

CUISR:

Community - University Institute for Social Research

Aboriginal Women Share Their Stories in an Outreach Diabetes Education Program

by Mary Pat Dressler



Building Healthy Sustainable Communities

Community-University Institute for Social Research

CUISR is a partnership between a set of community-based organizations (including Saskatoon District Health, the City of Saskatoon, Quint Development Corporation, the Saskatoon Regional Intersectoral Committee on Human Services) and a large number of faculty and graduate students from the University of Saskatchewan. CUISR's mission is "to serve as a focal point for community-based research and to integrate the various social research needs and experiential knowledge of the community-based organizations with the technical expertise available at the University. It promotes, undertakes, and critically evaluates applied social research for community-based organizations, and serves as a data clearinghouse for applied and community-based social research. The overall goal of CUISR is to build the capacity of researchers, community-based organizations and citizenry to enhance community quality of life."

This mission is reflected in the following objectives: (1) to build capacity within CBOs to conduct their own applied social research and write grant proposals; (2) to serve as a conduit for the transfer of experientially-based knowledge from the community to the University classroom, and transfer technical expertise from the University to the community and CBOs; (3) to provide CBOs with assistance in the areas of survey sample design, estimation and data analysis, or, where necessary, to undertake survey research that is timely, accurate and reliable; (4) to serve as a central clearinghouse, or data warehouse, for community-based and applied social research findings; and (5) to allow members of the University and CBOs to access a broad range of data over a long time period.

As a starting point, CUISR has established three focused research modules in the areas of Community Health Determinants and Health Policy, Community Economic Development, and Quality of Life Indicators. The three-pronged research thrust underlying the proposed Institute is, in operational terms, highly integrated. The central questions in the three modules—community quality of life, health, and economy—are so interdependent that many of the projects and partners already span and work in more than one module. All of this research is focused on creating and maintaining healthy, sustainable communities.

Research is the driving force that cements the partnership between universities, CBOs, and government in acquiring, transferring, and applying knowledge in the form of policy and programs. Researchers within each of the modules examine these dimensions from their particular perspective, and the results are integrated at the level of the Institute, thus providing a rich, multi-faceted analysis of the common social and economic issues. The integrated results are then communicated to the Community and the University in a number of ways to ensure that research makes a difference in the development of services, implementation of policy, and lives of the people of Saskatoon and Saskatchewan.

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ABSTRACT

Compared to other Canadians, Aboriginal people suffer disproportionately from manageable Type 2 diabetes and its complications. In an attempt to help better manage the disease, the West Side Community Clinic launched a monthly outreach education program for Aboriginal people with diabetes using an informal hands-on approach to learning about meal planning and looking at other forms of diabetes management. The purpose of this qualitative research project is to determine the impact that participants perceive the program has had on their health and well-being through group and individual interviews. Preliminary results reveal that the program's impact on participants' health and well-being is embedded within the context of their lives. Possible outcome indicators for the program are suggested.

Introduction

Diabetes is the seventh leading cause of death in Canada. A reported 25,000 potential years of life are lost due to this devastating disease (Health Canada, 1999a). Compared to other Canadians, Aboriginal people suffer disproportionately from Type 2 diabetes and its complications. Type 2 diabetes prevalence rates in Canada are three times higher among Aboriginal men and five times higher among Aboriginal women than in the non-Aboriginal population (Health Canada, 1999b; Bobet, 2000). Diabetes is the most common chronic illness reported among Canadian Aboriginal people (Saskatchewan Health, 2000). Based on reported cases among Aboriginal people, those who reside in Saskatchewan, Manitoba, and Ontario face the highest risk of diabetes while Aboriginal residents of British Columbia face the lowest risk (Health Canada, 1999a). In Saskatchewan, the epidemic is compounded by the proportion of the Aboriginal population, which is four times higher than in Canada as a whole—11% versus the 2.8% national average (Canadian Institute for Child Health, n.d.).

In general, diabetes prevalence rates increase with age. However, Aboriginal people over 65 years of age face a 28% risk of being diagnosed with diabetes, compared with a 10% risk faced by non-Aboriginal people (i.e. 2.8 times higher). In 1998, Pylypchuk et al found that more than 50% of the Aboriginal population in Saskatchewan over the age of 60 met the diagnostic criteria for diabetes (Saskatchewan Health, 2000: 74). Additionally, more Aboriginal children are being diagnosed with Type 2 diabetes, virtually unheard of in children in the past.

