VOICES FROM AN ABORIGINAL DIABETES AWARENESS, PREVENTION
AND TEACHING PROGRAM

by

Jennifer Eskes

B. Sc., (Integrated Sciences)
University of British Columbia, 2003

A THESISSubmitted in Partial Fulfillment of the Requirements
for the Degree of

Master of Science

in

The Faculty of Graduate Studies
(Human Nutrition)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

August 2010

© Jennifer Eskes, 2010
Abstract

The socio-economic and political inequities stemming from colonialism have adversely affected the health of Canadian Aboriginal people. In particular, type 2 diabetes affects these populations in disproportionately high rates. As a result, there have been calls for policy-makers, program designers and practitioners to create culturally appropriate health education programming. However, few programs have been successful. It has been argued that this is because traditional approaches to diabetes education programming do not address the unique history and lived experiences of Aboriginal people.

This project explored the experiences of participants, staff, facilitators and stakeholders with an Aboriginal Diabetes Awareness Prevention and Teaching Program (ADAPT) located in a major Western Canadian city. A total of 14 people were interviewed. The primary goals were to identify how the program activities and messaging were perceived, understood and acted upon by participants; to describe how the staff and facilitators envisioned their roles with the program; and to gain insight into how ADAPT fit with the lives of participants.

Critical theoretical perspectives, and in particular, postcolonial theory served as the primary paradigm for this project. Data analysis was guided by interpretive description. Program participants’ that were interviewed for this project described their experiences within two main themes: building relationships and building knowledge. Staff, facilitators and stakeholder’s experiences also centered around two main themes: building relationships with participants and facilitating change.

ADAPT participants, staff, facilitators and stakeholders all described the program as a place that recognizes the impacts of that colonialism has had on people’s lives and health. The program was seen as a safe and supportive place to build relationships with others and to learn about diabetes. The findings of this project can help to inform the design of Aboriginal-focused diabetes education programs.
Table of Contents

Abstract ............................................................................................................... ii

Table of Contents ............................................................................................... iii

List of Acronyms ................................................................................................. vi

Acknowledgments .............................................................................................. vii

Chapter 1: Introduction ...................................................................................... 1

1.1 Project Origins ............................................................................................. 3

1.2 A Brief Synopsis of this Thesis .................................................................... 7

Chapter 2: Review of the Literature .................................................................. 9

2.1 Health and Well-being of Aboriginal People in Canada .............................. 9

2.2 Impact of Colonialism on the Health of Aboriginal People in Canada ... 10

2.3 Type 2 Diabetes and Aboriginal People in Canada ....................................... 14

2.4 Why Are Aboriginal Diabetes Rates So Much Higher? ............................. 16

2.4.1 Controversial Genetic Theories ................................................................ 16

2.4.2 Inequality, Marginalization and Health ..................................................... 18

2.5 Aboriginal-focused Diabetes Programming ................................................. 20

2.6 Culturally Appropriate Health Programming .............................................. 21

2.6.1 Recognizing Impacts of Colonialism ....................................................... 22

2.6.1.1 Colonialism and Diabetes ................................................................. 23

2.6.2 Cultural Safety .......................................................................................... 24

2.6.3 Incorporation of Cultural Customs, Beliefs and Traditions ..................... 26

2.7 Conclusions .................................................................................................. 28

Chapter 3: Research Approach and Methods .................................................. 29

3.1 Data Gathering ............................................................................................. 30

3.1.1 Phase 1: Observation and Participation ................................................ 30

3.1.2 Phase 2: Story-gathering ......................................................................... 31

3.1.3 Recruitment ............................................................................................. 32

3.1.4 Open-ended, Semi-structured Interviews .............................................. 34

3.2 Data Analysis ................................................................................................ 36
3.3 Establishing Rigor .................................................................37
3.4 Dissemination .........................................................................38
3.5 Limitations .............................................................................39

Chapter Four: Findings and Discussion ........................................41

4.1 Introduction of ADAPT and the Downtown Eastside (DTES) ....41
  4.1.1 Community Context – Downtown Eastside .........................41
  4.1.2 DTES Demographics ...........................................................42
  4.1.3 Food and Food Security in the DTES .................................43
  4.1.4 Description of the ADAPT Program ................................ 46
    4.1.4.1 Program Vision and Design ....................................47
    4.1.4.2 Reaching Out .........................................................48
    4.1.4.3 Programs Geared to Interest ....................................49
  4.1.5 Description of a ‘Typical’ ADAPT Community Kitchen ........49
  4.2.1 Accessibility ....................................................................51
  4.2.2 Lack of Adequate Space ..................................................52
  4.2.3 Funding ..........................................................................54

4.3 Participant Experiences of ADAPT ...........................................56
  4.3.1 Building Relationships ......................................................57
    4.3.1.1 Presence of a Safe Environment ..............................58
    4.3.1.2 “Having Someone There for You”: Presence of a Supportive Environment ...............61
    4.3.1.3 Building Relationships in ADAPT’s Safe and Supportive Environment .................64
  4.3.2 Building Knowledge ........................................................59

4.4 Staff, Facilitator and Stakeholder Experiences of ADAPT .........69
  4.4.1 Building Relationships with Participants ............................69
    4.4.1.1 Earning Trust of Participants ..................................70
    4.4.1.2 ‘Meeting People Where They Are At’: Creating a Supportive Environment .............73
    4.4.1.3 Reducing Power Dynamics .....................................75
  4.4.2 Facilitating Change ..........................................................77

4.5 Chapter Summary .................................................................80

Chapter 5: Implications and Recommendations ..........................81

5.1 Lessons Learned: Implications for Aboriginal-focused Diabetes programming ..................................................81
  5.1.1 Incorporating Cultural Safety into Diabetes Education ..........83
  5.1.2 Evaluating Success ............................................................85
  5.1.3 Limitations of this Study ...................................................86
  5.1.4 Implications for Practice and Suggestions for Future Study ....87

5.2 Conclusions ............................................................................88

References ....................................................................................90

Appendix A: Recruitment poster ..................................................99
Appendix B: Interview Consent Form ................................................................. 100
Appendix C: Interview guides ........................................................................ 102
Appendix D: Luncheon invitation .................................................................... 104
Appendix E: UBC BREB Certificates of Approval ............................................. 105
**List of Acronyms**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADAPT</td>
<td>Aboriginal Diabetes Awareness Prevention and Teaching Program</td>
</tr>
<tr>
<td>ADI</td>
<td>Aboriginal Diabetes Initiative</td>
</tr>
<tr>
<td>BREB</td>
<td>Behavioral Research Ethics Board</td>
</tr>
<tr>
<td>DECK</td>
<td>Downtown Eastside Community Kitchen</td>
</tr>
<tr>
<td>DTES</td>
<td>Downtown Eastside</td>
</tr>
<tr>
<td>MOAUIPP</td>
<td>Métis, Off-Reserve Aboriginal and Urban Inuit Prevention and</td>
</tr>
<tr>
<td></td>
<td>Promotion Program</td>
</tr>
<tr>
<td>RCAP</td>
<td>Royal Commission on Aboriginal Peoples</td>
</tr>
<tr>
<td>VNHS</td>
<td>Vancouver Native Health Society</td>
</tr>
</tbody>
</table>
Acknowledgments

This thesis has been a struggle. In fact, I think that this project has been one of the most emotionally charged things that I have done. Partially, it is because this thesis has been much more than just a writing project – it has been tightly woven into my perceptions of what I am able to accomplish. Needless to say, it took me more time to complete this than it takes some to complete their PhD.

There have been more than a few people cheering me on to “just get the darn thing done!” and I thank everyone single one of them. In particular, I’d like to acknowledge Nola’s and Sonja’s cheers, ‘pep talks’, and their stern why-aren’t-you-working-right-now looks. Thank you. Thank you to Jody’s and the Arctic Health Research Network’s support in sponsoring my thesis writing retreat on the shores of beautiful Crag Lake. Thank you to Erin for helping me edit. And of course, a very hearty and sincere thank you to my supervisors and committee members Ryna Levy-Milne, Gwen Chapman and Annette Browne for your keen insights and patience.

Also, I would not have been able to conduct this project had it not been for the funds provided by BC ACADRE (now named Network Environments for Aboriginal Research BC). Thank you for your generosity.

Lastly, this project could not have happened without the kindness and willingness of ADAPT participants, staff, facilitators and stakeholders. The time that I spent with all of you has a special place in my heart.
Chapter 1: Introduction

ADAPT, an Aboriginal Diabetes Awareness, Prevention and Teaching Program, is a unique diabetes education program located in Canada’s ‘poorest postal code’—Vancouver’s Downtown Eastside (DTES). ADAPT has provided diabetes education and support via workshops, community kitchens and one-to-one education to Aboriginal individuals living in this neighbourhood for over 10 years.

The program is noteworthy for a variety of reasons. Firstly, it is located in a neighbourhood that is referred to as ‘Canada’s Slum’ (Hume, 2009), where levels of homelessness, crime and unemployment are high. Injection drug use is rampant and the neighbourhood has the highest HIV prevalence in the Western world (2010). Needless to say, this is a tough place to live and an even tougher place to locate a diabetes education program. Perhaps the more noteworthy aspect of ADAPT involves the ways that the program is delivered. It follows an informal, non-task oriented format and embraces diabetes education via multiple approaches. For example, the program coordinator is a Registered Dietitian who has expertise in communicating evidence-based diabetes education. The program is also staffed by a resident Aboriginal Elder who provides cultural and spiritual guidance to participants and key insight into program direction. Although ADAPT’s staff have different backgrounds and knowledge of diabetes, this pairing results in a diabetes education program where traditional indigenous knowledge and scientifically-based knowledge not only complement each other but exist side by side.
From 2004-2006, I spent time with ADAPT on a weekly basis with the aim to explore how participants, staff and facilitators experienced this program. I have taken the stories that were told to me during my time with the program and attempted to weave them together into a coherent narrative illustrating what I heard, saw, and learned. I have also attempted to place this narrative into a broader landscape that reflects how ADAPT’s approach to diabetes education fits within the context of the participants’ lives, as well as within the neighbourhood environment. In short, I saw an innovative approach to diabetes education that appeared to resonate with program participants, and ultimately helped many improve their ability to care for their diabetes. Much of this was possible because participants viewed the program as a trusted place to be. Instead of just providing a health program with diabetes information and advice, ADAPT played a larger role in people’s lives as a place to go for support, companionship and healing.

Many aspects of ADAPT’s programming are not common in the realm of diabetes education. But based on my experience with this program, I think that it is consistent with an Aboriginal-focused and holistic style of health programming that is increasingly demanded by Aboriginal organizations. My hope is that the information gathered here can add to the discussion about what constitutes appropriate health programming for Aboriginal people.
I.1 Project Origins

My journey with ADAPT began in 2004 with a fateful meeting with Kristen, then employed as their full-time Registered Dietitian/Program Coordinator. I was searching for a thesis project that would allow me to work in the areas of food security, Aboriginal health, and health promotion. I had few leads as the project that I was originally planning to work on had just fallen through. It was then that I was provided with Kristen’s name and contacted her with the hopes of identifying a project with her program.

During our conversation, she expressed a desire to capture participants’ stories about their experiences with ADAPT. She felt that many participants underwent some sort of subtle, positive transformation during their time with ADAPT that quantitative data could just not capture. These positive experiences were important stories to tell because they illustrated how diabetes programming could not only help educate people about diabetes but could also encourage healing on a grander, more holistic scale. This is the type of programming that we tend not to hear much about in the biomedical and academic worlds, yet it is very much what is being called for by Aboriginal leaders and organizations. These stories would also provide a great deal of insight into how an Aboriginal-focused diabetes program is experienced from the participants’ point of view, a perspective that is not often explored in the academic literature.

Kristen was initially hesitant to bring in a university-based researcher to do this work. Partially this was because academia is a privileged place with little in common with the DTES and also because many program participants would
likely be uncomfortable in the presence of such an outsider. Understandably so, as the reader will discover, ADAPT participants had already experienced numerous abuses at the hand of outsiders: many suffered abuses at residential schools, were placed into foster care, were incarcerated and one person’s spouse was a victim of the Pickton ‘Pig Farm’ murders (Canadian Broadcasting Corporation, 2010). For many, trust would be hard to come by. A project like this would be much more than a routine story-gathering exercise. It would take a great deal of care, respect, understanding, and time. We decided to forge ahead as Kristen felt it was important to give the participants’ journeys with diabetes a voice that might not otherwise be heard, especially by such a far away place as academia.

I began my work with ADAPT with the intent to evaluate the program. This was to include an assessment of the changes that participants made in their lives regarding their diabetes care and management, their perceived control over the disease, what they had learned about diabetes and their thoughts about the cultural relevance of the program. However, as I became more familiar with the participants, their lives and the program, these questions began to seem too rigid, too evaluative, and too reflective of what could be considered a colonial gaze. This was the beginning of my journey towards realizing the importance of practicing critical reflexivity. At the beginning stages of planning this project, I did not realize that my involvement with ADAPT could potentially be a colonizing act in itself – by the very nature of my wanting to assess, evaluate and observe, I was engaging in colonialism. This was not how I wanted to ‘show up’ in this
project. Thankfully, the program Elder taught me about Aboriginal people’s history, working respectfully and about working in a “good way.” In retrospect, I can see how my understanding of what working in a “good way” has shifted between then and now – from a place of unknowingness to a place of critical reflexivity.

As I was beginning to learn, many of the participants did not appear to look at ADAPT as just an avenue to learn about diabetes. So, for me to focus solely on my original agenda would have been to miss part of the very essence behind those subtle, positive transformations that Kristen initially spoke about. Instead, I tried to learn from the participants’ voices and feature their perspectives and experiences ahead of my research agenda. What became increasingly clear was that each person’s journey with the program was not just about increased knowledge of, or control of diabetes. Most journeys were much more. For example, I heard stories about learning new life skills, learning to embrace one’s identity as an Aboriginal person, developing friendships and having positive social contacts, and in the process, experiencing beneficial life changes. These changes were very much intertwined with how people learned about diabetes and likely the impetus for many to take even more steps in that learning process.

As I look back on my involvement with ADAPT, it affords me an opportunity to reflect on the transformative effect that this work has had on my own life. This project has both humbled and empowered me, and has perhaps made me a better person and better dietitian. I began this work as a well-
educated Caucasian woman with little knowledge of Aboriginal people’s historical or present day realities and certainly did not anticipate the emotional journey of learning about colonization and its ongoing legacy. Throughout this process, I learned how to apply a critical lens when analyzing issues facing Aboriginal people. I also re-examined my own assumptions and my own history. This has included the difficult – but necessary – questioning of other’s often ill-informed assumptions on these matters. On a professional level, I have learned many important things such as the great healing power of listening and being heard. At ADAPT, everyone was provided with room to share and given the kindness and respect of being listened to without judgment. I believe that was the first time some participants had such an opportunity. I have since moved to the Yukon to practice as a dietitian where the majority of my clients are Aboriginal. I feel strongly that ADAPT participants, staff and facilitators taught me some critical lessons about providing (what I hope is) appropriate care. I feel keenly tied to this work and cannot help but place myself amidst this project with participants and program facilitators. I believe that we all had effects on each other, subtle, positive effects.

This project took place over the course of two years. I interviewed a total of 14 individuals with the intent to learn what it was about ADAPT that facilitated many of these subtle, positive changes. Interviewees included those who attended the program, staff and facilitators who helped deliver it, and stakeholders involved with the program. I have explored the common themes threading through each of the stories to provide a shared narrative about this
program, and examined how ADAPT’s story may contribute to the current area of knowledge about Aboriginal-focused diabetes education. This is of particular importance as many Aboriginal-focused health education programs have been shown to have only limited effects on participants’ lives and health (Adelson, 2005). Therefore, listening to participants involved in such programs and learning from their perspectives can offer a key contribution to current knowledge in this area. This project aims to address this gap.

