the following steps:⁴⁸

- 1) Locate within the personal experience, key phrases and statements that speak directly to the phenomenon under study;
- 2) Interpret the meaning of these phases as an informed reader;
- 3) Obtain the interpretation of the participants about these findings;

^a Good, IJ. The Scientist Speculates: an anthology of partly-baked ideas. 1962. New York BasicBooks

- 4) Inspect these meanings for what they reveal about the essential, recurring features of the phenomenon being studied; and
- 5) Offer a tentative statement or definition of the phenomenon in terms of the essential recurring features identified in step 4.

III. Participants' Context

A. Calgary Health Region Programs and Services for Patients with Diabetes

Approximately 50,000 individuals in the CHR have diabetes. Diabetes can lead to complications such as blindness, renal disease, heart disease, and lower limb amputation.⁴⁹ The majority of diabetes cases are diagnosed and managed by family physicians. However, a typical visit to a doctor's office is insufficient for physicians to prepare newly diagnosed people with diabetes to deal with the changes in diet, exercise, and medication they need to make to achieve the glycemic control that ensures optimal management.⁵⁰

The Canadian Council on Health Services Accreditation identified a number of access points for diabetes care.⁵¹ The Council acknowledges that diabetes services are provided across the continuum of care and are delivered by a range of organizations and providers with varying roles and responsibilities. Today, health professionals working in primary care, outpatient care, and community care settings play a major role in the care of patients with diabetes. The following paragraphs describe the programs and services available to patients with diabetes for the management of their disease.

1. Primary Care

Primary care is defined as the first contact an individual has with the medical system. Family physicians provide patients with diabetes with a point of entry into the health system. They provide referrals for many available services including medical specialists, the DEC (for education), foot clinics, dietitians, psychologists, etc. Primary care providers who want additional support in managing patients with diabetes refer patients to Endocrinologists or specialists in Internal Medicine with an interest in diabetes. Today, health professionals working in primary, outpatient and community care settings, play a major role in the care of patients with diabetes.⁵²

2. Hospitals and Outpatient Care

Emergency services are accessed when patients have a crisis such as ketoacidosis (diabetic coma) or severe hypoglycemia (insulin shock). Patients can be admitted or stabilized and discharged with follow-up on an outpatient basis depending on the severity of the event. In addition, specialty clinics are available in the region to provide services to treat diabetes complications such as stroke, hypertension and renal problems. Referrals to these clinics come from primary care providers, emergency physicians or specialists. Diabetes in Pregnancy Clinics are located in each of the hospitals in the Calgary Health Region.

3. Long -Term Care and Home Care

Within the CHR, approximately 6,000 patients with diabetes receive home care services. A number of long-term care facilities provide for the needs of those requiring

round-the-clock nursing and rehabilitation support services. Other diabetics receive long-term home-care services. The monitoring and care of these patients is done directly in the patient's home. Physicians review patients on a regular basis when referred.⁵³

4. Diabetes Education Centre

The DEC provides education and training through group classes and one-on-one consultations, not only to patients with Type 1 and Type 2 diabetes, but also to their significant others and health professionals. Patients can be referred by physicians or self-referred. The DEC has developed and implemented a course to educate patients about self-management and diabetes. The key points of the course cover the basic physiological facts of diabetes, as well as provide useful background information about diabetes and the human body. This enables patients to better manage themselves and their care. A team of nurses and dietitians developed the seven-component program in-house and it has been in place since 1998. Because the study sample was taken from the DEC, a description of the education programs is included which outlines the common background and knowledge of the participants regarding diabetes self-management. The DEC programs and services as well as a description of the context of the education for patients with Type 2 diabetes are included in Appendix V.

B. Community Services

1. Pharmacies

Pharmacies provide pharmaceutical counselling and monitoring of prescription and non-prescription drugs. They offer medical supplies for diabetes care and track and

advise on the use of these supplies. They also provide free literature and sell books or magazines on a variety of topics related to diabetes care. Some pharmacies specialize in diabetes care and provide extensive training on diabetes medication and glucometers, as well as offer workshops on a number of topics related to diabetes complications. Some patients reported that the IDA pharmacy chain offers foot care services as well.

2. The Canadian Diabetes Association

The vision of the Canadian Diabetes Association (CDA) is to promote the health of Canadians through diabetes research, education, service, and advocacy. The CDA is a resource for people with, and affected by, diabetes, and for healthcare professionals treating those affected. They respond to inquiries about diabetes and diabetes care, support and organize workshops related to diabetes, and raise funds for diabetes research. In 2001, the Calgary and District Regional Branch office provided services to 477 walk-ins and 2,992 phone calls, offered presentations and displays totaling 36, and managed 13 symposiums.⁵⁴ The CDA's motto is:

*"Change for the better; reduce your risk of diabetes.
Eat healthy. Get active. Manage Stress. Talk to your doctor."*

IV. Sample

A. Sample Size

A sample size with as few as six participants can be adequate for qualitative research depending on study design and purpose.⁵⁵ The researcher must be satisfied that the data are rich enough and cover enough views of patients regarding the research topic and that the volume of data is large enough to support the desired analysis. Sampling in qualitative research is not concerned with assuring that the results can be statistically

generalized to the whole population. The goal is to select cases for in-depth study to generalize about the nature and interpretative process involved in the experience of the subjects. The number of participants is less important than the richness of the data. For this study, sample size was determined during data collection and analysis, as interviewing ceased when no new information was forthcoming. The aim was to identify the meaning of self-management by looking at cases that provide a full and sophisticated understanding of all aspects of the phenomenon.

The aim of purposive sampling in this study was to select information-rich cases to examine the meaning of self-management. In preparation for the study, the DEC program coordinator provided a list of patients who had attended the diabetes classes within the nine months prior to recruitment. This time frame was selected to include participants who had been practicing some self-management. These patients had signed a Research Opportunity Consent form given to them at the Diabetes Education Centre (DEC) at the time of enrolment (Appendix I).

For the study, a conscious effort was made to recruit two groups of patients; patients diagnosed with diabetes for less than two years and patients diagnosed with diabetes for more than two years but less than seven years. This provided some homogeneity of experience with the disease since a relatively small sample was recruited. The participants chosen to take part in this study were limited to patients with Type 2 diabetes who currently had no complications. Participants had attended the basic group education and had completed at least one individual two-hour session with a nurse and a dietitian. These individual sessions are available to help patients set and monitor their self-management goals.

B. Inclusion and Exclusion Criteria

Inclusion Criteria:

- patients between 20 and 80 years of age, who were able to read and speak English;
- patients with Type 2 diabetes, who had been diagnosed less than 7 years ago to limit the participants with diabetes complications;
- patients who had attended the six-hour diabetes education course and had had at least one individual assessment with a nurse and nutritionist; and
- patients who had good glycemic control as per glycosylated hemoglobin (HbA1c) levels in the range of 0.07 to 0.09 mmol/L or fasting glucose levels of less than 10 mmol/L.

Exclusion Criteria:

- patients who were living in long-term care facilities;
- patients who were on insulin treatment; and
- patients who were on dialysis, legally blind, or had undergone amputation.

V. Data Collection

A. Procedure

The study was conducted in Calgary, Alberta between August of 2001 and April of 2002. Twenty-five potential participants were contacted by telephone to determine their willingness to participate in the study. Appointments were scheduled and written informed consent was obtained before the interviews began. Using the inclusion criteria listed above, the investigator reviewed a total of 167 patient charts to identify eligible patients for the study.

Data were collected through in-depth, face-to-face, open-ended interviews, a brief demographic questionnaire, study notes, feedback provided by participants during a telephone interview after they had reviewed a summary of the findings, and feedback provided by nurses and dietitians at the DEC after an in-service presentation of the results of the study. The researcher was intentionally immersed in the text data by reading and rereading the interviews. The goal was to discover and to understand through immersion in the data. Collecting information from multiple sources provides the opportunity to explore multiple possibilities, new perspectives, new understandings and new theories.⁵⁶

The interviews were conducted from October to December 2001. Interviews were recorded with the approval of the participants and then transcribed verbatim. This allowed for better comprehension of the experience and a better understanding of how patients organize information. The interviews provided a rich source of text data. Guides containing open-ended questions and probes were used to initiate conversations. As Guba and Lincoln state, the researcher is the primary instrument in data collection.⁵⁷ Before each interview, the patient completed a short demographic questionnaire. The questionnaire and the interview guide were both pre-tested on a volunteer participant who has Type 1 diabetes.

The purpose of the interviews was to collect information on the perceptions of patients with Type 2 diabetes about the meaning of self-management and to identify which community resources were needed for patients to achieve their self-management goals. In-depth interviews were chosen to allow participants to provide confidential information on sensitive issues that they may have refrained from sharing in a group setting. The researcher used an interview guide with open-ended questions (Appendices

III and IV). This method was chosen because unstructured, open-ended interviews allow direct access to personal experiences and a deeper understanding of the social phenomena under study.⁵⁸ All participants received a \$20.00 honorarium to compensate for any out-of-pocket expenses incurred. As follow-up to the interviews, participants also received a thank-you letter (Appendix VII).

B. Interview Strategy

Interviews were conducted at the homes of the patients, with the exception of one interview conducted at the DEC. Through the use of questions and probes, the interviewer encouraged the participants to provide descriptive details to enhance the interviewer's understanding of their views. Although an interview guide was used, the order of the topics and the phrasing of the questions and probes remained flexible.⁵⁹

The first five informants were initially asked to describe what the term "self-management" meant to them. For the last five participants, the opening question was: "What do you think patients with diabetes need to do to take care of their condition?" This was followed with the question: "What is the term or phrase that you use to describe all these activities?" In the first five interviews, it was noted at the time that patients did not use an alternative word or phrase to "self-management." The interview guide was then revised to eliminate the use of the terms "self-management" and "community resources," allowing participants in subsequent interviews to use their own words to describe these concepts (Appendix IV). Such revisions are to be expected when conducting qualitative research.⁶⁰

During the interviews, the researcher remained neutral on the subject of self-management and community resources and adopted a dynamic listening role. By seeking

clarification and probing for additional information, the researcher sought to elicit the perspectives of the informants. Both summation and reflection were used as strategies to ensure that the meaning of the informant's messages was inferred correctly.⁶¹ At the beginning of each interview, the researcher was cautious to avoid introducing concepts that had not previously been introduced by the informant. During the interview, the researcher offered encouragement such as, "Another informant mentioned the same thing. Could you tell me more about it? ", "Please describe for me the details of that event." and "What do you mean by 'not being ready'?"

To concentrate the data, the researcher limited the number of general topics in the interview guide.⁶² The interview guide included the following four areas: 1) the meaning of diabetes self-management, 2) DEC diabetes education, 3) other diabetes education and 4) the use of community resources. Fifteen questions with sixteen probes were used. Questions were designed to encourage respondents to comment on their own self-management experiences and to identify how they were using community resources to help them manage their disease.

The following topics were included in the interview guide:

- activities for management of diabetes;
- experience with diabetes education;
- role and definition of patient utilization of community resources;
- expectations of community resources; and
- concerns about security and confidentiality when using community resources.

C. Questionnaire

The demographic questionnaire was comprised of 10 questions (Appendix II). It took approximately three minutes to complete. An abstraction manual was created to standardize the abstraction and data entry processes. The information collected from the questionnaire was entered into the MEDLOG ® database, version 99.10.⁶³

D. Study Notes

Although interviews were recorded, the researcher collected notes related to descriptions of the participant's environment and non-verbal cues like body language and emotions that provide clues to further questions or probes. The researcher relates to the participants in the study as real people. Body movements, facial expressions and gestures are background characteristics within the experience of the patients' self-management. The opportunity to be in the homes of participants provided some understanding about their support systems and personal environments. The study notes added insight that helped generate other questions. Documenting such things in the study notes to contribute to the richness of the data and acts as a reference when writing the results of the study. Other information collected through the study notes included researcher reflections on how to improve further interviews and on the emerging theories about the participants meaning of self-management, and the list of specific community resources. The notes also help to study the researcher's idea about what is going on in the text. The information collected was one of the principal techniques used to identify the relationships among themes. This is an iterative process of reflecting about the interview and analyzing and interpreting the data.⁶⁴

E. Member Checking

Member checking refers to the process of recycling interpretation back to key informants. After the interviews were complete, a summary with a cover letter was mailed to all participants (Appendices VIII and IX). During follow-up telephone interviews, participants provided feedback on the summary. The researcher searched to disconfirm evidence and to identify any wrong or incomplete messages in the summary.

F. Triangulation of Data Sources

Whenever possible, the data was triangulated by confirming the findings with data from other sources.⁶⁵ In 1994, Richardson explained the concept of crystallization, recognizing that there are many facets of any given approach to answering the research question of a study. Crystallization provides the researcher with a deepened, complex and multifaceted understanding of the phenomenon.⁶⁶

In this study, the researcher collected information through interviews, feedback provided by participants, feedback provided by the DEC clinical staff, and recorded study notes regarding non-verbal signals on the environment of the informant. Study notes were useful in identifying themes and exploring new lines of information as they arose, and integrating them into the theme list, where appropriate. A two-page summary of the findings regarding self-management and community resources was mailed to all participants. The members of the Supervisory Committee reviewed the preliminary summary and the thesis supervisor reviewed the revised summary and cover letter. Feedback on patient interview summaries was compared to data from both the interviews and study notes.

On April 16, 2002, the findings were discussed with dietitians and nurses at the DEC who were experts in the education of the self-management principles and skills for this patient population. The findings were discussed to determine if this study reflected the experiences of patients with Type 2 diabetes at the Centre. These professionals agreed that the findings reflected the experiences that patients had reported to them.