Canadian Aboriginal people with Type 2 diabetes encounter more serious long-term complications from the disease than do other Canadians (Daniel and Gamble, 1995). Diabetes is the leading cause of blindness, kidney failure, and limb amputations, and a major cause of heart disease and stroke. The economic burden caused by diabetes and its complications include increased health care utilization, disability, work loss and premature death (Health Canada, 1999a). For example, Saskatchewan's Aboriginal women were 24 times more likely to be hospitalized due to diabetes in 1996-97 than other women in the province (Saskatchewan Women's Secretariat, 1999).

The good news is that Type 2 diabetes and its complications are preventable and can be managed, in part, by a healthy lifestyle, which includes a healthy diet and regular exercise (Bachiu et al, 1998), and monitoring blood sugar and blood pressure levels (Health Canada, 1999a). Aboriginal communities across Canada are introducing programs that promote healthy living. The best-documented cases are in Northern Ontario (Gittelsohn et al, 1996) and Quebec (Macaulay and Dearhouse, 2000). Walking trails, cooking groups, Grade Three and Four curriculum changes, modification of school cafeteria menus, and the removal of vending machines from schools all fall within the range of interventions used to improve lifestyle practices in communities. In 1999, Saskatchewan Health initiated "Population Health Promotion Demonstration Projects for the Primary Prevention of Diabetes." Districts or service areas were invited to propose collaborative, intersectoral approaches toward addressing diabetes. Health districts, Aboriginal groups, community groups, and other sectors were encouraged to work collaboratively at the community level, implementing the broad range of health determinants from a population health perspective in addressing the growing issue of diabetes. While these initiatives are geared toward primary prevention, there is an overlap in primary and secondary preventative strategies to managing diabetes. So far, clinical aspects of secondary prevention do not appear to be highlighted in the population health strategy.

Whiting et al (1998) aimed to improve the health of Aboriginal diabetics, a secondary prevention strategy. A specific goal of their study was to involve the Saskatoon Aboriginal community and community agencies in the program development and evaluation process in order to improve the potential for continued intervention after the research project was complete. They found that Aboriginal people were not accessing existing diabetes education programs, such as the Diabetes Education Centre (DEC) located in the Royal University Hospital (RUH) and St. Paul's Hospital. They found that existing diabetes education programs addressed a need for basic information and skills to manage diabetes, but did not address complications caused by low income and relocation, such as isolation, inability to purchase appropriate foods, transportation needs, and lack of comfort within a trusting environment. These findings coincided with the First Nations and Inuit Regional Health Surveys in Northern Saskatchewan, which identified several gaps and challenges related to existing services. They found that gaps

in diabetes education/awareness program services, as well as accessibility to these services, needed to be addressed (Saskatchewan Health, 2000). Challenges include language, culture, lack of understanding of the health and social conditions facing Aboriginal people, education, geography, and food security.

Consequently, a partnership was formed between DEC and the Saskatoon Community Clinic to deliver an outreach diabetes education program from the latter's West Side location. The West Side Community Clinic is located within the core communities where many low income people reside. Diabetes Morning is a food resource program where people come together to cook. Information and support relevant to diabetes management, including blood sugar and blood pressure monitoring, care for eyes, and meal planning, is provided. Transportation and childcare costs are also available for those requiring them.

Diabetes Morning has been successful in terms of attracting Aboriginal women with Type 2 diabetes. Twelve to fourteen women, mostly Aboriginal, attend the group monthly. Men occasionally attend, but are less likely to continue. In order to continue to improve healthcare to meet the needs of Aboriginal people with Type 2 diabetes, more information is needed about effective intervention for managing diabetes — namely, what works and how. The staff of Diabetes Morning is interested in evaluating the program, and to understand how it has affected women's health and well-being, which may help inform the development of possible outcome indicators.

THE PRESENT STUDY'S PURPOSE

The present study aims to:

- · Determine the impact that Diabetes Morning has had on participants' health and well-being based on their experiences; and
- · Suggest possible outcome indicators based on participants' stories.

Qualitative methods are used in the present study as a means of capturing participants' multiple realities. This study is designed to identify Diabetes Morning's impact on participants' health and well-being through stories that they have shared in a group and/or an individual interview. Stories were obtained through the use of openended questions. The analysis involves abstracting themes and categories from participants' interview transcripts. Attendance rates are also be reported.

Results are compared with the Diabetes Morning conceptual model and that of a focus group that the staff conducted with participants about their expectations of the program. Possible outcome indicators for the program are suggested.

