# Understanding how workshops transform participants' lives by exploring their perceived experiences: the Kahnawake Schools Diabetes Prevention Project

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#### Abstract

**Aim:** To understand how the healthy lifestyle promoting workshops offered by the Kahnawake Schools Diabetes Prevention Project (KSDPP) bring about transformative experiences that change how participants live their lives.

**Design:** Qualitative study of semi-structured interviews.

**Setting:** KSDPP is a community based participatory research project created in 1994 in an effort to prevent diabetes in Kahnawake, a Mohawk community. Since 2007 KSDPP has implemented cooking, healthy lifestyle and physical activity workshops for adults.

**Participants:** Seventeen adult female Kahnawake community members with repeat participation in more than one KSDPP workshop, and one key knowledge holder, the Community Intervention Facilitator, who designed and implemented the workshops.

**Methods:** Interview transcripts were analysed following grounded theory.

**Results:** Deciding to attend a workshop required overcoming feeling selfish and accepting there is value in caring for oneself. Participants experienced transformative processes that gave them opportunities to learn cultural traditions, healthy lifestyle skills, stress coping skills and feel they were participating in community life. The outcomes of the processes were feelings of improved physical, intellectual, spiritual and emotional health. Other Kahnawake community members' health was impacted through the participants' role modeling and advocacy for healthy lifestyles.

Conclusions: This study shows how culturally relevant health promotion interventions can bring about changes in the overall health of participants. Diabetes prevention interventions could be designed to encourage the development of the transformative processes found in this study. Promotional material could emphasize that the decision to join an intervention is a choice to do something positive for oneself that may lead to better individual and community health.

#### Résumé

**Objectif**: Comprendre comment les ateliers promouvant un mode de vie sain, offerts dans le cadre du Projet de prévention du diabète des écoles de Kahnawake (PPDEK), permettent des expériences transformatrices qui modifient la façon dont les participants vivent leur vie.

Plan : Étude qualitative d'entrevues semi-structurées.

**Situation :** Le PPDEK est un projet de recherche participative communautaire créé en 1994, dans le but de prévenir le diabète à Kahnawake, une communauté Mohawk. Depuis 2007, le PPDEK a organisé des ateliers destinés aux adultes couvrant les thèmes suivants : cuisine, mode de vie sain, activité physique.

**Participants :** Dix-sept femmes adultes, membres de la communauté de Kahnawake, ayant participé à plus d'un atelier du PPDEK, ainsi qu'une personne ressource, soit l'intervenante communautaire qui a conçu et animé les ateliers.

**Méthodes :** Les entrevues étaient retranscrites, puis analysées selon la théorie fondée sur les données (« grounded theory »).

**Résultats :** La décision de participer à un atelier exigeait de surmonter le sentiment d'être égoïste, et d'accepter l'importance de prendre soin de soi. Les participants ont vécu des processus transformateurs leur donnant des opportunités d'apprendre des traditions culturelles, de saines habitudes de vie et des outils pour combattre le stress, tout en prenant conscience de leur participation à la vie communautaire. De ces processus résultèrent des sentiments d'amélioration de la santé globale : physique, intellectuelle, spirituelle et émotionnelle. L'implication des participantes dans la promotion de saines habitudes de vie et leur action à titre de modèle de rôle ont eu un impact sur la santé d'autres membres de la communauté Kahnawake.

**Conclusions :** La présente étude démontre comment des interventions en promotion de la santé, adaptées à la réalité culturelle des gens, peuvent entraîner des changements sur le plan de leur santé globale. Des ateliers pour la prévention du diabète pourraient être conçus pour favoriser le développement des processus transformateurs retrouvés dans cette étude. Du matériel promotionnel pourrait être utilisé pour mettre en valeur la

décision de joindre un tel atelier comme étant le choix de faire quelque chose de positif pour soi, qui peut aboutir à une meilleure santé individuelle et communautaire.

#### A Team Approach

The KSDPP includes community members who fulfill the roles of Community Intervention Facilitator, Project Coordinator – Community Mobilization, School Intervention Coordinator, and Administrative Assistant. The KSDPP Scientific Director is from McGill University, and the Co-investigators and Research Team members are from McGill University, Queens University, the Université de Montréal and the community.

The KSDPP is governed by the Community Advisory Board (CAB) which includes 15 community members.<sup>2</sup> The CAB was created to give the community control over KSDPP interventions and actions.<sup>2</sup> The CAB and researchers together co-created the KSDPP Code of Research Ethics in 1994<sup>3</sup> and updated it in 2007.<sup>2-4</sup>

Dr. Katherine Gray-Donald, Supervising Professor

Is the Scientific Director for the Research Team of the KSDPP. She is also an Associate Professor at the School of Dietetics and Human Nutrition at McGill University and an Associate Member of the Department of Epidemiology and Biostatistics at McGill University, the Centre de Recherche en Gérontologie et gériatrie, Hôpital d'Youville de Sherbrooke, and the McGill Nutrition and Food Science Centre. She is president of the Canadian Nutrition Society. Dr. Gray-Donald's research focuses on the health of Indigenous people and in particular the prevention of diabetes in indigenous communities. In the past she has worked with the Cree and has a longstanding research relationship with the KSDPP and the Mohawk of Kahnawake.

Dr. Ann C. Macaulay, Committee Member

Is a member of the KSDPP Research Team. Dr. Macaulay is a professor of family medicine at McGill University and is the Director of Participatory Research at McGill. She has received the Wood Award (2009) for Lifetime Contribution to Primary Care Research, College of Family Physicians of Canada (CFPC) Family Medicine Researcher of the Year (2008), and the Order of Canada (2006) for contributions to indigenous health. She is a past advisory board member of the Institute of Aboriginal Peoples' Health, the Canadian Institutes of Health Research, and an international member of the Institute of Medicine USA (2005). Dr. Macaulay was a practicing family physician in

Kahnawake from 1970 to 2008 and was the Scientific Director of KSDPP from 1994-2006.

Dr. Richard Hovey, Committee Member

Is an Adjunct Assistant Professor for the Division of Community Health Sciences at the Faculty of Medicine at the University of Calgary, adjunct professor in the Department of Family Medicine at McGill University, the Senior Director of Applied Educational Research at the Michener Institute for Applied Health Science, a program consultant for Ryerson University and Sunnybrook Health Sciences Center, and is a project and evaluation team leader for both Participatory Research with Consumers Advancing Patient Safety and with the Rapid Access Clinic II at the Tom Baker Cancer Center. Dr. Hovey is a qualitative researcher with experience in health education and promotion and joined the KSDPP research team in 2009. His experience is in human science research with vulnerable populations.

Jayne Murdoch, MSc Nutrition Student, McGill University

Is a Master of Science student of Nutrition at McGill University with an interest in Indigenous people's health issues. Jayne is a recipient of the Anisnabe Kekendazone – Network Environment for Aboriginal Health Research fellowship for Masters students. Jayne is a member of the KSDPP Research Team and is a registered dietitian with the College of Dietitians of Ontario. She has been volunteering for the KSDPP since May 2009. During this time she has assisted the Community Intervention Facilitator with the setup before and clean-up after workshops and by preparing PowerPoint presentations.

#### **Contribution of Authors**

The author of this thesis was responsible for the development of the study protocol and performed all data collection and analysis. This was under the supervision of Dr. Katherine Gray-Donald and supervisory committee members Dr. Richard Hovey and Dr. Ann Macaulay. Dr. Treena Delormier provide additional guidance in her roles as KSDPP Research Team member and Kahnawake community member.

Ms. Elaine Delaronde provided guidance as a Kahnawake community member and employee of KSDPP.

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#### 1.0 Introduction

#### 1.1 Objectives

- To conduct a qualitative, naturalistic study with the participants of the Kahnawake Schools Diabetes Prevention Project (KSDPP) workshops for adults.
- 2. To explore the perceived experiences of the participants in the workshops in order to understand how the workshops enable participants to change their lives.

#### 1.2 Significance and Background

#### **Obesity and Diabetes in Indigenous Populations**

The traditional diets of Indigenous\* peoples are adapted to the environments in which they live.<sup>5</sup> For example, the Inuit living on Baffin Island consume sea foods including fish, shellfish and sea mammals.<sup>5</sup> The Iroquois, who live inland are traditionally agriculturalists who planted beans, squash and corn.<sup>6,7</sup>

Indigenous peoples' consumption of traditional foods has decreased due to the change from a lifestyle that included traditional foods and regular physical activity to a diet heavy in western foods accompanied by infrequent exercise which resulted in increased rates of obesity and comorbid diseases like diabetes. Indigenous people who consume traditional foods may be healthier than those who consume western diets, suggesting that obesity and diabetes can be avoided by maintaining a healthy lifestyle.

Regarding the general population, an American randomized clinical trial, the Diabetes Prevention Project, showed that study participants with prediabetes had a 58% reduction in type 2 diabetes incidence after making positive diet and exercise related lifestyle changes. Thus postponing or preventing type 2 diabetes is possible with major lifestyle modifications such as those followed by the participants of this study: 150 minutes of moderate exercise per week while consuming a low fat and low energy diet leading to weight loss. Developing and maintaining healthy behaviours and healthy

<sup>\*</sup> Note: The term indigenous refers to the Indigenous people of North America including First Nations, Inuit and Métis people.

body weight are the keys to reducing diabetes incidence. One way to achieve healthy behaviours and healthy body weights would be to re-introduce or increase the consumption of traditional foods which in Mohawk communities are based on plants with some animal products and to increase physical activity.