VI. Data Analysis

A. Management

The researcher listened to each interview tape before it was transcribed. An assistant transcribed the interviews verbatim into a computer file. The transcripts were reviewed for accuracy and the investigator completed any missing sections. The computer software used for data management was Microsoft Word 2000®.⁶⁷

B. Coding and Sorting

Data from the first interview was analyzed as soon as it was transcribed. The analysis included identification of codes, subcategories, categories and themes. The interview transcripts were systematically reviewed, line-by-line, and each sentence was labeled with a code or idea. Every line was numbered and associated with a code (a word or phrase that captured the meaning in the text). Analysis of such data requires sensitivity to detail and context, accurate access to information, and methods of rigorous and careful exploration of themes and discovering of testing patterns.⁶⁸ Whenever possible, interviews were transcribed and analyzed prior to subsequent interviews. Each sentence was compared with other sentences having the same code. A coding system was developed as data from the first interview were analyzed and the same codes or new

codes were created with the subsequent interviews. The codes were then sorted so that subcategories emerged. As subcategories became saturated, categories emerged. The categories were given major headings and the subcategories were given sub-headings.⁶⁹

The researcher attempted to reconstruct the participant's reality by looking for associations that joined contextual statements and events into a coherent whole. Similar data was then grouped together to look for connections and patterns of associations. The investigator grouped the codes and the categories developed from the group of codes. Each category was labeled and defined and then categorized based on similar characteristics. Categories received descriptors that were often the words of the informants. An expert qualitative researcher coded four of the interviews to ensure consistency of the coding. Codes were compared and contrasted and the two researchers discussed the data themes, categories and subcategories until consensus was achieved. This in-depth process helped prevent both over and under interpretation.⁶⁰

In addition to the identification of categories and subcategories, themes were identified by looking for duplication of words, processes and actions and then refined to a point where they were applied to a large interpretative analysis. The next step of the analysis was to identify how these themes were linked to each other in a model. Models are sets of abstract constructs and their inter-relationships. Once the model starts to take shape, the researcher looks for negative cases that do not fit. These negative cases need to be accommodated in the model and as a result, the model is changed.⁷⁰ The model can be validated by knowledgeable subjects who are familiar with the research. Models are simplifications of realities and they may capture all or a portion of the variance in a given set of data.⁷¹

C. Software

NVivo® Version 1.2.142 software was used to manage the retrieval and sorting of text data and codes. The software is designed to support qualitative research projects in almost any field of application and to utilize most qualitative methodologies. The original data was tagged in order to cross-reference the categories and themes. The software helped to manage and synthesize ideas, providing a range of tools for clarifying and understanding the data.⁷²

VII. Ethical Considerations

The proposal for this study was approved by the Conjoint Medical Bioethics Review Board in the Faculty of Medicine at the University of Calgary and by the Centre for Advancement of Health at the Foothills Hospital. Consent forms were developed and used (Appendix VI). Protecting the anonymity of participants was of paramount concern during the study. At the time of each interview, the researcher explained the study and asked if the participant was still willing to proceed with the interview. Then, the researcher reviewed the consent form with the participant, asked the participant to sign the form and gave the participant a copy for his or her records.

General principles of politeness were observed throughout the research process. In order to maintain anonymity, only study numbers identified patients and the data were presented only in aggregate form.⁷³ The quotes used to illustrate themes included only the sex and marital status of the informants.

VIII. Conclusion

Qualitative methodology was chosen for this study because limited information was available regarding the perceptions of patients on the subjects of self-management and community resources. In this study, eleven informants participated in open-ended interviews. One patient was insulin-dependant, so data is reported only for these ten patients who met the study criteria.

An interview guide containing open-ended questions and probes was used. After the initial five interviews, the guide was modified. The thesis supervisor coded four out of the ten interviews. Interviews were transcribed verbatim and transcripts were reviewed. Data was then analyzed and coded to identify themes, categories and subcategories within the data. The results are presented in the next chapter.

CHAPTER IV - RESULTS

I. Introduction

This chapter presents the results of the study. It begins with demographic information about potential participants, non-participants, and the general Diabetes Education Centre (DEC) patient population. Data collected from both the study notes and through the follow-up telephone interviews are presented. In addition, a table is included, showing the community resources that participants have “used,” “identified as needed,” or recognized as “existing although never used.” The twenty subcategories that emerged from the data are grouped into the following six categories: Information, Motivation, Support, Barriers, Familiarity with Diabetes and Stages of Readiness. Each category is described together with its subcategories and is illustrated with direct quotes from the interviews. Next, the themes that emerged from the data are discussed.

II. Participants

This section provides a detailed description of all patients contacted, including potential participants, and those who declined to participate. While it is not typical of qualitative research, study participants were compared with data from the DEC population, when available, to see if the study participant details were similar to the sample frame population of the DEC.

A. Sample

Twenty-five potential participants in the study were identified through a review of 167 patient charts at the DEC. These patients had signed a Research Opportunity Consent form (Appendix I). Of these, five individuals were not eligible to participate (two patients had diabetes for more than seven years and three were insulin-dependent). Ten of the twenty potential participants who matched the inclusion criteria for the study declined to participate. Eleven participants were interviewed but one participant was insulin dependent and, therefore, excluded from the study. With the exception of two participants, the rest of the participants were married and living with their spouse. Out of the two un-married participants one was single and one was widowed. Seven participants had diabetes for more than two and less than seven years and the other three participants for less than two years. Table 1 includes all potential participants of the study.

Table 1: Potential Participants Contacted

Potential participants	Total
Charts reviewed	167
Patients contacted	25
Ineligible patients	5
Eligible patients	20
Refused	10
Participants	10

B. Characteristics

Participant information on sex, age, marital status, place of residence, level of education, employment status, disease duration, time since receiving diabetes education, and referral to the DEC is presented. Information regarding non-participants is also

included. In order to compare the demographics of the study participants to the demographics of the DEC population past data on DEC client demographics were examined. Between June 1 and August 31, 2000, a total of 1,510 individuals were seen at the DEC. The DEC has detailed information on 1,459 patients, including new and follow-up patients within the three-month period.⁷⁴ The demographics of study participants were similar to the DEC patient population in general.

1. Sex

Of the ten participants interviewed, five were female. Out of the four ineligible patients, two were female. Six out ten refusals were female. Slightly less than half of the DEC population, or seven hundred patients, are female. This is consistent with the incidence of diabetes in the general population, which affects both sexes equally.⁷⁵ (Table 2).

Table 2: Sex of Participants, Refusals, and the DEC Population

Category	N	Female (N %)
Ineligible	4	2 (50)
Interviewed	10	5 (50)
Refused	10	6 (60)
DEC patient	1,459	700 (48)

2. Age

The mean age of participants was 68.5 years with a range of 41 to 79 years. Patients unwilling to participate were younger, with a mean age of 58.7 years and a range of 39 to 72 years. The mean age of the DEC patient population is 56.4 years. The age distribution of the DEC patients was not available. The fact that the mean age of the DEC population is younger may reflect the fact that it includes the 11% of patients with Type 1 diabetes (Table 3).

Table 3: Age of Participants in the Study and the DEC Population

Category	N	Mean age in years (range)
Interviewed	10	68.5 (41-79)
Refused	10	57.8 (39-72)
DEC patient population	1459	56.4

3. Marital Status

Eight of the ten participants interviewed were married and lived with their spouses. One participant was widowed and one was single. Of those who refused to participate, six were married, two were single, and two were widowed. Data on the marital status of the DEC patients were not available (Table 4).

Table 4: Marital Status of Participants and Refusals

Category	N	Married	Single	Widowed
Interviewed N (%)	10	8 (80)	1 (10)	1 (10)
Refused N (%)	10	6 (60)	2 (20)	2 (20)

4. Residence

Of the ten eligible participants, five resided in the southwest, four in the northeast and one in the northwest of the city. Three individuals who declined participation lived in the southwest, two in the southeast, two in the northeast, and three in the northwest of the city. The area of the city in which people live was recorded since one of the objectives of this study was to explore the view of patient about community services.

Resources are available throughout Calgary but some communities tend to have more resources than others. In this study, participants indicated they used the community resources that best fit their self-management goals regardless of location and traveled to other areas of the city where resources were most attractive to them. Data about area of residence was not available for DEC patients (Table 5).

Table 5: Residence of Participants

Category	N	SW	SE	NE	NW
Interviewed N (%)	10	5 (50)	0	4 (40)	1 (10)
Refused N (%)	10	3 (30)	2 (20)	2 (20)	3 (30)

5. Education

Most participants had obtained what is considered higher education. Three (30%) participants had completed secondary education, three (30%) were college graduates and three (30%) were university graduates. One (10%) had post-graduate education. Education statistics for DEC patients and those who declined were not available.

6. Employment

Five (50%) participants were employed full-time, one (10%) participant worked part-time, four (40%) participants were homemakers, one (10%) was a student, and three (30%) were retired. Some patients reported more than one employment status, so the total percentage is greater than one hundred. Data for DEC patients and those who declined were not available.

7. Disease Duration and Time Since DEC Education

Participants had a mean disease duration of 39 months, with a range of 13 to 84 months. The mean time lapse between the DEC education and the interviews was 10 months. None of the participants had attended a previous diabetes education class.

8. Referral, Prior Diabetes Education, and Number of DEC Visits

All of the participants in the study were referred to the DEC by their family doctors. From all the DEC patients, fifty-eight percent were referred by their physicians and 20% had an unknown referral status. The percentage of the DEC population with Type 2 diabetes was 89%. This study included only patients with Type 2 diabetes.

The DEC education included a basic, 6-hour, group diabetes education class, a single, two-hour individual session with a nurse and dietitian and a one hour follow-up assessment every three months for one year. The mean number of follow-up assessments for the study participants was two sessions, whereas for the DEC population it was three.

This may reflect the fact that that the study participants were recruited when they were active patients at the DEC and may have had one final assessment before being discharged from the DEC (Table 6).

Table 6: DEC and Study Participants

	Study Participants N = 10	DEC N = 1459
Referred by GP (%)	100	58
Referral status unknown (%)	-	20
Prior DEC Education (%)	0	17.9*
Type 2 Diabetes (%)	100	89*
Mean DEC visits	2	3

*Available data for patients with known referral status only

II. The Emergence of Categories and Subcategories

As data were reviewed and analyzed, twenty subcategories, six categories and five themes concerning self-management and community resources emerged. Six categories regarding self-management emerged from the interview data: 1) Information, 2) Motivation, 3) Support, 4) Barriers, 5) Familiarity, and 6) Stages of Readiness. Although all participants addressed elements of each category, issues pertaining to three categories (information, support, and barriers) dominated the interviews. Definitions of the six categories and twenty subcategories that emerged from the interviews are provided, along with supporting interview excerpts. Subcategories were assigned to the categories that provided the best match.

1. Information

Information is defined as the knowledge, skills, and abilities required to understand diabetes and to manage the disease. Five subcategories are included:

1.1 Confused By Too Much Information: Patients were confused by the amount of information presented at the diabetes class. Some patients suggested that the classes should be presented in different sessions instead of all in one day. They were also confused by the number of topics covered in the class, amount of information they had to learn, and the degree of adjustment to their daily routine required. After the class, they felt they had to make a number of substantial changes in their lives. The following quote is typical of this subcategory:

"I was confused, I had too much information given to me in a short period of time and it was too much to get through."
(married female)

1.2 Liked Multiple Formats of Information: Patients found it beneficial when information was presented in multiple formats. They preferred information be presented in different ways so that the message was repeated over and over until it was integrated into their life routines. This was particularly helpful in the learning process. Patients liked having the education booklet that summarized the classes and included a number of graphics and forms for patients to track diet, glucose levels, etc. In addition, they received pamphlets and magazines that presented the same information from different views. The following quote typifies descriptions of this subcategory:

"I already know from the classes. I would ask of the staff or will phone them after the class for clarification but I also have to read. The booklet they gave us is very good. I also bought a pocket book from the drug store on Type II diabetes."
(married female)

2.3 Sought Information: After the classes, patients were encouraged to look for their own sources of information. They were highly motivated to identify different ways to follow the advice and tailor it to their own needs and capabilities. Patients looked for information from community resources and searched for appropriate information to meet their individuals needs.

“Yes, I never thought [that the library] was a community resource. I wouldn’t have found both these exercise books if I hadn’t been to the library.”

(married male)

1.4 Isolated from Information: Some participants felt isolated from information, resulting in an apprehension of pursuing desired activities. They felt they were not involved due to a lack of appropriate information to make empowered decisions. It must be noted that even patients who felt isolated had a positive approach to gathering information.

“If I have known the daily requirement in starches, protein, fruits and milk then, I should have been able to follow my diet. Now, with the knowledge I gained at the DEC, I am able to plan my meals better.”

(married male)

1.5 Knowledge from Media Coverage: Patients learned about diabetes via radio broadcasts, television, the Internet and advertisements in newspapers and magazine articles. They view media information valuable for becoming familiar with diabetes, although they often felt that the media focused more on negative outcomes and complication than on prevention and awareness.

“One of these country singers that I’ve enjoyed listening to all these years, he was born in 1940 (I was born in 1941), Johnny Russell, just died with complications from diabetes. So, like, now you get the wake-up call that diabetes is important.”

(married female)

2. Motivation

Motivation is defined as the act or process of providing an incentive or encouragement to action. In this category, three subcategories are included. The subcategories reflected the need for participants to gain knowledge and skills to self-manage their life. It was apparent, even in the initial interviews that patients did not distinguish between information for diabetes care and information for their general health. Participants were actively seeking information and reinforcing their knowledge until they felt they had mastered it.

“My sister has diabetes in her 20th year so [I] have to start managing and keeping it under control so that those things [complications] don’t come rushing in on me. At the DEC, I find out information on diabetes ...so I understand it better.”
(married female)

2.1 Possessed Proactive Attitude: Patients discovered ways to understand the diabetes process better and developed approaches and attitudes that encouraged action. A very significant change for many participants, especially women in caregiver role was to understand that managing their disease needed to be top priority. Participants were taught that they, the individual and their health, are the most important things to consider.