I.2 A Brief Synopsis of this Thesis

The purpose of this thesis was to explore the experiences of the participants, staff and facilitators of the ADAPT program. The primary goals were to better understand how the program activities and messaging were perceived, understood and acted upon by participants; how the staff and facilitators envisioned their roles with the program; and to gain insight into how ADAPT fit with the lives of participants. This thesis will guide the reader through this process beginning with Chapter 2. This second chapter provides an introduction to the literature surrounding diabetes and Aboriginal people, as well as describing some of the factors contributing to the health issues facing this population. Chapter 3 discusses the chosen methodological approach to this project. Chapter 4 is divided into three main sections. The first section provides some context and information about ADAPT and about the DTES. The second
and third sections present the voices of the participants, staff and facilitators.

Chapter 5 discusses the findings of this project and concludes this thesis.
Chapter 2: Review of the Literature

The main intent of this literature review is to provide context for the reader to better understand why Aboriginal people experience disparities in health and well-being compared to non-Aboriginal people. I have chosen to focus this section on how colonization has significantly influenced Aboriginal people's lives by impacting many of the social determinants that influence health. As such, I will present information about how the disproportionately high rates of type 2 diabetes among Aboriginal people exist in a broader context of history, politics, social structures and power relationships. I will also briefly explore how these factors may impact the content and delivery of diabetes education to Aboriginal people.

Although this section lends itself to a review of the literature surrounding models of health behaviour and health education programming, I made a choice not to include this information in this thesis. My reasoning for this is not to diminish the importance of this information but to instead ensure that the focus remains largely on the ramifications of colonization on Aboriginal people’s health.

2.1 Health and Well-being of Aboriginal People in Canada

The health of Aboriginal people is tightly embedded within their history of colonization. For decades, colonialism has politically, economically and socially marginalized Aboriginal people where they have been subjected to land loss, language loss, forced relocation, social exclusion, racism and more (Adelson, 2005; King, Smith, & Gracey, 2009). The damaging effects of these and other
acts of colonization have materialized as a variety of socioeconomic inequalities and ultimately, as a variety of health disparities. Some of the many socioeconomic inequalities experienced by Aboriginal people include higher unemployment, lower education levels and overcrowded housing conditions. For example, the Community Well-being Index – a measure of well-being based on characteristics such as income, education, housing and employment – places Canadian Aboriginal people well below that of non-Aboriginal people (Reading & Wein, 2009). Aboriginal people’s health compared with other Canadians’ health is poorer, according to most indicators. The life expectancies of Aboriginal people are 5 to 14 years less than other Canadians and infant mortality rates are 1.5 to 4 times higher. According to the 2004 Canadian Community Health Survey, 33% of off-reserve Aboriginal households are food insecure compared to 8.8% of non-Aboriginal households (Health Canada, 2007). Data for on-reserve households are less comprehensive but estimates vary between 21-83% (Power, 2008). Also, Aboriginal people experience higher rates of acute and chronic illnesses. Acute conditions such as tuberculosis are 5 times more prevalent in Aboriginal populations and there is an increased prevalence of many chronic illnesses, including type 2 diabetes (Health Canada, 2000; Waldram, Herring, & Young, 2006).

2.2 Impact of Colonialism on the Health of Aboriginal People in Canada

Since 1876, Canadian Aboriginal peoples’ lives have been governed by the Indian Act. Although some of the paternalistic and discriminatory practices
outlined in this Act have been repealed, their effects on the health and well-being of Aboriginal people have endured. Two of the more destructive colonial policies stemming from the *Indian Act* were the implementation of the reserve system and the residential school system (Royal Commission on Aboriginal Peoples [RCAP], 1996). Aboriginal people were also prevented from self-determination; traditional ceremonies and activities were outlawed; and the movement of Aboriginal people was significantly limited (RCAP, 1996; Waldram et al, 2006).

In his book, *A National Crime*, Milloy (1999) writes that “the [residential] schools have been, arguably, the most damaging of the many elements of Canada’s colonization of this land’s original peoples” (p. xiv). The residential school system was begun in the 1870’s by the Canadian government in joint partnership with the Anglican, Catholic, or Presbyterian churches. They continued to operate until 1986. According to the government of the time, the aim of the schools was to remove children from their families and cultural traditions and to ‘kill the Indian’. Aboriginal children were forcibly removed from their homes and families, were forbidden to speak their mother tongues and were often subjected to various forms of physical, emotional, and sexual abuse (Milloy, 1999).

Most residential schools became breeding grounds for disease due to neglect: children were undernourished and inadequately dressed, overworked, abused, and overcrowded in buildings whose conditions were frequently appalling. Many children fell ill and died from tuberculosis, measles, and influenza (Kelm, 1998).
The collection of these adverse conditions and experiences negatively affected residential school survivors’ long-term health by breaking their spirit and sense of self, contributing for many to a lifetime of shame, poor self-esteem, trauma, chronic stress, and substance abuse (Kelm, 1998; Milloy, 1999; Mitchell & Maracle, 2005). Many of the elements that normally form a healthy foundation of cultural and personal identity were withheld, affecting their development at a critical age. The toll that the residential school system has taken is illustrated in an Assembly of First Nations document: “Every First Nation has suffered a disintegration of political and social institutions of culture, language, religion and economic existence. The destruction of the personal security, liberty, health, dignity…has been felt by successive generations (1998, pp. 4-5).”

The reserve system provides another example of how a colonial policy has had long-lasting effects on the health of Aboriginal people. Like residential schools, reserves were initially implemented as a tool for assimilation (Miller, 2000). By keeping Aboriginal people in one place year-round, they would not be a threat to the incoming settlers who were taking up residence on traditional Aboriginal lands. Aboriginal people were not able to leave reserve lands without permission and so were restricted from following a hunter-gatherer lifestyle that was looked upon as ‘savage,’ and instead took up sedentary agriculture or were forced to accept food rations (Waldram et al., 2006). This significantly changed the nutrition of Aboriginal people as they moved from consuming foods harvested

---

1 The impact of residential schools was only recently acknowledged by a federal formal apology in 2008.
from the land to foods high in fat, sugar and low in micronutrients (Kelm, 1998; Waldram et al., 2006).

Because Aboriginal people were viewed as naturally sickly and diseased, it was believed that by confining them to reserves, they would be less likely to infect nearby settler communities (Kelm, 1998; Miller, 2000). This perception became particularly heated around the issues of poor health standards and cleanliness of the reserves, which were often lacking in the most basic amenities, such as access to clean water or adequate sewage disposal. Settlers’ attitudes to these conditions were rarely compassionate, often adopting a victim-blaming approach, attributing them to the people’s lack of will to remedy the situation.

Bartlett (2003) argues that the "involuntary cultural change" of colonialism has placed multiple generations of Aboriginal people under “extreme stress.” This has contributed to “social and psychological pathology” manifesting as suicide, depression, substance abuse, and violence (p.165). Others have similarly described the legacy of colonialism as historical trauma, “a collective emotional and psychological injury over the lifespan and across generations” (Mitchell & Maracle, 2005, p. 15)

It has become increasingly acknowledged that historical trauma stemming from the actions of colonialism – even those that have occurred in the distant past – can contribute to current day health disparities. Historical trauma theory was first conceptualized in the 1960’s from studies of Holocaust survivors of World War II (Mitchell & Maracle, 2005; Sotero, 2006. The offspring of the Holocaust survivors manifested very similar trauma symptoms to their parents,
despite never having experienced the direct trauma associated with the Holocaust. The premise of this theory is that populations subjected to long-term and large-scale trauma display a greater number of health disparities, even multiple generations after the trauma has occurred. Thoughts as to how this occurs are multi-fold: one belief is that feelings of mistrust, shame and guilt among the traumatized population can become embodied into the culture and transmitted as learned behaviour from generation to generation (Sotero, 2006).

Rock (2003) takes this argument one step further, speculating that this collective and longstanding trauma of Aboriginal people has implications on the increased prevalence of diseases, like diabetes. She states that, “across Aboriginal populations the collective experience of having suffered over several generations is now being expressed in the sweetening of the blood” (p.152).

2.3 Type 2 Diabetes and Aboriginal People in Canada

It has been claimed that type 2 diabetes was unknown in most Aboriginal cultures around the world prior to the 1940’s (Daniel & Gamble, 1995; Young, Reading, Elias, & O’Neil, 2000). Since that time, however, type 2 diabetes has become a major health issue for Aboriginal people around the globe (Daniel & Gamble, 1995; Health Canada, 2000; Young et al., 2000). These indigenous populations are now disproportionately affected by this illness.

In Canada, diabetes is estimated to affect approximately 6.2% of all Canadians (approximately 2 million people) (Public Health Agency of Canada, 2009). There are no comprehensive surveys of diabetes rates among Aboriginal
Canadians, however, it is estimated that diagnosis rates are 3 to 5 times higher than non-Aboriginal people (Health Canada, 2000). Existing data report 8.3%-8.7% of Aboriginal people living off-reserve have been diagnosed with type 2 diabetes (Statistics Canada, 2003; Tjepkema, 2002). Another survey reports much higher rates with 19.7% of Canadian Aboriginal adults living on-reserve diagnosed with diabetes (First Nations Centre/First Nations Information Governance Committee, 2007). To further complicate matters, it is thought that these already elevated prevalence rates may actually be 2 to 3 times higher than reported due to underdiagnosis, lack of access to health care, or physical, linguistic, and cultural barriers (Daniel & Gamble, 1995; Health Canada, 2000).

Compared to non-Aboriginal people, type 2 diabetes in Aboriginal people is associated with a greater severity at diagnosis often due to late detection and/or diagnosis (Hanley et al., 2005). These populations also tend to experience higher rates of diabetes-related complications such as micro- and macrovascular complications (Hanley et al., 2005). For example, a recent study in Manitoba found amputation rates among First Nations individuals with diabetes to be approximately 18 times higher than other Manitobans with diabetes (Martens, Martin, Neil, & MacKinnon, 2007).

Not only do these complications come with a tremendous personal cost and reduced quality of life, but they also present significant costs to the healthcare system. In general, the healthcare costs, both direct and indirect, of treating type 2 diabetes are vast. A person with diabetes and its associated conditions, such as cardiovascular disease, can be expected to incur direct
medical costs as high as $15,000 per year. (Canadian Diabetes Association, 2009).

The costs are even higher for treating type 2 diabetes and its complications in the Canadian Aboriginal population. One report from Manitoba (Jacobs, Blanchard, James, & Depew, 2000) cites that the cost of treating Aboriginal patients with type 2 diabetes-related complications was 68% higher than for non-Aboriginal patients. Another report from Saskatchewan cites similar statistics with healthcare costs 70% higher among Aboriginal people with diabetes than the general population with diabetes (Pohar & Johnson, 2007).

2.4 Why Are Aboriginal Diabetes Rates So Much Higher?

2.4.1 Controversial Genetic Theories

One of the more commonly cited, but much disputed, theories as to why Aboriginal people experience disproportionately high rates of diabetes is the genetic theory proposed by Neel in 1962. Neel attributed the high rates of diabetes among Aboriginal people to a predisposed “thrifty genotype” (Neel, 1962). This “thrifty genotype”, a great asset to hunting and gathering populations, was theorized to be highly efficient in the utilization and storage of food energy, conferring survival advantages in times of famine. He postulated that this genotype allowed for rapid energy uptake and storage (i.e. weight gain) when food was available, thus providing protection against starvation when food was scarce. Neel further hypothesized that because Indigenous peoples around the globe have experienced relatively recent industrialization and sedentarization
of their traditional lifestyle patterns, this genotype is no longer useful, and instead has predisposed these populations to disproportionately high rates of obesity and type 2 diabetes (Neel, 1962).

Genetically based theories like Neel’s have not withstood the rigors of science and instead have been criticized for their reductionist and deterministic focus. According to McDermott (1998) and Fee (2006), such theories conjure up notions of Social Darwinism and contribute to racializing discourses where diseases like diabetes become attributed to ‘race’, instead of to environmental, historical, economic, and political factors that significantly influence health. To illustrate this, a recent analysis in Winnipeg, Manitoba found that although there was a strong correlation between Aboriginal individuals and diabetes rates, Aboriginal status lost all meaning as a predictor of diabetes when analyzed alongside socioeconomic variables such as low socioeconomic status, poor environment (i.e. residing in a high crime neighbourhood), and lifestyle (i.e. smoking and nutrition) (Green, Hoppa, Young, & Blanchard, 2003).

As will be discussed further in the next section, socioeconomic conditions stemming from colonialism have contributed to numerous inequalities in living conditions for Aboriginal people. These inequalities, rather than flawed genetics, are more likely to be the major contributor to the increased rates of type 2 diabetes among this population.
2.4.2 Inequality, Marginalization and Health

It has been clearly established that the social determinants of health such as income, education, employment and housing play a significant role in individual, family and community health. Those at the lower end of the socio-economic scale are more likely to live in deprived or disadvantaged conditions, be exposed to environmental or occupational hazards, and have a lower quality diet. As discussed previously, these and other living conditions associated with socio-economic marginalization have consistently been linked with an array of health disparities including higher rates of chronic illness such as heart disease, cancer, and diabetes (Raphael, 2008).

There is also an increasing body of research to indicate that social exclusion plays a significant role in determining health beyond that of socio-economic contributions (Marmot, Ryff, Bumpass, Shipley, & Marks, 1997). Galabuzi (2008) describes social exclusion as “an expression of unequal relations of power among groups in society, which then determine unequal access to economic, political, and cultural resources” (p.254). Populations most likely to experience exclusion are commonly ‘othered’, marginalized, or oppressed by race, class, gender, disability, or sexual orientation (Johnson et al., 2004). They include new immigrants, Aboriginal people, persons with disabilities, the elderly, single parents and gay, lesbian, and transgendered people. Excluded populations are further marginalized as they are commonly left out of political and social institutions and have little influence or voice in these arenas. With regards to health, these same groups are usually those who are also poor –
and thus already at higher risk of ill health. But by also factoring in exclusion and its concomitant feelings of powerlessness and victimization, these populations tend to experience greater degrees of ill health. Reasons for this have been cited as stemming from a lack of belonging, despair, few life options, depression, unsatisfactory or inappropriate health care experiences, and greater levels of psychosocial stress (Raphael, 2008).

Aboriginal people are often a socially excluded population in Canada. Numerous documents (and a formal apology) prove that the Canadian government aimed to either assimilate or marginalize Aboriginal peoples via forcing them to attend residential schools, to live on reserves, and by other colonial policies. This exclusion and discrimination continues to this day. For example, in a recent survey almost 40 percent of First Nations adults living on reserve claim they had experienced racism in the preceding 12 months (Reading & Wein, 2009).

The exclusion and marginalization of Aboriginal people has influenced both their perceptions of the health care system and the health services they receive. This has, of course, had a significant influence on health status. Structural inequities and socio-political issues facing Aboriginal people have entered into the healthcare arena and have influenced patient-provider relations (Browne, 2005). As a consequence, it is not uncommon for Aboriginal people to experience discriminatory or marginalizing encounters when seeking care (Levin & Herbert, 2004; Browne, 2001). For example, First Nations women in northwestern Canada described some of their invalidating encounters with health
care services (Browne & Fiske, 2001). These encounters included feeling like they were not being listened to, to feeling that they were being judged and not feeling entitled to receiving care. Levin and Herbert (2004) report similar findings from urban Aboriginal people’s health care experiences. Many study respondents claimed they experienced feelings of discrimination and racism from health providers, such as being passed over in the emergency department for less ill non-Aboriginal people. This and another study also take note that such situations are worse for Aboriginal people who are visibly identifiable as such in appearance, dress or speech (Levin & Herbert, 2004).

Scenarios such as these are particularly problematic in that Aboriginal people experience more ill health but feel shut out by the very system that is intended to promote and maintain health. It is therefore key that health care services, such as diabetes education programs, and health care professionals are aware of, and able to respond sufficiently to the larger contributing forces to Aboriginal people’s health.