The traditional foods of Indigenous peoples are high in nutritional quality compared to many western foods. <sup>5,11-15</sup> Traditional diets and foods are high in protein, vitamins and minerals. <sup>9,16,17</sup> Diets based on contemporary western foods are higher in refined foods, energy, carbohydrates, fat, sodium, and low in fibre. <sup>5,16-21</sup> It is probable that following a traditional diet will have positive health benefits. Diet quality has been found to improve when traditional foods are included. <sup>22</sup> It is possible that the nutrient profile of traditional diets could be less likely to lead to obesity and diabetes when consumed in moderation.

Indigenous peoples have lost much of their traditional food security, their health and way of life over time.<sup>23</sup> This is a gradual process that has been ongoing since the colonization of North and South America by Europeans and has been brought about by several forces of change.<sup>5</sup> With colonization came political instability, discrimination and oppression creating an environment in which it was and is difficult to maintain traditions not of the dominant culture.<sup>5,24</sup> The colonizing food culture is promoted in the media and by institutions and typically does not take indigenous food cultures into account in any significant manner.<sup>5</sup> A loss of traditional land used for hunting and gathering along with forced resettlement to reserves, urbanization and employment has caused a decrease in the availability of land, plant and animal species, time and energy available for harvesting and consuming traditional foods.<sup>5</sup>

With these changes goes a decrease in knowledge sharing of how to procure and prepare traditional foods which results in an overall disappearance of this knowhow.<sup>5</sup> Kuhnlein and Receveur suggest that in losing knowledge of traditional foods, Indigenous peoples are also losing food related cultural experiences, food variety, and related morale.<sup>5</sup> Cultural integrity and individual identity for Indigenous peoples are tied into the spiritual and symbolic meaning given to traditional foods.<sup>11,25-34</sup> Traditions in terms of language and skills give people pride in their culture.

Frequent consequences of these lifestyle changes are high levels of obesity and diabetes. <sup>16,35-41</sup> Obesity is caused by the habitual intake of excess calories for the level of physical activity. Many people, including Indigenous people, do not get enough physical activity. Only 21.3% of First Nations adults get at least 30 minutes of moderate to vigorous exercise 4 times per week. <sup>42</sup> Another study found that 37.2% of American Indigenous peoples<sup>\*</sup> leisure activities did not include any exercise. <sup>43,44</sup> The 2004 Canadian Community Health Survey found that 56% of Indigenous people living off reserve and non-Indigenous people in Ontario were not physically active during leisure activity. <sup>45</sup> Obesity and sedentary lifestyles are major risk factors for the development of diabetes. <sup>46</sup> Obesity and diabetes rates are high in indigenous communities. In 2002-2003, 31.2% of First Nations adults were obese compared to 15% of Canadian adults. <sup>43,44</sup> Compared to non-Indigenous people, those who lived off-reserve in Ontario in 2004 were 2.5 times more likely to be obese. <sup>47</sup> In 2002-2003 the prevalence of diabetes for First Nations people was estimated to be 19.7% which was four times higher than the national Canadian average of 5.2%. <sup>48</sup>

Type 2 diabetes occurs when the body is unable to reduce blood sugar levels to normal amounts due to either a lack of insulin or the development of cellular resistance to insulin. Insulin is the human hormone that enables cells to uptake glucose. Diabetes is a devastating disease particularly when blood sugar levels are left uncontrolled. In the more developed form of the disease, the short term risks of hyper- and hypoglycaemia include nausea, vomiting, abdominal pain, electrolyte imbalances, coma, and death. The long term effects of uncontrolled blood glucose include vascular damage leading to heart attacks and strokes, kidney disease leading to dialysis, retinopathy, amputation and neuropathy.

Impaired glucose tolerance (IGT) means to have an elevated blood sugar level two hours after consuming 75g of glucose.<sup>46</sup> Impaired fasting glucose (IFG) means having an elevated fasting glucose level after an eight hour fast.<sup>46</sup> A person with IGT or IFG can be

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Note: In this thesis American Indigenous people have not been referred to as Native or Aboriginal Americans. In Kahnawake the term indigenous is considered more appropriate than the terms native or aboriginal.

said to have prediabetes as they are indicators of having a high risk for developing type 2 diabetes.<sup>46</sup>

Some of the major risk factors for developing diabetes include: a family history of diabetes, a history of gestational diabetes, overweight, obesity and dyslipidemia. As stated earlier, consuming a diet lower in total energy, total fat, saturated fats and higher in fibre and participating in 150 minutes of moderate exercise per week will lower the risk of developing type 2 diabetes. 46

#### **Background: Kahnawake Schools Diabetes Prevention Project**

The Haudenosaunee, which includes the Mohawk Nation, have a tradition of agriculture and a food system based upon a balance of beans, corn and squash and hunting game and fish. <sup>6,7</sup> The lifestyle of the people of Kahnawake, a Mohawk community near Montreal, Quebec has changed dramatically since the arrival of colonizer society. From the late 1800s to the 1950's their reliance on agriculture, farming, fishing and gathering decreased drastically due to employment in particular of men in the steel and iron industries, government expropriation of land and the loss of traditional fishing areas due to the construction of the St. Lawrence Seaway. <sup>50</sup> Today, many people in Kahnawake complete higher education and have white-collar jobs. <sup>50</sup> For the people of Kahnawake, given these changes and the influences past and present of colonizer society, for example, residential schools and now the plethora of instant foods, there has been transformation in traditional ways of living that included the loss of some cultural food knowledge and food preparation.

Type 2 diabetes is becoming more and more prevalent in Canada. <sup>51,52</sup> The percent of Canadians with diabetes increased from 3.4% to 4.9% between 1994/1995 and 2005. <sup>51,52</sup> Diabetes in Kahnawake is becoming more prevalent, but at a higher rate than for Canadians in general. In Kahnawake, between 1986, and 2003 the percent of diabetes in males 18 years and older increased from 6.0% to 8.4% and in females 18 years and older from 6.4% to 7.1%. <sup>53</sup> Some of this increase may be attributed to a change in the diagnosis of diabetes from a fasting blood glucose level of 7.8mmol/L to 7.0mmol/L as of 1998. <sup>54</sup> Since these rates were calculated using a diabetes registry, it is possible that the actual rates, including non-registered people with diabetes, are potentially higher. <sup>53</sup>

The Kahnawake Schools Diabetes Prevention Project (KSDPP) was created by Kahnawake community members, health professionals, educators and academics from McGill University, Université de Montréal and supported by the Kahnawake Education Center and Kateri Memorial Hospital Center via a National Health Research and Development Program grant in 1994. <sup>50</sup> This was in an effort to reduce the incidence of diabetes with a focus on preventing childhood obesity and a concern for the health of their future generations. Using the tenets of social learning theory, the precede-proceed model of health education, the Ottawa Charter for Health Promotion and traditional Haudenosaunee learning styles, initiatives were created to promote positive health attitudes, healthy eating and physical activity for children, parents and the community. 7,55 As a result, KSDPP has developed school based interventions for children including a health education program that includes in-class physical activities and a healthy nutrition policy for Kahnawake schools was created. 7,56 KSDPP is active in the community by providing interventions for adults and families. For example, KSDPP was involved in the development of a walking and bicycling path, volleyball team, walking club, healthy food contests and continues to offer frequent family activities, maintains involvement in many community events and works in partnership with other community organizations. <sup>7,56</sup>

The main focus of KSDPP is to work directly with children to encourage healthier lifestyles and to provide supporting activities for parents and extended families. As a result, some changes occurred for example, a repeat cross-sectional study found that for children in grades 1 to 6 between 1994 to 2002 there was a significant decrease in the consumption of foods rich in sugar and fat.<sup>57</sup> However, the age and gender adjusted BMIs of these children increased significantly during this same time period from 18.86 kg/m² in 1994 to 19.46 kg/m² in 2002.<sup>57</sup> In addition, the amount of fruit and vegetables consumed significantly decreased.<sup>57</sup> Overall, the project has not produced sustained decreases in children's development of diabetes risk factors.<sup>57</sup> Therefore, excess caloric intake and physical inactivity remain significant problems for the children of Kahnawake. This could possibly be due to a lack of sustained positive change in the children's overall food and physical activity environments. It is important to expose children to healthy food at school, teach them about healthy eating and introduce them to new foods. However, if the

home environment does not support healthy food choices then this may explain the difficulty in sustaining or achieving significant changes. Since 1994, KSDPP has offered a variety of interventions to Kahnawake parents and extended family members to adopt healthy lifestyles with the belief that all children also need a healthy home environment.

Since 2007, KSDPP has added new interventions to help change adults' eating and physical activity habits in an effort to reduce adult obesity rates and their risk of developing diabetes. As a result, KSDPP created several initiatives for adults and in particular young mothers. These include Healthy Mind in a Healthy Body Workshops, yoga classes, Haudenosaunee Foods Cooking Workshops, a Fitness Program for Young Women/Mothers, qigong classes and cultural food presentations. In this thesis, these programs, other than the cooking classes, will be referred to as "physical activity classes." Free public skating is also offered to encourage physical activity in the community.