You know, like, before you were the mother you were not important, like your family is always important you know, so you’re doing for them, doing for them, but you somehow always forgot to do for yourself.”
(married female)

Patients felt that a proactive attitude towards diabetes was essential for them to follow the advice and recommendations of health care providers in addition to putting into practice the knowledge and skills gained at the DEC. They had an action plan that

they modified to fit their own needs. Participants arrived at the classes with enthusiasm and an open mind to learning.

“At the Centre, I came to view how my case would be improved they gave us a book on diabetes about dieting and diabetes. It required me to come periodically and have my health checked by the doctor, nurse and dietitian.”

(married male)

2.2 Incorporated New Behaviours: Patients integrated knowledge and skills into their routine and acknowledged difficulties in changing behaviours when they lacked motivation to do so. Incorporating the new knowledge and skills required time and patience. For the first couple of months following the classes, patients used the booklet daily until a routine was established and the knowledge was incorporated in their lives. Even ten months after the classes, participants were referring to the booklet. They used community resources to gain more knowledge and to incorporate new behaviours into their lives. The use of community resources helped patients achieve goals that they otherwise would not have been able to reach.

“I don’t like exercising. I know I need it for my health and I got a membership [in the Southland Leisure Centre]. I realize that the only way to lose weight is by exercising or dieting. You can’t lose weight by doing nothing.”

(married male)

2.3 Acknowledged Health Care Provider’s Role: Health care providers play an important role by encouraging participants to follow directions and to meet their goals. Participants perceived the role of health care providers to be an important factor in becoming successful self-managers. Some patients reported however that their family doctors assumed they were not ready for diabetes education, they knew enough about

diabetes, they were not interested in learning or that they were not prepared for the classes. As a result, family doctors did not always refer their patients. These patients took the initiative to request a referral to attend the education classes. They identified health care providers as a source of motivation and emotional support. The latter is clearly evident in the following quote.

“Health care providers give motivation and mental support as well as an educational resource - a knowledge base. I like to be able to know what's going on and they motivate me to stay healthy and to follow their advice. I need reminders and encouragement to do self-management so the educational centre staff and my doctor have been very good.”

(widowed female)

3. Support

Support is defined as the individual, immediate family and external people, providing the strength and assistance “to bear the weight” of keeping diabetes under control. Under *support*, four subcategories are included:

3.1 Not Alone: Some patients found out what other patients with diabetes do to keep the disease under control and realized that they were *not alone*. When patients began to learn about diabetes and how to keep the disease under control, they found out that diabetes was a serious but common disease and that other people were in the same situation as they were. Some patients felt alone and lacked the opportunity to talk about their progress and relapses. They felt isolated from activities and discussions that mattered to them and this stood in the way of their self-management activities.

Participants said their experience at the DEC opened their eyes to diabetes self-management so that they didn't feel alone because they belonged to a group with similar needs. The following quotation illustrates this view:

"For the first few years I thought it was a nuisance, being diabetic, but then I finally realized that with proper eating [you could] properly manage the [diabetes]. I started to feel better, you know? At the clinic [DEC] you appreciate that you are not alone."

(married female)

3.2 Support from Relatives and Friends: Most of the participants sought support everywhere and were open to talking about their experiences. The development of associations and relationships with family members, friends, extended family, co-workers, etc., was an essential factor in their diabetes management.

"I think every little bit helps, even calling somebody and talking with him or her [is good], like I have my sister-in-law, she's diabetic. I call her and ask her [questions] and she calls back to answer me. At first, (when) I didn't know much about it and I got a lot of information from my contacts. When I went bowling, one of the men that I was bowling with, I told him I had just got diabetes. He said, "I've been diabetic for seven years" and he said I have to learn to control it."

(married female)

3.3 Support from Patients and/or Employees at the DEC: Patients reported that being a part of group that serves diabetics was important to them. They recognized how knowledgeable the staff at the centre was and, most importantly, they appreciated the way they were treated. The education sessions provided a source of support to the participants. Participants enjoyed learning about the experiences and viewpoints of other patients. They benefited from asking questions about diabetes management and the group classes provided the opportunity to build relationships that supported their

management goals. They recognized a group that they felt they belonged to. Some of the participants shared their phone numbers and kept in contact after the sessions were completed. In addition, the DEC staff was recognized as a source of support. Patients felt they could ask any questions and found the DEC staff responded to their questions in a timely manner. This idea is reflected in the following quotation:

“Educational resources [are important], such as classes for ongoing support, which are available through the diabetic centre downtown ...and a follow-up with the clinic downtown. I look [at] the diabetic centre as a support system rather than a treatment system, if that makes sense.”

(married male)

3.4 Support from Family Doctors and other Health Care Providers: Patients reported that the support and assistance given by health care providers increased their management success. Family doctors and health care providers were identified as a source of support as well as a source of motivation to meet self-management goals. In general, health care providers were open to talking with patients and took the time to explain things.

“Obviously you need a doctor first of all, [and you] need a diabetes care centre like the DEC. It’s great for diabetes information. I saw one [doctor] of theirs [DEC]. It was very helpful.”

(married male)

4. Barriers

Barriers are defined as limitations and obstacles to achieving control. In this category three subcategories are included and explained below.

4.1 Time Constraints: One important reason for not being able to follow the advice of health care providers was the inability of patients to fit their diabetes management activities into their busy schedules. They reported that their busy schedules prevented them from following the advice of health care providers. Even retired subjects

volunteered, babysat grandchildren or were involved in sports and community activities.

Most participants reported more than one employment status. Some reported that their health care providers did not consider homemaking activities when advising health care regimes. They acknowledged that looking for information, learning, or getting involved in additional activities was time-consuming. Participants recognized that they had missed many opportunities due to lack of time.

"I probably work 80/90 hours a week [all] year round I can not check my glucose level all the time and I can not follow my diet and exercise routine."

(single male)

4.2 Financial Limitations: Patients identified a number of items that they were lacking due to financial restrictions. They mentioned others who did not have health insurance and recognized the difficulty of achieving self-management goals without proper equipment and adequate supplies. They complained that they could not follow their healthcare provider instructions about monitoring blood glucose level due to the high cost of the test strips. They protested that the government required them to go for an annual medical check up to renew their driver's license when regular renewals occurred every five years without physical exam requirement. The concerns over financial limitations are echoed in the following quote.

"We have to buy our meters and the strips, but I think the government should pay for those. The strips are expensive."

(married male)

4.3 Communication barriers: Some participants reported that the diagnosis and information about diabetes was not clearly conveyed by health care providers and, in

particular, by their family doctors. Participants also noted that sometimes they were not able to discuss personal concerns with their health care provider.

“When I found out about diabetes, I was just told I had it and then I wasn’t even told to go get a meter. I was given my two prescriptions and I left the doctor’s office and I didn’t know anything about diabetes.”

(married female)

5. Familiarity

Experience with diabetes contributes to an understanding of the condition and provides the patient with the skills and knowledge to self-manage. The two subcategories of *familiarity* are discussed below.

5.1 Previous Exposure to Diabetes: Previous exposure to diabetes was an important experience that contributed to successful self-management. Patients indicated that having a close family member or friend who had diabetes positively impacted on their self-management. If others had controlled their diabetes well, the patient gained knowledge, understanding and acceptance applicable to their own condition. Alternatively, when death was attributed to diabetes complications, some patients started to think about how to improve their own self-management. In addition, some patients were familiar with diabetes but confused the diet requirements of Type 1 with Type 2 diabetes. For example, the participant in the following quote wanted to follow the same diet schedule and regimen as his son, a Type 1 diabetic, although the parent was Type 2.

“My youngest [son] is diabetic so I’m very familiar with diabetes care, so it was like rubber-stamping for me but I think for someone that doesn’t have any diabetes in his or her family, you need the DEC hospital.”

(married male)

5.2 Previous History of Other Chronic Conditions: Having had or been exposed to other chronic conditions helped the participants with their approach to their diabetes in acquiring timely help from health care professionals and taking personal action towards self-management.

“And what’s wrong with me is just as serious in the long run as cancer is for them [husband and the Tom Baker cancer clinic patients] because if I don’t take care of this diabetes... I’m going to die sooner than I should, the same as if they don’t take care of their cancer, they will too.”

(married female)

Previous exposure also helped patients with the process of becoming familiar with the condition and communicating their self-management goals to the health care provider.

“Controlling my diabetes, it’s the same thing than with my colitis. The specialists I went [to] say, “You know you’re going to be on medication for the rest of your life.” If you have any problems give me a phone call and come back and see me. [They] don’t have a known cure for it and I have to go every year to have tests.”

(married male)

6. Stage of Readiness

Stage of Readiness is defined as the state of being ready and willing to learn new skills and facts to become a proficient self-manager as well as accepting the need for diabetes control. Three subcategories are included.

6.1 Trust in Information: Patients needed to accept information as valid. Even if the information came from a professional, patients posed the same question to other professionals until they were convinced that the information was true. In order to integrate new information into their lives, patients first had to accept that the information was true, so they critically appraised the information and inquired until they

were satisfied with its validity. Even when the source was a recognized health care provider, participants sought additional information and only took action afterwards.

"I'm quite happy with my relationship with the pharmacist. He said to take the [medication] after meals and my doctor said to take it before the meals, and the pharmacist said no you should have a bite or two of food in your stomach first. I don't know which one is right. So in this case I checked the directions of the manufacturer and my pharmacist, I think, was correct."

(married male)

6.2 Taking Action: Acquiring diabetes knowledge and self-management skills increased patient confidence and led to action on utilizing resources and making decisions to achieve self-management goals. Patients who were motivated and had the information were willing to act:

"Food has got a great deal to controlling blood sugar levels. I have learned that one-cup of potatoes after 2 hours will produce a 1/8th of a cup of sugar in your body. If I have potato because of the sugar content, I don't cook a sugar vegetable like carrots, peas and beets. What I do is have potatoes every other day. I have rice the rest of the time. This is how I manage."

(married female)

Patients who took action often made changes in their life. Patients went through a gradual process from the diagnosis phase to the action stage. Some participants reported that incorporating new behaviours was a difficult process. The key to success was the ability to incorporate these small changes regularly. Their management approach reflected their plan of action regarding the changes required to achieve their goals. Participants believed that their self-management had changed after receiving education.

"Oh, definitely my views changed after the education. I realized that, like, you know, when you went there, they showed you portions and you're supposed to eat six small meals a day rather than three large meals."

(married female)

6.3 Selection of Participants for Diabetes Education: Group education was identified as important because patients identified with other participants, but it was suggested that a homogenous class would be beneficial. For example, segregating the classes based on characteristics such as a patient's readiness to learn, age, education and employment was suggested. Some felt that the group to which they were assigned for training was inappropriate. The following quotation reflects this view:

"I think [the DEC should] segregate the class based on participants lifestyle, education and employment."

(single male)

The previous section presented the subcategories and categories that emerged from the data. In the following section themes are presented and illustrated with interview excerpts.

IV. Member checking

The interviews were summarized after they were completed in order to verify that the researcher had understood the patients' perspectives. The summary sent to participants included information on personal care and external support. Participants clarified that co-habitant support was different from external support and that those who had co-habitant support still lacked external support and vice versa. During follow-up telephone interviews, participants had the opportunity to add additional community resources that came to mind when the list was presented to them. One patient asked why multicultural organizations were included as a community resource. The patient was reminded that the summary reflected the views of ten participants and that one participant had used multicultural organizations as a community resource.

V. Use of Community Resources

Patients utilized many resources for their overall well being, not just for diabetes self-management. Unfortunately, most of the resources identified as “needed” were not used due to the financial barriers. The community resources used by the participants illustrated the holistic perspective of the informants regarding self-management. These resources were not solely related to their diabetes, but applied to their well being and social lives as well. Continuing education and participation in volunteer organizations such as the Girls Guide of Canada and the Catholic Women’s League were also important community resources. In addition, the participants identified resources they perceived as needed. In their hunt for resources to meet their self-management goals, informants believe that services such as support groups and a phone line for diabetics seeking quick information would be beneficial.

Participants mentioned resources that they knew existed but had never used. This additional information was sent to participants as part of the study summary and feedback was positive. The list of community resources was an important source of information for all participants. Participants indicated that community resources included involvement and participation in a variety of organizations used for education, recreation, and support. It was not restricted to diabetes management, but rather was an important source of social and emotional support, which increased the well being and quality of life.

Table 7 presents the community resources identified by participants. All participants said that although they were aware of the diabetes education offered by pharmacies, none of them had used this service. The formal diabetes education was the beginning of the process in which patients took action and found personal motivation to use community resources in order to fulfill their self-management goals.

Table 7: Community Resources Identified by Participants

Used	Identified as Needed	Known but not Used
Bowling, golf, hockey, bridge and Jazzercise	Alberta Health Care (AHC) to pay for diabetes meds	Diabetes education offered at pharmacies
Community & shopping malls walking groups	AHC to pay for an annual check-up required to renew driver license	Programs offered by community associations
Community newsletters	AHC to pay for medical supplies	Social workers
Continuing Education (SAIT and at the University of Calgary)	AHC to pay for special shoes and arch support	The Canadian Diabetes Association
Exercise facilities/Leisure centres	Better triage of participants for group education	
Family doctor's and specialist's Offices	DEC's classes should be offered in various sessions instead of all in one day.	
Foot clinics offered by the DEC and IGA	Education to treat diabetic emergencies	
Pharmacist services and support	Exercise classes led by trainers specialized in diabetes	
Laboratory services	Help phone line for diabetics to access quick information	
Multicultural organizations	Suggestions for quick nutritional food preparation	
Girl Guides of Canada	Support group for diabetics	
Psychologist services		
Public libraries		
Religious organizations		
Senior's centres		
The Alberta Children's Hospital		
The Catholic Women's League		
The Diabetes Education Centre		
The Internet		
TV advertisements		
Weight control centres		

VI. Themes

Themes are abstract constructs identified before, during and refined after data collection. Themes emerged as the data were reviewed line-by-line, and were identified by the repetition of words and ideas.⁵⁴ The five self-management themes are 1) personal care, 2) co-habitant support, 3) external support, 4) the balanced patient and 5) the holistic approach. The themes and categories that emerged from the data are the foundation of the study model to be introduced in the next chapter. The themes reflect the perspectives of participants on self-management. At the beginning of the interviews, participants identified the term "self-management" as a business term. A common response to the question about the meaning of the term was,

"Self-management? Well it refers to business management."
(married male)

Like the term "self-management" participants related the term "community resources" with "social assistance" or activities that involved government funding provided to economically disadvantaged individuals.