THE DIABETES MORNING PROGRAM

The following section describes the Diabetes Morning program — how it began, its conceptual framework, program records, and results of a focus group conducted by program staff members. This information was obtained in consultation with program staff.

ORIGIN

Diabetes Morning arose from DEC's desire to increase community involvement and improve services for managing diabetes in Saskatoon's Aboriginal community. Diabetes Morning was originally intended for Aboriginal people, but low-income men and women of all backgrounds are welcome to attend the program. However, the core group of participants of the Diabetes Morning program is Aboriginal women.

Diabetes Morning employs a hands-on experiential learning style for managing diabetes. The program provides an opportunity to socialize with others within a familiar environment. Advocacy is also provided for participants who face financial restraints and require an increased dietary allowance from the Department of Social Services to purchase necessary foods and a glucometer for regular blood testing.

Diabetes Morning has met monthly at West Side Community Clinic since fall, 1998. It is primarily a food resource program that provides information and support relevant to diabetes management, including blood testing and blood pressure checks, care for eyes and feet, and meal planning. Low cost meals are chosen by the clinic's nutritionist in consultation with participants and prepared on a monthly basis. One meal is shared as a group and another is prepared to take home. The rationale for using a hands-on approach is that participants can learn to make wise food choices within the confines of financial restraint, and to control portion size by showing them what a proper serving size looks like.

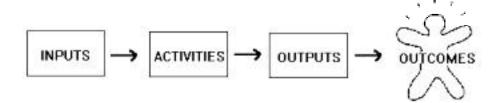
THE PERFORMANCE IMPROVEMENT CONCEPTUAL MODEL

The following section describes Diabetes Morning as it is structured around the Performance Improvement Model (United Way of America, 1996), as adapted from the United Way's Program Outcome Model (see **Figure 1**). The description includes the objectives, inputs, activities, outputs, and outcomes, as summarized in **Table 1**.

The following objectives were stated when Diabetes Morning was first developed:

- · Participants will learn to plan and prepare low-cost diabetes-friendly meals and snacks; and
- · Participants will gain a greater understanding of diabetes management and control through informal education sessions and discussions with diabetes educators (see **Table 1**).

Figure 1. Performance Outcome Model



Inputs are "resources dedicated to or consumed by the program" (United Way of America, 1996). Inputs utilized by Diabetes Morning include money, time, personnel, the facility, advertising, materials, and input constraints (see **Table 1**). Saskatoon Community provides one nutritionist and the Clinic's Health Promotion committee pays for food, bus tickets, taxi fare and childcare. A dietitian and diabetes educator are provided by DEC of Saskatoon District Health (SDH). The West Side Community Clinic kitchen has been chosen for its comfort, safety, and accessibility. The program was initially advertised to potential participants using posters, letters, and phone calls. Additionally, doctors from West Side Clinic referred their patients to the program. Materials include recipes, blood glucose monitors (glucometers), educational videos, and door prizes.

When developing this list of inputs, constraints were also recognized. For example, twelve to fourteen participants stretch the kitchen's capacity. Also, personal challenges can inhibit a participant's ability to make changes, while language and cultural barriers may hinder communication. Financial barriers can also affect the ability to buy food, and family members may influence food choices.

Participant-directed services (*activities*), as listed in **Table 1** and described below, are "what the program does with the inputs to fulfill its mission" (United Way of America, 1996):

- The women gather at the Westside Community Clinic to cook together. They cook diabetes-friendly recipes of their choice for about two hours, and then share lunch together before taking home the meals they prepared. The participants subsequently learn to make affordable healthy food choices and control portion sizes.
- The women direct the learning/teaching sessions through informal discussion. Staff pass on their knowledge about topics such as caring for eyes and feet, proper use of glucometers, sugar equivalency of foods, and diabetes-friendly meal planning.
- · Staff members facilitate sharing knowledge among participants about managing diabetes. Participants are also encouraged to seek further knowledge by attending individual counseling sessions at St. Paul's Hospital or DEC at RUH.

Table 1. Structure of Diabetes Morning Based on the Performance Improvement Model.

Performance Improvement Model

Specific Objectives:

- Participants will learn to plan and prepare low-cost diabetes-friendly meals and snacks.
- Participants will gain a greater understanding of diabetes management and control through informal education sessions and discussions with diabetes educators.