2.5 Aboriginal-focused Diabetes Programming

There are numerous Aboriginal-focused diabetes education programs in Canada. For example, The Aboriginal Diabetes Initiative, a major federal sponsor of diabetes programming, reports that its funds “deliver a range of primary prevention, screening and treatment programs and services to more than 600 communities throughout Canada in partnership with Tribal Councils” (Health Canada, 2010). Provincial and Territorial governments or Aboriginal
organizations also fund some programs but as with the federally funded initiatives, most programs are small and without readily available documentation on design or participant impact.

There are a few notable and well-documented programs such as the Kahnawake Schools Diabetes Prevention Project (KSDPP) and the Sandy Lake Health and Diabetes Project (Kahnawake School Diabetes Prevention Project, n.d.; Sandy Lake Health & Diabetes Project, 2006). Both have been in operation for over 15 years and have multiple components such as school and community-based interventions.

Information gleaned from available publications on the design or outcome of Aboriginal-focused diabetes programs, indicate that many programs have had limited success (Daniel et al., 1999; Young et al., 2000). Speculations on this include: a lack of meaningful community or participant input into program design; approaches that pay little attention to other ‘larger-picture’ issues such as poverty, unemployment, and racism affecting the health of Aboriginal people; and inadequate understandings of the experiences Aboriginal people have with diabetes or with diabetes programs (Adelson, 2005; Bartlett, Iwasaki, Gottlieb, Hall, & Mannell, 2007; Daniel et al., 1999).

2.6 Culturally Appropriate Health Programming

It is not practical to assume that health programming on its own will be the magic bullet that can improve Aboriginal people’s health but it can arguably make a powerful contribution. As such, it is important to look at how to create suitable
and relevant programming that offers an environment to meet Aboriginal people’s health needs. Discussions in this area primarily focus on making programming more culturally appropriate by recognizing or acknowledging the impacts of colonialism on Aboriginal people’s health, and making programming more culturally safe and by including cultural customs, beliefs or traditions into programming design.

2.6.1 Recognizing Impacts of Colonialism

As already discussed, colonialism has affected Aboriginal people’s health in broad and complex ways. Most health programming aimed at Aboriginal people, including diabetes education, does little to acknowledge these broader issues. Instead, many focus on promoting lifestyle changes such as diet and physical activity. Yet, the lifestyle approach to health programming can be particularly problematic when used with marginalized or impoverished populations as it implies that health (or ill-health) results primarily from individual free choice rather than from larger, more systemic factors (Robertson, 1998). Because an individual’s ability to control their life circumstances is largely dependant on their socio-economic circumstances, the expectation that people living in poverty just need to try harder, trivializes and blames them for their ill-health.

McGibbon (2008) argues that the lifestyle approach, particularly for Aboriginal people, is not only an ineffective way to promote health, but it is also unethical as “the healthy-lifestyle approach shifts the locus of responsibility and
intervention to the individual level rather than toward systemic social change” (p. 328). An example of a program that addresses the impacts of colonialism on the health of its participants is described in Benoit’s (2003) paper, In Search of a Healing Place: Aboriginal women in Vancouver’s Downtown Eastside.

Participants of a program for drug addicted mothers praised the program’s services because staff understood the “historical wounds and were aware of the lingering racism and sexism that continue to negatively affect their health, language, identities and self-respect” (p. 830).

Culturally appropriate health programming needs to acknowledge the greater systemic forces that have shaped Aboriginal people’s health. With respect to diabetes, this takes on even larger importance, not only because health programming in this area commonly utilizes the lifestyle approach, but also because diabetes has clearly and repeatedly been associated with colonialism.

2.6.1.1 Colonialism and Diabetes

As already established colonialism has served to socially, economically and politically marginalize Canadian Aboriginal people. Moreover, for Aboriginal people, diabetes is very much associated with poverty and inequality. It is therefore no surprise that diabetes is commonly attributed with colonization and its associated involuntary cultural change. There are numerous examples documented in the academic literature. Participants in a study by Boston et al (1997) believe that the onset of diabetes for Aboriginal people is from the decline
of “bush life” or traditional ways, a lack of access to traditional food, and the loss of traditional knowledge. There are similar findings from other studies where diabetes is associated with increased consumption of store-bought foods, too much ‘junk food’ and not enough consumption of traditional foods or wild meat (Bruyere & Garro, 2000; Gregory et al., 1999; Neufeld & Marchessault, 2006; Travers, 1995). To many of the participants in these studies, diabetes also represented a sense of loss, stress and a lack of control (Grams et al., 1996; Gregory et al., 1999; Iwasaki, Bartlett, & O’Neil, 2004). Some participants commented on feeling fearful about a diabetes diagnosis because they had witnessed family or community members experience diabetes-related complications like amputations and kidney failure, and felt that this would also be their inevitable fate (Iwasaki et al., 2004).

This illuminates the important point that for many Aboriginal people diabetes is rooted within a broader context and not just within the individual body. It could even be argued that diabetes is an extension of colonialism as both are associated with cultural loss, socio-economic marginalization and traumatic emotions such as self-blame, loss, shame, fear and stress.

2.6.2 Cultural Safety

Cultural safety is a concept developed by a Maori nurse and academic in New Zealand (Brascoupe & Waters, 2009; Browne & Fiske, 2001). It was developed to draw attention to the effects of colonization on the health of Maori people as well as to provide a platform to envision how to change the way
healthcare is delivered to Aboriginal people. For example, the delivery of culturally safe healthcare," is a two-way relationship built on respect and a bicultural exchange, which aims for equality and shared responsibility” (Brascoupe & Waters, 2009, p.6). In addition, this concept can provide a lens with which to critically examine the social, economic, and political positions of Aboriginal people and how health care policies and practices can perpetuate the legacy of colonization (Brascoupe & Waters, 2009). Due to the inherent power imbalances and institutional discrimination that exist for Aboriginal people in Canadian society, this can easily be amplified within the healthcare context (Browne & Fiske, 2001). Health practitioners hold a unique position of dominance and control and can create culturally unsafe experiences for Aboriginal clients by not engaging in a mutually respectful relationship.

Culturally unsafe experiences have frequently been cited as contributing to negative health experiences, such as feelings of anger or alienation, hesitancy to seek timely health care or to participate in health programming (Benoit, 2003; Browne & Fiske, 2001; Levin & Herbert, 2004). Often these accounts appear to stem from situations where the health care provider does not understand or is not aware of Aboriginal people’s colonial history and its impacts on current day living conditions. On the other hand, culturally safe practices begin with the establishment of trust and respect between healthcare provider and client. This includes respect not only for the individual but beyond that to culture, to the traditional knowledge, teaching and practices.
2.6.3 Incorporation of Cultural Customs, Beliefs and Traditions

Aboriginal customs, beliefs, and traditions vary widely within Canada but it is commonly stated that Aboriginal worldviews are generally community-centered and focus on balance, holism, and interconnectedness (RCAP, 1996). The individual in Aboriginal cultures, for example, is often inexorably linked to the greater context of family, community, and to the natural and spiritual world. In contrast, the Euro-Canadian emphasis is on the individual (Kirmayer, Brass, & Tait, 2000; RCAP, 1996).

A common representation of this Aboriginal worldview is the Medicine Wheel, which symbolizes the interconnectedness and interdependence of all things in the universe (Bopp, Bopp, & Browne, 1984). It teaches that each person has a mental, physical, spiritual, and emotional aspect to their nature and each aspect must be nurtured and developed in order to be healthy. According to the Medicine Wheel, the ill-health of an individual can be connected to problems with family, the community, and/or the larger social milieu. The following excerpt from the Royal Commission of Aboriginal People summarizes a commonly endorsed view of the Medicine Wheel’s role in health and well-being:

…the Aboriginal concept of the circle that links body, mind, emotions and spirit and each individual to the community and the land in which the human being is rooted. The cumulative research on health determinants agrees. It paints an increasingly complex picture of the impacts on physical health of disturbances in the mind, emotions or spirit. ‘Health’ is the total effect of vitality in and balance between all life support systems.

---

2 The Medicine Wheel is commonly used as a general symbol of Aboriginal spiritual beliefs. The writer acknowledges that this symbol is by no means embraced or endorsed by all Aboriginal Canadians and does not wish to imply otherwise. However the Medicine Wheel symbol was specifically chosen as an avenue to discuss cultural customs, beliefs and traditions and in the context of health programming due to its common application in this area. It was also chosen as the Medicine Wheel is a key component of ADAPT and thus specifically relevant to this thesis.
With the concept of the Medicine Wheel in mind, approaching health promotion with Aboriginal populations takes on a new and different meaning. In contrast to a biomedical public health approach where health occurs at an individual level such as with lifestyle change, this concept envisions health stemming from multiple, broader sources. Therefore, more appropriate, or more specifically, culturally appropriate approaches to health programming are likely those that address not only physical health, but also mental, spiritual and emotional health.

This is echoed in one of the recommendations set by RCAP stating that the next steps towards Aboriginal health and healing systems should include holistic approaches, such as “holism in approaches to problems and their treatment and prevention.” A more recent report published by the Aboriginal Healing Foundation (2006), echoes these recommendations. The report states that, “Cultural intervention plays a vital role in the health and healing fields. Solid arguments can be made in favour of embedding healing practices in the specific cultures, traditions, languages of Indigenous people, nations, tribes and communities” (p. 49).

Recognition of these views may further help to build mutual understanding and to bridge biomedical and Aboriginal paradigms. Mundel’s example of the Urban Aboriginal Community Kitchen Garden Project – an offshoot program of ADAPT – helps to illustrate this point. The Garden Project is a health promotion project that aims to bridge healing, skills building and capacity building via “working to treat the whole person, addressing the interconnected health needs,
and recognizing the connection between human and ecological health (Mundel, 2008, p. 93)

2.7 Conclusions

Diabetes is a disease that disproportionately affects Aboriginal people and incurs a large personal, social and economic cost. Despite increased awareness among leaders and policy makers, the prevalence and complications of this disease continue to rise to levels well above those in the non-Aboriginal population. For Aboriginal people, diabetes does not exist in a vacuum and cannot be separated from the inequalities stemming from a history of colonization. Exploring alternate approaches to diabetes education is needed since the commonly employed biomedical or individualistic approaches have not adequately incorporated or addressed the effects of this larger-scale issue. However, there are still significant knowledge gaps about how to approach diabetes education in more appropriate and successful ways. This project aims to contribute to this area of knowledge by providing information and insight about the experiences of participants and staff, facilitators and stakeholders with a diabetes education program named ADAPT.
Chapter 3: Research Approach and Methods

Critical theoretical perspectives, and in particular, postcolonial theory has served as the primary paradigm for this project. Critical theory or critical research can be described as aiming to bring light to social injustices or inequities that are “fundamentally mediated by power relations that are socially or historically constituted” (Kincheloe & McLaren, 2000, p.304). Browne, Smye and Varcoe (2005) describe the cornerstones of postcolonial theory as the need to examine the effects of our colonial past on current day realities, such as the need to decentralize dominant culture, and to examine how modern constructions of race and culture are shaped by a shared colonial history. This theoretical construct serves as a way to contextualize health inequalities experienced by Aboriginal people as part of a past and present colonial history, rather than due to individual lifestyle choices or behaviours. The postcolonial lens is of particular relevance to this project since ADAPT participants have indeed been affected by colonialism. Without this lens, one could make many assumptions about these individuals based on stereotyped ‘cultural’ characteristics centered on issues of poverty, substance abuse, or dependency (Browne, Smye, & Varcoe, 2005). However, a postcolonial framework provides a platform to re-examine these assumptions and to locate them into a broader social, historical and economic context.

This project was guided by interpretive description methodology. Interpretive description as outlined by Thorne, Reimer-Kirkham, and MacDonald-Emes (1997) is a non-categorical approach to developing understandings of
health and illness experiences with the aim to inform clinical practice. This approach does not intend to produce truth claims about a situation but rather to produce new insights into health care practice. Interpretive description shares a similar philosophy to other qualitative methodologies in that it “acknowledges the constructed and contextual nature of the human experience that at the same time allows for shared realities” (Thorne, Kirkham, & O’Flynn-Magee, 2004, p.5). As such, this methodology explores health and illness experiences in a fashion where they are not detached from the subjective realities in which they exist but rather in such a way as to fit the experiences into a “mental heuristic to make that new understanding accessible to practice logic” (Thorne et al., 2004, p.8)

3.1 Data Gathering

This project took place over two years (July 2004 - August 2006) and was divided into two phases: prolonged engagement with ADAPT and its participants in year 1 and story-gathering in year 2.

3.1.1 Phase 1: Observation and Participation

During the project’s first phase (the first year) I focused on getting to know the participants and becoming a part of the ‘fabric’ of the program. I actively participated in and observed program activities, such as the community kitchens, workshops, and information sessions. On average, I spent approximately two to four hours each week with ADAPT. My role was explained to participants as that of a graduate student and as the eventual story-gatherer for the program.
This first phase of prolonged engagement with ADAPT was a key time for me to develop rapport with participants, and, according to Lincoln and Guba (1985) to increase the chances of producing credible findings of the phenomena being observed. It was also a necessary step to not only familiarize myself with the program but for the program participants to become familiar with me and for us to build a mutual degree of trust. My time was also spent gaining a sense of what it would be like to be a program participant; to observe and interact with others and to better understand the context of participants’ lives. The observations that I was able to make during that first year were instrumental for me to gain an understanding of the more subtle aspects of ADAPT. I began to record field notes after spending time at ADAPT activities, that included my observations, thoughts and questions. I also gathered documents such as program calendars, participant handouts, articles written about the program and other miscellaneous materials that I encountered. My experiences with ADAPT and the insights that I gleaned during phase 1 informed the rest of my actions during the project, from the way interview questions were formulated to how interview data was analyzed.

3.1.2 Phase 2: Story-gathering

It was in phase 2 that the importance of drawing on decolonizing methods in this project became clearer to me. As Linda Tuhiwai Smith (1999) states, research “is probably one of the dirtiest words in the indigenous world’s vocabulary” (p.1). Research has historically been performed ‘on’ and until
recently, has rarely been used ‘with’ Aboriginal people, and symbolizes one of the foundational avenues for colonialism to objectify and study Aboriginal people. Thus, the guidance offered by the program Elder, Corinne, was significant in the design of phase 2. The timing of this phase was decided with guidance from Corrine. Corrine also played a significant role in deciding the appropriate language that should be used when asking participants to share their stories. She recommended that when recruiting participants, it was very important to avoid using the word ‘research’ due to its negative, colonial connotations. We reframed the work completed in this phase more appropriately as ‘story gathering’.

3.1.3 Recruitment

In total, I conducted 14 open-ended semi-structured interviews with ADAPT participants, staff, facilitators and stakeholders. 7 were program participants (3 women and 4 men), 2 were staff, 2 were facilitators and 3 were stakeholders. The recruitment process began during a sharing circle at one of the bi-monthly community kitchens. As the Elder, Corrine began each sharing circle with a story or with some of her thoughts. On this day, she began the circle by explaining that we were interested in gathering people’s stories about their time with ADAPT because each participant’s story was a piece of ADAPT’s story. Corrine continued to explain that she wanted to share ADAPT’s story with others because of how proud she was of the program and of its participants. When it became my time to talk in the circle, I talked with participants about what would
be involved with the story gathering process. A handout containing information about the recruitment process was also provided for participants (Appendix A). Some program participants approached me afterwards to express interest in being interviewed and we set up a mutually agreeable time for us to meet. The recruitment process continued after this first day for approximately three more months. Staff and I would continue to casually mention that I was interested in gathering people’s stories about their time with ADAPT and for any interested parties to approach me. The recruitment process ended when no further participants expressed interest in being interviewed.

I did purposely approach three participants to be interviewed, as each had been involved with the program for an extended period of time and had varying levels of participation, i.e., periods of active participation and periods of lapsed participation. One individual consented to participate while another did not. Although not stated, I believe that this individual did not consent to be interviewed was due to what I perceived as a general level of apprehension and lack of trust of others. The third participant did consent but was terminally ill and passed away shortly afterwards.