"No that's something I initiated on my own. I had to pay for the membership [at the fitness club]. The community doesn't cover it for me."
(married male)

In the following section, five different themes and the types of support identified as necessary for self-management are outlined.

1. Personal Care

Personal care includes only those activities accomplished by the patient such as taking medication, checking blood sugar levels, exercising and diet control. Participants often pursued more information after advice was offered. They assessed information from a variety of sources and applied this information to their personal care activities. One notable aspect of self-management defined by some participants was choice. This included choosing not to perform activities they knew they should be doing when they were preoccupied with other life events.

2. Co-habitant Support

Co-habitant support is defined as support provided by individuals with whom patients shared accommodations, had emotional bonds with or were related to through birth or legal means. This allows for a variety of family configurations (i.e., "single" could mean divorced, never married and widowed). Co-habitant support generally impacts health management behaviour, through functions in the home and the family as a system. If, for any reason, the co-habitant support network is compromised, less time could be devoted to health management activities as the patient recovers from the loss.

3. External Support

This source of support includes co-workers, friends and health care professionals. Participants considered the DEC to be an external support system as well as an education and treatment centre. They reported that good communication with family doctors, nurses, dietitians and pharmacists was important in their disease management. Participants in this study experienced community through family and friends, ties at

work, school and places where they volunteered their time. This highlights that self-management includes not just the patient but family and external support as well.

4. The Balanced Patient

During the interviews, it became apparent that self-management was not an individual task alone but a more complex process in which the individual's social and community support systems played an essential role in their management success. Participants also acknowledged that in order to comply with recommendations and achieve their management goals they needed different types of support. Participants with stable care and support from various sources achieved Balanced Patient Care.

"To control your diabetes obviously you need a doctor first of all. [You also] need a diabetes care center like the DEC. You also need your family, Friends, coworkers, social activities and the churches are active sources of support too."

(married male)

For all participants, the education they received at the DEC was their first formal instruction. Following the class, participants were actively looking for more information and, as a result, were motivated to look for community resources to fulfill their management goals. These extra activities were not easy, particularly considering time restrictions, economic limitations, and communication barriers. Family members, extended family and friends, as well as other patients and health care providers supplied support. Examples of participant definitions of community resources are seen in the following excerpts:

"Well, it involves participation from other entities maybe. We have a Filipino neighbor who is a diabetic and we often communicate. We do sometimes try to learn together I think its sort of community."

(married male)

5. The Holistic Approach

The Holistic Approach is the belief that self-management is not only related to diabetes but is also important for social and cultural needs as well as for the overall health and wellness of the patient. Participants considered day-to-day activities for diabetes care as integral to general life. In addition, involvement in community activities not only helped the individual achieve diabetes self-management, but was also considered an important source of general social support. It is apparent that the factors affecting self-management go beyond diabetes care and the use of health services. Participants used organizations outside the health care system and they built relationships and interacted with members of community organizations that they perceived to be important for their overall well being.

A very significant realization for many participants was that their decision to manage their disease was needed and was of a high priority. Women, especially, had great difficulty putting their own needs first when considering self-management.

Participants learned that they, the individual, were most important.

"I'm going to water exercises because I enjoy it. I know I feel better afterwards, not [only] because it's going to make my diabetes better or not [just] because it's going to help me lose weight, although those are both good and positive effects."

(widowed female)

VII. Conclusion

This chapter presented the demographic characteristics of the participants, the non-participants, and the DEC patient population. Data was compiled from ten interviews, which, whenever possible, were compared with other sources of data such as member checking, study notes, and feedback from an in-service presentation to the DEC clinical staff. The categories, themes and subcategories that emerged from the data during analysis were presented. Six categories, twenty subcategories and links between these were described. A table of the community resources the participants used, needed, and identified as existing but never used was also presented. The themes of the study are the components of self-management. These were personal care, co-habitant support, and external support, balanced patient and the holistic approach. In the next chapter, the results of the study will be discussed in more detail and a self-management model, based on the data collected, will be introduced.

CHAPTER V – DISCUSSION

I. Introduction

This chapter provides a discussion of the results obtained from the study. It begins with the introduction of the self-management model, which was developed based on the results of the study. The various components of the model are introduced and used to illustrate the relationships between the different elements of the model. The results of this study are then compared with the findings of previous studies on self-management and chronic care. This chapter also summarizes the approaches used in this study to maintain rigor of the data, including credibility, confirmability, dependability and transferability.

II. Self-management

The knowledge and skills participants gained, in part from the Diabetes Education Centre (DEC), helped them initiate self-management activities. They took action after receiving education by gathering more information about the disease and by looking for community resources. Self-management included tasks performed by participants to gain knowledge, understanding and skills to control diabetes.

Participants recognized that they needed to follow the recommendations of the DEC and other health care providers to manage their diabetes. They mentioned that the skills and knowledge gained through education were not beneficial unless they applied the advice to their diabetes care. After learning new skills and gaining new knowledge, participants took time to master the skills and incorporate new behaviours into their lives.

Marital status and support networks also played an important role in self-management.

An unexpected aspect of self-management that emerged was that participants chose whether or not to perform recommended activities as a form of self-management. It was expected that participants would use resources available within their communities.

However, no difference was found in the use of community resources or self-management between participants. Participants looked for the best resources regardless of geographic location.

III. The Self-management Model

A. Preamble

As data were collected and analyzed, what emerged were not just a definition of self-management and a list of community resources, but also a description of the components that make up self-management. The categories within self-management that emerged are: information, motivation, support, barriers, familiarity, and stages of readiness. The themes are Personal Care, Co-habitant Support, External Support, Balanced Patient and The Holistic Approach. These categories and themes were the basis for components of the self-management model and represent the patients' interpretation of self-management.

B. Components of the Model

The model is composed of macro and meso environments as well as the micro-environment and support in the micro-environment. The relationships between these environments conform to the definition of self-management based on patients' views.

1. Macro and Meso-environments

The macro-environment includes social structures and their products, culture and ideology.⁷⁶ For this study, the health care system was the most important macro-environment arena for self-management (Figure II). The meso-environment is thought of as stable, but patients should be aware of the evolving availability of programs and services in order to fully utilize them. The meso level corresponds primarily to community organizations in which individuals operated (Figure II). These organizations have a specific function in the patients' lives. Participants accessed the health care system for regular diabetes management, follow-up, education and after exacerbations or complications of the disease. Patients used community resources after education to find programs to help them achieve their management goals.

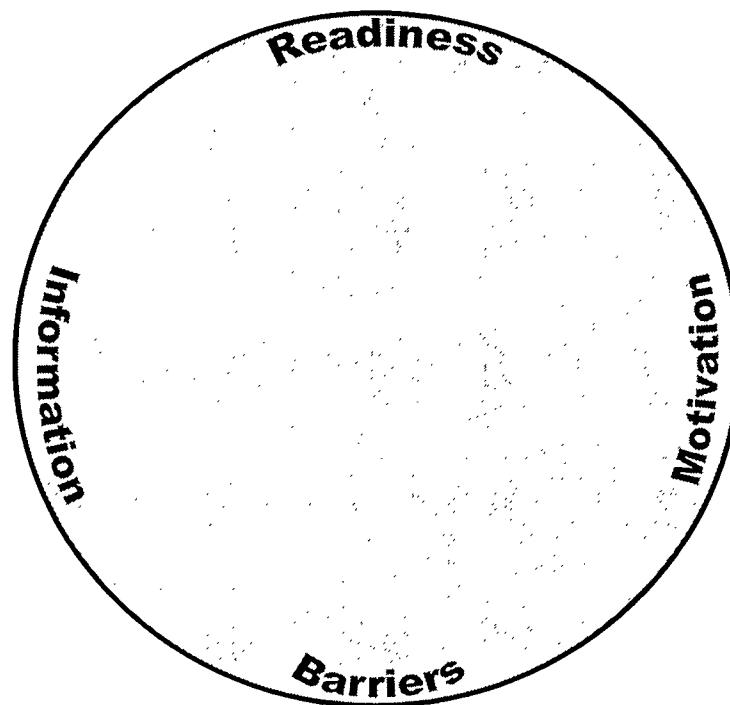
Figure II. Self-management Macro and Meso-environments



2. Micro-environment

The micro-environment or immediate settings in which the individuals live consists of the elements that may directly or indirectly influence their abilities to utilize resources to achieve self-management goals. The immediate settings are the schools, workplace, leisure centres and other arenas in which individuals are physically located. Participants identified four components of self-management: information, motivation, readiness and barriers (Figure III).

Figure III. Self-management Micro-environment



Participants perceived *information* as the foundation of self-management. They received information at the DEC and it prompted them to obtain more information. For example, patients who were advised on exercise, reviewed books at the library, joined walking clubs or registered in exercise programs.

Readiness was another important factor in self-management. Some participants recognized that they were not ready to accept new information. Others were going through difficult times in their lives and learning about diabetes was not a major priority. Patients needed to be ready and disposed to learning new facts and skills in order to become proficient self-managers. Patients must also identify and acknowledge the need for diabetes control.

Motivation is incentive or encouragement that leads to action and a pro-active attitude. The most important sources of motivation for the participants were other individuals with diabetes, health care providers, family, friends, and co-workers.

Patients encounter several *barriers* to self-management. The two most common barriers that were identified were lack of time and lack of funds. The time constraints made it difficult to follow the recommendations and to participate in activities recognized as important to the management of diabetes. The high cost of test strips limited the number of times blood glucose level were checked resulting in the second barrier to self-management

3. Support in the Micro-environment

In the course of the day and across their lives, participants move from one micro arena to the next. It is within the micro arenas that social interaction takes place, whether it is face-to-face interaction, or interaction with cultures, mass media, co-workers or others. The other micro-environment section is composed of overlapping components of support contributing to self-management. These interrelated themes are, *Personal Care*, *Co-habitant Support* and *External Support*.

- 1) *Personal Care* included activities such as taking medications, checking blood sugar levels, controlling diet, and exercising;
- 2) *Co-habitant Support* is defined broadly as support from a spouse, partner, or people who share accommodations with the patient;
- 3) *External Support* included support from relatives, friends, co-workers, community members, health care providers, and the Diabetes Education Centre (DEC).

Figure IV. Self-management Support in the Micro-environment

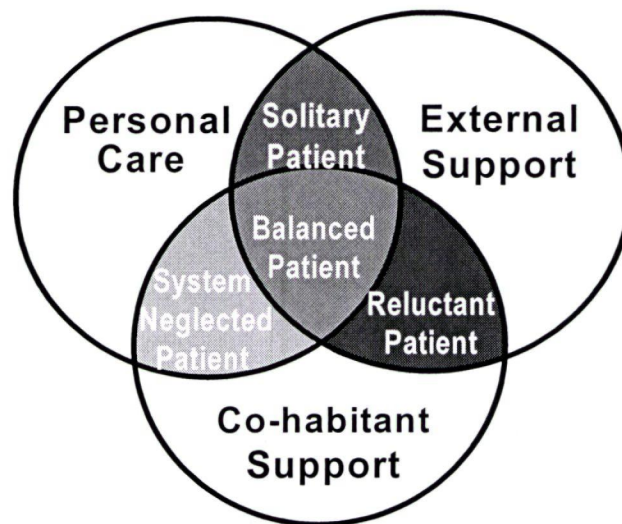


Figure IV illustrates support in the micro-environment components of the model with overlapping areas. There are four overlapping areas in this diagram. The central and most important is the “*Balanced Patient*” area. This area includes patients who want to be in control so they can take the initiative towards achieving their self-management goals. They have the necessary support required to be in control so they can take the initiative towards achieving their goals. Patients indicated that, in order to achieve self-management, personal care, Co-habitant support, and external support are necessary.

These three areas of support provide a stable environment for the patient. If any one of the areas of support is missing, self-management is in jeopardy. The model illustrates the need for a balance between personal care, co-habitant support, and external support to successfully achieve balanced patient care as evident in the following quote.

“Self-management is keeping my diabetes under control by getting help from the doctor, my family and myself.”

(married female)

In the overlapping area between personal care and co-habitant support, there is a lack of external support (health care providers and/or community resources). Patients who have been neglected by the social system and lack external support, in spite of a willingness to learn and to take care of themselves and support from their family, are called *“System Neglected Patients.”*

“The doctor just handed me pills, I don’t even know how bad my diabetes is, you know... Just here’s your pills and I’ve got to take you off of your water pill and stick you on another pill that will look after your heart and your kidneys at the same time.”

(married female)

The next overlapping area between personal care and external support is differentiated by the lack of family influence. In this area, patients have excellent external support from health care providers as well as personal care but lack co-habitant support and as a consequence fail in achieving a balanced-patient care approach. Patients with a lack of co-habitant support are called *Solitary Patients*. Family may affect health behaviours by providing practical help and emotional support. Family is defined broadly as a spouse or partner(s) or people who share accommodations and have an emotional

bond with the patient. When co-habitant support is lost, patients take a long time to recover from grief. Self-management is compromised during this time of grief.

The relationship between social structure and social support influences lifestyle practices, and the social network or negative life events can have a direct effect on lifestyle practices, health practices and health status. Life events were defined as changes in the social network i.e., death of a spouse.⁷⁷

"I'm on my own, there are things I have to do and learn to recognize for myself, whereas before, when I had my husband, he was there and he would act as a reminder or he would be very forbearing and non-judgmental when I got too cranky, just the fact that he was there was a big help for me. But he was there, there were no questions, there was no reluctance to be available so he was a good support for me, yes."