INPUTS	ACTIVITIES	OUTPUTS	OUTCOMES	
[Resources]	[Services]	[Products/Quantifiable]	[Benefits to the People/Changes]	
Money (+)	• Meet monthly	Attendance	New Knowledge	
• Time/personnel (+)	• Cook	Regular//Irregular	• Skill Development	
• Facility (+)	• Share	New Participants	• Attitude	
• Advertising (+)	Take home	• Increased Number	• Values [Prevention]	
• Materials (+)	Advocacy	• Friends/relatives	• Behavior	
• Constraints (-)	Teaching	Recipe/info Sheets Dispersed	• Improved Condition	
	Facilitation	Number of Glucometers Number of Used Glucometers	• Lowered High Blood Pressure	
		Advocacy Needed	• Lowered blood glucose Levels	
		Number of Participants	Altered Health Status	
		Number Accessing RUH/ St. Paul's Hospital Education Programs	Peer Support	
		Number of Target population	Primary Prevention	
		Number of Outside Target Population	• Empowerment	
		Use of Transportation Allowance Use of Childcare Allowance	Ultimate Goal: decrease health c are costs through improved diabetes management	

Adapted from Diabetes Morning program Documentation.

- · Staff members facilitate sharing knowledge among participants about managing diabetes. Participants are also encouraged to seek further knowledge by attending individual counseling sessions at St. Paul's Hospital or DEC at RUH.
- Advocacy for support may occur between staff, participants, physicians, Social Services, and/or Indian Affairs to purchase glucometers and increase special dietary allowance for some participants. An alliance with a local drug store has been established to supply required glucometers.

Program *outputs* (see **Table 1**) are viewed as a direct product of program activities (United Way of America, 1996). For example, the number of people attending Diabetes

Morning sessions is an output or result of the program's activities. Other outputs include the number of:

- · People who attend the program on a regular basis
- · New participants drawn into the program
- · Participants who bring friends or relatives
- · Recipes/information sheets distributed
- · Glucometers acquired and used
- · People for whom advocacy is necessary
- · Participants who access St. Paul's and/or RUH programs
- · People outside the target population who attend sessions
- · People who use transportation and childcare allowances.

Program *outcomes* (see **Table 1**) are recognized as the potential benefits or changes for participants as a result of attending Diabetes Morning. The ultimate outcome is decreased health care costs through improved diabetes management. Intermediate outcomes include acquired new knowledge and skills, changes in attitude and behaviours, new values, improved/altered health status, peer support, and primary prevention and empowerment. Improved health status can be measured, in part, by changes in glycated hemoglobin (Hb_{Alc}) and blood pressure over time.

New skills relating to diabetes management and control are evident in behaviours such as increased use of glucometers and closer adherence to prescribed diet. Participants may start eating a greater variety of foods, serve different foods to their family, and make healthier lifestyle choices, such as taking part in physical activity and eating a healthier diet. If medication is required, participants may learn to use it more appropriately. They may begin using their glucometers more regularly, and maintain a more constant and acceptable blood sugar level. Their condition may improve with fewer crises and, in general, feel better. Other health problems that may or may not be related to diabetes may also improve.

Attitude changes are described as covering a multitude of areas, such as acceptance of diabetes, increased confidence in the ability to make a difference in one's condition, and recognizing the ability to satisfy ones own, as well as the family's, needs. Program documentation states that participants may become more hopeful and optimistic as they learn more about diabetes care and dispel myths such as insulin use being a last resort. A change in attitude or belief about insulin use can encourage values like disability prevention and other diabetes complications. The term "beliefs" may be more appropriate than "attitudes." Unlike the positive/negative association with attitudes, beliefs are held in varying degrees. They are neither right nor wrong, positive nor negative.

Finally, peer support is projected to impact strongly on the program's outcome. New relationships may form, and knowledge that one is not alone in experiencing the challenges associated with diabetes can ease feelings of isolation. Participants may pass information on to others and become a role model for family and community members. Ultimately, they may feel empowered to have control over the disease.

PROGRAM RECORDS

Records are kept about individuals who join the program and about program activities. Individual records include general, medical, and progress information. Records about the program include debriefing notes and problem management.

Individual information is recorded on a two-sided form — General and Medical Information on one side and Progress information on the other. The General and Medical Information form includes the date when the participant is first assessed for the program, the person's name and address, as well as that of her/his physician. A "yes/no" response is recorded for the presence or absence of hypertension, altered lipids, other health problems, mobility difficulties, limits to exercise, whether they have attended a foot care session, own a glucometer, need advocacy to obtain a glucometer, need advocacy for social assistance program (SAP) increase, need for transportation/childcare, and whether the person brings family members to meetings. There is also space to list additional health problems and other comments. Information about medications is documented on the Progress Information side of the form. This side of the form also includes spaces to enter the date, blood pressure, lipid values, blood sugar levels, and additional comments. Blood sugar levels include Hb_{A1c} (glycated hemoglobin, the percentage of glucose within the red blood cells, which must be tested in a lab), Spot (glucose levels in the blood without fasting), and Fasting (glucose levels in the blood after a fasting period).