Stories were also gathered from program staff, facilitators, and program stakeholders. Program facilitators included individuals who had regular exposure and firsthand involvement with ADAPT activities and participants, usually via partnerships with other organizations. Stakeholders included individuals who did not have regular exposure to program activities or with participants, but who had either an arms-length involvement in the program or a specific interest in it (i.e.,
past program coop student, Executive Director of Vancouver Native Health Society (VNHS)). The recruitment process for staff, facilitators and stakeholders was much different than for participants. I approached each person to request permission to interview them for the purpose of gathering information about their perceptions of ADAPT and its activities, as well as their perceptions of the impact that the program has had on participants and on the community. All persons approached were willing to be interviewed.

All participants were provided with a gesture of thanks in the form of a 25 dollar gift card. Participants were provided with a gift card to Safeway, and staff, facilitators and stakeholders were provided with a gift card to Chapters, Safeway or Starbucks.

3.1.4 Open-ended, Semi-structured Interviews

All program participants had been diagnosed with type 2 diabetes by a medical doctor and had been attending program activities regularly or sporadically for between one and three years. All but one staff member and one stakeholder self-identified as Aboriginal. I have limited demographic information, such as age, as I did not feel that such questions were appropriate to ask all interviewees, especially the program Elder. However, most participants visibly appeared to be middle-aged adults. From my time spent with ADAPT, it appeared that not all participants were comfortable divulging personal information about themselves. Some were forthcoming, yet others were visibly uncomfortable discussing such information. I did not want to guess who would
be comfortable providing this type of information, and also tried to be as respectful as possible by not asking much personal information.

Participant and staff, facilitator, stakeholder interview questions were developed in consultation with staff, Corinne and Kristen. Not all questions from the interview guides were asked as some interviewees were more conversational than others and covered much of the information that I sought without being probed. I also found that some of the questions did not resonate with, or have meaning for participants (i.e. ‘Can you describe if and how the ADAPT program fits with your views and experiences of wellness and diabetes?’) and so after the first few participant interviews, I chose to not ask these questions. Interview guides (Appendix B) and consent forms (Appendix C) were approved for use by the UBC Behavioural Research Ethics Board (BREB). I was granted permission from the UBC BREB to obtain written consent from participants to conduct the interviews, but sought an amendment in March 2005 to also obtain oral consent. I realized that the formality of a written informed consent form could be intimidating to the individuals involved in this project and might affect their sense of comfort during the interview process. At the same time, I also realized that some participants had low literacy skills and would potentially be either unable or uncomfortable with a written consent process. Once the amendment was approved, I asked all participants their preference for providing consent, and most preferred to provide oral consent. This process involved a declaration of consent on audiotape and each participant was provided with an unsigned consent form for their records. All participants were made aware that I was a
university student and was gathering stories for what would eventually be written into a thesis. All interviews were audiotaped with interviewee’s knowledge and consent, and transcribed verbatim.

Names or pseudonyms have not been used in the findings section of this thesis. Instead, interviewees are referred to as a “participant”, “facilitator” or “stakeholder.” The exception to this is that I have used both staff members’ first names with permission.

3.2 Data Analysis

With interpretive description, data interpretation is not as much based on smaller details such as coding and sorting of data but on ‘larger picture’ interpretation. The researcher is encouraged to ask overall questions about the data as a way to distinguish patterns and see connections (Thorne et al., 2004). Thus I did not endeavor to conduct a line-by-line analysis of the data but instead approached this process with a broader intent to better understand the overall picture. Part of this was approached by asking big-picture questions of the data such as, “what is happening here?” and “what does this mean?” (Thorne et al., 2004). My analysis of the interview data began by reading and re-reading transcribed interviews multiple times to gain a sense of the overall content. I also reviewed all the field notes and documents that I had gathered. I then identified some initial common themes within participant interviews and within the staff, facilitator, and stakeholder interviews. These themes were compared in an iterative process within and across both interview groups (participant group and
staff, facilitator, stakeholder group) multiple times. Then I explored the initial common themes in more detail by concept mapping quotes, words, or phrases from the transcripts and from my notes. I repeated this process for participant interviews and for staff, facilitator, and stakeholder interviews multiple times. Each time, I looked for opportunities to condense or find more fitting ways to regroup the themes. To ensure that the results of the analysis process did not alter the context or overall meaning of the data, I then reread all interviews in their entirety to determine if the themes did indeed align with the interview data as well as to provide a meaningful interpretation.

3.3 Establishing Rigor

Rigor in data analysis is particularly important to establish the data’s trustworthiness. In ensuring the rigor of this analysis, I utilized Lincoln and Guba’s concept of trustworthiness (Lincoln & Guba, 1985). This concept, the qualitative substitute for reliability and validity in quantitative research includes four components: credibility, transferability, dependability, and confirmability. To enhance credibility (truth value), dependability (neutrality) and confirmability (consistency), I tried to make sure that my findings were as consistent as possible to the phenomena being studied. During the data gathering phase, I kept field notes to document my activities as well as to record my thoughts and observations while attending ADAPT programming. I also gathered documents from other sources, such as articles written about ADAPT, clinical literature, and other documentary reports. Member checks were performed after all interviews.
Once I had completed and transcribed an interview, I drafted a letter to the interviewee with a synopsis of my thoughts and interpretations of the interview content. This information, along with a copy of the transcribed interview, was shared at a follow-up meeting. In case a participant had low literacy skills, I asked all interviewees if I could read them the letter. Due to time constraints I did not also read aloud the transcript. Each individual was asked for feedback and approval. With three interviews, I generated further questions, or required some clarification after our meeting. This was usually because I realized that I had missed opportunities to request clarification or elaboration during the original interview. I requested a second, shorter interview. Each person kindly consented to be interviewed a second time. These follow-up interviews were also audiotaped and transcribed verbatim. During the data analysis phase, I discussed interview transcripts and sought feedback from other qualitative researchers in a graduate student discussion group forum. I also discussed my data analysis at various stages of completion with my committee members.

Transferability refers to the applicability of the findings to other settings. I addressed this by providing a detailed description of ADAPT and of my inquiry into people’s experiences with this program.

3.4 Dissemination

After some preliminary data analysis, I hosted a catered luncheon located at Vancouver Native Health in August 2006 (Appendix D). The purpose of the
luncheon was multi-fold: I wanted to thank everyone at ADAPT for sharing their time, their thoughts and their space with me. I also shared my data findings as I was relocating to Whitehorse the following month. All ADAPT participants, staff, facilitators and stakeholders were invited and 20 people attended – a great turnout considering the initial hesitation that a researcher may not be welcome.

3.5 Limitations

One of the limiting aspects of this project was my inability to recruit any interviewees who did not continue their involvement with ADAPT. This included participants who attended just one or two program activities and then decided that the program did not suit their needs or tastes. They often did not provide staff with their contact information or the details as to why they chose not to continue participating. Another difficult to recruit group was participants who attended program activities prior to my involvement with the program, and who had since left with no forwarding address or telephone number. One participant who did attend some program activities (but shortly ceased involvement with the program) agreed to be interviewed but did not show up on the day of the interview or return to attend program activities. I was not able to reschedule an interview with this individual.

A second limiting aspect of this project is that participants may have felt compelled to communicate only positive feelings or thoughts about ADAPT despite it clearly being communicated that all interview conversations were confidential and would not be shared with program staff. Even when specifically
asked about what they would like to change or improve about the program, it is very possible that participants may still have only wanted to share approving information. This, however, is only based on a personal feeling of mine as no participants directly expressed thoughts or feelings of this nature.
Chapter Four: Findings and Discussion

This chapter is structured in a non-traditional format as contextual and background information about ADAPT are mixed with interview findings. I decided on this approach as there was no linear or logical way to separate this information into discrete chapters without losing the stories or voices.

I will present this chapter in four sections. The first section introduces the ADAPT program and describes the location, program activities and other pertinent information. The second section describes some of the limitations of the program as perceived by ADAPT staff, facilitators and participants. Section three and four explore the findings, with the third section presenting the voices of the participants and the fourth section, the voices of the program staff, facilitators, and stakeholders. The intention behind separating participant and staff, facilitator, stakeholder interviews was to ensure that all voices are heard equally, and to distinguish between their slightly differing perspectives.

4.I Introduction of ADAPT and the Downtown Eastside (DTES)

4.1.1 Community Context – Downtown Eastside

The Downtown Eastside of Vancouver (DTES) is an area facing a multitude of social issues such as drug addiction and dealing, high unemployment, high crime rates, and lack of adequate housing. Centrally located in one of Canada’s more affluent cities, the median annual income in this neighbourhood is $12,000 (City of Vancouver, 2005-2006). The DTES area has a much higher unemployment rate at 22% than the rest of Greater Vancouver (8%)
and has a significantly greater number of individuals who receive some form of income assistance (40%) or who are considered low-income (67%) compared to the rest of the city (10% and 27% respectively) (City of Vancouver, 2005-2006).

The majority of residents of this neighbourhood live in Single-Room Occupancy hotels (SROs) and non-market housing. Quite often SROs are one room with shared bathrooms and many do not have kitchen or cooking facilities. It is not uncommon for these SROs to be infested with rodents or cockroaches, and house drug dealers or other illicit businesses.

4.1.2 DTES Demographics

Proportionally, there are more Aboriginal people living in the DTES than in other areas of Vancouver. Of the approximately 16,000 DTES residents about 10% are Aboriginal (compared to 3% elsewhere in Vancouver) (City of Vancouver, 2005-2006). However, it is thought that this percentage is likely much higher (up to 50%) due to the high mobility of this population, the tendency for census figures to underestimate populations that are marginalized, and for some Aboriginal people to choose to not participate in the enumeration process, (Benoit, 2003; Vancouver/Richmond Health Board, 1999).

Many of the Aboriginal people who live in the neighbourhood have been displaced from their home communities in other areas of the country and may be socially isolated and lack strong social support systems (Benoit, 2003). The ADAPT participants that I interviewed did not specifically mention why they live or

---

3 Non-market housing is owned by government, a non-profit or co-operative society. Rents are determined not by the market but by the residents’ ability to pay. (City of Vancouver, 2010)
have lived in the DTES (if they no longer live in the neighbourhood), nor did I ask them. However, I did observe many participants who were socially isolated, financially impoverished, and lacking in social support; some were the only caretakers of sick or dying family members, some were financially struggling as the single parent of many children, and others were constantly on the verge of homelessness.

4.1.3 Food and Food Security in the DTES

For some DTES residents, local food services such as soup kitchens, food banks, and other venues that provide free meals or snacks are the main way to access food. This was no different for many of the participants that I interviewed. Most received disability payments or other forms of income assistance. This presented a significant financial barrier to access enough food, let alone healthy or fresh foods (Dietitians of Canada & Community Nutritionists Council of BC, 2009).

During the time that I spent attending group activities, I observed that many of the participants were unable to meet their food needs on a regular basis. Some came to the community kitchens knowing that it would be the only meal of their day. Not all of the participants mentioned their financial struggles to purchase adequate food during their interviews; however, some described what it was like to try to eat a healthy diet while receiving income assistance. This is one person’s description of his struggle to obtain enough food on a day-to-day basis: “I know you’re supposed to eat small amounts throughout the day but I
have to eat one big meal because that’s the only choice I have otherwise I’d run out of money way before the month was over.” Others also expressed frustration at knowing that it was a necessity to eat healthy foods in order to control their diabetes, but not being able to afford such foods on a regular basis, “you want to buy cheese; it’s like over six dollars, almost ten dollars. I can’t afford that on disability, really that much anyways. Maybe just one small piece for the whole month.”

Another participant described his similar situation, “some of us are struggling with very few dollars a month to survive and for a diabetic who is allowed to eat decently for two weeks but the other two weeks remaining on this month, this diabetic person has to be eating only peanut butter sandwiches. That is not good for somebody who has diabetes. It’s not good.” This individual called me the morning of our interview to tell me that he was going to be late to meet me as he needed to go a local soup kitchen for lunch. He was completely out of food and could not take his diabetes medication. We rescheduled our interview for later that afternoon.

To further compound the struggles that many face to obtain enough food, there are few nearby grocery stores that offer a variety of fresh produce and healthful food items. Many stores in the area are convenience stores with a limited selection of fresh food items that are sold at high prices. Although bountiful fresh produce is for sale, just a couple of blocks away, some participants commented that they do not feel welcome and choose to stay away. Those who cannot afford to purchase any or enough food for the month often rely
on the many emergency food providers in the area to provide meals, coffee, and snacks. However, many of these meals consist of foods that are high in sugar and fat and are low in fibre and micronutrients. One participant described his experiences eating at a local emergency food provider in the neighbourhood, “when I first moved down here I gave it a shot. I went a few times and I got sick, right? I wasn’t feeling well. I got upset stomachs and that, and as soon as I stopped eating those darn disgusting, cheap hot dogs at [name of food provider], I just felt a lot better.”

Neighbourhood residents may not have access to facilities to prepare or to safely store food. As already mentioned much of the housing in the DTES lacks kitchen facilities or is infested with rodents and cockroaches. One participant who I interviewed lived in an SRO and described why he did not attempt to cook meals in his room, “I can’t do any cooking, or not at home because there’s no stove, no fridge, so I have to eat every meal out. I can’t take in little things … like cereal and that because the rats and the mice and the cockroaches would like to adopt them and walk them away before I could ever get to them and eat them.” Another participant discussed some of the strategies that he used to cook meals despite having no kitchen in his SRO, “I have a stove that I use every Saturday that has the full oven and controls on top. That’s the boss’s, the boss’s stove, and I usually sit in for him on Saturday, eh? So I can cook my own meals then.”
4.1.4 Description of the ADAPT Program

The ADAPT program started in 1999 with funds from the federal government’s Aboriginal Diabetes Initiative (ADI) Métis Off-Reserve Aboriginal and Urban Inuit Prevention and Promotion Program (MOAUIPP)\(^4\). The program employs one full-time Registered Dietitian/Program Coordinator and one part-time Elder and is housed on the premises of VNHS, along with many other DTES-based programs\(^5\). The VNHS has been a fixture in the neighbourhood since 1991 and based on the consistently busy waiting room in its medical clinic, it is regarded as a comfortable place among locals to access health services.

Corinne’s description of VNHS’s services illustrates her thoughts about the level of care provided by the staff and of VNHS’s standing within the community:

> But I think the place here has already been established. It’s not so brand new. Vancouver Native Health Society has been here for a long time and so, you know, they have credibility. You know, they have staff that it’s the genuine caring, you know, the humanness I think is making it easier. There is the contact for example, say medication, where the pharmacist is here. [The pharmacist] is wonderful. He’s been here for a long time and people already had their experience, good experience, with him. The doctors that are here, you know, we’ve had referrals from them and they keep a close contact, you know, with individuals.

Upon entering the VNHS building, a client is greeted by an intake worker in the medical clinic and then directed to the appropriate service. It is often while

\(^4\) The purpose of the ADI - MOAUIPP program is to provide culturally appropriate diabetes primary prevention and health promotion programs that raise awareness of diabetes and its risks and address the occurrence of type 2 diabetes among Métis, off-reserve Aboriginal people and urban Inuit. (Health Canada, 2000)

\(^5\) The VNHS services include a walk-in medical and dental clinic, an HIV/Hepatitis C peer support program, an alcohol and drug recovery program, Aboriginal Child and Family Services, and a support program for substance-using women who are pregnant or parenting young children (Vancouver Native Health Society, n.d.).
accessing other health services at VNHS that potential ADAPT participants are informed about and referred to the program. Referrals can also originate from staff at other DTES service agencies, or from other ADAPT participants. There were very few ‘walk-ins’ during the time that I spent at ADAPT. ADAPT clients are generally known by the medical clinic intake workers and ‘buzzed’ up to the ADAPT office on the second floor.