(widowed female)

In the third overlapping area between external support and co-habitant support patients are either not able to accept change or are not motivated to change. These patients are called "*Reluctant Patients*."

"I've got too many other things to do - [diabetes] is last on my mind - I'll ignore it for a while. I'll worry about [diabetes] later. I have a very busy life."

(single male)

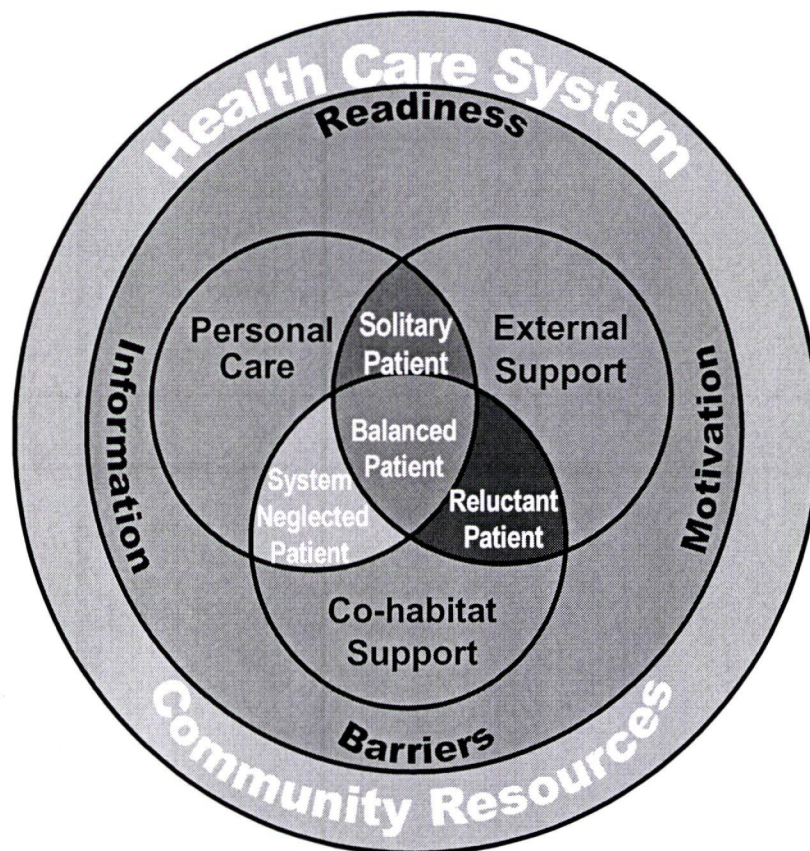
To achieve successful self-management, patients wanted to be in control of their own care. Balanced-Patient Care is at the heart of the model, representing the well being that is most important to patients. The proposed self-management model can be used as a guide to identify where patients are at any given point in time. Some participants practiced personal care inconsistently, reflecting the complexity of adjusting diabetes management to the demands of everyday life and circumstances. The model is dynamic

with patients moving in and out of the four overlapping areas, reflecting changes in the patient's life circumstances. Demographic characteristics, such as marital status, living arrangements, occupation, and employment status, as well as the social environment are essential for understanding the patient's situation.

C. The Self-management Model

The self-management and community resources model was developed by layering the previous described components about self-management and community resources.

Figure V. Self-management and Community Resources Model



IV. Revisiting the Literature

A. Self-management

The Task Force for Diabetes Self-management Education defined self-management education as an interactive, collaborative, ongoing process involving the person with diabetes and the educator(s). This process includes 1) assessment of the individual's specific education needs; 2) identification of the individual's specific diabetes self-management goals; 3) education and behavioral interventions directed towards helping the individual achieve identified self-management goals; and 4) evaluation of the individual's attainment of identified self-management goals.⁷⁸ This definition echoes patient views regarding self-management and their experiences at the DEC. One of the findings based on that study was that patients recognized self-management as an evolving process that can change based on life circumstances.

The Task Force recognized that, in order to improve diabetes self-management, a continuous quality improvement system should be implemented, consisting of a series of assessments leading to improved patient and program outcomes. The goal of the initial assessment was to create a plan and to identify individual self-management targets. This idea is reflected in the DEC education pathway. Following the diabetes education, the DEC offers a two-hour assessment to help set individual goals. These goals are identified and reviewed with a nurse and a dietitian at the DEC every three months for one year.

There is a growing body of literature that supports the notion that effective interventions tend to be coordinated by a team of individuals who emphasize the acquisition of skills, rather than knowledge alone. Such a team systematically tries to motivate and increase the confidence of patients in managing their condition.^{24, 79, 80, 81}

It is very valuable to note that most of the participants in the study wanted to be at the centre of their own care. Patient should be the primary managers of their condition and coached by the primary care provider to work out the best therapeutic plan.

Current research examined how the health care providers can put patients at the centre of their care through self-management.^{82, 83, 84} Coulter identifies ways for doctors to include patients as active participants in their own care and indicates that engaging patients in treatment and management decisions can improve appropriateness and outcome of care. She highlights the importance of informing and involving patients in decisions and the need to provide patients with counseling and support, as well as facilitating patient feedback and listening to their views and personal needs.⁸²

It was evident in this study, and was also supported by Glasgow's findings, that to achieve successful diabetes management, the patients and their families need to provide support alongside health care providers.⁸⁵ Much research has shown that patients often do not follow regimen recommendations upon leaving the physician's office.¹⁵ Rather than prescribing regimens for patients to adhere to, providers and patients need to develop realistic goals and strategies together. Government has also recognized that the most important recommendation in maintaining a sustainable health care system in Canada is to put the patient first and give them more control and responsibility for their own health by encouraging them to stay healthy.⁸⁶ This was the number one recommendation in the recent Framework for Reform Report from the Premiers Advisory Council. This recommendation highlights, in essence, the importance of the patient-wellness care that the participants in the study were seeking, but in order to have more control and responsibility for their own care, patients need health care providers that

work with them to achieve this. Doctors should talk with patients about diagnosis, prognosis, prevention and treatment. Patients should share their illness experiences, social circumstances, values and preferences. These two sources of information and knowledge are needed jointly to achieve successful chronic care management.

In this study some participants were confused by the massive amounts of information presented at the diabetes class, which is in accordance with the research of M.J. Price. She concludes that diabetes self-management is learned over time. The first phase involves the patient's initial attempts at self-management and ends when management becomes routine and the patient becomes a proficient manager. In this phase, patients achieve their goals based on personal realities related to the constraints of their busy schedules. When patients encounter new situations, they are found to have little confidence in their ability to manage and they start the process over again.³⁰

Hernandez, who used a grounded theory approach, also demonstrated a view of life with diabetes as a process that involves integrating skills and knowledge, progressing through phases, and acknowledging diabetes as part of the patient's life.⁸⁷ This process of self-management supports the findings of this study, in that after the DEC classes, participants were encouraged to look for their own information and were highly motivated to identify different ways to tailor the advice to their own needs and resources. Participants acknowledged that it took time to integrate the new skills and knowledge into their lives. Research identified that in addition to time, another barrier to effective diabetes care is that many patients and providers do not consider Type 2 diabetes as a serious problem. Terms such as "borderline" or "pre-diabetes" are often used.^{29, 88}

According to Ellison, the process of understanding self-management consists of three phases: management-as-rules, management-as-work, and management-as-living. These phases are not primarily concerned with medical issues, but rather are part of an individual's social, cultural, and philosophical nature. The approach is consistent with this study, in that the ultimate goals of patients are well being and quality of life, which encompass many aspects of life, holistically. Ellison describes a *self-management trajectory* in which the patient moves from pre-management to being a good self-manager. In this study, being in different stages of the trajectory influenced a patient's motivation to learn.²⁸

B. Care for chronic conditions

A theoretical perspective related to this study is the Wagner Chronic Care Model.³⁵ Chapter II of this thesis provided information on Wagner's model (Figure I). The goal of Wagner's model, which promotes collaboration between the health care system and community, is to reduce disability and improve the care of patients with chronic conditions. This collaboration is supported by the following components: 1) self-management intervention, 2) a delivery system with current practices reorganized to fulfill patient needs, 3) decision support, ensuring that health care providers have the necessary expertise and training, and 4) a clinical information system that supports population-based care. Functional and clinical outcomes are based on productive interactions between informed active patients and a prepared, proactive practice team.

The self-management model in this study reflects the meaning of self-management from the patient's perspective. It describes the different stages patients may be in and their position in a dynamic multidimensional self-management model. Patients

may be balanced or may be in an Isolated, a System Neglected or a reluctant situation. This model expands the concept of the “*informed, active patients*” envisioned in the Wagner’s model. The model proposed in this study provides a multifaceted view of patients. This study has demonstrated that these interactions are shaped by the status and role of the individual as well as self, family and external support. In the literature, the successful management of chronic illness depends on the patient’s ability to effectively deal with self-management challenges of the disease and its treatment.^{13, 15} However, this study and the findings reported by Hunt (et al) suggest that the self-management perception of patients represents a much broader view: participants practiced self-management when it contributed to their optimal health and quality of life rather than when it addressed diabetes alone.²³

C. Community

After attending the DEC education session, patients looked for community resources to help them achieve their self-management goals by participating in programs and activities offered by various organizations in the community. In addition, the community resources of this study are, as described by McIntyre, organizations outside of the health care system. From community resources, patients received more information and motivation, but some also encountered barriers in accessing these resources. In this study, the most prominent barrier to personal care was the individual’s social role. Women had difficulty putting themselves first. This was consistent with the literature that identified a woman’s role as housewife and caregiver for the family as often being a limiting factor in looking after her own health.^{21, 89} One of the important things that participants learned at the DEC was the importance of prioritizing their health.

Glasgow reports that environment and geographic region form part of the definition of community. This study did not find any differences in access and use of community resources based upon location. Participants used community resources regardless of their location, when a health care provider referred them or when they were motivated to access the service.³⁴ An additional characteristic reported by Macintyre et al, which can improve community participation, is owning a house and/or having access to reliable transportation.¹⁹ All the participants in the present study owned a vehicle and a house, which may explain why they were all able to actively use community resources. It is well documented that these factors influence community interactions and the relationships that patients have within their communities.^{39, 40} In previous studies, lack of community-based support was identified as a barrier to self-management.^{15, 90}

D. Diabetes Education

The current trend in diabetes education is toward empowering patients and enabling them to make informed decisions.^{15, 22} Self-care behaviours are not based on single decisions but are part of an ongoing process of making many small decisions. One of the goals of the DEC education is to inform patients and help them become proficient self-managers through diabetes education.

Before education takes place, patient attitudes towards specific aspects of self-management need to be assessed. If individuals hold negative attitudes due to fear or misconceptions it is important that the attitudes be addressed before self-management is taught. Negative attitudes will prevent participants from learning and integrating self-management into their lives.²⁹ Hernandez reports that participants believed the content of the diabetes educational program emphasized the dangers of diabetes without providing

relevant information on solutions.⁸⁷ In this study however, participants had a positive view of DEC education. They identified the amount of information as too big to absorb, and the content as appropriate and as offering solutions to potential problems.

E. Support and Attitude

Quantitative studies have shown a significant difference in self-care between participants who have support either from family or diabetes support group and those without support.⁹¹ Qualitative studies have also indicated that patients specifically emphasized the need for family involvement and support from relatives and friends to achieve successful self-management.⁹² In this study, participants identified that knowing other patients with diabetes was positive for their self-management activities because the other patients provided strong support.

This study differs from the literature in that having previous exposure to diabetes was a positive event for participants. For example, patients who had relatives or friends with diabetes found, in them, a source of support and information that helped them with self-management. Other studies report that knowing a patient with diabetes can have a negative effect on the patient. They may fear loss of health, complications and death.^{26, 28}

V. Rigor in Qualitative Research

A qualitative project should give rigorous attention to establishing “trustworthiness.” This was accomplished in this study by demonstrating the following: credibility, confirmability, dependability, and transferability.⁹³

A study is credible (*has internal validity*) if its results are authentic and there are no reasons to question its findings. One way to achieve credibility is by member checking. In this study, all interviewed participants had the opportunity to review and comment on a two-page summary of the study findings. The summary of participant views about self-management and community resources was mailed to all participants with a cover letter (Appendices VII and VIII). Each participant was contacted by phone and asked about each section of the summary. All the participants were pleased with the summary. Three participants offered further information about community resources that they identified after reviewing the summary. A participant, who had lost her husband, mentioned that although the summary was very good, the loss of co-habitant support was very painful and in her opinion this was not adequately highlighted in the summary.

The self-management and community resource model from the study was revised to incorporate the comments from the telephone interviews with participants. Overall, participants indicated the summary was accurate. One participant expressed his support as follows: “*This summary reflects my views about self-management. I would like a copy of the scientific paper.*” There was also internal consistency between the original definition of self-management and the definition that emerged in the follow-up phone interviews.

Confirmability (*objectivity*) means freedom from researcher bias. It is achieved when another investigator confirms the findings by objectively coding sections of the interviews and codes for comparison and discussion. This was accomplished by having four out of the ten interviews reviewed by the student supervisor who has experience in qualitative research methods. In addition, study notes were collected and researcher decisions were documented to help the investigator guard against bias, as well as to ensure that the study methods were adhered to.

The DEC clinical staff, approximately 20 nurses and dietitians, discussed the findings after an in-service presentation. These clinicians work closely with this patient population at the DEC. The clinical staff agreed with the subcategories, categories and themes that had emerged, as well with the model that was developed to describe the components of self-management and its relationship with community resources. In addition, they found the suggested recommendations practical to implement use on regular basis with their patients.

The results are supported by quotes from the interviews that are representative of patient views regarding self-management and community resources. Categories, subcategory and the overlapping areas in the model are illustrated with passages from the data. Finally, transcripts and tapes have been retained for potential re-analysis.