The Program Records form is also two-sided and filled out by program staff. One side contains debriefing notes about program activities and inputs, while the other is devoted to documentation of problem management. The Diabetes Morning Debriefing Notes includes the date of the session, location, number of participants, and the number of guests (if any). Staff and volunteers present are also recorded. There is also a table featuring eight topics for documentation. They include: snacks provided; recipes prepared; the session's education component; costs for groceries, childcare and transportation; door prizes given; next month's menu and snacks; resources used; and participants' request for resources. The Problem Management side of the form is used to "describe any problems reported by participants in or out of group session that needed individual attention (e.g. Problem with diabetes management, and/or personal issues [such as] housing, lack of food, problems with family, etc...)."

FOCUS GROUP RESULTS

In fall, 1999, Diabetes Morning program staff conducted a focus group with sixteen women who attended the program. The focus group's main objective was to gain insight into participants' experience and thereby develop outcome measures. Their findings are presented in **Tables 2** and **3**. Participants were involved in an exercise to generate a list of things that they felt made a difference in their health and well being, and to have participants identify those outcomes that would make them think Diabetes Morning a success. Two main questions were posed: (1) "I come to Diabetes Morning to...?" and (2) "What I need to be healthy is...?" Additional questions included: "Are there other people with whom you share this information?"; "For those of you who have attended Diabetes Morning before, are there any things that you do different now?"; and "Identify five ways in which Diabetes Morning can help you the most." After brainstorming a list of possible outcomes, participants were asked to choose five answers that were the most important to them.

Based on the responses, program staff found that the sixteen participants came to Diabetes Morning to learn and share knowledge about how to eat a healthier diet. Peer support was also an important part of the program. Participants reported that what they needed was to engage in health altering behaviours, such as eating properly portioned foods, exercising, seeing their doctor regularly, getting enough rest, looking after their feet and eyes, and testing their blood.

While information gained from the focus group is useful, it is insufficient for developing outcome measures. The focus group results only indicate what participants believed they needed to learn and why they were attending Diabetes Morning. The focus group captured the expectations that participants had of themselves and Diabetes Morning in managing diabetes. The present study moves beyond expectations and is designed to capture indicators of changes that have occurred over time to participants' health and well-being. Knowledge about participants' experiences with the program, what they understand about managing diabetes because of the program, and the impact that they perceive the program has had on their health and well-being can help define these indicators.

METHODOLOGY

This section describes qualitative methods as they apply to the present study, issues of rigor in qualitative research, and a description of the study's process.

QUALITATIVE METHODS OF ENQUIRY

Qualitative research methods can be very useful in evaluating the impact that Diabetes Morning has had on participants' health and well-being. An evaluation of the program's

Table 2. "I Come To Diabetes Morning To...." Focus Group Results Based on the Five Most Important Statements Chosen by Participants and Rated by Program Staff (N=14).

I come to Diabetes Morning		%	Outcome Measure Categories
To learn what to cook		71	Skill development
To learn what to eat		64	New knowledge
To share information with others		64	Peer support
To learn how to eat		57	New knowledge
Help prevent us from feeling we're alone		43	Peer support
To share feelings and thoughts	5	36	Peer support
To sample new recipes	4	29	New knowledge
Help me kno w how to prevent me getting diabetes	4	29	Values
Take away fear, anger, why me feeling		21	Attitude
Help family cook better meals		21	Skill development/ behavior/primary prevention
Develop self confidence		14	Attitude/Empowerment
Feel less discouraged- its an upl ifting experience		7	Attitude
To eat	0	0	

Adapted from Diabetes Morning program Documentation.

Note: Sample size is smaller than participation group as two members offered little or no input to survey.

Table 3. "What I need to be healthy is...." Focus Group Results Based on the Five Most Important Statements Chosen by Participants and Rated by Program Staff (N=14).