The Healthy Mind in a Healthy Body Workshops offers two sections (a day time and an evening section) of 5 sessions which first ran from August 16 to 25, 2008 and was repeated again from September 14 to October 19, 2009. This series of workshops promotes positive lifestyle changes to young parents and community members. The Workshop includes cooking modules, group physical activity sessions and lessons on mental and spiritual health.

Two versions of the yoga classes, one standard and one gentle, ran once a week from October 7, 2008 to February 10, 2009. These classes were offered at no cost to participants. When the funding ended, many participants were willing to pay their own way and continued attending the yoga classes. The next instalment of the gentle yoga started on September 15, 2009 and continued weekly until February 23, 2010. The regular yoga class started September 14, 2009 and continued until February 22, 2010.

The Haudenosaunee Foods Cooking Workshops began on November 16, 2007 and continue to be held intermittently at the discretion of the intervention coordinator, for example, when funding and time allow or in response to requests from the community. The workshops are designed to teach adult community members how to make healthy meals using traditional Haudenosaunee foods. The workshops involve cooking skills

development via participants collaborating to prepare assembled ingredients into a communal meal.

The Fitness Program for Young Women/Mothers started in April 2009 and ran until March 2010. The program is a community intervention designed to assist 20 to 40 year old women to develop a routine of physical activity and a support network between participants. The workshop includes a free Kahnawake Youth Center membership, access to the weight and exercise room, and one session with a personal trainer. Participants attend weekly fitness program sessions, but also have access to the Youth Center gym at any time.

Weekly qigong classes were held starting in January 7, 2008 to March 31, 2008. Qigong is a Chinese form of meditation, which includes breathing exercises and mild physical activity. Free public skating has been offered twice a week for one hour for the last three years from October to March.

Data were collected for the present study during the years 2010 to 2011. The Healthy Mind in a Healthy body Workshops, yoga classes, Haudenosaunee Foods Cooking Workshops, Fitness Program for Young Women/Mothers and cultural food presentations continue to be offered by KSDPP.

Participants of the interventions were recruited through radio advertisements, posters and word of mouth. Under the leadership of an excellent role model from the community, the Community Intervention Facilitator (key information holder), this new approach is attracting young mothers, some of who are overweight, sedentary and at risk of developing diabetes. The intervention facilitator brings a significant level of experience, expertise and community integrity to the interventions. These programs show promise in that they are well attended and some of the cooking class participants even started a small catering service for community organizations. This suggests the cooking classes give young mothers a chance to get together and form new friendships. Their new cooking skills appear to have enabled them to organize and create a new healthy eating environment. These workshops have not been studied to date and they need to be explored in order to understand what is working, how it could work better and how it

could be helpful to Kahnawake and other communities struggling with the problems of rising rates of diabetes.

It would be useful to KSDPP to know why participants attend, what are the effects and affects of the workshops on participants and what do participants perceive to be the results and benefits? In addition, what is it about the experience of the workshops that enables participants to transform their lifestyles?

If the programs are meeting their goals of bringing about positive change in food and physical activity behaviours, the potential benefits to the participants and their community are great. On an individual level, the participants may develop healthier lifestyles. In terms of the community, the workshops' participants could become involved in creating a healthier community via role modeling and knowledge sharing.<sup>58</sup>

It is important to learn why and how some individuals, families and communities are able to move toward healthier practices. It would be helpful to find out which aspects of the program participants perceive to be the most beneficial or transformational as this information could be used to enhance existing initiatives or used to develop new community programs. In addition, this information may be useful to the developers of diabetes prevention programs in other indigenous communities.

KSDPP has excelled at transmitting their new knowledge within Kahnawake and to other communities via training sessions, publications, research projects, and scientific conferences and is seen as a leader in the struggle against the obesity and diabetes epidemic. The results of this study will be made available to others via the KSDPP Training Program in Diabetes Prevention, indigenous and non-indigenous conferences, the KSDPP website and scientific publications.

#### 2.0 Literature Review

#### 2.1 Cooking Classes

Cooking classes are frequently given as part of nutrition interventions for skill building that include other forms of learning for example, lectures or discussion groups. For this study, a cooking class is defined as being a class where participants participate in the preparation of food. Classes where participants only observe the preparation of food are considered to be food or cooking demonstrations.

The effects of cooking class interventions for adults have not been studied in depth. In particular, there is very little scientific literature on cooking classes given in indigenous communities. In fact, only one study examined the effects of a cooking class to train tribal cooks, defined as being Alaskan Natives or American Indians employed by institutions like schools and jails, to use US Dietary Guidelines in their cooking and menu planning.<sup>59</sup> Another study examined the effects of cooking classes given to Aboriginal Australian with or at risk of developing diabetes.<sup>60</sup>

The study with tribal cooks included a presentation during the intervention of the stories of five tribal cooks on how they felt about their work. <sup>59</sup> This was well received and participants appeared to identify with the presentation cooks. <sup>59</sup> An example of a common response from the participant evaluation regarding the presentation of the stories was, "What I liked best was that American Indians were interviewed." <sup>59</sup> This shows how making the cooking class culturally relevant was appreciated by the participants. The Aboriginal Australians in the Abbott et al study reported enjoying the culturally appropriate setting of the cooking classes. <sup>60</sup> Culturally relevant cooking classes teach participants how to prepare traditional foods from the participants' culture. It is possible that cooking classes designed to be culturally relevant could inspire participants to adopt cooking skills and methods more readily than interventions that are not culturally relevant.

In general cooking classes for non-Indigenous people have been geared toward an audience that is disadvantaged or historically marginalized and is at risk of nutrition related health problems. Studies have been completed with tribal cooks in indigenous communities, older single men, women with rheumatoid arthritis, adults with low

socioeconomic status, with or at risk of developing diabetes, with schizophrenia, low income families, pregnant teens, prostate cancer survivors and on breast cancer prevention. <sup>59-71</sup>

Several studies showed that participants made healthier food choices as a result of cooking classes. <sup>59,60,62</sup> At follow-up, the tribal cooks study found that participants were using whole wheat flour based bread products, making smaller fry breads and tortillas, preparing more vegetables and fruit and using low fat yogurt instead of mayonnaise. <sup>59</sup> However, this information is contradicted by the finding in the same study that the cooks did not make any significant changes to their menus. <sup>59</sup>

The most common improvement in cooking class participants' diets was an increase in fruit and vegetable intake, although in one case the increase in fruit intake was only short term. <sup>60,61,63,66,68,69,72</sup> Other common dietary improvements included a decrease of fat and or saturated fat intake. <sup>60-62,68-70,72</sup> Fibre intake was often improved as well. <sup>62,69,70,72</sup>

Other less commonly measured dietary improvements included increases in food variety<sup>62,65</sup>, fruit and vegetable variety<sup>66</sup>, legume intake<sup>68</sup>, grains<sup>65</sup>, commodity foods<sup>65</sup>, vegetable proteins<sup>70</sup>, lycopene<sup>70</sup>, carotenoids<sup>70</sup>, soy<sup>70</sup> and a decrease in the use of salt<sup>60,62</sup> and animal protein.<sup>70</sup>

Other than changes in dietary intake, a few studies (one randomized controlled trial and five pre- versus post-trial studies) showed additional benefits that included increases in cooking skills, confidence, self-esteem and social benefits. One study showed that participants were using new food preparation methods as a result of the intervention. Food safety skills improved in two studies. Electron Keller et al., in a small process evaluation study of cooking classes given to older men, found increases in the ability to read and follow recipes. Duncombe et al found that cooking classes significantly improved cooking skill in schizophrenic patients. Qualitative data from interviews and a focus group showed that some participants in the Wrieden et al. study had tried the program recipes at home. Three studies showed that participants' were now using foods new to them. The CookWell program showed a significant increase in participants' confidence using recipes.

classes resulted in increased cooking confidence, enjoyment of cooking, and time spent cooking. An other study found increases in overall confidence and self-esteem. Abbott et al in their study with Aboriginal Australians all reported experiencing increased healthy eating knowledge and improved cooking skills. An other study with Australian Aboriginal women found that cooking workshops helped participants gain the confidence to cook new foods for their families.