Dependability (*reliability*) is the process used to ensure that the study is consistent and follows a systematic approach over time and between investigators. A second person reviewed the interview codes, subcategories, themes and categories to provide dependability. In addition, progress reports were presented to the Supervisor Committee members and their suggestions were recorded and incorporated. The use of a guide for

the interviews contributed to dependability (Appendices III and IV). Although the interview guide evolved to some extent during the course of the study, it provided a reliable foundation for the interviews. In addition, the same investigator conducted all the interviews in order to provide consistency. There are some limitations with this approach since it is susceptible to investigator bias. This bias was addressed by having another qualitative researcher review some of the interviews.

Transferability (*generalizability or external validity*) refers to the degree to which the results can be applied to other contexts, other situations, or other groups, not necessarily to generalize the experience to a larger population. The participants interviewed were compared with the entire DEC population, including those who declined to be interviewed. The demographics of the study population were comparable. Therefore it is reasonable to generalize the views of participants regarding self-management and community resources to the population from which the sample was drawn i.e. participants who received DEC education who agreed to be interviewed. Diabetes has been used as a model of chronic care. The description of the stages might be applicable to patients with other chronic conditions. The model developed in this study would also need to be tested with other groups of Type 2 diabetics who have undergone diabetes education in settings other than the DEC or in other regions where access to community resources and information differ from that in the Calgary Health Region. Another way to accomplish transferability is by providing adequate detail about the study so that other researchers can determine the relevance or generalizability of the study to their own work. This was accomplished by providing considerable detail about the demographic characteristics of the participants and the study methods.

The principles of credibility, confirmability and dependability are all interrelated. The use of member checking and review by content experts established credibility and confirmability. The consistency that was evident among the interviews with all participants supports both dependability and credibility. The use of different researchers to review the codes and results supported credibility, confirmability and dependability.

VI. Conclusion

This chapter explained the self-management model that was developed to illustrate the components of self-management that emerged from the interviews and the relationships between self-management and community resources. The contribution of this study to the existing medical literature on self-management and chronic diseases was also discussed here. The final section of this chapter described and summarized the ways in which this study meets the requirements of rigor in qualitative research. The last chapter concludes this report including recommendations and speaks to the significance of the study, its strengths and limitations, and ideas for future research.

CHAPTER VI – CONCLUSION

I. Introduction

This final chapter presents the study implications for health care providers related to the views of participants regarding self-management. This includes some practical recommendations that are a summary of categories identified in the study. It includes a discussion of the study significance and the strengths and limitations of the study, as well as suggestions for future research.

II. Implications for Health Care Providers

Because the participants were drawn from the Diabetes Education Centre (DEC) some of their comments are related to that organization. There are also comments regarding other community resources that the informants used. Although the recommendations are organized according to the six categories that emerged from the data, not all the categories have recommendations. When results were presented to the DEC staff they indicated that the suggestions were valuable.

A. Information

The information participants received from the 6-hour session at the DEC was central to their definitions of self-management. The participants believed that the information they had received about diabetes could be applicable to any other chronic condition. Patients found it very beneficial when information was presented in multiple formats. Some participants felt isolated from information. They felt they were not

clearly informed or knowledgeable enough to make proper decisions. Some patients were confused by the enormous amount of new information presented at the diabetes class, and some participants requested different teaching strategies or expressed the desire to have the information presented in three two-hour blocks instead of one six-hour block. On the other hand, there were patients who found it convenient to be able to cover all the information offered in one day. Finally, patients needed to accept the information as valid. Generally, patients verify the information they are given until they are satisfied with its legitimacy.

- a) Patients learned by receiving the same information in different formats. For example: A summary booklet for participants to review the diabetes educational program as well as videos, audiotapes, magazines, or books providing supplementary information about diabetes.
- b) Communication among participants as well as with the DEC staff should be encouraged in order to reduce isolation.
- c) Self-management education should include a component regarding doctor-patient communication. This should include the importance of preparing for a doctor's appointment, and how to be assertive with health care providers.

B. Motivation

The data from this study suggests that the part of the process of taking action to achieve self-management goals follows from the education session. By participating in classes, patients understood the disease process better, developed an optimistic attitude and discovered ways to undertake proactive approaches. Individuals participated because

they were motivated to learn about their disease. Patients in this study integrated knowledge and skills into their routine and acknowledged the difficulties they had changing certain behaviours when they lacked the motivation to do so. Patients wanted to be in control so they could take the initiative in achieving their self-management goals.

- a) Continued contact with health care providers such as a reminder note or a Christmas or birthday card with some educational information may help to motivate the patient to follow self-management practices.
- b) Health care providers need to work with patients to identify clear goals for them by talking to the patients about management goals in order to advance self-management and to achieve the shared vision of care.

C. Support

The relationships with family members, friends, extended family and co-workers were identified as an important part of external support and an essential factor in self-management. Participants also viewed the support received from other patients with diabetes as a form of external support. For some participants, realizing that they were not alone in their experiences with diabetes was an important benefit of attending the DEC class. Patients reported that participating in a group that served diabetics was important to them and they recognized that the DEC staff members were very knowledgeable. Patients reported that the support and assistance provided by health care providers increased the likelihood of their management success.

D. Barriers

Patients identified a number of barriers that prevented them from becoming successful self-managers. First, as participants described their daily routines, it was evident that they sometimes allowed their busy schedules to restrict their ability to follow the advice of health care providers. Second, patients identified a number of financial restrictions. Examples of these restrictions are the high cost of test strips, the cost of annual physical exams, and the annual cost of renewing a driver's license. Ultimately, patients identified lack of time as the greatest barrier to achieving their self-management goals. They stated that they are limited in their ability to perform exercise or attend support groups and leisure activities due to an already over-loaded lifestyle. Isolation was also recognized as yet another barrier. Some patients felt abandoned and that they lacked any opportunity to discuss their progress and relapses with someone who cared.

- a) Barriers such as lack of time, economic factors, and isolation, should be factored into the planning of self-management education. To plan management goals, a clear view of the patient's life situation and motivation is necessary.

E. Familiarity

It is important to identify whether patients have had previous exposure to diabetes. It seems that the experience may aid in self-management. As participants learn new knowledge and skills to manage their condition, they often compare their experience with those of other individuals with Type 2 diabetes or other chronic conditions. This

may help the patient in the process of becoming acquainted with diabetes care and in acquiring timely assistance from a health care provider when required.

Mass media has raised awareness about the disease and was used by participants as a source of information. However, participants found that diabetes information provided by the media usually emphasized its negative aspects.

- a) A skilled health care professional, knowledgeable about diabetes, should be involved to validate the accuracy of the information used in mass communication. Participants identified Media as an important source of diabetes information. Health policy makers should advocate for media directors to have the information verified by health professionals.

F. Stages of Readiness

Participants attending the classes must have a personal desire to be involved in their own diabetes care. Knowledge and skills provide the patient with the power to make decisions and take action by utilizing resources and achieving self-management goals. Only patients who were ready to learn and willing to make changes were able to achieve successful self-management and make the long-term commitment necessary for success in chronic care.

Patients needed time to incorporate information and skills into their daily routines. Participants were encouraged to look for community resources and to enroll in activities to fulfill their self-management goals. Such agencies bring people together so that they gain experience and are exposed to others who are willing to change.

- a) Patient readiness is not static and patients need to identify how to adapt self-management behavior to their individual circumstances. Health care providers can inquire as to what patients need to be able to succeed in their self-management.

G. Self-management and Community Resources

Participants defined diabetes self-management as the tasks performed to gain knowledge, understanding, and skills to control diabetes and the changes in lifestyle required regarding diet, exercise, checking blood glucose, and taking medication regularly. In addition, patients recognized that there were times when they chose not to perform the recommended activities because other life circumstances, such as illness or a death in the family, made this impractical or too stressful. Their experiences should remind health care providers that diabetes self-management involves reorganizing one's life. This is reflected in the ups and downs in the patient's life experiences. Their experiences should help health providers understand that individual efforts do not always equal success and that individuals vary in their ability to re-work the cultural repercussions of illness.

No difference was found in the use of community resources or self-management between participants from different parts of the city. Participants used community resources located in all quadrants of the city. Participants experienced community through close family and friendship ties as well as relationships formed where they worked, played, worshipped, studied, and volunteered. A revised model for effective chronic illness care must include patient perspectives and should include community resources outside of the health system as part of a larger definition of community.

- a) Policy makers and health care providers can further assist patients to achieve self-management by promoting partnerships with community organizations.
- b) Health care providers should encourage patients to use community resources to achieve self-management goals.
- c) It would be helpful for the DEC and other health care providers to create a comprehensive list of available community resources, which could assist patients in taking advantage of those resources.

III. The Study

A. Significance

This study was conducted because of a general lack of information in the literature about the perspectives of patients regarding self-management and the use of community resources to self-manage their condition. This study contributes to an evolving body of knowledge on self-management and contributes to a formal theory of self-management based on patient perspectives. Also provided, is a description of what self-management and community resources mean to patients with Type 2 diabetes. It highlights the perspectives of self-management from the viewpoint of the participants and identifies the type of support patients need to achieve optimal self-management.

The goal of self-management intervention is to provide skills training, confidence building, and sustained follow up. In addition, self-management programs focus on encouraging individuals to become more active participants in their care at home, at work, and at the health care provider's office. Some programs have made patient empowerment a primary goal of the intervention and have achieved improvements in attitude, behaviours, and physiological indicators. Patient participation in diabetes care is

almost certainly a critical element in their illness management.⁹⁴ The major contributions of this study are the analysis of patient views regarding self-management, the development of a comprehensive self-management model, and identification of the various components of the model. It is important to understand patient perceptions regarding self-management, since these perceptions influence the way patients view diabetes education and follow through on self-management practices. The model is not static and evolves due to changes in patient circumstances and social changes.

An unexpected finding that health care providers should be aware of is that patients might decide not to follow instructions due to life circumstances and that decision should also be considered a form of self-management. Health care providers should assess management goals and should be aware that the findings in the literature describe self-management as being performed by informed, active patients. This study moves beyond the previous findings, describing three types of support required by participants: Personal Care, Co-habitant Support and External Support. The model identified four phases of self-management for patients: Balanced Patient, System Neglected Patients, Solitary Patients and Reluctant Patients. Patients can move from one phase to another based on life circumstances.

This study indicates that most patients take a holistic approach to self-management. Self-management is defined as the day-to-day activities undertaken, not only for diabetes care, but also for general well being. Participants provided a definition of self-management that included not only their personal care role but also acknowledged the importance of co-habitant support and external support towards their general health. They used community resources that best fit their self-management needs regardless of

the location of the resource or area of residence and started using them more after receiving education. A very significant adjustment, for many participants, especially women, was understanding that their decision to manage their disease was needed and of high priority. Participants were taught that they, the individual and their health, are the most important things to consider.

These results provide a foundation for future quantitative and qualitative studies. The findings of this study may also apply to patients with other chronic illnesses who would be interested in self-care initiatives whereby they would take more responsibility for their own disease management and share that responsibility with health care providers. In addition, this study expands on Wagner's Chronic Care Model by adding the perspectives of patients and identifying different stages patients may be in with respect to the self-management of their disease. A patient may move from one stage to another due to ups and downs in their personal circumstances. The Wagner's model only identifies the informed, active patient. In the Self-management and Community Resources Model, these patients are represented by the category of balanced patient. Not all patients are in this stage, however. Not all individuals have the personal care, co-habitant support, and external support that were found to be essential factors in achieving Balanced Patient Care.

B. Strengths

In a study such as this where little information is known about patient perspectives regarding self-management and community resources, a qualitative approach allows for the development of a valid, deep understanding of the phenomena being studied and uncovers a wealth of information related to the topic. In this study,

there was in-depth interaction and conversation with ten Type 2 diabetes patients. The results reflect their views and their perspectives on the significance of self-management and community resources. All participants were interviewed by the same researcher, and received a summary of the findings. All participants acknowledged that the summary reflected their views. In addition, the DEC clinical staff agreed with the findings.

The participants paralleled the demographics of the DEC population in terms of the number of diabetes educational sessions attended, the mean number of dietitian and nurse follow-up visits, and sex. This study provides a first step to understanding the need patients have for community resources, both in terms of their use and their availability. No prior studies focusing on patient perspectives on self-management and community resources were identified.

C. Limitations

The views illustrated in this study are those of the participants only. The study was limited to those individuals who were willing and able to participate. Participants in this study may have been unusually knowledgeable and motivated, since they were participants in the DEC education and were intentionally selected to represent those with no complications and with good glucose control. The study exclusion criteria eliminated patients who did not speak English and those who may have received diabetes education elsewhere. The results may not be applicable to the excluded subjects, or those who were not eligible for class education and/or did not meet the inclusion criteria of the study. Further work is needed to validate the findings of this study with other diabetes patients.

This study explored only the views of patients with diabetes. It did not attempt to capture the perspectives of family members or health care providers. In some instances,

family members were present during the interviews but they assisted only by providing details of the patient's history or experience. The study was restricted to patients with Type 2 diabetes, without complications, who had been referred to the DEC for education and who had been diagnosed less than seven years ago. Participants were interviewed only once, so the entire self-management process was not captured. The validity of the data may be limited since some participants may have been unwilling to share information or they may have been unable to remember previous self-management views and experiences.

In addition, participants with complications, patients on insulin or those with poor glycemic control were excluded. Due to these constraints, the results may not be applicable to such patients. It is important to note that the findings of this study may not be transferable to populations located in different geographical communities, other health regions, or populations with special needs. The location of the DEC also may have been inconvenient for some people. This would also have introduced a selection bias since only participants who were able to come to the DEC were included in the study.

A potential limitation of qualitative research is *researcher bias* when coding and analyzing data. This was minimized by using direct quotes, by having an expert in qualitative analysis code a number of interviews, by sending participants a summary of the findings to review, and by presenting the results of the study to a group of clinicians at the DEC who validated the findings.