ADAPT’S office space is understated – the aging building and its offices are simply furnished; staff are most often found wearing blue jeans and sneakers or something equally casual. Program participants are on a first-name basis with both ADAPT staff and, in many cases, with the rest of the VNHS staff.

4.1.4.1 Program Vision and Design

ADAPT’s vision centers primarily on capacity building, and includes: increasing awareness, knowledge and ownership of diabetes and diabetes prevention among urban Aboriginal people; increasing knowledge and adoption of healthy eating and lifestyle strategies to prevent diabetes; promoting innovative approaches to diabetes primary prevention and health promotion projects; and increasing opportunities for Aboriginal individuals and families to access healthy food (Vancouver Native Health Society, n.d.).

The main underpinning of ADAPT’s approach to program delivery centers around the Medicine Wheel. ADAPT staff recognize that health and healing do not just belong to the physical realm, but also to all four quadrants of the Medicine Wheel. In this light, Kristen and Corinne talked often about the
importance of approaching diabetes care from multiple vantage points. As Kristen pointed out, their interactions with participants may sometimes not even revolve about diabetes, depending on the particular needs of the person. For example, a participant can stop by for a cup of tea and diabetes may not be mentioned but these encounters are still linked to diabetes care. Kristen described how ADAPT’s approach to health and healing involves supporting the whole person:

For the medicine wheel, this entails that a holistic approach be taken to achieving good health. By just being there for the participants, this helps to address their spiritual and emotional needs by recognizing that participants are much more that their diabetes-they are also people who are struggling with many other issues in their lives that will ultimately affect how they manage and control their diabetes or their blood sugars (both short and long term). If the participant is struggling to pay their rent, for example, they will be struggling with managing their stress, their finances and their food consumption - all things that hamper good diabetes control.

4.1.4.2 Reaching Out

To inform local residents and program participants about the program activities, staff would post leaflets and posters at the various local service agencies. Copies of monthly activity calendars were available at all of the drop-in sessions for participants to take home with them. Participants, like most residents of the DTES, were highly mobile and it was always a challenge for program staff to keep track of everyone’s contact information to remind or invite them to program activities. To ‘check-in’ as well as to keep program activities in the forefront of participant’s minds, Corinne would telephone each participant with a personal reminder of upcoming activities one or two days beforehand.
4.1.4.3 Programs Geared to Interest

ADAPT program activities have changed over the years, depending on participant and staff interest and need. During the time that I spent with ADAPT (2004-2006), program activities included a bi-monthly Community Kitchen, bi-monthly ‘Living Healthy’ drop-in information sessions on various health and healing topics, weekly attendance at an Elders’ Group called ‘Our Elders Seek Wisdom’ (held at the Vancouver Aboriginal Friendship Centre), participation in various health fairs in the downtown/ East Vancouver area, and hosting various diabetes-related and/or healthy eating workshops for ADAPT participants and outside agencies (i.e. daycares, other service providers in the DTES). The program hosted a bi-monthly activity group (walking and bowling) but it was cancelled in 2004 due to decreasing attendance. One of ADAPT’s newer projects is a community Garden Project in partnership with the UBC Farm. This project began in 2005 as the brainchild of ADAPT staff and now has its own funding and staff (Mundel & Chapman, 2010).

4.1.5 Description of a ‘Typical’ ADAPT Community Kitchen

By far the most well-attended program activity was the bi-monthly community kitchen, held every second Tuesday. At times, upwards of 15 people attended this activity. The goal was to introduce healthy lifestyle habits and to increase the capacity of participants to prepare healthy food. While this community kitchen was originally facilitated by the two program staff, in 2005 ADAPT partnered with Vancouver Food Bank’s Downtown Eastside Community

---

6 ‘Living Healthy’ drop-in sessions were cancelled in 2006 due to low attendance.
Kitchens (DECK). This new partnership introduced a third facilitator and other types of program support (i.e. food procurement funding, menu planning).

A typical community kitchen ran from 1:30 to 4 p.m., beginning with participants arriving, signing in, and everyone greeting each other. Snacks would be available: usually cut-up vegetables or fruit, tea and coffee. The day’s recipes, along with the ingredients, would be laid out on the kitchen counter ready for preparation. Recipes were chosen to be low-cost and easy-to-prepare. Typical meals would include: stir-fries with brown rice, casseroles, and soup with whole-wheat baked bannock. Staff and/or the DECK facilitator would introduce the recipe and participants were welcomed to begin food preparation.

Some participants were more engaged in food preparation than others. This appeared to be dependent on: the participant’s mobility, i.e., some depended on scooters or other mobility aides; food preparation skills; and comfort level with the group. Some people would help prepare food intermittently and take breaks to socialize. Others would take more of a lead role in food preparation. Staff and facilitators would participate in food preparation and act as overseers of the overall process, i.e., ensure that food was cooked completely; timers were set, hands were washed, etc.

During the time that the food was being prepared, participants, staff and facilitators socialized. All ADAPT activities would include a sharing circle and a prayer led by the program Elder. At the community kitchen, these occurred right before the meal was ready to eat. Once the meal was ready, everyone helped themselves (buffet-style) and ate together. People would continue socializing
and catching up. Often, staff and/or facilitators would take this opportunity to tell participants about the meal, such as why the foods in the meal were healthy choices (i.e. why baked whole wheat bannock is a healthier option than fried bannock), or to discuss the cost of the meal ingredients. This was intended to demonstrate that healthy food options were not necessarily expensive food options. Sometimes, a meal (including leftovers) could be prepared for 10-12 people for under twenty dollars.

After everyone finished eating, participants were encouraged to take any leftover food with them. Plastic containers were supplied or participants brought their own. Clean-up would be completed by participant volunteers and staff. Participants were provided with bus tickets to get home, if needed, and goodbyes said.

4.2 Limitations of ADAPT

4.2.1 Accessibility

Participants did not make many suggestions for improvements to ADAPT however, a few participants did identify a couple of things that would have liked to change about the program. Some expressed a desire to have more regular access to the program and its facilities, such as an informal drop-in meeting space to stop by during the day and have a cup of coffee. Although the program has an open door policy and participants are welcome to drop-in, they need to do a few things in order to access program staff. The ADAPT office is located on the second floor of the VNHS building and visitors need to be ‘buzzed into’ the
building (which gets them into the medical clinic on the main floor) and then get ‘buzzed up’ to the second floor by the clinic security person. Participants who are familiar and comfortable with this process would likely be the only ones to access this service, rather than those who are new to the program or generally more apprehensive.

Another accessibility issue is that the stairway leading to ADAPT’s office on second floor is steep and narrow. Also, there is no elevator in the building. This makes the office and its staff virtually inaccessible to individuals using mobility devices or with physical disabilities.

4.2.2 Lack of Adequate Space

Another limitation of ADAPT mentioned by staff, facilitators and participants was the difficulty in accessing safe, clean and accessible meeting space. Such venues are in short supply in the DTES, especially spaces with kitchen facilities. The first year that I spent with the program, the community kitchen was located on the main floor of the VNHS building, adjacent to the medical clinic. This part of the building did not house any other programming besides the ADAPT community kitchens and consequently was quite private. From my observations, this space appeared to be perceived as a comfortable place by participants. It was also convenient for staff as ADAPT was the only group to use the kitchen supplies and food, and thus, it was easy to maintain and keep track of.
Unfortunately, this space was only for temporary use as it was slated to become a community dental clinic and ADAPT was required to relocate. Another shared kitchen space was located a block away at another DTES service agency. However, there were a few negative aspects associated with this new location for both staff and facilitators and participants. One downside to the new space was that the only available time slot required ADAPT to change its community kitchen to another day of the week. Although a change in the schedule may seem insignificant, change in general did not seem to be well tolerated by participants perhaps due to a need for a sense of consistency or predictability in their lives.

Another unfortunate aspect of the new location was that service agency that housed the kitchen space serviced clients who were generally more street-involved (and drug-involved) than ADAPT participants. This service agency was a busy place that provided many services such as laundry, a lounge and various types of drop-in programming. It was also a loud place that would sometimes be the scene of fights, yelling, or other outbursts. This presented quite a large issue for participants. I remember when the announcement about the location change was made. A few participants were quite upset and one person refused to attend programming at the new location (he did eventually change his mind) due to the nature of the clientele at the service agency. After the move, it was difficult to keep the ADAPT community kitchen separate from the rest of the happenings in the building. There were many times where non-participants entered the kitchen area and attempted to join in the group’s activities only to disrupt and upset
ADAPT participants. The staff did express concern about the new space and its effects on program participants:

I think it’s hard on the participants - not having gone from where they were in a place where everything was theirs and it was quiet and uninterrupted and everything was, you know, familiar, to having that shift to being in a place that isn’t theirs and they’ve got to share and just all those things of just how different it is.

Eventually, staff started locking the door to the kitchen once the community kitchen began. Participants and staff appeared to get used to the new location but, in my opinion, they seemed more on edge, and there was less of a feeling of ownership of the space.

4.2.3 Funding

A significant limitation facing ADAPT was the funding source. The major source of program funds during the time that I spent with ADAPT was from the Aboriginal Diabetes Initiative’s MOUAIIPP. Funds were not granted to the program on a multi-year basis and thus there was no guarantee that they would be renewed from year to year. At one point, the MOUAIIPP program was set to ‘sunset’ at the end of the 2004-2005 fiscal year and staff were unable to secure alternate funding to continue the program. As a result, staff were getting set to shut down all programming. They informed participants of the situation and everyone was prepared for activities to cease as of March 31st. Luckily, program funds were renewed for another year and then eventually renewed again for another two years. I believe that this situation served as a reminder to all of the very real possibility that the program would one day cease to operate. The
impermanence of funding was a significant concern for staff as one of their goals was to establish trust with participants. It was difficult to build trust when participants are anticipating a very real end to a source of support.

The other part I feel that’s not right, it’s the funding source where we’re left so last minute. You know, do we say to our participants in the program, ‘Sorry, we’re not going to be here, you know, in two weeks.’ ‘Sorry, we’re going to be closing doors, you know, in four weeks, you know.’ And, you know, having to go, you know, first was the three years and then the extension of the year and now, you know, we’re having to wait and see what the funding source is going to be. There’s so much work that has to happen. We’re just beginning with the youth and the children. I think initially the promotion, it takes time. It takes time building up a trusting, respectful relationship.

Another barrier posed by the MOAUIPP funding was that it was only intended for diabetes prevention education and not for care and treatment. However, as the reader will have noticed, virtually all ADAPT participants had a diagnosis of diabetes and by this fact alone, the ADAPT program provided care and treatment. This limitation posed barriers for staff and facilitators both in developing and delivering programming. There is little diabetes programming of any sort in the DTES yet there is a perceived need for such programming. ADAPT staff were aware of this gap and also the likelihood that many individuals with diabetes living in the DTES were not receiving care or information elsewhere. For them, turning individuals with diabetes away from program activities was not an ethical option.

The limitations that the funding placed on program activities were clearly a source or frustration for program staff as they endeavored to meet the varied needs of their participants while keeping their source of funds intact.
People don’t understand the differentiation between prevention and care. It’s just diabetes. And so that’s what we do. We fill the need, and we felt quite strongly around that what we were doing was the right thing. But Health Canada came back to us, like this year for the funding and was quite clear our mandate has always been just to do primary prevention and they were putting their foot down around that and held our contract over our head until we said we wouldn’t do any more care, what they see as care for diabetes. So obviously we don’t want to end the program so we said okay.

Close to the end of the time that I spent at ADAPT, program funders began to question if some of ADAPT’s activities were not solely aimed at diabetes prevention and consequently not in keeping with the funding criteria. As a result, the approach to staff made efforts to schedule activities that were geared towards individuals without diabetes. This was a difficult transition to make as there were no other programs available to refer individuals to and they were not willing to turn away anyone seeking help or information. Kristen commented on her thoughts about this, “If someone hears from word of mouth and they come to this scary place of a health professional, I’m not going to give them yet another negative experience. That’s not good. That’s just not right. So we will continue to do that [counsel individuals with diabetes].

4.3 Participant Experiences of ADAPT

Two themes emerged from the analysis of participants’ stories: building relationships and building knowledge. I have further subdivided the building relationships theme into three sub themes: presence of a safe environment, presence of a supportive environment and building relationships within ADAPT’s safe and supportive environment.
4.3.1 Building Relationships

In the DTES, building relationships between health program staff and DTES residents is hard work. The neighbourhood is a transient place as both neighbourhood residents and program staff frequently come and go, leaving few opportunities to build long-term relationships. Even though there are many health-related services in the DTES, residents are unlikely to consistently have access to the same practitioners. Many services are walk-in only and practitioner turnover is high due to the stressful neighbourhood environment (Adilman & Kliewer, 2000). To further undermine the relationship-building possibilities in the DTES, there exists a profound lack of trust. Partially, this is due to the high-risk nature of this neighbourhood where poverty, theft and drug use are common. Many DTES residents have also been victims of trust from personal, systemic, and historical abuse.

With these barriers in mind, it is noteworthy that ADAPT participants spoke of the relationships they formed while attending program activities. The relationships that were built were multi-dimensional and varied but mainly centered on the relationships built with the ADAPT staff, facilitators and with other participants. The presence of a safe and supportive environment appeared to be a key factor in facilitating these relationships. Along with the participants’ descriptions about building relationships with others were also glimpses into other types of newly built relationships with themselves and, for some, even with diabetes.
4.3.1.1 Presence of a Safe Environment

Many of the ADAPT participants who I interviewed claimed to have experienced unsafe experiences, such as systemic discrimination or emotional trauma, at some point in their lives. For example, one participant suffered from post-traumatic stress disorder (PTSD) stemming from undisclosed abuses experienced while attending residential school. Another spoke of living with an alcoholic father during his childhood, and consequently, spending his adolescence living in foster homes. Many also spoke of their life experiences without enough money to sustain themselves and their families, living in inadequate housing, or of not having enough food. Being in a safe environment was thus something that appeared to be particularly valued by participants.

Some participants mentioned that the program provided a physically safe environment in a neighbourhood filled with unsafe situations. One person described his perception of the physical safety that ADAPT provided, “It’s a safe place to come away from the drugs, like you get tired of going into these drop-ins where they’re using drugs all the time, right, and having to deal with drug dealers and drug addicts, right?” Also, perhaps by default more than anything else ADAPT was likely considered by some to be a safe environment because of its location. Not because of where it is located, but because of where it is not located. One of metropolitan Vancouver’s main diabetes education programs is located in a hospital in downtown Vancouver. According to one of the people that I interviewed, “Some people refuse to go to [name of hospital] because it looks like a residential school. And I’ve even asked my own grandmother who’s
down here to help translate for an Elder, and I asked her, like without telling her about the stories about like other people not wanting to go to because it looks like a residential school. And I asked her, “What does this building remind you of?” and she told me, “It reminds me of a mission school (residential school).”

In addition to a need for a physically safe environment, participants also referred to a more abstract type of safe environment provided by ADAPT. All of the participants that I interviewed claimed to feel comfortable at ADAPT activities, with ADAPT staff and with other ADAPT participants. This level of comfort and safety appeared to comprise the foremost factors for participants to become comfortable enough at ADAPT to start to build relationships.

The first of two aspects discussed, pertaining to the presence of a safe environment, was that participants claimed to feel safe from stigma or shame while at ADAPT. ADAPT staff made a concerted effort to establish an environment, and to talk about diabetes in ways where there was no shame for having diabetes or for not taking care of their diabetes. One participant, despite being frequently unable to attend program activities because of her PTSD, spoke about finding a safe environment when attending program activities:

> It was a very comfortable feeling to go up there and share that I’d failed miserably and no one is going to beat me up for it. (laughs) I mean look down at me, you know, make fun or anything towards me, you know. At least, you know, it was actually . . . how would you say it? It was like a second home to go to. It is like a second home to go to, to that program. I look forward to going to it, and I enjoy going there.