Little is known about the impact of cooking classes on shopping habits. Levy did not find significant increases in grocery shopping frequency for both cooking class and cooking demonstration participants.<sup>74</sup> Qualitative research has shown a reported improvement in grocery shopping skill<sup>62</sup> and changes in shopping behaviour including purchasing basic cooking ingredients and less expensive food.<sup>75</sup>

The participants of the Keller at al. study enjoyed the social nature of the class because it gave them incentive to attend and improved their feelings of self-worth. 62 Similarly, Wrieden et al. found that the motivation to attend was related to being able to bring friends to the class, the casual atmosphere and that the food was free. 67 Abbott et al found that motivation to attend and enjoyment of the cooking classes were facilitated by the social nature of the program. 60

Some studies examined whether interventions with cooking classes had an effect on participants (as compared to control groups) by measuring changes in quantitative variables, for example blood pressure and blood values. A treatment group of women with rheumatoid arthritis were given cooking classes focused on teaching the Mediterranean diet. Compared to a control group the authors found a significant decrease in systolic blood pressure and significant improvements in the outcome measures of rheumatoid arthritis, for example pain score and early morning stiffness. Two other studies showed no effect of dietary changes on quantitative variables. Carmody et al. found no significant differences in the prostate-specific antigen level between the control and treatment groups of men with recurrent prostate cancer and attributed this result to a small sample size. Pierce et al. found no effect of changes in the diets of breast cancer survivors on the recurrence of breast cancer or mortality over the 7.3 year study period. All three studies that examined participants' physiological

outcome variables found positive changes in the dietary habits of the treatment groups who received the cooking classes. <sup>61,70,72</sup>

The association between cooking skills and having a healthy diet has been examined in three cross-sectional studies. Hughes et al. interviewed older men who lived alone to investigate the relationship between cooking skills and the obstacles to healthy eating. <sup>76</sup> Larson et al. studied young adults (18 to 23 years) to find out the effect of food preparation skills on their diets. <sup>77</sup> Winkler et al. surveyed cooking confidence in relation to vegetable purchasing habits and socioeconomic status of adults. <sup>78</sup>

Studies of cooking skills have not been consistent in the definition of the term cooking skills. In Hughes et al. skill level was qualitatively determined by participants perception of whether they had basic, adequate or good skills. Larson et al. took a more quantitative approach and defined an average food preparation score based on how often participants performed behaviours like buying fresh vegetables and making dinner. Winkler et al. similarly calculated an average cooking confidence score based on participants confidence to prepare a variety of vegetables and to use different cooking techniques.

An association between having better cooking skills and having a healthier diet was observed. Specifically a higher level of skill has been linked with a higher intake of vegetables. People who prepare food more often have a lower fast food intake and have lower intakes of fat and higher intakes of calcium, fruit, vegetables, and whole grains. Hughes et al. found that men with better cooking skills also reported feeling healthier physically. An Australian study by Winkler et al. found the confidence to cook vegetables was significantly associated with being female, English speaking, older, well educated, having a higher income and living with an adult or a minor. Associations have been found between lower cooking skill levels and being male, of African American descent, student status (part-time or non-student), not living with other adults and having lower education levels. It must be emphasized that since these studies were cross-sectional, the above associations do not represent cause and effect relationships.

Focus groups aimed at reaching people at nutritional risk due to a variety of diseases and conditions have examined what participants would like to find in a nutrition

education program.<sup>79-82</sup> Cooking classes have been identified as desired nutrition education methods.<sup>80,82</sup> Specifically people wanted cooking classes that were hands-on and allow them to actively partake in the food preparation.<sup>79,81</sup> This is backed up by the cooking class participants of the Pelican et al. study who indicated they appreciated the opportunity to cook at the workshop.<sup>59</sup> Other aspects of cooking classes identified as being desirable included: holding the class at a convenient time,<sup>81</sup> at a location that is easy to get to,<sup>81</sup> providing child care,<sup>81</sup> working as a group,<sup>79</sup> providing straightforward health messages,<sup>79</sup> learning recipes,<sup>79</sup> learning about healthy prepared food,<sup>79</sup> and using a food budget.<sup>82</sup>

Food demonstrations are a type of cooking class where the participants do not get to partake in the cooking or preparation of the food. In a study by Levy et al, compared to cooking demonstration participants, cooking class participants displayed increases in positive attitudes including, for example, feeling that cooking is enjoyable. 74 However, this study had a weak design. The intervention group received four, two-hour cooking classes, but the comparison group received only one, one-hour food demonstration.<sup>74</sup> Thus, it is not possible to rule out whether the time spent at the intervention or number of interventions had an effect on causing the efficacy of the food demonstrations to be lower versus the cooking classes. Keller et al found a non-statistically significant improvement in positive attitude toward cooking that was reinforced by their interview data that showed the same. 62 In a controlled trial of cooking classes, Auld et al also found a nonsignificant increase in positive attitudes toward cooking. 65 Also, the cooking class participants when compared to the food demonstration participants, had significantly higher increases in positive attitudes toward cooking, the confidence to use different cooking techniques and the benefits of cooking. 74 Participants of both groups experienced an increase in their cooking skills knowledge. 74 The participants self-selected to partake in this study, but were randomized to either the cooking class or demonstration class.<sup>74</sup> 90% of participants at the start of the study indicated they could cook and that many had taking cooking classes in the past. <sup>74</sup> Thus, the participants are not representative of the general population or groups at risk of nutritional problems so the study results may not hold true for other populations.

Cooking demonstrations have been used as part of larger interventions aimed at addressing health problems like diabetes, obesity and heart disease. 83-87 Demonstrations were sometimes included as components of store grocery interventions and nutrition classes.

Only one study was found where the cooking demonstration was not part of a larger intervention. The Kentucky State Fair Cooking School was an intervention of cooking demonstrations given to the public attending the fair. Bastin reports that 100% of participants at the intervention, through a raising of hands, indicated they would try the recipes, cook with new foods, switch to grilling food and read food labels more often. This method of data collection seems somewhat dubious since it could be imprecise and invites potential bias since participants may have felt pressure to answer the questions positively. Five years after the intervention participants were contacted to answer the same four questions. Their answers were given in percent and appear not to have been tested for statistical significance.

Two interventions in indigenous communities, one aimed at reducing diabetes<sup>84</sup> and the other at reducing obesity,<sup>85</sup> included cooking demonstrations in local stores and other community locations. Both studies were process evaluations during which both customers (rating themselves) and process evaluators rated the participants' response and interest in the food as high.<sup>84,85</sup>

The two studies that included cooking demonstrations as components of nutrition classes did not examine the effects of the demonstrations separately from the overall intervention effects. Ref. One study of a diabetes intervention used the stages of change theory to analyse changes in dietary habits (for example cooking with healthy fats) and social cognitive theory to study participants' confidence to make healthy dietary choices. The results of this study were weakened by the fact that at the start of the intervention most participants were already in the action and maintenance stages of change. The second study focused on modifying the diets of people at risk for coronary artery disease measured changes in total cholesterol and LDL cholesterol.

Several of the studies in this literature review focused on examining the facilitators and in particular, the barriers to healthy eating. <sup>60,76,77,79,81,82</sup> Barriers included

lack of cooking skills, <sup>76,77,79</sup> low inspiration to change eating habits, <sup>76,79</sup> poor health, <sup>76</sup> lack of time to prepare food, <sup>77,79,82</sup> limited financial resources, <sup>77,79,82</sup> differing family members' food preferences, <sup>79</sup> lack of knowledge about healthy eating, <sup>79,82</sup> unhealthy social environment <sup>82</sup> and lack of social support. <sup>82</sup>

Facilitators or motivators for healthy eating included concern about appearing overweight, <sup>81</sup> concern for physical health, <sup>79</sup> the desire to lose weight, <sup>79</sup> concern for the health of family members <sup>79,82</sup> and positive social support. <sup>82</sup>

Only one study qualitatively examined the barriers and facilitators to health eating as experienced by cooking class participants. Abbott et al found that facilitators to healthy eating included being recently diagnosed with an illness, concern for the health of family members, family support and the desire to live longer for the sake of family. Barriers to healthy eating included lack of time, bad oral health, lack of family support, depression, limited financial resources, having a desire to eat unhealthy food, unstable social circumstances, and feeling secluded from family members because of following a different diet.

Only one entirely qualitative study of cooking classes was found in the literature, <sup>60</sup> however four quantitative studies contained qualitative components. <sup>59,62,67,76</sup> One study used qualitative research methods to develop virtually quantitative data for quantitative analysis. Hughes et al. used grounded theory and content analysis to code participants' levels of cooking skill into three ordinal categories of no/poor or basic, adequate and good. <sup>76</sup> These three categories were used in the quantitative analysis in order to examine whether cooking skill had a statistically significant effect on other outcome variables, for example, vegetable consumption. <sup>76</sup> This quantifying of qualitative data undermines the potential use of qualitative data to learn new information that can stand on its own. It is difficult to understand why Hughes et al. chose qualitative interviews to determine the three categories of cooking skill when they could easily have been defined in advance and added to the quantitative questionnaire. Descriptive qualitative data were used to enrich quantitative study findings. <sup>76</sup> It appears that the overarching themes examined in the research, including cooking skill, were imposed before the analysis and did not emerge from the qualitative interviews. A good, clear

explanation was given of how the thematic sub-categories, levels of cooking skill, emerged from the data. Reliability was also addressed and inter-rater reliability was calculated.<sup>76</sup>

In qualitative studies it is imperative to identify the philosophical orientation or theoretical perspective or paradigm, since it informs every aspect of the research from the research question to the way results are explained. 89-91 The Men's Cooking Group study identified descriptive and thematic analysis as their qualitative methods. 62 No further details regarding their research methods were provided. These "methods" identified by Keller et al. are not recognized theoretical perspectives, but are instead common elements of analysis that would be found within a theoretical perspective. No qualitative theoretical perspective appeared to have been followed thus weakening the credibility of their methods. Qualitative data were used to enrich quantitative data, but also stood alone as a source of new information. Themes were clearly identified and emerged from the data or were known in advance of the analysis. The methods of triangulation were thorough and clearly identified. 62

A poor quality study by Pelican et al. indicated they followed the "basic principles of qualitative data analysis" as their qualitative research method and cited Patton's book Qualitative Evaluation and Research Methods. <sup>59,92</sup> No theoretical perspective was identified which is surprising considering Patton's text contains an entire section on the subject. In addition, the text is more of an introduction to qualitative methods and does not provide the level of detail necessary to perform the analytical methods typical of any of the sixteen plus major theoretical traditions identified by Patton. <sup>91</sup> Qualitative data identified in the study were descriptive and appeared not to have been investigated for themes.