IV. Implications for Future Research

- 1) The questions raised by this study generate potential for a number of possible related studies. To continue developing theories related to patient perspectives of self-management, similar qualitative studies should be conducted. What are the views of patients with Type 2 diabetes who received diabetes education from other services or the views of patients who have never received education? The views of patients with complications or patients from other cultures should also be investigated. Although this study focuses on patient perspectives, other perspectives are also important. What about the perspectives of the spouses or other significant people in the patient's life? Such key people play an important role in the self-management success.
- 2) This study suggests that patients take a holistic approach to self-management to improve their general "wellness." The development of a self-management vision in collaboration with the primary health care provider is essential to the success of patients' self-management.
- 3) This study did not investigate which component of the DEC program were perceived as more important for improving the ability of patients with Type 2 diabetes to self-manage their disease. Therefore, research in this area would help to enhance self-management programs.
- 4) Longitudinal studies are needed to demonstrate the impact of self-management education. Health outcomes for patients that have completed the program at the DEC

could be compared with those of patients that receive usual care. Data for this type of study is available in this region.

Measurements of knowledge, quality of life could be useful in intervention programs for patients with diabetes by providing assessments of the patient's coping ability and knowledge before and after education. This information could be investigated through randomized, controlled trials comparing patients receiving education with patients on a usual care path that does not include education. These are just a few examples of the many potential research questions that may be generated from this study.

V. Conclusion

During the course of this study, the investigator gained a more comprehensive understanding of the views of patients about self-management and their use of community resources. The use of qualitative methodology allowed for an in-depth understanding of the phenomena to emerge from the open-ended interviews. The complex interactions within and between categories indicated that patients use a dynamic approach to self-management. The support patients receive changes over time; new information is gathered on a regular basis, stages of readiness change based on a patient's situation, and patients constantly face barriers to self-management.

This study identifies several suggestions for changes related to diabetes self-management and community resources. Health care providers need to recognize that the patient's view is not related to diabetes alone. Patients have a holistic approach. They use community resources and engage in self-management to improve their overall health and well being. Therefore, a key issue is how self-management

education and practices can be integrated into existing routines. The challenge for health care providers is to translate the contextual factors of successful management into practical applications.

The recommendations in this chapter are intended for health care providers and policy makers. The intent is to encourage diabetes care and education that is tailored to the needs and circumstances of individual patients so that patients can achieve optimal self-management as well as fully benefit and take advantage of available community resources. As with all research studies, this study has limitations, which are identified in this chapter. Suggestions for future qualitative and quantitative research are also presented.

This study advances the current knowledge regarding self-management and community resources from the patient perspective. A major contribution is the development of a dynamic, multidimensional, self-management model. The model is grounded in data from the interviews and illustrates the various transition stages that can be experienced, based on the patient's life and circumstances.

APPENDICES

CHR Diabetes Education Centre Research Opportunity Consent FormUNIVERSITY OF
CALGARY**RESEARCH OPPORTUNITIES**

We are conducting several research studies for treating diabetes and/or high cholesterol and high blood pressure. You may be eligible to participate in one of these studies.

Your name and address is entered onto a confidential database which we use to help us provide care for you and to ensure that we provide a high quality of care to every patient. We would like to use this information for research and would like your permission. This permission would allow us to review your chart and use the information in a research study. Your confidentiality would always be preserved and the information would be anonymous. All of our studies are approved by the University of Calgary.

There will be research studies in which you may be able to participate. We would like your permission to contact you to inform you about such research. If you were to enroll in such research, you would be given full information and would only participate if you gave your permission at that time.

- By signing this form, you give us permission to review your clinic chart and our database to see if you may be eligible to participate.
- You also agree to have us call you to provide details of a particular study so you can decide whether you would like to be involved.

You are NOT REQUIRED to participate in research at our Centres, it is entirely voluntary.

- You should not feel any pressure to be involved in research.
- Your medical care here will not be affected if you choose not to participate.
- You can withdraw this permission at any time by calling us at 541-2194.

Your Name: (Print) _____	(Signature) _____
Today's Date: _____	
Phone Number: (Home) _____	(Work) _____
Date of Birth: _____	
Year of Diagnosis: Diabetes: _____ High Blood Pressure: _____ High Cholesterol: _____	
Medications: (Please List)	
Diabetes: _____	
Hypertension: _____	
Cholesterol: _____	
Other: _____	

Patient ID# _____**Demographic Questionnaire**



calgary health region



**Perceptions of Patients with Type 2 Diabetes Regarding
the Meaning of Self-management and the Community
Resources Needed to Achieve Self-management Goals**

I. Patient Demographics

All the information collected in this study will be kept strictly confidential. Your voluntary participation is essential to its success and you are free to refuse to answer any questions you do not wish to respond to. A summary of the study findings will be mailed to you. Please remember there are no right or wrong answers.

Name _____
Last First

Address _____

City _____ Postal Code _____

Work Phone Number _____ Home Phone Number _____

Contact Name _____
Last First

Contact Home Phone Number _____

1. Date of Birth _____ YY/MM/DD
2. ☐ Male ☐ Female
3. What is your weight? _____ Kg / lb (Please circle one)
4. What is your height? _____ Cm / meter (Please circle one)
5. Is English your first language? ☐ Yes ☐ No If not please specify: _____
6. What is your marital status? (Please check one) ☐ Married/Common Law
☐ Never Married ☐ Widow ☐ Separated/Divorced
7. Whom do you live with? (Please check all that apply) ☐ Alone
☐ With spouse/partner ☐ With children ☐ With parents ☐ With roommates
8. What level of education have you completed? (Please check the highest)
☐ Elementary ☐ Secondary ☐ College ☐ Technical ☐ University
☐ Postgraduate education
9. Have you ever smoked? ☐ Yes ☐ No
If you currently smoke, how many cigarettes per day? _____
10. What is your employment status? (Please check all that apply)
☐ Part-time ☐ Full-time ☐ Unemployed ☐ Homemaker ☐ Retired ☐ Student

Thank-you for completing this questionnaire

Individual Interview - Interview Guide (October 1, 2001)

The purpose of the interview is:

- to explore what **'diabetes self-management' means to you.**
- to examine the need for CR to help you achieve your management goals.

All the information collected in this study will be kept strictly confidential. Please remember there are no right or wrong answers.

Meaning of Self-management

-What does Self-management mean to you?	-When attending to the management of diabetes, what do patients with diabetes call these activities? E.g., checking blood glucose, taking medications, diet and regular labs and f/u visits.
-What do you think patients with diabetes do/need to take care of their diabetes?	-What reasons do you have to get diabetes education at this time?
-Have your views about diabetes management changed over the course of the disease?	

Diabetes education

-What impact does diabetes education have on the management of your disease?	-Are you satisfied with the diabetes education that you have received? E.g., Hours of operation, location and schedules of the classes, f/u.
-Why did you take the DEC Diabetes Ed?	

Other Diabetes education

-What kind of education/information do you need?	-What are your needs with respect to diabetes education (e.g., hours of operation, location and schedules of the classes or services)?
-Where, and for how long, did you receive education?	-How often have you received diabetes education?

Community Resources

-What types of resources are available in your community to help patients with diabetes deal with their condition?	-What types of services, for example, exercise, diet, community association activities, cooking classes, or pharmacies are available? How would additional community resources help?
-What is your view on comm. resources?	
-What kinds of community resources do patients with diabetes need?	-If you used community resources in the past, why did you stop using them?
-Have you used, or will you use, community resources?	-Are you using community resources?
	-Which community resources are you using or would you use?
-How could community resources help patients with diabetes?	-What are the benefits you have obtained from using community resources? In what way?
-What is your understanding about community resources?	-How long will you need the services?
-Did they make any difference to your health?	-Do you feel the use of the services helped you to more effectively manage your diabetes?
-What are your expectations from community resources?	-Can you provide an anecdote about community resources that you have used?
-What concerns regarding security and/or confidentiality using community resources?	-What impact have the services had on your condition?

Updated Individual Interview - Interview Guide (December 7, 2001)

The purpose of the interview is:

- to explore what **'diabetes management' means to you.**
- to examine the need for resources in the community to help you achieve your management goals.

All the information collected in this study will be kept strictly confidential. Please remember there are no right or wrong answers.

Meaning of diabetes management

-What do you think patients with diabetes do/need to take care of their diabetes?	-What do patients with diabetes call these activities? E.g., checking blood glucose, taking medications, diet and regular labs and f/u visits.
-What is the term or phrase that you use to describe all these activities?	
-What does diabetes management mean to you? -What part of day-to-day diabetes care are you responsible for?	-What reasons do you have to get diabetes education at this time? What is/NOT Self-management
	-Have your views about diabetes management changed over the course of the disease?

Diabetes education

-What impact does diabetes education have on the management of your disease?	-Are you satisfied with the diabetes education that you have received? E.g., Hours of operation, location and schedules of the classes, f/u.
-Why did you take the DEC Diabetes Ed?	

Other Diabetes education

-What kind of education/info do you need?	-What are your needs with respect to diabetes education (e.g., hours of operation, location and schedules of the classes or services)?
-Where, for how long, and how often did you receive education?	

Resources

-Where do you go for exercise, foot care, lab and information on diabetes etc.	-What is your perception about community resources?
-What types of resources are available in your community to help patients with diabetes deal with their condition?	-What types of services, for example, exercise, diet, community association activities, cooking classes, or pharmacies are available? How would additional Community Resources help?
-What kinds of resources do patients with diabetes need? <u>Associations or Organizations</u>	-If you used community resources in the past, why did you stop using them?
Have you used, or will you use resources?	-Are you using community resources?
Do you belong to or have a membership in any organization or association?	-Which resources are you using or would you use?
	<u>-Canadian Diabetes Association?</u>
-How could Community Resources help patients with diabetes?	-What are the benefits you have obtained from using Community Resources?
-What is your understanding about Community Resources? -Do you feel the use of the services helped you to more effectively manage your diabetes?	-What impact have the services had on your dis?
	-How long will you need the services?
	-Did they make any difference to your health?
-What term/phrase would you use to describe these activities?	-Can you provide an anecdote about Community Resources that you have used? -Can you identify some barriers to access the community resources?
What concerns regarding security and/or confidentiality do you have about using	-To self-management: Is TIME a barrier?

The Diabetes Education Centre

A. Description

The Diabetes Education Centre (DEC) is located on the fourth floor of the Colonel Belcher Hospital. The Regional diabetes program was implemented at the DEC in 1996. Since then, significant effort has been aimed at standardizing classes, educational content, the referral process, and patient data, and streamlining clerical processes. The Centre operates as a resource for providers within the CHR. It provides up-to-date education and clinical management but only tracks patients for one year. Patients need ongoing education and support that is not available in the CHR system.⁹⁵

The Canadian Diabetes Educator Certification Board, a national program, administers a certificate whereby a nurse, dietitian, pharmacist, social worker or physician can become a Certified Diabetes Educator (CDE).⁹⁶ They must achieve a mark of 70 % or higher to be certified. To qualify for the exam, the health professional must have spent the equivalent of two years working in diabetes education.^a At the DEC, all clinical staff members are required to become CDE certified within two years of commencing employment.

B. Programs and Services

The DEC offers classes on special topics, such as foot care, insulin use, and pump use. The DEC also offers classes at the Chinese Cultural Centre and the Kerby Centre throughout the year. Education is provided by a team consisting of a nurse and a dietitian and focuses on the following components: management of diet, pharmaceuticals, exercise, lifestyle and education about complications.

^a Canadian Diabetes Educator Certification Board

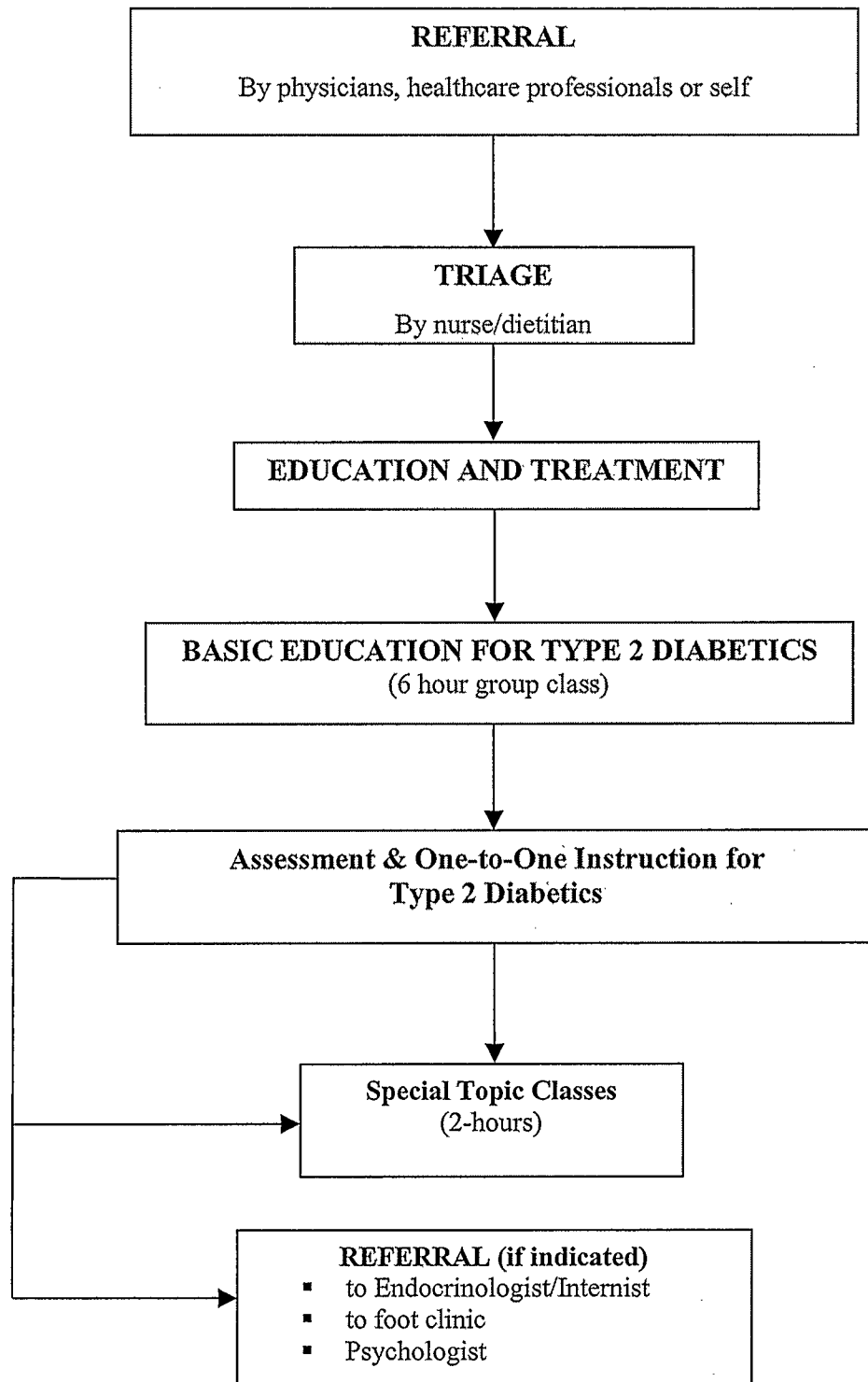
In June 2002, the DEC has a staff of 26 (FTE) nurses and dietitians and one psychologist. Seven associate physicians provide fee-for-service consultations as well. In the 2000/2001 fiscal year, the DEC averaged the following each month: 1,115 appointments, specialized education classes attended by 163 newly diagnosed Type 2 diabetes patients, and 356 new referrals from community physicians.⁹⁷ The DEC offers at least two educational classes for patients with Type 2 diabetes every week and the classes have an attendance of approximately 20 patients per class. Classes are also available for patients who have been diagnosed before but have never taken a self-management course or for those who desire a refresher course. The services provided by the DEC have increased dramatically over the last two years. New referrals have increased by 25%, the average number of appointments increased by 16%, and the number of patients attending educational classes increased by 42%.