What I need to be healthy is	#	%	Outcome Measure Categories
Eating properly portioned foods	10	71	New knowledge/ behavior
Exercise	10	71	Behavior
See doctor regularly	8	57	Behavior
Enough rest	7	50	Behavior
Look after your feet and eyes	7	50	Altered health status
Blood testing	7	50	Skill development
Friends/company	5	36	Peer support
Cleanliness	4	29	Behavior
Label reading, what's in food	4	29	Skill development
Affordable food	2	14	Primary prevention
Quit smoking	1	7	Behavior
Not using a large amount of alcohol	0	0	Behavior
What I need to be healthy is	#	%	Outcome Measure Categories

Adapted from Diabetes Morning program Documentation.

Note: Sample size is smaller than participation group as two members offered little or no input to survey

strengths and weaknesses from the participants' perspective is a necessary step toward identifying the overall dynamics of the program. A qualitative method of inquiry allows for going beyond the expected outcomes of the program and exploring identifiable outcomes through the experiences of the participants and the impact that the program has made on their health and well-being.

The methods of inquiry to be employed in this study to enhance the validity of the results include individual interviews, a group interview, and attendance rates. Each method carries its own strengths and weaknesses. Using more than one method of inquiry allows picking up on information that might otherwise be missed. For example, a group discussion can encourage dialogue and reflection on a given topic. Common to experiential learning, knowledge can be acquired without a conscious awareness that it has occurred unless opportunity to reflect on the matter is present. Shared experiences may elicit more information than a one-on-one interview. However, a one-on-one interview allows individuals to share information that they may not feel comfortable sharing in a group setting.

Abstracting information such as attendance rates from written documentation also has its strengths and weaknesses. Attendance rates can be useful to fill in details about the experiences that they share. For example, individuals may not remember when they started attending the program (and for how often), or to which education sessions they were present. Program records could reveal a more complete account of these dates. However, a limitation that is characteristic of historical records is that they are often incomplete.

RIGOR IN QUALITATIVE RESEARCH

Qualitative researchers have come to know about the phenomenon of interest in a different manner than quantitative researchers, and this divergent focus is grounded in the dissimilar assumptions between them. Therefore, establishing rigor should be grounded in the appropriate assumptions because error is prevented in different ways for each paradigm (Leininger, 1994). Lincoln and Guba (1985) presented four categories for evaluating qualitative research and describe their relationship to more commonly known criterion used to evaluate quantitative research. These categories are truth value/credibility, applicability, consistency, and neutrality.

Truth value, also referred to by qualitative researchers as credibility, is related to the issue of internal validity in quantitative research. The question to be answered in this category is, "Are we measuring what we set out to measure?" An analysis of qualitative research should ask if multiple perspectives have been recognized. Triangulation, the use of more than one method of data collection, can be used to increase the results' credibility/truth value.

In qualitative research, the term applicability is related to the quantitative term

called external validity, the generalizability of the findings. In evaluating qualitative research, one asks how applicable the findings would be in a similar setting. However, applying the results of a qualitative analysis is different than generalizing results in quantitative research due to the complex nature of qualitative research. The results of a qualitative analysis should not be mistaken as a singular truth but as a variety of instances in an ever-changing process.

Consistency is related to the term reliability. In qualitative research, consistency in findings refers to consistently finding that multiple realities exist in the same or similar settings. Reliability refers to the ability of the instrument of measurement to yield the same results after repeated measures are performed. If the qualitative methods used to collect information allow more than one reality to be revealed, then consistency can be assured. Again, triangulating information through more than one form of data collection can increase the capacity to verify consistency.

Finally, neutrality, also referred to as confirmability, is related to the quantitative evaluation criterion called objectivity. Neutrality refers to freedom from bias. Qualitative researchers achieve neutrality by reflecting on their own biases with other researchers or through journals, and by spending time with participants (Leinginger, 1994). Recording subjective interpretations of events can keep the qualitative researcher conscious of his/her potential biases. Leininger suggested that researchers should return to participants for their input on the interpretation or analysis of the data as a means of confirming the findings and establishing neutrality.

Leininger (1994) established six criteria for substantiating qualitative research. Credibility, confirmability, and transferability coincide with Lincoln and Guba's (1985) categories of truth value, applicability, and consistency, respectively. She reinforced the need for prolonged time spent with participants, and an audit trail documenting the researcher's activities and reflections. Her other three criteria are meaning-in-context, recurrent patterning, and saturation. Meaning-in-context relates to the contextualization of the data, the meaning that people ascribe to their lived experience within the phenomena being studied. Recurrent patterning can be substantiated by numbers or percentages, and relates to cumulative occurrences of a pattern of instances, events, experiences, or ways of life. Finally, she referred to the importance of saturation, or a comprehensive understanding, of the phenomena being studied. The terms dense or thick data are used to describe a point of saturation whereby the phenomenon has been examined broadly and deeply.