Wrieden 2003 et al. indicated they carried out qualitative interviews and focus groups in their mixed methods study.<sup>67</sup> The qualitative methods used are not identified in this paper. Though not stated clearly, in the methods section the reader is directed to an earlier study of the Food For Life program.<sup>67</sup> The reader is forced to assume that the qualitative methods explained in the Symon and Wrieden<sup>93</sup> article were used again in this

study. The results of the qualitative data seem to be a descriptive summary of what the participants enjoyed about the intervention given in no clear thematic order.

Abbott et al did not indicate what paradigm they followed but instead reported using a design where the analysis results of an interview were used to guide the next interview.<sup>60</sup>

In sum, cooking classes have been studied most in terms of their effect on participants' food intake. Some studies also examined the effect of the classes on biomarkers of dietary change, for example blood pressure. A small number of studies examined the effects of cooking classes on food preparation and skills, confidence, self-esteem and social benefits. The few cross-sectional studies that examined cooking skills showed positive correlations between cooking skill level and having a healthy diet. Little can be learned from the literature on the effect of cooking demonstrations on intervention participants' cooking skills and knowledge. Lastly there is barely any literature on cooking classes in indigenous communities. As a result, the KSDPP cooking classes provide a good opportunity to explore a gap in the literature and also the effects of culturally relevant cooking class given in an indigenous community.

#### 2.2 Physical Activity Classes

Physical activity classes in indigenous communities have also not been well studied. For the purposes of this study, only physical activity classes in North American communities have been examined. Only one study did not exclusively focus on Indigenous people, but reported the effects of racial differences in their results. 94

Studies ranged from pilot tests, randomized controlled trials, to un-controlled trials. 83,84,94-107

Most studies were created to prevent or treat type 2 diabetes and consequently also obesity. 83,84,94-103,105,107 One study was aimed at reducing cardiovascular disease. 106 Healthy Children, Strong Families focused on preventing and treating obesity in children, but included parents in the intervention. 108 The Sawchuk et al. study focused simply on physical exercise in older Indigenous Americans and not on the prevention of any specific disease. 104

These studies have investigated the effects of a variety of types of physical activity. Two studies included gym based physical activity interventions for example an aerobics class and strength training sessions. <sup>98,101</sup> The Sawchuk et al. study examined the effect of wearing a pedometer on daily activity. <sup>104</sup> Some interventions tested other sources of physical activity like gardening, weight-loss competitions, water aerobics, power walking; church and worksite based interventions. <sup>83,95-98,102</sup>

Most included a combination of exercise, nutrition education, and lifestyle modification. 83,84,94-100,102,103,105,106,108 For example, the Native American Diabetes Project's Strong in Body and Spirit intervention tested the effects of a program that included 5 sessions on exercise, dietary fat, sugar and creating and maintaining healthy lifestyles. Heffernan et al. studied an intervention that incorporated among other things classes in traditional herbal medicine, traditional diet, and a modern exercise program that included group exercise following a Richard Simmons exercise video. The Traditions of the Heart intervention for preventing cardiovascular disease, included cookbooks, stress management techniques and tobacco cessation. Cherokee Choices included grocery store tours and cooking demonstrations.

Some studies examined the effects of the same intervention but administered differently to different groups. Gilliland et al. examined the difference between an intervention given to friend groups versus another group who received the intervention in a one-on-one basis and lastly compared the outcomes of both groups to that of a control group receiving regular medical care. The Native Hawaiian Diabetes Intervention Program study included a treatment group that received more in-person contact with intervention workers and participants required to bring a family support person to sessions. Narayan et al. compared two different interventions to an observational group. The first intervention involved a self-directed learning style with a cultural focus on diabetes prevention and the second intervention had a more structured method of delivery (for example, structured activities and classes) and no cultural component.

Most interventions were designed to be culturally relevant by including for example traditional values, foods and culture and traditional methods of learning like storytelling. 83,84,95-97,99,100,102,103,105,106,108 It appears that culturally relevant interventions

are developed in an attempt to connect with participants on a cultural level in the hope that new healthy lifestyle behaviours will be more readily adopted. Armstrong et al. argued that Indigenous people face barriers accessing the dominant cultures health care system for several reasons including travel time to clinics from reserves, disliking doctors and because doctors do not treat the spiritual and emotional side of diabetes. By making interventions culturally relevant it is hoped these barriers can be overcome. Cultural relevance is also helpful for gaining community and key stakeholder support for interventions. 100,106

Several studies suggested culturally relevant interventions need to take into account the importance placed by Indigenous people on the support of extended family, community and spirituality and their relationship to health. 83,95,96 Other interventions were designed to include traditional indigenous learning methods for example storytelling which is a respected method of learning values from elders. 96,108 Interventions were frequently made relevant by including traditional indigenous physical activities (for example snow games), seasonal and cultural traditional foods (for example berries) and print material with images or art featuring Indigenous people. 96,105,106,108

The Carter et al. and LaRowe et al. studies did not provide outcome measures because at that the time of publication the interventions were in pilot stages. <sup>96,108</sup> The How healthy am I? – Treating the Whole Person intervention's funding was cancelled and as a result the program was not fully implemented and thus evaluative results were unavailable. <sup>95</sup> All other studies examined provided outcome measures, but three studies provided measures with no indication of whether findings were statistically significant. <sup>83,84,101</sup>

In most studies the success of the intervention was examined via quantitative biomarkers and anthropometric values. Common biomarkers included HbA1c, total cholesterol, LDL cholesterol, HDL cholesterol and blood glucose levels. 97-99,101,103,105-107 Anthropometric values frequently measured included blood pressure, weight, BMI (body mass index) and waist circumference. 83,94,97,98,100,101,103-108 Additional common measures included whether the use of hypoglycaemic medication was continued or discontinued,

movement within the stages of change, alterations in dietary intake and exercise level. 83,94,98,100-106

Using these measures, the studies have met with varying degrees of success. The three studies that examined physical activity alone showed clear, concrete positive changes in participants. <sup>98,101,104</sup> For example, participants of The Zuni Diabetes Project who partook in the exercise program had significant decreases in weight, fasting blood glucose and decreased use of hypoglycaemic medication compared to a control group of non-participants with type 2 diabetes. <sup>98</sup> However, interventions that included mixed methods of exercise, diet and lifestyle modification met with less clear and often showed no effect. <sup>83,94,97,99,100,102,103,105</sup> For example, in the Traditions of the Heart study, significant increases in walking and exercise self-efficacy occurred, but there were no significant changes in participants' BMI, blood pressure, or cholesterol level. <sup>106</sup>

Some studies examined qualitative outcomes, but not in any depth. The participants of the Haida Gwaii Diabetes Project reported a feeling of increased well-being and increased energy due to the traditional medicine trial and a brief one paragraph description of the participants' experience in the exercise portion of the intervention was provided. Pima Action and Pima Pride intervention also included a very short one-paragraph qualitative analysis of the Pima Action groups' experience with motivation and behaviour change. The Zhiiwapenewin Akino'maagewin: Teaching to Prevent Diabetes intervention study by Rosecrans et al. used qualitative methods to find out the acceptability of and suggestions for improvement of the of their community events.

The quality of these qualitative studies is questionable due to a lack of in-depth methodological detail. The Heffernan et al. study describes the results of the second phase of the Haida Gwaii Diabetes Project. <sup>99</sup> The methods section indicates that the first phase used grounded theory as a as the general qualitative analysis method, but does not provide further detail. <sup>99</sup> The results section of this article appears to present qualitative data for phase two, but it is not clear how these data were acquired and the analysis method is not identified.

Rosecrans et al. performed a mixed methods qualitative and quantitative process evaluation.<sup>84</sup> The methods section indicates that interview transcripts were read and analysed for themes, but no further detail is given of how this was performed.

In the mixed methods study by Narayan et al. the methods section does not indicate any qualitative data were collected. However, partway through the results section the reader is advised that qualitative data were collected, but the methods and philosophical underpinnings are not indicated. In a few lines the data briefly covered facilitators and motivators for behaviour change as experienced by participants. Quantitative data on percent of participants interested in continuing the intervention, changing the intervention they attended or quitting the intervention were lumped into the paragraph on qualitative methods.

In sum, most diabetes interventions in indigenous communities' were measured using quantitative methods, focused on biomarkers as outcome measures and have met with varying levels of success. In addition, most of these studies involved little to no qualitative data and analysis of outcome measures. The KSDPP exercise interventions provide an opportunity to use qualitative research to learn new information about the impact of physical activity classes.

### 2.3 Qigong

Qigong is a 3000-year-old type of meditation with thousands of forms and includes performing breathing exercises while holding postures, sitting or moving slowly. The goal of qigong is to encourage the healthy flow of qi, which in traditional Chinese medicine is understood to be the body's energy. Qigong is a type of self-regulation that affects both the mind and body. The mind is regulated by clearing it of any thoughts by focusing on breathing and a part of the body near the navel called the dantain. The body is regulated via the qigong movements and relaxation. Breath regulation refers to taking deep, slow breaths.