Some described their experiences at ADAPT in contrast to previous ‘unsafe’, or shaming experiences at other diabetes programs. A participant described his
time spent with another diabetes program, “There was a woman conducting the thing and, you know, these courses and she was kind of rude, you know. She was kind of embarrassing people who couldn’t pay for the meals.” Another person also described her unsafe experience at a different program, “you’re sitting there in the classroom structure area feeling like a student and, you know, and educators there, facilitators, whatever, ask me questions. Who knows what? First I get intimidated. “

Another aspect of a safe environment that participants mentioned was that they did not feeling pressured by ADAPT staff or facilitators to follow a particular diabetes regimen or to learn at a particular pace. One participant described how he refused to use his glucometer to check his blood sugar levels despite experiencing many episodes of hyperglycemia, and yet felt safe to express this to staff without reproach:

Yeah, because so far nobody has – since I expressed myself concerning the poking of my finger nobody has said to me, “Oh, but you should use it.” Nobody has pushed me to do it, and I don’t know them but I don’t think it’s their duty to do so. Because even if the doctor said, nobody’s going to force me to do it. But I feel nice that nobody has disrespected my decision, by even mentioning. I know its right to do it. I know it’s medically the right thing to do at the present time but I am against it.

Another participant described a similar situation in which she felt able to work and learn at her own pace, “Well, I think it [ADAPT] creates a comfortable atmosphere, you know. They don’t push the information down your throat…You know, when you’re ready you can come and get it.”
4.3.1.2 “Having Someone There for You”: Presence of a Supportive Environment

In addition to feeling safe, it was clear that being in a supportive environment was of great importance for participants in order to create a foundation for building relationships. Having “someone there” for them and being “treated with respect” were the supportive elements most often identified. Phrases such as, “you are not just a number” were used when participants referred to how they felt they were treated by ADAPT staff. Participants mentioned that they could count on ADAPT staff to listen and talk with them. One participant described her feelings of talking with a staff member, “She has helped me through a lot of sad parts in my life…from just talking.” Such interactions with health professionals and paraprofessionals were quite foreign amongst participants. It was not uncommon for the participants that I interviewed to describe previous negative or unhelpful experiences with health professionals. In fact, some even expressed fear, “This would’ve never gone deaf if I went earlier to a doctor, right? It, um…I was scared of doctors and um, so that’s why we have these groups so that we can talk to them-like, foot care and eye and ears.”

Some participants’ previous healthcare experiences often included not feeling listened to, not being provided with enough information about their condition, (i.e. only being handed pamphlets), and not feeling able to ask for more information or help to understand their diabetes. For example, one participant had been provided with a glucometer by her doctor but was unsure how to use it and was afraid to ask her doctor for instructions. She carried it in her purse for over a year. She did not ask for help until she started attending
ADAPT programming: “I just found out about four years ago that I was diabetic. And um, two years I denied. And ‘cause people didn’t tell me what to do with my medication. My machine, I kept it in my bag and until I met Corrine. Um... I went down there and she said, “What’s the matter?” ’cause Dr. [name] didn’t tell me what to do.” Another participant mentioned that he waited for a year to be referred to a diabetes education program after his diagnosis.

One aspect that appeared to facilitate the feeling among participants of having someone there for them was the informal, welcoming and accepting atmosphere at ADAPT. There were no classes or situations where participants were required to perform specific activities, and participation was by no means mandatory. Even when a person’s attendance was sporadic or lapsed altogether, staff would continue to welcome them back or to inform them of all upcoming program activities by telephone. Participants’ comments on the atmosphere of the program were often in contrast to other programs that they had attended. “Yeah, it was very impersonal. Whereas here, we know each other down here.” Another participant had a similar comment, “Like up at [name of program] they’re very too professional like, you know, for my liking, eh? Here they’re more personal. You can sit down and talk with anybody, you know, in the program. Like the other participants, even the people running it, you know.”

Also, participants could access ongoing support from staff via an open door policy. Whenever staff were in the ADAPT office, they were available to participants. As mentioned, participants were welcome to stop by for some assistance or just for a cup of tea. This was especially important in the DTES
where people’s daily lives are often unstructured and the need for help or advice could arise at unexpected times. Staff also availed themselves to participants by telephone.

The following excerpt illustrates that the flexibility of the staff to provide support on the participant’s schedule (rather than the staff or program’s schedule) allowed her to get support when needed:

You know, and the support you get from the staff, this was oh, awesome. Like you know if I was having trouble with my sugar then Corrine or Kirsten would, you know, guide me. If I was going through a stressful time too, then I’d phone them. I’d phone Corrine and she would meet with me privately at a certain time. And there was times I couldn’t [attend program activities] because of the issues I was facing at the time about the residential schools. Perhaps I just couldn’t come over and I’d have to speak to Corrine.

Participants also described feeling that that staff genuinely cared about them and their well-being. One person described his thoughts:

But here, when you hear somebody asking you, “How are you? Is everything okay? You know, “how was your week?” or you know, “What are you planning to do this summer?” Questions like that, like some people would say, “Well, this is an irrelevant question, you know, that it doesn’t really concern you,” but when you see how the question is asked, that it’s asked with meaning, you see, then you feel okay about it.

For some, especially those with few friends or social supports, the sense of caring and support from others may have been an uncommon occurrence in their lives. For example, for one fellow, who was used to being the self-described “loner” and “bad guy”, it was life altering:

Well, they I think probably showed you more than just wanting me to be there and they showed me that these people, they could be friends to me, right? If I had something to ask they were always happy to answer and they were always willing to share with me, so
that showed me that if they could do that, then I could do it myself as well. They made it easy for me to really open up to people, right? See that was one thing I learned, like in my way to this point here, that was one of the things that happened to me was my change in attitude towards people. I never liked people before. I didn’t need friends before, but when I started coming here I was able to look back on my life and see a lot of things that really didn’t look or sound too good. Something happened in the way that I started having a big change, and that’s probably because the attitude towards people and wanting to do things with people and stuff like that, and by coming to these diabetes community kitchens. The diabetes workshop really opened up a whole new world for me, and they showed me that throughout their programs.

4.3.1.3 Building Relationships in ADAPT’s Safe and Supportive Environment.

It was difficult to clearly delineate between the sub-themes presence of a safe environment and presence of a supportive environment. A supportive environment should by nature be a safe environment and vice versa. However, I felt there were some subtle differences in how the participants described their various experiences with ADAPT. Using these two descriptors allowed me to highlight these subtle differences rather than to define them. The section concludes with a more specific focus on how participants’ experienced building relationships within a safe and supportive environment.

ADAPT program activities facilitated building relationships with others by allowing each person space to share something about themselves. As mentioned, each ADAPT activity would involve a sharing circle which was facilitated by Corinne. The sharing circle involved participants, staff, facilitators, and guests sitting in a circle (or around a table) sharing whatever was on their minds – worries, questions or perhaps a recap of their recent activities. Corinne would always start the circle by sharing a personal story, such as her own
personal struggles for health and wellness. The circle was clearly established as a safe space where no one would feel obligated to share more than was comfortable. One participant described her feelings about the sharing circle and how it was pivotal in her continued involvement with ADAPT:

As soon as I went to the one at Corrine’s diabetic group area, it was in a circle, you know, like a sharing circle. It felt so good! Everyone had a chance to talk without getting interrupted or without being criticized …So like, you know, it felt more like being at home with that sharing circle, and also, you know, the praying. Like if she spoke in her language that is great, and I thought, "Wow! This is great. This is where I’m going to come," and I’ve been going to that program whenever I find the chance.

A participant explained how he felt safe and supported when participating in the sharing circle and how his experiences of sharing helped him to be comfortable enough to begin to open up to others, “But by coming to ADAPT and doing things that they do, you know, telling your story or whatever, this helped me to be open and to be honest with people.” Another person mentioned her feelings about how the sharing circle created an environment of trust within ADAPT programming, “But yeah, to me anyone that comes into that circle is family. That’s the way it is there in the circle.”

Lastly, participants claimed that the sharing circle was an opportunity to build relationships with others with similar circumstances. It appeared that this activity was a safe space where participants felt at ease in sharing their difficulties, successes, and advice with each other:

I found it very helpful that way. I was able to share, you know, about my [blood] sugars and someone after a while, you know, would suggest a few ideas, and that is great. And the other people would, you know, have been also and share their own ideas and it’s just like that whole family came together and was solving the
problem, yeah. And then that was – that’s wonderful, you know, to be in that type of environment.

One participant commented on the support that he felt from the other participants when he shared some of his experiences with diabetes, “I think it gives people a chance to get together, talk, and make new friends. Because what I did, I used to take the attitude, you know, back off, stay away. So now when I come to these things it’s easy for me to talk to people.” Another participant described how the sharing circle helped her with a problem she was experiencing, “A lot of things comes out, you know. And they said, “Oh yeah! I had the same problem and you know what I did? I did this thing and it solved the problem.”

4.3.2 Building Knowledge

The theme of building knowledge appeared in a few different ways throughout the participants’ interviews. The most common was the participants’ descriptions of their increased knowledge about diabetes including increased knowledge of healthy eating, healthy lifestyles, physical activity, self-care and medications. All participants that I interviewed were able to describe specific information about what they learned from attending ADAPT activities and how they used what they learned in their daily lives. For example, one person described the virtual overhaul that he made to his eating practices:

I ate a lot of really sweet stuff. I liked pastries and sweet stuff. I drank a lot of pop, right, and stuff like that. I ate a lot of really greasy foods because I liked the taste of grease, right? I liked bacon but there’s really a lot of grease in that. I bought a lot of burger meat, hamburger, and I would buy usually the cheap stuff, eh, so I could buy more, right, and usually it had a lot of grease in it,
right, and the more greasy it was the better I liked it. I used to eat a lot of bread, white bread, and use a lot of butter, margarine, you know. I used to eat stuff like wiener, bologna, a lot of red meats, right, stuff like that. But now I eat a lot of vegetables now. See when I make my salads I usually like to have five things in it. Tomatoes, cucumbers, onions, lettuce and maybe some peppers in it.

Other participants perhaps didn’t make as many comprehensive changes but described some specific things that they learned or changed:

Well, I think by coming to the kitchens they’ve done a lot for me because when I first started coming to these things I couldn’t figure out why they were just buying stuff like say vegetables and stuff like that, right, and why they only had – like if they were making stuff like bannock and stuff like that, right, that they would buy brown flour, brown flour rather than white flour, and I was told that it’s healthier to eat stuff like brown flour than it is white flour. Because see if you eat things with just white flour there’s not that many good things about that. It’s like chewing on a piece of paper.

Some participants reflected on some of their new ways of eating in terms of what they have given up, “But I’m more conscious now at this point in time of what I eat. I used to eat a lot of candy, drink a lot of pop and stuff like that but now it’s something like watered down juices and milk. I cut back on my coffee and teas, sugars, and the whiteners in the coffee, stuff like that I don’t use that anymore.” Surprisingly, these reflections were not framed by a sense of deprivation or of loss one could expect when discussing dietary changes. This leads me to believe that such changes were made when ready.

Along with increased knowledge about diabetes-friendly lifestyle changes, many participants also described an increased sense of control of their diabetes because they better understood the disease and its management. Such descriptions were framed with comments such as “I know what to do” or, “I know
the kind of medications I’m taking now and what are they for.” Participants also
talked about how they made their decisions for self-care based on what they
learned about long-term health effects of diabetes. For example:

I’m more self-aware of the consequences. If I don’t take my
medication, if I don’t eat the things that are not harmful for my
diabetes such as an excess of carbohydrates or trans fats, you see.
And now that I’m more self-aware of these things, than that level of
risk I think is no longer there” and, “they explained to me the harm
that it can do to the muscles in the body and your eyes and that,
with [blood sugar] being out of control. And that, it’s not something
that you can take lightly. I wasn’t taking it lightly before but I wasn’t
taking it as seriously as I should.

There were more abstract increases in knowledge that were mentioned by
participants such as learning new skills, encountering new experiences, and
gaining abilities to navigate life situations. For one example, one participant
discussed his interest in sharing what he learned about living with diabetes to
help other people live with diabetes. “I would like to be an inspiration for other
diabetics, you know, just to go out and do something like that. I would like to be
the spark plug I guess. So yeah, I would like to be the role model, yeah.” This
participant did act on his desire to share with others by narrating his story about
his experiences with diabetes to a local newspaper. Another participant
described her newfound ability to advocate for herself as a diabetic,

When everyone sees me coming out of the clinic they say, “Boy,
she lost a lot of weight. OOOhhh, she’s got AIDS and she’s got this
disease. Finally I got fed up. Got so fed up I yelled. I said, “I got
diabetic and I’m proud.” My old man was coming up the street and
he says, “I heard you way off.” “What did you hear?” He says,
“You’re diabetic and you’re proud.”

Lastly, there were a few participants that commented that they were
motivated to learn more about their own history as Aboriginal people due to their
time spent at ADAPT. One participant described his journey to explore his own history, “When I was growing up I grew up White basically. I was doing everything White, but in the past close to three years now I’ve learned a lot about Native people because of the Native person who is a part of the program, right?”

The participants who appeared more apt to make such comments were those who had little previous exposure to stories of their own traditions. Some, like the participant who made the following comment, were unaware that they had Aboriginal ancestry until they were adults, “I used to cheer for the cavalry in the movies (laughter). And then after I got older I realized, “Hey, I’m cheering for the wrong side here (laughter).”

4.4 Staff, Facilitator and Stakeholder Experiences of ADAPT

Similar to the organization of the themes in section two, this section is also composed of two main themes – Building Relationships with Participants and Facilitating Change.

4.4.1 Building Relationships with Participants

This theme explores the multifaceted ways that relationships were built with participants. To best describe some of the various ways that relationships were built, I have subdivided this theme into three sub themes: Earning Trust of Participants, Meeting People Where They are At and Reducing Power Dynamics.

---

7 Since this interview, I have learned that this participant has applied for, and received his Indian Status card (with help from ADAPT staff). His family lost Indian Status when his father became disenfranchised during the participant’s childhood. I have recently been informed that he has also moved back to his home community in an effort to connect to his roots and to become closer to his estranged family.
4.4.1.1 Earning Trust of Participants

ADAPT staff and facilitators all spent a good deal of time describing their approaches to working with program participants. It was clear that one of the main goals was that ADAPT be perceived by participants as a safe, trustworthy and welcoming place to be. Corrine described the importance of creating a safe space by working towards earning the trust of participants, “And to do what could be beneficial was first, you know, earning the trust, earning the trust with individuals.”

Additionally, Corrine was able to bring her own life experiences to her work in such a way that allowed her to not only understand many of the program participant’s life experiences but which also facilitated a level of trust between herself and participants. “So to complement the program, I suppose the experience and the knowledge that I have gained right from when I was very young. I too, you know, had the experience like so many, the big one, of the residential school. I’m a survivor too. I went to two residential schools. I know exactly what it did to me.”

One part of this process was the open-door policy implemented by ADAPT staff. Participants were welcome to drop by the program offices whenever staff were on the premises to talk, to ask questions (diabetes-related or not), or just to chat. These were the times that many of the more heartfelt conversations occurred and where the foundations for relationships were built. Corrine felt that these interactions were important for listening and learning where participants were at in their lives. She described the value of the open-
door policy: “I think the part that they value is that they’re being heard. You know, they’re being heard. They’re respected, and they have a place where terminology, for example, is easily transmitted, you know, if it’s through pictures or doing the one-to-one, you know, they enjoy that. It’s open door, you know. ‘Come whenever you’re around the neighbourhood or call anytime, you know. Come have tea. There’s coffee, water, you know.’

The open door policy created an atmosphere where the program ceased to be solely a health education program staffed by health professionals and became a space where individuals meet and share. For participants, staff and facilitators the basis for building relationships appeared to start here. A facilitator nicely captured the essence of the open door policy: “They are open to delivering information in a different way and not in a biomedical way where, ‘I am the teacher and you learn and I talk and you listen.’ They have actually been open to discussing issues and meeting with people one-on-one and being able to just be there for people to walk in on them.”