The design of the present qualitative research project considers the criteria presented by Lincoln and Guba and Leininger. In general, the methods used to improve the rigor of the study include triangulation, time spent with participants, reflection, and returning to the group with initial interpretations. The study is designed to utilize more than one method for collecting information about participants' experiences in Diabetes

Morning. As previously mentioned, triangulation is used to increase the results' credibility. The weakness of one method may be the strength of another, and the combination of these methods can strengthen the overall trustworthiness, consistency, and applicability of the findings. Neutrality is attempted through personal reflections about the process and personal biases, as well as the prolonged period of time (one and one-half years) spent with those in the Diabetes Morning group. And, as suggested by the above authors, the group will be consulted before writing the final results.

THE PROCESS

According to Wendy Sword (1999), a qualitative researcher serves as a "research instrument" and needs to account for his or her own presence within the research process as a means of strengthening its integrity. She stated, "[N]o research is free of the biases, assumptions, and personality of the researcher ... [W]e cannot separate self from those activities in which we are intimately involved." Thus, observations regarding my association with Diabetes Morning were recorded and analyzed in an attempt to remain cognizant of my presence within the research process.

I chose this project because of my interest in various aspects of health promotion programming. In particular, I am interested in exploring programs that address a wide range of health determinants, including socioeconomic status, gender, and culture. This project intersects with many of these interests as it involves women, mainly Aboriginal, some of whom face socio-economic challenges.

Research is often perceived as taking information away from the community without any benefits to that group. I wondered if I would be perceived as "one of those researchers" who take what was needed and then forgets about the research subjects. Thus far, my apprehensions have been unfounded. The women expressed interest in participating in the process, and their rich stories verify that interest.

The participants in Diabetes Morning are warm, sincere, and genuine people. When possible, I continue to attend the program to cook, talk, and learn with them. They continue to be my teachers. They have shown me the comfort of their humor. They have also demonstrated that, even though it is not always easy to find the energy to attend the program, they come together and support each other. They have taught me about teamwork, too. Some of the women who feel better than others on a given day carry the workload for those less well so that everyone can take food home.

While listening is important, reflection is like "listening again." I have experienced the value of reflecting on my time with the group and writing down my experiences. As I write, I ask myself questions and allow their stories to unfold before me. As Wendy Sword (1999) suggested, I continue to reflect about the meaning that I attribute to my experiences with the group.

The stories are a gift of wisdom gained from experiences living with diabetes,

something acknowledged by the broad spectrum of partners involved in the ongoing process of Diabetes Morning. I am also inspired by the possibilities that underlie health promotion initiatives like Diabetes Morning that evaluate the process from the perspective of the people "whose health is being addressed" (World Health Organization, 1998). Such practices allow us to move beyond the limitations of what we think we already know about groups of people by involving them in the evaluation process in an attempt to inform that process. Those who shared their stories have done precisely that — they informed the program process by sharing what they have learned. Their stories can teach various stakeholders about service delivery that is relevant to, and appropriate for, their lives and communities.

TRADITIONAL PROTOCOL

As a non-Aboriginal researcher working with mainly Aboriginal women, I understand the importance of increasing my awareness and understanding of the cultural background. To help me with this, I have sought the guidance of a First Nations Elder, beginning in May 2000, when the idea for this project arose.

POINT OF ENTRY

I have been attending Diabetes Morning sessions since September 2000. After a staff person introduced me to the group, I explained that Diabetes Morning facilitators requested that I interview program participants about their experience regarding Diabetes Morning, and informed them that I was under the guidance of an Elder/teacher. On my fourth visit, I explained to the group that I believed that this program belonged to the participants and that their feedback was being requested to evaluate the program, how well it was doing, and how it could be improved. I asked the participants how they would like to be involved in the process and suggested one-on-one interviews, sharing as a group, or both. The group agreed that it would be a good idea to have both options. For example, one woman said that she might not be able to attend the group session but could make an appointment for an individual interview. Alternatively, if there was information that a person preferred to share privately, the option for a personal interview was made available.