Literature reviews on qigong interventions and their effects on diabetes and other chronic health conditions found most studies were of poor quality because they were not replicable and contained significant procedural issues and bias when qigong was self-administered. Most Chinese studies were not designed to meet Western standards

of scientific research.<sup>113</sup> A review of the Chinese literature on the effects of qigong on diabetes found that 12 studies reported a complete cure in some patients.<sup>113</sup> These studies are particularly questionable since the generally accepted Western scientific perspective is that diabetes has no known cure.<sup>114</sup>

Studies have found qigong can lead to improvements in well-being and reductions in symptoms of anxiety and depression. Randomized controlled trials of qigong interventions for chronic health conditions have shown significant improvements in total cholesterol, immune cell counts, systolic and diastolic blood pressure, cardiac function, lung function and mood. Studies examining the effect of qigong on pain have shown inconsistent results. Two studies showed no significant effect while another study found a significant improvement in pain in both trial and control groups, but no significant difference between the two groups.

Not many randomized controlled trials have been carried out to examine the effect of qigong on type 2 diabetes. The intervention arms of randomized controlled trials of qigong plus usual diabetes care showed significant decreases in HbA1c levels, 112,113,123-125 blood viscosity, 112,126 2 hour serum glucose levels, 113,123, fasting blood glucose levels higher insulin sensitivity 113,123 and a significant improvement in blood glucose control 112,125 versus control groups of participants receiving usual diabetes care. One Chinese study by Feng et al tested the effect of qigong as the sole diabetes treatment in the intervention arm of a randomized control trial versus a control group receiving medication only. 113,128 They found a significantly larger decrease in fasting serum glucose and higher plasma insulin levels in the intervention versus control group. 113,128 A case-control study of qigong given two times a week for 10 weeks found no within-group or between group effects of the intervention on fasting plasma glucose, 2 hour plasma glucose, HbA1c or insulin sensitivity index. 129

Many uncontrolled, pre-post observational studies have been conducted that show the effects of a qigong interventions on type 2 diabetes by comparing outcome measures with baseline measures. These studies have found significant reductions in fasting plasma glucose, <sup>112,130-133</sup> 2 hour plasma glucose, <sup>112,130,131,133</sup> blood glucose, <sup>112,134</sup> total

cholesterol, <sup>133</sup> and triglycerides. <sup>133</sup> Inconsistent results were found for fasting insulin <sup>133</sup> and HbA1c levels. <sup>133</sup>

Only one study examined the effects of qigong as an intervention given to women at risk of developing type 2 diabetes. This study was of questionable quality since it was a pre-post test design with a very small sample of seven participants. Gates et al. found a significant increase in perceived healthiness, but no significant changes were found in other outcome measures including blood pressure, blood lipids and fasting blood sugar. 135

Chow and Tsang suggest that the biopsychosocial effects of qigong can lead to improved mind-body well-being. Their theory is twofold. First, via cognitive behaviour therapy, social interaction theory and distraction theory they suggest the psychosocial effect of qigong is mind regulation which could help reduce anxiety, calm and improve coping with illness and pain. This is developed through hypnotic suggestions to relax, cognitive cue words to suggest relaxation, use of visual imagery to clear the mind, progressive relaxation of muscles, joints and organs, participating in a mindfulness practice that stops one from thinking about stressors and by providing a non-competitive, relaxing social environment that may impact how practitioners experience personal relationships. Second, they suggest there is a physiologic effect of qigong that can be explained using cardiovascular fitness theory and the neurophysiologic theories: amine theory and endorphin theory. They suggest that qigong results in a process of body and breath regulation that could lead to improved mood and physical fitness. These two pathways lead to an overall sense of improved mind-body well-being.

#### 2.4 Yoga

Yoga is an 8000-year-old practice of exercise and meditation that includes many techniques and schools. Participants learn asanas that are poses held for set periods of time in order to increase physical strength and flexibility. The period of time a position is held is based on pranayamas that are breathing techniques that include cycles of inhalation, holding the breath and exhalation. Meditation, which is effortless concentration, is facilitated by focusing the mind on asanas, pranayamas and also mantras

or other meditation techniques. <sup>109,138</sup> This results in clearing the mind of thought and an increased awareness of the present. <sup>109,139,140</sup>

Much of the scientific literature on yoga is of poor quality for a variety of reasons including inappropriate use of controls, <sup>141</sup> a lack of randomization, <sup>141,142</sup> selection bias, <sup>141,142</sup> unaccounted for confounding variables, <sup>141</sup> problems with statistical analyses, <sup>141</sup> small sample sizes <sup>141,142</sup> and incomplete methods descriptions. <sup>141</sup> Study results are also difficult to compare due to the large number of styles of yoga tested and the duration and frequency of interventions. <sup>141</sup>

Yoga has been found to significantly reduce pain in carpal tunnel syndrome, <sup>143,144</sup> osteoarthritis, <sup>143,145</sup> chronic lower back pain, <sup>143,146-149</sup> hemodialysis, <sup>143,150</sup> fibromyalgia, <sup>143,151</sup> migraine <sup>143,152</sup> and joint pain in breast cancer survivors. <sup>143,153</sup>

Randomized and non-randomized controlled trials of yoga and its effect on stress in healthy subjects have found significant decreases in anxiety, depression, mental fatigue, perceived stress and negative affect. Well-being, mental health, degree of optimism and perceived overall health were significantly improved. 154,158-160,162

In addition, studies on the effects of yoga have found significant increases in strength, <sup>142,163</sup> endurance, <sup>142,163,164</sup> flexibility <sup>142,160,163,164</sup> and balance. <sup>142,164</sup>

Randomized controlled trials investigating the effects of yoga on mixed populations including participants with type 2 diabetes are inconclusive, with some studies finding significance where others have not. Randomized controlled trials found significant decreases in fasting blood glucose, <sup>141,165,166</sup> fasting HbA1c, <sup>141,166</sup> total cholesterol, <sup>141,165,167,168</sup> triglycerides, <sup>141,167-169</sup> low density lipoprotein cholesterol, <sup>141,167,168</sup> very low density lipoprotein cholesterol, <sup>165</sup> body weight <sup>141,167,168,170</sup> and the need for diabetes medications. <sup>141,166</sup> A recent randomized controlled trial in the UK of a yoga intervention given for 12 weeks found no significant changes in HbA1c, weight, waist circumference, blood pressure, blood lipid levels, cardiovascular risk score, quality of life or self-efficacy. <sup>171</sup> An American randomized controlled trial of yoga, given to participants with metabolic syndrome, recently found a significant increase in perceived energy level versus controls. <sup>172</sup> No significant changes were found for weight, BMI, waist circumference, blood pressure, insulin sensitivity index, fasting blood glucose, 2-hour

blood glucose, blood lipid levels, stress level, well-being, depressing, self-rated health, calorie intake, nor physical activity. <sup>172</sup>

Non-randomized controlled trials on patients with type 2 diabetes and mixed populations including participants with type 2 diabetes have found significant reductions in total cholesterol, <sup>141,173</sup> body weight, <sup>174</sup> HbA1c, <sup>174</sup> and low density lipoprotein cholesterol. <sup>141,173</sup> A study examining the effect of a yoga based lifestyle intervention found an overall significant increase in subjective well-being scores. <sup>175</sup> However, when analysed by disease, the results were not significant for participants with diabetes. <sup>175</sup> A recent study of healthy, male, long-term yoga practitioners versus controls found the practitioners had significantly lower fasting plasma insulin and higher insulin sensitivity. <sup>176</sup>

Uncontrolled, pre-post clinical trials of yoga on participants with type 2 diabetes and mixed populations including participants with type 2 diabetes found significant reductions in fasting blood glucose, <sup>141,177-181</sup> postprandial blood glucose, <sup>141,177,179-182</sup> blood glucose following a oral glucose tolerance test, <sup>179</sup> fasting HbA1c, <sup>141,177,180,181</sup> serum insulin, <sup>183</sup> total cholesterol, <sup>141,178,184,185</sup> low density lipoprotein cholesterol, <sup>178</sup> very low density lipoprotein cholesterol, <sup>178</sup> triglycerides, <sup>178</sup> systolic blood pressure, <sup>177</sup> diastolic blood pressure, <sup>177</sup> the need for diabetes medications, <sup>141,177,179,182,184</sup> and significant increases in high density lipoprotein cholesterol <sup>178</sup> and post-prandial serum insulin measured 30 minutes after performing yoga. <sup>183</sup>

A qualitative study of a yoga intervention given to participants with or at risk of developing type 2 diabetes found emergent themes regarding the motivators and barriers to yoga class attendance, physical and social environmental barriers or facilitators to yoga participation, and the difficulties surrounding making yoga a regular habit. Regarding the social facilitators to yoga participation, emotional support from other participants was appreciated. One participant indicated a benefit was stress reduction. Reference at al. defined the concept of being yoga which meant experiencing the effects of yoga throughout daily life. To explain this concept they quoted a participant who attributed their ability to perform the physical tasks of daily living to participating in yoga. The majority of their participants did not continue taking yoga classes, but instead integrated

into their daily lives the elements of yoga they found the most useful. <sup>186</sup> This study was of good quality since the paradigm, research methods and methods for ensuring the trustworthiness of data were well described.