Another way that ADAPT was able to earn the trust of participants was that the program is located within the DTES, meaning that ADAPT staff and facilitators are located in the participant’s environment, not vice versa. As such, they can interact with participants in situations other than at ADAPT activities. Staff would regularly run into participants on the street or while visiting other service agencies. This appeared to contribute to a greater level of familiarity and comfort between staff and participants. For
example, staff would be able to get a sense of how participants were
faring and to provide needed support much earlier than if the program was
located elsewhere where chance encounters were unlikely. “The other
thing that I think that we are very fortunate here as, you know, as medical
professionals and also the participants, because we see them every week,
you know. And we see them every week and because, you know, I was
just telling the St. Paul’s Hospital nurses that came to visit us. I says, “You
do a great job.” But the only problem is – well, you know, the guy, the
minute he leaves your room, you have no way to see how he is doing
except for six months later.”

Because of the program location and program design (i.e. open door
policy) ADAPT staff and facilitators were able to better understand
participants’ day-to-day struggles. As a result, staff and facilitators were
aware that diabetes education would not necessarily be always a first
priority on the participant’s agenda. They were consequently prepared to
offer support when participants dropped by to chat about topics that did
not involve diabetes. To Corrine and Kristen, however, these
conversations were still a chance to help participants with their diabetes
because building trust involved supporting participants on multiple levels
and in multiple ways. Kristen commented on how she approached care
within the context of participant’s everyday lives:

Okay, we do understand. You don’t have food. We do understand
this so let’s work on those issues before we start talking about
diabetes.’ Whereas if someone comes to a place and the person
says, ‘Oh, well I can’t help you with housing. I can’t help you with all
these other stuff. I’m here to talk to you about how to prevent diabetes or how to manage your diabetes. I can’t help you with those other things,’ then that relationship has stopped and it’s not going to go anywhere and that person’s not going to come back.

4.4.1.2 ‘Meeting People Where They Are At’: Creating a Supportive Environment

Staff and facilitators were aware that it was important to meet each person “where they were at” and to “work gently.” Not everyone would be ready to talk about their diabetes, to hear the same messages or to learn the same things. As such, staff and facilitators described that it was important to begin from a safe place and to progress slowly. Corrine described her approach when working with participants, “everyone’s coming to the table with such different needs and a different awareness of what’s going on, and we try to keep this say, sort of like as open and accepting as possible.” Kristen reflected on how this approach appeared to work for some participants:

A lot of people in this neighbourhood through mental health issues and whatnot can’t do groups very well, but we have clients who typically don’t do well in groups are working well in our group. They say that it’s created a safe place. It’s more like a family than a group, and we’re all so gentle that it works for them. I’m thinking of like two clients, three clients actually. Yeah, three clients who have mental health concerns that really weren’t often able to participate in groups. One is anger. They just whoosh, anger, and so she’s been kicked out of a lot of places and people won’t have her in groups and things like that. And we’ve never experienced any problems from her.

Interestingly, a staff member and a facilitator similarly described their experience of meeting the same participant ‘where he was at.’ This participant
had been attending program activities for quite some time and was consistently resistant to taking steps to care for himself or for his diabetes. Despite this, staff and facilitators did not push him to make changes that he was not ready to make:

He was one of the most difficult people I think I’d ever encountered in this program. But to see where he’s come along and that ADAPT has actually worked with him and actually been able to influence change in a positive way and not go, “Okay, well you’re not going to listen to us so we’re not going to help you.” It’s more like, “Okay, we’ll work on this next time, you know, we’ll talk more about this next time.” You know, working and having him progress over time. Because that’s how people are. They change that way. I mean even us, we try to change our habits. It’s not going to happen overnight.

And:

And he spoke about, ‘If broccoli tasted like lemon pie, I’ll eat broccoli.’ And just a few weeks ago, he had a whole bunch of vegetables and I think it was a little bit of a shock. We tried not to stare. Kind of, what’s in the dish that has made him, you know, eat vegetables? Well, how did we cook it? It must have been blessed in a good way. And for the very first time, I would say two and a half years, to see somebody that wouldn’t eat, you know, vegetables. It’s so significant, this one gentleman

I remember the day that this person ate vegetables after consistently refusing to eat them at the community kitchens. The featured meal that day was a beef stir-fry. He dished himself a plate of rice, meat, and vegetables and sat down to eat. We were all so surprised and could not help but stare. We began to cheer him on and I believe every one of us began to laugh. It was a memorable day.
4.4.1.3 Reducing Power Dynamics

Another way that staff and facilitators participated in the building relationships was that they attempted to reduce the power dynamics between themselves and the participants. Instead of being the authorities leading ADAPT – they opted to be its gracious hosts. Due to previous negative experience with authority, many participants described their resistance to seeking help for their diabetes or to acting on recommendations from health care providers. Staff and facilitators acknowledged this, “People, like a lot of people don’t want to go to health units or go to their doctor all the time. Just because, I think sometimes they feel disregarded. They feel disregarded by the information. Doctors rush. They’ve all got better things to do.”

Tragically, for one participant, her hesitation to seek help from a health care provider was due to the physical abuse that she had experienced at residential school. A program facilitator described the conversation she had with this participant about her hesitancy to see a visiting podiatrist:

I was sitting beside her at that sharing circle, and so after the circle was finished she said, 'You know, I'm really nervous about having a podiatrist in,' and she started to talk about why she was nervous and what had happened with her, and it had gone back to the residential schools and there was something about that they would either whip their feet if they didn’t either stay in bed or there was some – the punishment was that their feet were whipped, and so now she’s had diabetes for quite a while and she knows that a complication of diabetes is neuropathy and she knows she needs to be checking her feet and having that looked at but this, the childhood memory of that just had inlaid a fear in her.

This story speaks to the reasons as to why the staff and facilitators avoided a traditional approach to diabetes education programming and instead
aimed to support participants with as little air of authority as possible. “There’s not some agenda that we’re trying to push through. I think just trying to remove the barriers of like an ‘us versus them’ environment, of like, “We are the health care workers and we know so much,” and really trying to let people be their own – recognize like their own power.” This part of the program delivery was clearly taken seriously by staff and facilitators as it was discussed at length by each interviewee. They felt that it was key to approach each participant with respect, “You’re giving to individuals you value their time, you know, and they value ours. I think it’s the mutual respect. It’s how people feel if you’re treating them well. You’re honest. You’re with a good heart.”

Another part of reducing the power dynamics was encouraging the program to be as participant-led as possible. Similar to the open door policy, staff and facilitators did not dictate what was offered by, or discussed at the program. Participants were routinely asked for programming ideas and staff tried to implement most of the suggestions. For example, staff offered a grocery store tour, bowling trips, and trips to a local Park from participant requests. The community kitchens were also mainly participant driven:

You know, those very practical pieces of managing their diabetes are getting there and are being said and noted and they are being communicated. It’s just that it’s that’s not the focus, I guess is what I was saying. It’s not that that – it’s not the focus and it’s not – yeah, it’s not like it’s enforced, you know, like we don’t HAVE to talk about diabetes at the Kitchen, you know. We talk about whatever’s going on for someone or for people, you know, and if it happens to be about their diabetes then it’ll be about their diabetes but if it happens to be about whatever else is going on then that’s of equal value.
Lastly, the sharing circle was also a way for participants, staff and facilitators to alter the power dynamics in the program. Because everyone shares something in the circle – their feelings, worries, what is on their minds – staff mentioned that they felt able to reduce their air of authority as they also shared about themselves:

It creates an equal playing field where everybody is honored and respected by giving them the floor, the opportunity to speak for as long as they need. Or if they choose not to, that's fine too, but it gets rid of the hierarchy of Corrine or I teaching, or knowing everything and talking and them supposed to be learning. We all learn from each other there. We all, Corrine and I, the way we conduct ourselves, we talk about the struggles we have in our own lives. It's not just the participants talking about that, and we're all perfect and have it all together as the professionals. We meet on a level of we're all people.

The sharing circle was also a way for everyone to have a say in what happened at ADAPT because it gave everyone a chance to speak and to be listened to. “Allowing people to say what's in their mind, hearing that. Letting that come with greatest respect. And when we have our circles, you know, we say, “What is said around the circle stays in the circle. It doesn't go anywhere.” It's the honour and the respect.”

4.4.2 Facilitating Change

The theme of facilitating change encompasses the ways staff and facilitators described the changes that they saw in participants. The changes that they described ranged from increased knowledge and management of diabetes to more abstract changes, such as enhanced self-efficacy. Demonstrable changes such as increased knowledge, of course, were much
easier to see than the more abstract changes. However, because of the relationships built between participants, staff and facilitators, there was more of a platform for interaction, and thus greater opportunity to observe subtle changes. Interestingly, these were the types of changes that staff and facilitators spoke most about in their interviews. My sense was that perhaps this was because they found these changes to be more profound and indicative of changes that could move participants to a place where they would be more able to care for themselves and their diabetes. These subtle changes also translated into some participants taking steps to become more proactive in their communities:

And then also knowing that from participating in the group that a couple participants have gained, you know, like self-respect and self-confidence and, you know, just having an environment where knowing that people care about you and then taking that. They’ve gone out and volunteered with different programs or have gotten different work or, you know, written poems or written stories for different magazines or different publications, been involved with different celebrations. Just things that they hadn’t done before or were probably familiar with, but actually sort of took that extra step to go and get involved.

Kristen discussed how she found participants to become more open about their diabetes and to begin to advocate for themselves:

So we have group members talk about how they’re sharing it with their families, standing up for themselves, where they go in their days, you know, saying, “I have diabetes. I have to have a snack,” or whatever, where people normally wouldn’t. There’s a lot of silence and a lot of shame around diabetes in the Aboriginal population and so they’re helping to break that.
Kristen also noticed that as participants began to share information about their struggles or successes, it provided an avenue to help each other learn about diabetes. The sharing circle was one example of how information exchange and peer-to-peer learning occurred:

The use of the sharing circle for sure really allows for peer teaching and people talking of their own experiences. And how we’ve seen that play out is that in the sharing circle someone will bring something up and they all know that whoever’s talking is the only person talking and then they go around the circle. But then afterwards when they’re eating, they'll be like, “Oh, you were talking about this and, you know, like I had a really bad experience,” or whatever the experience was, they reflected on it with their own experience and like, “You know, you should go to this person at this organization because they helped me with something,” or, “You know, I found a really good deal on this food,” or just whatever it was. Then they have the resources within the group, you know, and they share that openly.

Role modeling on the part of participants and on the part of staff or facilitators also became an avenue for facilitating change. One participant moved from keeping her glucometer in her purse for a year because she did not know how to use it, to acting as a role model for others by showing them how to test their own blood sugars. Participants also claimed to learn from watching staff and facilitators:

One gentleman had said to me, he commented to me that he watched how I would dish up my plate when we were eating and how I would always have half of my plate sort of be the greens or the salad or whatever vegetable we were having, and then a smaller bit be sort of a quarter to a third or whatever just be the casserole or whatever it was. And he thought that that was a good way to eat, you know, that that would be the right way to eat.
4.5 Chapter Summary

This chapter illustrates the stories of how participants, staff, facilitators and stakeholders experienced the ADAPT program. All parties discussed the importance of building relationships as a way in which to facilitate program participation, to enhance trust and to learn about diabetes. The impetus for relationship building stemmed from the presence of a safe and supportive environment where trust was key. From this place, participants were able to move towards learning about diabetes in a way that was appropriate for their needs and abilities.
Chapter 5: Implications and Recommendations

In the first section of this chapter, I will look to the perceptions of the participants, staff, facilitators and stakeholders as well as to the literature reviewed in Chapter 2 to discuss and thread together a bigger picture understanding of how Aboriginal-focused diabetes programming can be informed by the lessons learned from ADAPT. I will then conclude with a summary of my findings and ideas for future study in this area.

5.1 Lessons Learned: Implications for Aboriginal-focused Diabetes programming

The main emphasis of this thesis has been that, for Aboriginal people, diabetes is intertwined with many larger forces associated with colonialism. These larger forces, such as marginalization, history, and poverty, not only influence Aboriginal people’s risk of being diagnosed with diabetes, but they also affect how the disease is perceived, as well as how care is sought and received. Thus, diabetes exists in the political realm as well as in an individual realm and needs to be addressed as such. Although referring to the field of psychology, I believe that Duran and Duran's words ring true for any program or intervention aimed at Aboriginal people, “Successful clinical interventions are not possible in a Native American setting unless the provider or agency is cognizant of the socio-historical factors that have had a devastating effect on the Native American family system” (Duran & Duran, 2000 p. 97).

Despite such dialogue, Travers (1997) notes that nutrition education (I will expand this to include diabetes education), has historically emphasized
individualistic behavior change and “negates the role of social context in shaping behavior, and thus implies a separation of people and their environment” (p. 58). Aboriginal-focused diabetes education programs are no different and largely seek to educate participants about making lifestyle changes, such as physical activity, healthy eating, and weight loss. Bartlett et al (2007), like Travers, continues this argument by calling for programming that can, “take into account broader aspects of the lives of Aboriginal people’s living with diabetes” (p. 2380).

Further, according to Sunday and Eyles (2001), healthy lifestyle practices are more or less attainable depending on the subject’s position in society. Thus, focusing primarily on lifestyle modification is meaningless if participants are not able to navigate the larger social or political constraints on their lives. Such approaches can instead be viewed as paternalistic. Not only do they not have the capacity to adequately contextualize colonialism’s influences on Aboriginal people’s lives, but also their inherent attempts to control and predict behaviour may not be welcomed from a population who has already been deeply controlled by repressive policies, practices, and discourses (Tuhiwai Smith, 1999).

It is clear that there is a need for practitioners, program designers and policy makers to understand, and respond to, the multiple forces that influence Aboriginal people’s lives. ADAPT staff and facilitators responded to these socio-political forces through a number of ways, such as by a non-goal oriented and participant-oriented approach. Part of this was that staff and facilitators recognized the very real effects of colonialism and its social, economic and political effects on the participant’s lives. As per the Medicine Wheel approach,
program staff and facilitators worked with each participant as a whole person, not just as someone with diabetes. Participants were welcomed and accepted regardless of how they looked or dressed, how they managed their diabetes or how often they showed up – ADAPT was not a place of judgment. This appeared to facilitate the development of trust both among participants and between participants and staff/facilitators, which then led to the formation of relationships and eventually to the acquisition of knowledge and change. Also, participants were encouraged to find out what they wanted to take from the program instead of following a predetermined curriculum. As a result, participants learned about diabetes according to their personal needs and ‘where they were at’ in their lives. This approach appeared to resonate with the participants as many told stories of feeling relived or pleased that they were not asked to adhere to particular regimes or taught about diabetes in a classroom setting. Instead, each person’s process and autonomy was respected by being given the freedom to participate with the program on their own terms. This was one of the central parts of ADAPT that I believe kept participants returning to the program.

5.1.1 Incorporating Cultural Safety into Diabetes Education

I would also argue that it is essential that cultural safety is incorporated into any Aboriginal-focused health program. With the increasing attention to health disparities affecting Aboriginal people there is increasing pressure on the health system to develop and provide culturally appropriate programs, such as
diabetes education. However, Browne and Varcoe (2006) provide a critical response to this by arguing that attempts to create culturally appropriate programming “can sometimes mask the racialized assumptions embedded in such discourses” (pg. 160) and instead contribute to a culturally unsafe situation. Assumptions and stereotypes held by health care providers about Aboriginal culture (and consequently Aboriginal people’s health needs) can further marginalize people. By reducing culture to a set of assumptions implies that it is a set of static, identifiable characteristics that are inherent to all Aboriginal people. Rather, culture is a changing, relational process that, “is lived within and among groups and people and therefore as deeply enmeshed in power relations and in economic, political and historical contexts” (Browne, 2005 p. 66). Although such situations may occur inadvertently by well-intentioned individuals, they nonetheless can create culturally unsafe situations and can result in the recipient feeling ‘othered’, unwelcome and less likely to participate in seeking care (Browne, 2005).