C. Education

Figure VI details the resulting process. A nurse or dietitian triages the referral. Patients can be referred for the six-hour self-management course or for a one-on-one assessment. After the group education session, an individual two-hour assessment with a nurse and dietitian who has specialized in diabetes is scheduled with each patient. At this session, the specialist reviews with the patient how well he or she has absorbed the information and they establish preliminary self-management goals. Following this individual session, patients are scheduled to attend follow-up visits every three months for one year. At each follow-up session, the self-management goals are reviewed and re-evaluated. Patients can be referred to classes on special topics or to an Endocrinologist or foot clinic.

D. Community Resources Information

At the DEC, patients receive limited information regarding community resources. The Centre has developed educational material for their programs and compiled information about the Canadian Diabetes Association (CDA), the Alberta Monitor for Health Program (a source of support for insulin-dependent patients), and a list of books on the general topics of diabetes, exercise, and nutrition. They are also given web links and access to two software programs on nutrition. It is expected that better-informed patients will be proactive when dealing with the health care team. The key points of the course are to provide the basic physiological facts about diabetes, as well as useful information about how the body works so that patients can better manage themselves and their care.

Figure VI: DEC Instruction and Care Pathway Components

E. Class Content for Type 2 Diabetics

The 6-hour group class covers seven topics and cultivates skills and knowledge in the areas of: the diabetes disease process, physiology, risk factors, the emotional stress of having diabetes, physical activity, blood sugar monitoring, diabetes medication, cookbooks, cooking tips, label reading, long term complications, and foot care.⁹⁸ While attending classes, patients are provided with a handbook, which summarizes the points made on each topic. The manual is composed of easy to follow, point-form notes. The 6-hour course is divided into sections as follows.

1) What Is Diabetes? (60 minutes)

A nurse, specializing in diabetes, teaches this 1-hour module. It covers the main physiological issues of diabetes such as: types of diabetes, signs, symptoms, and blood sugar goals. This class also introduces the components of diabetes management and teaches on the topics of risk factors and control issues and briefly deals with the emotional stresses of having diabetes.

2) Healthy Eating (60 minutes)

The topic of healthy eating is studied with a dietitian and includes a thorough examination of the different food groups. It is especially important for patients to understand how to regulate carbohydrates, starches and sugars in order to achieve a balanced diet.

3) Physical Activity (30 minutes)

Physical activity is another very important control mechanism for persons with

diabetes. This section of the program explains how physical activity helps manage diabetes. The module also covers the dangers of being involved in physical activities without a controlled diet and provides recommendations on specific activities.

4) Blood Sugar Levels (30 minutes)

This topic covers one of the most important tasks for patients with diabetes to master. It deals with the techniques and optimum times to check blood sugar levels, as well as advice on how to find the best equipment to use in performing these tasks.

5) Medication (60 minutes)

Medication is very important to discuss with the patients as many of them have side effects and specific instructions. Topics include types of medications, their effects, and how medications work to improve control over sugar levels.

6) Food Preparation (60 minutes)

Healthy cooking, healthy eating, knowing what to cook, and how to slowly adapt one's diet are vital topics of interest to people with diabetes. This section covers information on how to incorporate snacks and convenience foods into the diet, as well as being able to identify visible and hidden sources of fat. Patients are made aware of how to read labels, given recipes and taught about artificial sweeteners.

7) Disease Complications (45 minutes)

This topic deals with the potential side effects of having diabetes. This module discusses facts on nephropathy, neuropathy, retinopathy, cardiovascular problems, how to identify symptoms for early detection, and how to prevent these conditions.

Each person living with diabetes is at risk of developing complications and should be aware of the possible long-term developments. The importance of implementing the Diabetes Care Record and self-advocating for a variety of blood test, urine test are also stressed in this portion of the class.

8) Closing Remarks (15 minutes)

This time is used to review the topics discussed and repeat the fact that diabetes is manageable by employing good health care practices to prevent complications.

Special scenarios are played out to prepare the patient for the future. Patients are encouraged to contact the DEC with any questions or concerns after completing the classes. They are also encouraged to use the manual for reinforcement and guidance.

A two-hour follow up appointment with a nurse and dietitian is scheduled.



Patient Consent Form

Project title: Perceptions of Patients with Type 2 Diabetes Regarding the Meaning of Self-management and the Community Resources Needed to Achieve Self-management Goals

Investigators: Alexandra Harrison, Alun Edwards, Sandra Delon, Wilfreda Thurston and Rosario Talavera.

Sponsors: Alberta Research Council Inc., and Calgary Health Region.

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Diabetes is a chronic condition that affects many Canadians and there are currently about 1.8 million patients with diabetes in Canada. Patients with Type 2 diabetes or non-insulin dependent diabetes mellitus represent approximately 90% of this group. This study will involve only patients that are attending the CHR Howard McEwen Regional Diabetes Education Centre (DEC).

Your participation in this study will involve the following:

- 1) a brief questionnaire about you that will take about 5 minutes to complete.
- 2) a face-to-face interview that will last approximately one hour. If you agree, the interview will be tape-recorded and will take place in a location convenient for you.

OR

- 3) a small group discussion of approximately 5 to 8 people. This discussion will last approximately one hour and will be tape-recorded.

Participation is voluntary and you are free to withdraw from the study at any time and to refuse to answer any questions you do not wish to respond to. The goal of the face-to-face interview is to help add to the understanding of what the term self-management means to you and your perceptions about community resources and their importance to patients with diabetes. The purpose of the focus group is to verify, learn and elaborate on the information gathered in the interviews. Your diabetes care will not be altered in any

way. The information gathered from this project will help to enhance understanding about your views on self-management and community resources. This information may be used to adjust the current program offered by the DEC.

All tapes will be transcribed and the information collected will be stored in locked filing cabinets with access being given only to Dr. Alexandra Harrison and Dr. Rosario Talavera. The tapes will be destroyed after the study is completed. Data will be kept confidential and only reviewed by investigators. It will be kept for five years after the completion of the study. The results from this study will be reported as group data and at no time will any information about you, as an individual, be reported. There will be no way of identifying individuals in any report. A summary of the study findings will be sent to you.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and have agreed to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact:

Dr. Alexandra Harrison 220-2740

Dr. Rosario Talavera 210-5276

If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

Participant signature Participant name (Please print) Patient ID#

Phone Number: (Home) _____ (Work): _____

Mailing Address: _____

Alternate Contact Name: _____ Phone Number: _____

Witness signature Witness name (Please print) Today's Date

Investigator signature Investigator name (Please print) Today's Date

A copy of this consent form has been given to you to keep for your records and reference.

Thank-You Letter to Participants

<Participant Name>

<Participant Address>

Calgary, AB, <Postal Code>

Date:

Thank-you very much for meeting with me the other day. I appreciate the time you spent to tell me about your views regarding the meaning of Self-management and the need for community resources to manage your condition. Your participation is essential to help us to understand patient views on these topics.

As I mentioned to you, when the data analysis from all interviews is completed, I will send you a summary of the findings of this study and follow up with you by phone.

If you have any questions, please do not hesitate to contact me.

Thank-you again for your invaluable participation.

Yours truly,

Rosario Talavera
210-5276

Summary Interview Cover Letter

February 10, 2002

Rosario Talavera
3608 – 33 Street N.W.
Calgary, AB, T2L-2A6

Mr./Mrs. Name
Address
Calgary, AB Postal Code

Dear;

RE: Diabetes Self-management and Community Resources

Thank you for meeting with me to discuss your experience with diabetes. As I promised at the time of our interview, I am enclosing a copy of the interview summary. This summary incorporates the views of the ten participants I interviewed between October 16 and December 15, 2001.

I will telephone you sometime during the next two weeks to get your feedback on the summary. I would like to know if you feel it accurately reflects your views on Self-management and Community Resources.

In the mean time, please do not hesitate to contact me if you have any questions or concerns. Thank you again for your invaluable participation. I look forward speaking with you soon.

Yours truly,

Rosario Talavera
210-5276

cc. Participant's file

Informant Interview Summary

Participant views about Self-management and Community Resources

This is a brief summary of the views of ten participants, interviewed between October 16 and December 15, 2001. Your feedback will be appreciated.

Self-management

Self-management includes tasks performed by participants to gain knowledge, understanding and skills to control diabetes. Generally, respondents found it challenging to integrate a care routine of diet, exercise, checking blood sugar levels and taking medication into their busy lives. For some participants, diabetes is a very private issue. A commonly used phrase when talking about diabetes was, "It's my way of life. I'm a diabetic." One aspect of the definition of self-management was the option of choosing whether or not to perform recommended activities. Participants acknowledged the impact of work, time constraints and changes in lifestyle on how well they managed their condition. If, for any reason, the support network was compromised, it took time to recover and get back on track. Participants pursued more information after advice was offered. They accept the information if it came from a trustworthy source. Initially, some respondents were not sure about using the word 'management' because of its association with business. After using the word in conversation, however, participants defined management as the day-to-day activities undertaken not only for diabetes care but also for general well being.

Participants identified two main components of diabetes management:

Personal Care

This included activities such as taking medications, checking blood sugar levels, controlling diet and exercising.

External Support

This included input from family members, friends, relatives, health care providers, and the Diabetes Education Centre (DEC). Participants considered the DEC to be a support system as well as an education and treatment centre. They received support both from DEC staff and from other participants attending the classes. Participants reported good communication with family doctors, nurses, dietitians and pharmacists was important in their disease management. For all participants, the education they received at the DEC was their first formal instruction. The information received at the DEC motivated respondents to seek further information. Limited information about diabetes made participants feel isolated. Skill and knowledge gained through education was not beneficial unless the participants applied the advice to their diabetes care. Respondents recognized that they must be compliant with the recommendations from the DEC and the health care providers in order for this advice to have an impact on their diabetes management. After learning new skills and gaining new knowledge, participants took time to master the skills and incorporate new behaviours into their lives. The participants believed their self-management changed after receiving education. Previous exposure to diabetes or other chronic conditions helped individuals understand their self-management roles better. Participants agreed with the DEC program's emphasis of the importance of the individual and self-management. In addition, they found the teaching from the

nutritionist regarding eating smaller portions and six small meals rather than three large meals a day very helpful.

Community Resources

Respondents identified Community Resources as the involvement in and participation with various organizations and associations. Participants used community resources for education, recreation, and support. Respondents have to pay for their own blood testing strips and this limited the number of blood checks for some respondents because of financial constraints. The use of community resources is not restricted to diabetes management but rather is important for the social and emotional support gained to increase the respondent's wellness and quality of life. Some participants initially interpreted the term "community resources" as services offered to economically disadvantaged individuals, but after discussion were able to offer examples of other types of community resources relevant to their own experiences.

The table below lists in alphabetical order community resources, which informants have "used", identified as "needed" or recognized as existing but personally have "never used." Please feel free to add more examples when we speak on the telephone.

Table 1. Community Resources

Used	Needed	Never used
Bowling, golf, hockey and bridge sports	Alberta Health Care (AHC) to pay for diabetes meds	Diabetes education offered at pharmacies
Community & shopping malls walking groups	Suggestions for quick nutritional food preparation	Programs for diabetics offer by community associations
Community newsletters	AHC to pay for annual check-up required to renew driver license	The Canadian Diabetes Association
Exercise facilities/Leisure centres	Better triage of participants for group education	
Family doctor's and specialist's Offices	DEC step by step education rather than all information at once	
Foot clinics offered by the DEC and IGA	Education to treat diabetic emergencies	
Girl Guides of Canada	Exercise classes lead by trainers specialized in diabetes	
Laboratory services	Help phone line for diabetics to access quick information	
Multicultural organizations	More detailed nutritional plan similar to Type 1 diabetes	
Pharmacist services and support	Support group for diabetics	
Public libraries		
Religious organizations		
Senior's centres		
The Alberta Children Hospital		
The Catholic Women's League		
The Diabetes Education Centre		
The Internet		
TV advertisements		
Weight control centres		

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