PARTICIPANTS

Sixteen participants were recruited from among approximately thirty women who participate in the Diabetes Morning program. Selection was based on a desire to participate in the study. Eleven women participated in the group interview and an additional five participated in individual interviews. Total duration since first attendance ranged from three to twenty-two months. Total visits ranged from one to twenty-two visits. Attendance rates were calculated per individual, using total months since first attendance per individual divided by total visits per individual. Attendance rates ranged from 18% to 100%. The number of visits made to the program or the length of time belonging did not

restrict participation in the study. Those who attend every session may have a different experience with the program than those who attend sporadically; it is important to capture these differences. People who have only attended within the last month or two, as opposed to those present from the program's onset could bring a new perspective to understanding the program through their experiences.

FUNDING

The Community-University Institute for Social Research (CUISR) internship provided approximately \$3000 paid out over a six-month period from 1 November 2000 to 30 April 2001 to subsidize expenses. Diabetes Morning program paid cabfare and \$10 in childcare incurred by program participants in the present study. Diabetes Morning also provided space at Westside Community Clinic for the interviewing process.

GATHERING INFORMATION

As previously stated, the methods used for collecting data included a group interview, individual interviews, and attendance rates. The process involved building on information already obtained, beginning with the group interview and followed by individual interviews and review of attendance records. Information was analyzed on an on-going basis from one phase to the next, with continued analysis of my own reflections.

Information gathered from the group interview enriched the individual interview process. In the individual interview process, I shared the preliminary analysis of the group interview with the participant and asked her to expand on the information shared in the group interview. At this point, I obtained the remaining attendance records. Each of the participants received a copy of the interview transcript for review. Participants will be given an opportunity to respond to this analysis during a session of Diabetes Morning.

INTERVIEWS

The group interview took place in May 2001 at West Side Community Clinic during a regular Diabetes Morning session. Individual interviews took place in the individual's home or, in one case, a quiet restaurant during May and June 2001. The specific objective of the interview process was to determine the impact that participants believed Diabetes Morning had on their health and well-being.

Open-ended questions were used for the group and individual interviews. Once a dialogue began to flow, more specific questions were asked. Prompts were used in instances when answers were unclear, encouraging further reflection. However, prompting did not occur without using other interview techniques including silence and non-technical language (e.g. "blood testing" rather than "glucose monitoring") and non-threatening language (e.g. body language, a patient, friendly, and respectful manner, and asking permission during various stages of inquiry).

During the introduction stage of the group interview, I explained that a sharing stone would be passed around to facilitate respect for each other's uninterrupted time to share. I asked them to share a little bit about themselves, such as where they were from and how long they had had diabetes. The rest of the interview was focused on questions on what had changed since they began attending the program. They were asked to think back to when they first started to come to Diabetes Morning and their early impressions. They were then asked to think about the present and what it is like for them when they come to Diabetes Morning, and what, if anything had changed. I then asked them to think about their health and well-being, if that had changed since they started to come to Diabetes Morning, and if they thought that coming to program had had anything to do with this. I concluded by asking if they had any further comments or suggestions.

During the individual interview process, the same questions were asked, enhanced by information gathered from the group interview. Participants of the individual interviews had not taken part in the group interview. Conversations were recorded except in those instances where permission to do so was not received from the individual or they appeared uncomfortable with recording. In either case, transcripts were returned for participant review and approval.

Consent

Consent was obtained from participants by their signature on appropriate forms. Large print and plain language was used. Information on the consent form was presented orally to the whole group in the group interview and with each individual in the individual interviews. Those who chose to participate were asked to sign the consent form after it had been explained to them. Debriefing details were given to them on a separate form. The consent form was signed in duplicate—one copy for the participant and one for myself. Transcripts were returned to the participants for their review and release. At that time, they were asked to sign a transcript release form.

ATTENDANCE RECORDS

Attendance records are kept for each session of Diabetes Morning. After the interviews were complete, attendance information was obtained to provide an objective view of participants' frequency and intensity of involvement.

My Reflections

I reflected on my own experiences, insights, and questions while participating in the Diabetes Morning program, performing interviews and obtaining information about attendance. The reflections raised awareness of my own biases during the process of data collection and analysis.

PRELIMINARY ANALYSIS

Interview transcriptions have been analyzed into meaningful themes and categories. Preliminary results suggest that the impact that the program has had on participants' health and well-being is embedded within the context of their lives. Participants' stories about the impact that the program has had on their health and well-being include information about what they have learned, shared, and experienced while attending the program. Embedded in these stories are their experiences living with diabetes. Those experiences include factors relating to diagnosis, treatment, self-management, supports, and stressors. Final results, discussion, and conclusion will be published in my thesis.

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