A study by Skoro-Kondoza et al was a good example of how qualitative and quantitative methods can be used together. They examined an exploratory randomized controlled trial and performed a process evaluation of the effects of yoga given to participants with type 2 diabetes. <sup>171</sup> Extensive qualitative data were collected including: focus groups, text messages, participant and yoga instructor interviews, observational ethnographies, and relevant documents, for example, meeting minutes. <sup>171</sup> The qualitative paradigm of the study is explained as being thematic analysis following the constant comparative method and framework analysis. <sup>171</sup> From their references it is clear they followed the grounded theory methods of Glaser and Strauss. 171,187 However, it is interesting that they chose to follow a 1967 text when both Glaser and Strauss have since refined their methods and even branched off into different philosophical directions within the grounded theory paradigm. <sup>188</sup> No statistically significant results were found for any quantitative measures. <sup>171</sup> The qualitative results reported appeared to be somewhat limited considering the breadth of qualitative information sources. In summary, participants reported being nervous before the classes, that they liked the instructors, felt better after class and enjoyed socializing. 171 The voga instructors reported that the participants were not suited to a general yoga class due to their health conditions, classes should be longer, they disliked the class locations and that participants need to be encouraged to practice at home. 171 Ethnographic observation showed that participants enjoyed the classes and due to the health condition of participants either the instructor had to tailor the class to the participant or the person did not participate in the whole class. 171

# 2.5 Lay Health Workers in Diabetes Prevention

A lay health worker (LHW) is a non-health professional who provides health information to members of their own community. In the KSDPP context, the Community Intervention Facilitator is a lay health worker. Very little research is available on lay health workers involved in the primary disease prevention of diabetes. Most of the

diabetes prevention studies that utilized the expertise and experience of lay health workers, examined very little of their direct effect on the study outcomes.

Studies have shown that the experience of LHWs in diabetes prevention programs can enrich results. The LHWs in the Staten et al. study reported observing positive changes in participants, for example walking for exercise, which backed up the objective study result that showed a significant increase in moderate to vigorous walking. <sup>189</sup> In another study, the LHWs provided a valuable insight that participants were remarking on the psychosocial impact of the diabetes prevention program which lead the researchers to investigate this phenomenon. <sup>190</sup>

Other studies of LHWs in diabetes prevention and treatment interventions show that LHWs play an important role in making interventions culturally relevant. An analysis of the La Vida study, sought to identify the roles of LHWs. The LHWs were respected because of their ability to meet community needs in a culturally sensitive manner. LHWs have knowledge of the community infrastructure which is useful to help ensure study participants receive the health services they need and to overcome barriers to using the system. LHWs can communicate with study participants in the language of the participants using lay terminology. LHWs also help community members to make positive health behaviour changes. LHWs participate in capacity building in terms of health promotion to, for example, community institutions and businesses.

Williams et al. believed LHWs improve the cultural relevancy of diabetes prevention programs. Page 192 Increased cultural relevancy was found to be linked to increased satisfaction with the Eat Well Live Well Nutrition Program and increased satisfaction was linked to increased attendance. This suggests LHWs contribution to cultural relevance could be important to program satisfaction and attendance as well. The LHWs in the Simmons et al. study observed that the culturally relevant program was well received.

## 2.6 Stress and its role in type 2 diabetes

In humans, stress is experienced as a threat to internal homeostasis caused by internal or external forces that are physiological, environmental or psychological. <sup>194,195</sup> General adaptation syndrome is when individuals experience three stages of stress starting with alarm, which refers to the individuals' initial fight-or-flight response to the

stressor, followed by resistance to the stress and then exhaustion with prolonged stress. 194,196,197

Stress activates the hypothalamic pituitary adrenal axis (HPA axis) and sympathetic nervous systems (SNS). <sup>198,199</sup> When the former is activated, cortisol is released and inhibits the gonadal, growth and thyroid axes, inflammatory response and immune systems resulting in decreased lipolysis and increased bone and muscle catabolism. <sup>195,199,200</sup> The activation of the SNS results in increased catecholamines, inflammatory markers, central nervous system changes and decreased autonomic functions. <sup>195,199,200</sup> Prolonged exposure or inappropriate responses to stressors could thus result in metabolic or disease consequences. <sup>194,199,201</sup> Psychological and emotional stress can result in behavioural changes of decreased physical activity, increased caloric intake and also the activation of the HPA axis and the SNS which can all result in increased body fat which in turn could lead to the development of insulin resistance and type 2 diabetes. <sup>194,196,199,202-207</sup>

A growing body of evidence from longitudinal studies shows depression, anxiety, emotional stress, anger and hostility as potential factors in the risk of developing of type 2 diabetes. <sup>196,205,208-213</sup> However, Pouwer et al. found conflicting evidence for the relationship between stressors of childhood neglect, life events and work stress and the development of diabetes. <sup>196,214-221</sup>

Only one study was found that examined of the relationship between stress and diabetes in an Indigenous population. In a cross-sectional study of two American Indigenous peoples' reservations Jiang et al. found participants' risk of diabetes was significantly associated with psychological stressors including: early life interpersonal trauma 1.67 OR 95% CI (1.01, 2.77) and chronic stressors including discrimination 2.76 OR 95% CI (1.49–5.11) and community addiction problems 1.91 OR 95% CI (1.10–3.30).

## 3.0 Research Approach and Methods

## 3.1 Research Question

## **Development of the Research Question**

We determined that a qualitative analysis of the programs would be useful to find out how participants experienced the KSDPP workshops for adults and what meanings they attached to those experiences. Exploring the participants perceived experiences allowed for the investigation of how the workshops impacted participants' lifestyles. We wanted to find out if the perceived benefits of the workshops were the explicit goals of the programs (developing healthy eating habits, performing daily physical activity and feeling positive on a mental and spiritual level) or if there were other benefits for example, social interaction. We wanted to understand what encouraged and motivated participants to make lifestyle changes and if this was related to the support of friends and family, the Community Intervention Facilitator's teaching style, the participants' ability to incorporate the lessons into their own lives or the cultural focus of the workshops. We wanted to know the meaning that being engaged in a program to help prevent diabetes held for participants and how it affected their interactions with their family and the community. The research question was designed to guide the development of a theory to understand participants' experiences in a program to improve healthy lifestyles.

## The Research Question

How do the healthy lifestyle promoting workshops, as a process in which people participate, bring about transformative experiences that change how participants live their lives?

# **Meaning of Transformation**

Since the research question uses the term transformative, it is important to review how others have interpreted its meaning. Mezirow developed transformative learning theory - a theory of adult education. <sup>223</sup>

This theory suggests that people perceive the world through a frame of reference.<sup>223</sup> Frames of reference are one's assumptions about how the world and life work and include mental habits and points of view.<sup>223</sup> People use their frame of reference to understand and give meaning to their life experiences and to guide their actions.<sup>223</sup>

Frames of reference can be changed when an individual is exposed to a significant transformative personal or social crisis or by many small transformative experiences. When confronted with this kind of experience a person is forced to critically reflect on their basic assumptions that inform their frame of reference. Through personal reflection and discourse with other trusted people, assumptions can be changed and thus so too are the interpretations, beliefs, mental habits and points of view which make up a frame of reference.

Transformative learning is a process where new knowledge gained through metaphors, analogies and reflective dialogue leads to a transformative crisis or many small transformative experiences that results in a changed frame of reference or perspective. <sup>225,226</sup> New knowledge is then acted on from the revised frame of reference. <sup>225,226</sup>

# 3.2 Research Approach

## **Qualitative Research**

Qualitative research, unlike quantitative research, is not designed to result in numeric objective data that can be gathered to test a linear hypothesis.<sup>227</sup> Instead, qualitative research is designed to search out the reasons why phenomena are as they are and how they came to be.<sup>227</sup> It is useful for gaining deeper insights into personal transformational experiences. The data are necessarily subjective and ontological, because in this research approach true objectivity is believed to be neither possible nor beneficial. This methodology suits the research question since it provides the required data on the subjective perceptions and experiences of the workshop participants. The researcher is considered to be a participant in the research whose background, biases and opinions inform the entire research process. 227 This is unavoidable and acceptable because within the context of qualitative real world research, the fore-understanding of the research topic, is shared by the researcher and the participants. Instead of hypothesis testing, the theory of the phenomenon in question is revealed as the project develops, and in this way it is an emergent form of research. 227 The theory is not linear, but may be more of a map of interrelated factors, because this methodology seeks to find the multiple and complex ways in which events are influenced.<sup>227</sup>

Corbin and Strauss suggest sensitivity as an alternative goal to objectivity.<sup>228</sup> Sensitivity is the researcher's ability to find meaningful data and is achieved through the researchers' experience, knowledge, background and through a deep familiarity with the data.<sup>228</sup> It enables the researcher to be sensitive to the meaning in participants words, recognize when data are important, to comprehend and explain the participants' viewpoint and identify concepts and relationships between concepts.<sup>228</sup>