Culturally safe health care, on the other hand, does not attempt to make such assumptions and instead recognizes the changing, power-laden, and relational processes that surround notions of culture (Brascoupe & Waters, 2009; Browne, 2005). The findings of this study suggest that ADAPT provided a culturally safe program. Participants vocalized that the programming approach as well as the staff and facilitators were aware of the contexts of their lives and of Aboriginal people’s history of colonization. Further, there were no overt attempts to incorporate aspects of Aboriginal culture into ADAPT. Although the program
included some common notions of Aboriginal cultural practices such as the sharing circle and the Medicine Wheel, the program was not defined by any particular cultural approach or activity. I would argue that this in itself is a significant contributor to ADAPT being a culturally safe program as participants were not asked to take part in cultural activities that they may or may not identify with. Moreover, as already mentioned, participants felt welcome to attend the program as who they were rather than who they thought they should be. By this I mean that participant and staff or facilitator interactions were not power-laden and as voiced in other studies, participants were not concerned about how they would be perceived based on their social location.

5.1.2 Evaluating Success

Evaluating a program like ADAPT is inherently difficult. There is little in the way of specific curricula and many of the participants' reported outcomes are abstract rather than concrete. Moreover, the attitudes and backgrounds of staff and facilitators are key elements in the delivery of the program. For example, Corrine's involvement was likely very instrumental in how ADAPT was perceived by participants. Not only was she a survivor of residential school (and thus able to understand its emotional effects), but she also embodied the very essence of holistic health through her daily life.

Therefore, how does one evaluate success in such a program and how does one determine indicators for success? At ADAPT, I would claim that it would have been unreasonable and culturally unsafe for staff or facilitators to
have asked participants to have their hemoglobin A1c (a three month average of blood glucose levels), cholesterol levels or other conventional diabetes measurements tested every year. Similarly, expecting increases in physical activity, intake of fruits and vegetables, or glycemic control would be equally unreasonable given the life context of many of the participants. However, ADAPT participants did discuss their process of moving up the continuum of diabetes knowledge and management, whether it was via food choices and blood sugar monitoring, by dropping by the ADAPT office for a cup of tea and a chat, or just by attending a community kitchen to share about themselves. These changes are all arguably indicators of success, just applied in a unique way.

5.1.3 Limitations of this Study

At the time that I participated in this project, ADAPT was involved with other activities in the community that I did not capture in this thesis. For example, ADAPT hosted workshops about diabetes or about healthy eating for other DTES service agencies. They also did some activities with the local Aboriginal Head Start daycare. The UBC Garden Project was just in its beginning stages and has since become an independent program at VNHS. These activities and projects were no less important and would have been an appropriate addition to this project. However, due to time limitations I was unable to interview individuals involved.

Also, this project took place in a unique neighbourhood in Canada. People find their way to the DTES from all over the country for various reasons
but many are disenfranchised, struggling with alcohol or drugs, or are struggling with other life situations. As such, the findings are not applicable to all urban Aboriginal people. Yet Aboriginal people’s history of colonization of is a shared one. Thus, many of its consequences are also shared.

5.1.4 Implications for Practice and Suggestions for Future Study

The findings from this study can help to inform clinical practice in a variety of areas. As my practice area is in dietetics, I will speak to the implications for practice with regards to the areas of dietetic practice and education. As with any health profession, education is a primary avenue to shaping the attitudes and norms of practitioners. As such, this is a prime area to engage future practitioners in learning about critical reflexivity, cultural safety and the interplay between social context and health. Discussions of these issues have occurred mainly in relation to nursing education and center on engaging nurses in dialogue, reflection and actively questioning popular notions of culture, to better understand assumptions of dominant society and to reflect on the discourses that influence practice (Browne & Varcoe, 2006; Browne, 2005).

There are fewer discussions of this nature in the field of dietetic education. Yet with the variety of roles for dietitians in public health settings, there is a need to have a workforce that is able to competently navigate discourses surrounding notions of culture and health. Ways to address this could include similar strategies employed by nurse educators in classroom and clinical settings. Future options could be the incorporation of cultural safety competencies into
professional regulation and continuing education portfolios as has been done in
New Zealand (New Zealand Ministry of Health, 2008).

As a preceptor with the Yukon First Nations Dietetic Internship Program (a post-graduate program), I am poised in a unique position to encourage dietetic interns to practice reflexive learning as well as to engage them in incorporating cultural safety into their practice. I see students arrive to our program with little to no knowledge of Aboriginal people’s history and usually with only a vague understanding of the meaning of ‘socio-cultural context of health.’ There are ample opportunities for me to not only role model culturally safe practice for dietetic interns but to also facilitate the development of critical consciousness among my dietitian colleagues and fellow preceptors.

5.2 Conclusions

The purpose of this project was to explore participant, staff, facilitator and stakeholder experiences of an inner-city Aboriginal Diabetes Awareness, Prevention and Teaching program (ADAPT). Interviews with participants indicated that ADAPT was a place that facilitated the acquisition of diabetes knowledge via the presence of a safe and supportive environment. Staff and facilitators endeavored to assist participants to learn about diabetes via building relationships. This took place by earning participant’s trust, by creating a supportive environment, and by reducing the power dynamics between participants, staff and facilitators.
Within a broader context, this study helps to illustrate aspects of the complex effects of colonization on Aboriginal people’s health. It also speaks to the need for culturally safe health care via practitioners and program design. ADAPT was seen by program participants as a place to seek support and information. This is notable in itself as many participants discussed their experiences of ADAPT within a context of general mistrust of health care institutions and practitioners. ADAPT staff and facilitators were responsive to the needs of participants by creating a culturally safe place. Staff and facilitators were aware of the socio-political influences of colonization on their lives and recognized their roles as gentle and respectful facilitators of change.
References


Appendices

Appendix A: Recruitment poster

What would be involved in recording ADAPT’s story:

• You would be asked questions (by Jennifer) about diabetes, your thoughts about ADAPT, and about yourself.

• Anything that you say will be kept confidential. Your name (or anyone else’s names) will not be used. No-one from the group will know what you say.

• The questions will take about 1-1 ½ hours. Jennifer will meet you when & where it is convenient for you. Bus tickets will be available if you need them.

• Before Jennifer asks you any questions, she will ask you to sign a consent form. This will show that you have given her permission to ask you questions.

• These questions will be part of a report that Jennifer is going to write about ADAPT.

• Afterwards, ADAPT will have a big dinner for everyone who participates!

• You do not have to take part!

• If you decide to take part and then change your mind, that’s okay, too!
Appendix B: Interview Consent Form

THE UNIVERSITY OF BRITISH COLUMBIA

Food, Nutrition and Health
Faculty of Agricultural Sciences
2205 East Mall
Vancouver, B.C. Canada V6T 1Z4
Phone: (604) 822-2502
Fax: (604) 822-5143

A Qualitative Evaluation of an Aboriginal Diabetes Awareness, Prevention, and Teaching Program (ADAPT)

Consent Form

Principal Investigator:
Ryna Levy Milne, PhD, RD. Assistant Professor of Nutrition, Dept. of Food, Nutrition and Health, Tel: (604) 822-6869 or 822-2502, Fax: (604) 822-5143, E-mail: rlmilne@interchange.ubc.ca.

Co-Investigators:
Kristen Yarker, BASc, MSc, RD. Nutritionist, Vancouver Native Health Society. Tel: 604-254-9949, Fax: 604-254-9948. E-mail: adapt_diabetes@hotmail.com

Gwen E. Chapman, PhD, RD. Associate Professor of Nutrition, Dept.of Food, Nutrition and Health, Tel: (604) 822-6874, Fax: (604) 822-5143, Email: gec@interchange.ubc.ca.

Annette Browne, PhD, RN. Assistant Professor of Nursing, Dept. of Nursing. Tel: (604) 822-7558, Fax: (604) 822-7466, E-mail: browne@nursing.ubc.ca

Jennifer Eskes, MSc. student, Dept. of Food, Nutrition and Health, Tel: (604) 822-2502, E-mail: jdeskes@interchange.ubc.ca

(Part or all of this research may be included as part of a graduate thesis).

Purpose:
This research will evaluate a Aboriginal Diabetes Awareness, Prevention, and Teaching Program (ADAPT) to see if it is effective in improving the knowledge, beliefs, and attitudes toward healthy eating and healthy lifestyles, and about the prevention and/or management of type 2 diabetes. You have been asked to participate in this study because you or one of your family members are or have been a participant in the ADAPT program, or because you are otherwise affiliated with the ADAPT program.
Study Procedures:
You will be asked to be interviewed up to two times by a research assistant about your own and/or your family’s experiences with the ADAPT program, your feelings about the ADAPT program, and about your and/or your family’s experiences with type 2 diabetes. Each interview will take between 1-1.5 hours and will be tape-recorded. The interviews will be transcribed at a later date.

Confidentiality:
Your identity in this research study will remain confidential. Names or other features that may identify you will be removed from all transcripts. You will not be identified by name or by any other identifying features in any transcripts, summaries or reports created about this study. All audiotapes and printed documents will be kept will be kept in a locked filing cabinet and documents will be identified by only a code number. Any computer files containing information on this study will be kept in password protected computers that will only be accessed by members of the research team. In addition, your participation in this study or anything that you say during the interviews will not be discussed at any ADAPT activities or with other ADAPT participants.

Contact for concerns about the rights of research participants:
If you have any questions about your rights or treatment as a research participant, you are free to contact UBC Office of Research Services Research subject line at (604) 822-8598. You are also free to contact the research assistant, Jennifer Eskes at (604) 822-2502.

Consent:
Your participation in this study is purely voluntary and you are free to withdraw at any time or to refuse to answer any questions without jeopardizing your participation in the ADAPT program. You can also request that any portion of the transcripts that contain your statements be deleted at any time and without any explanation. By signing this form, you are indicating that you consent to participate in this study and that you have received a copy of this form for your own records.

Participant’s Signature: __________________________

Date: __________________________

Participant’s name: __________________________
Appendix C: Interview guides

Stakeholder Interview Guide

1. What are your opinions on ADAPT?
   *Possible probes:*
   a. Do you feel that this program has been successful in educating participants on diabetes, healthy eating, and healthy lifestyles?
   b. Is there anything that you think should be added to the program?
   c. Is there anything that you think should be eliminated?
   d. Do you think that there are any aspects of ADAPT that are particularly beneficial for participants?

2. How would you describe your experiences with or observations of ADAPT activities?

3. Could you describe any positive changes that you have observed in ADAPT participants that you feel are a result of their involvement with the program?
   *Possible probes:*
   a. Do you feel that participants have become more knowledgeable about diabetes prevention and management?
   b. Do you feel that participants have become more knowledgeable about healthy eating and/or healthy lifestyles?
   c. Could you describe any behaviours that you have observed in ADAPT participants that would indicate that they are more knowledgeable about diabetes prevention and management, healthy eating, or healthy lifestyles?
   d. Could you describe any other changes that you have observed in ADAPT participants?

4. What are your opinions on how ADAPT incorporates Aboriginal culture into the program?
   *Possible probes:*
   a. Do you have any comments on the cultural appropriateness of ADAPT?
   b. Do you have any suggestions on how ADAPT could better incorporate Aboriginal culture into the program?

5. Do you think that the ADAPT program complements the community in which it is located?
Participant Interview Guide:

1. Can you describe one or more things that you have learned from the ADAPT program?
   *Possible probes:*
   a. Can you describe what you have learned about healthy eating or healthy lifestyles from ADAPT?

2. Do you do anything different in your daily life because of what you have learned from ADAPT?

3. How would you describe your experiences with ADAPT?

4. For individuals with diabetes:
   *Possible probes:*
   a. Can you describe how you control your diabetes now compared to before you attended ADAPT?
   b. Do you feel that you have more control over your diabetes now compared to before you attended ADAPT?

5. For individuals without diabetes:
   *Possible probes:*
   a. Can you describe what you do to prevent diabetes now compared to before you attended ADAPT?
   b. Do you feel that you have more control over preventing diabetes now compared to before you attended ADAPT?

6. Can you describe if and how the ADAPT program fits with your views and experiences of wellness and diabetes?

7. What are your opinions on how ADAPT incorporates Aboriginal culture into the program?

8. What are your opinions about the physical space in which ADAPT program activities take place?

9. Could you tell me a bit about yourself?
   a. What is your age?
   b. Where is your home community?
   c. Do you consider yourself as a member of a particular band, First Nation, or Aboriginal group?
   d. Does anyone in your family have diabetes?
Appendix D: Luncheon invitation

A qualitative evaluation of an urban Aboriginal diabetes, prevention, and teaching program

Aug. 17 2006

Please join us as we share what we have learned about participants’ and stakeholders’ perceptions of an urban Aboriginal diabetes awareness, prevention, and teaching program (ADAPT).

Lunch will be served.

Please RSVP to Jennifer Eskes at jeskes@gmail.com or 778-233-9435

Time: 11:30 am – 1:00 pm
When: Thursday, August 17th 2006
Where: Vancouver Native Health Society
       (upstairs)
       449 E. Hastings Street, Vancouver
Appendix E: UBC BREB Certificates of Approval

The University of British Columbia
Office of Research Services and Administration
Behavioural Research Ethics Board

Certificate of Approval

PRINCIPAL INVESTIGATOR
Levy Milne, R.

DEPARTMENT
Family & Nutr Sci

NUMBER
104-0765

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT
Vancouver Native Health Soc. Clinic

CO-INVESTIGATORS
Brownie, Annette, Nursing; Chapman, Gwenneth, Food Science; Luske, Jennifer, Psychiatry; Mitchell, Corinne; Yarker, Kristen, Food Science

SPONSORING AGENCY

TITLE
A Qualitative Evaluation of an Urban Aboriginal Diabetes Awareness, Prevention and Teaching Program

APPROVAL DATE
May 20, 2004

TERM (YEARS)
1

DOCUMENTS INCORPORATED IN THIS APPROVAL
Sept. 2004, Consent form / Questionnaire

The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval of the Behavioural Research Ethics Board by one of the following:
Dr. James Frankish, Chair,
Dr. Cay Holbrook, Associate Chair,
Dr. Susan Rowley, Associate Chair
Dr. Amia Hubley, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures.
# Certificate of Approval

**PI/INSTITUTION:** Levy Milne, R.  
**Department:** Family & Nutr Sci  
**Study #:** B04-0765  
**Location:** Vancouver Native Health Soc. Clinic.

**SUBJECT/INVESTIGATOR:** Browne, Annette, Nursing; Chapman, Gweneth, Food Science; Eskes, Jennifer, Psych; Mitchell, Corinne; Yarmer, Kristin, Food Science

**PROTOCOL NUMBER:**

**TITLE:** A Qualitative Evaluation of an Urban Aboriginal Diabetes Awareness, Prevention and Teaching Program

**APPLICATION DATE:** 02.12.06

**AMENDMENTS:**

<table>
<thead>
<tr>
<th>Amendment</th>
<th>Date</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>March 29, 2005</td>
<td>Procedure</td>
</tr>
</tbody>
</table>

**PRELIMINARY STATEMENT:**

The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

**Approval of the Behavior:**

Dr. Jamie Frankish, Chair,  
Dr. Gay Holbrook, Associate Chair,  
Dr. Susan Rowley, Associate Chair  
Dr. Anita Hubley, Associate Chair

**This Certificate of Approval is valid for the above term provided there is no change to the experimental procedures.**
Endnotes:

1 In discussing culture as it pertains to health programming, it is important to be aware that the inclusion of cultural components (i.e. drumming or traditional crafts) aimed to increase adherence or enhance participant ‘buy in’ to program teachings can also divert attention towards a static notion of culture and away from lived contexts. Culture and tradition are not experienced in the same way by all Aboriginal people, especially in an urban environment, where individuals may have originated from various parts of the country and have been familiar with very different traditions (Browne, McDonald, Elliott, 2009).