Qualitative analysis, including analysis following grounded theory, is an interpretive act, in that the researcher must interpret participants' words and translate them into study results. Depending on their field of analysis, researchers may interpret the same data differently. Researchers must use procedures flexibly in order to provide logical interpretations of the data that are grounded in the data. 228

## **Participatory Research**

This research project is situated in the KSDPP, which has formalized principles of participatory research as its research approach. This is an approach to research where members from the community work actively with academic researchers as equal partners in the research. <sup>229,230</sup> A resultant benefit of participatory research is the combining of community and academic expertise.<sup>231</sup> In participatory research the research project is often chosen and controlled by the community. <sup>230</sup> This is because the outcomes of the work must be relevant to the community so they can be used to facilitate positive social change and influence public health, that is, to improve their lives. 229-231 The end goal of this research approach is to reduce health disparities and improve the quality and length of life for people in the community where the research is performed.<sup>231</sup> This type of research arose as a remedy to a history of positivist, colonialist research done on marginalized communities by outside researchers. 230,231 With participatory research, marginalized groups gain control of the work and they are active participants in the research and in their community development. <sup>232</sup> In this way, participatory research is political. It allows disadvantaged groups to express their own voice and thus power and as such is a form of political activism that counters the hegemony of the dominant culture. 230,233 In addition "[participatory research] is a political process because it involves people in making changes together that will also affect others."233

The members of the KSDPP and the Community Advisory Board were interested in finding out information to guide the development of the workshops outlined above and other programs. In keeping with the principals of participatory research and the KSDPP Code of Research Ethics, the goal of this research was first to provide useful information to the community, secondly to provide results that add to an identified gap in the literature and thirdly to offer guidance to other communities, in particular indigenous communities.

The MSc nutrition student developed the research question with much assistance from the Community Intervention Facilitator, the KSDPP Research Team, the KSDPP Community Advisory Board and the academic supervisory committee. The MSc nutrition student drafted the interview questions, performed the data collection and analysis, however, this was under the review and guidance of the KSDPP Community Intervention Facilitator, Research Team, Community Advisory Board and the academic supervisory committee.

# Ontology, Epistemology and Reflexivity

Participatory research, sometimes called participatory action research (PAR), community based participatory research (CBPR), and action research or emancipative research has evolved into a paradigm in its own right. The ontology of PAR is such that reality is participated in and co-created through a reflective process by the community members and the researchers. <sup>232</sup> The process of PAR has been described as, "a spiral of cycles of planning, acting, (implementing plans), observing (systematically), reflecting and then re-planning, further implementation, observing and reflecting."233 PAR is thus reflexive. It involves frequent reflecting on the work done thus far in order to adjust the plans for work vet to come.<sup>233</sup> This reflection is done by all participants of the project: the community members and the researchers.<sup>233</sup> The epistemology of PAR is that knowledge is co-created and experienced by the community members and researchers via participating in critical subjective thought as part of the reflexive process.<sup>232</sup> This results in practical information or findings.<sup>232</sup> Cargo and Mercer suggest that then taking this research knowledge and translating it into useful, actionable knowledge is key. 231 The way knowledge is translated depends on the value or driver of the research which is usually social and environmental justice or self-determination.<sup>231</sup> This information can

then be used for positive community development. This is as McTaggart wrote, "a process of using critical intelligence to inform action, and developing it so that social action becomes *praxis* [practice] through which people may consistently live their social values."

### 3.3 Research Methods

### **Study Location**

The study participants are from Kahnawake which is located on the south shore of the St. Lawrence River near Montreal and was settled in 1716.<sup>55</sup> As of 2009, approximately 8000 members of the Mohawk Nation live in Kahnawake.<sup>234</sup> The Mohawk Nation are part of the Six Nations Iroquois or Haudenosaunee Confederacy.<sup>50,235</sup> Haudenosaunee means "People of the longhouse" in the Mohawk language Kanien'keha.<sup>50,235</sup> This community is committed to the preservation of Mohawk culture.<sup>55</sup>

Descriptions of the KSDPP and the workshops are in the significance and background section of this report. The KSDPP office shares a building with the community K103 Radio station and the Mohawk Council of Kahnawake Language and Culture Training Center. The workshops are held in a variety of locations including the Kahnawake Shakotiia'takehnhas Community Services Community Center.

## **Study Design**

The study design is a naturalistic inquiry of qualitative design. That is the data were collected via interviews and analysed using grounded theory as a research method.

In the context of participatory research there is room for a variety of research methods as it does not prescribe specific methods to follow. "In addition, PAR is versatile enough to be able to incorporate or adapt traditional evaluative methods of research." Participatory research could therefore include grounded theory. Grounded theory is a process of using data to form theories. The theory does not precede the data collection, but is developed only after data are gathered and as data are analysed. This research method is a good fit with the research question. It allowed for the analysis of workshop participants' experiences in order to construct a theory of how the intervention affected their lives.

In PAR, the cycle of reflexivity means that theories may develop as the data are collected. Thus in this study theory development proceeded during and after the data collection.

Criticisms of grounded theory include that grounded theory is bound to a specific time and place. The experiences of the workshops participants are bound to a time and place and thus generalizations formed from the research about them are generalizable to similar groups in a similar time period. This suits the participatory research approach quite well in that the knowledge uncovered by this study will be located in Kahnawake in the KSDPP workshops and may be used for their revision or the development of new workshops. This information will likely be useful to other organizations within Kahnawake for the development of their interventions. Also, other Haudenosaunee communities within the six Iroquois Nations may also benefit from the results of this study. In addition, non-Iroquois communities with similar backgrounds facing high rates of diabetes could use this information to develop or revise their own workshops.

Another criticism is that the method results in generalizations that overlook the specifics of the situation. <sup>236</sup> In keeping with participatory research approach, and the KSDPP Code of Research Ethics, it is acknowledged that the knowledge or theory developed from this study must be specifically relevant and useful to the community for project development or redesign and must meet the academic standards of researchers. There is no reason why any generalizations found using grounded theory methods would not be specific to the workshops because the study goal is not to find a universal theory but to find a theory relevant to the experience of the workshops participants.

Another criticism is that grounded theory results in linear relationships between variables.<sup>236</sup> There is no reason why the relationships found between variables would have to be linear because the data found via a grounded theory analysis may involve a web of relationships.

# The Research Participants

The research participants are the adult Kahnawake community members who participated in KSDPP workshops between 2007 and December 2010. According to the KSDPP Community Intervention Facilitator, the workshops are usually attended by

mothers (aged 18 to 40 years) of young children. This definition of the research participants was purposefully broad in order to not exclude those potential participants who are not young mothers, but were still be able to provide rich information toward answering the research question.

## **Key Information Holder**

A key information holder was the KSDPP Community Intervention Facilitator who instructs the workshops. She is devoted to her work and has strong conviction in its importance. Her status in the community is such that she is recognized as a leader for diabetes prevention. She has been running the programs since 2007 and had a wealth of insight to add to this study. Her knowledge informed each aspect of the research.

# **Sampling and Respondent Selection**

This study uses the purposeful sampling method called criterion sampling. Purposeful sampling is when participants are selected based on their knowledge about and experience with the research subject. 91 "Studying information-rich cases yields insights and in-depth understanding rather than empirical generalizations". 91 Purposeful sampling is not meant to be representative of the general population, but of the specific group under study. 91

Criterion sampling involves choosing participants who meet a specific criterion. <sup>91</sup> Criterion sampling can be used to find cases that elucidate weaknesses in programs in order to develop program improvements. <sup>91</sup> In this study, criterion sampling was used to select cases that helped elucidate how the workshops transformed participants' lives. The criterion for this study was repeat participation in multiple KSDPP workshops for adults. It was assumed that participants who returned to the interventions would be information rich cases. Participants with repeat attendance at more than one workshop were selected and no participants with repeat attendance at only one of the workshops were selected. It should be noted that this did not exclude workshop participants who ceased their participation in the workshops.

The Community Intervention Facilitator assisted in this process by preparing lists of potential study participants. Using her attendance records she selected participants who had participated in two or more different workshops. Her experience with the participants

was helpful in order to select those whom she believed would provide information rich cases. Using these lists, the Community Intervention Facilitator contacted potential participants by telephone to introduce the study. The Community Intervention Facilitator did not ask the subjects to participate, but asked if she could give their contact information to the MSc nutrition student. The Community Intervention Facilitator did not use a written script to follow when contacting potential study participants, as it was not felt to be appropriate since she knows these women well and it would have made the conversation artificial. However, a typical conversation followed along the lines of:

Hi [Participant's name]. How's it going? I just called to ask if you would be willing to talk to Jayne, about the workshops you've been coming to. Jayne's a researcher working with KSDPP. You might remember her. She came to some of the workshops. She's trying to find out how they might have helped you. If you're interested, could I give her your number so she could call you about it? She can tell you more about the research.

This process involved being present frequently at KSDPP in order to meet regularly with the Community Intervention Facilitator to find out who could be contacted. The MSc nutrition student via telephone calls to those who consented to be contacted did the enrolment. Participants were telephoned as soon as possible once their contact information was given to the MSc nutrition student. Interviews were scheduled for as soon as was convenient for the participant.

The sample size was originally set at 15 people including the Community Intervention Facilitator. It was increased to 18 because four participants were associated with KSDPP. Their association with KSDPP cannot be further defined here because this would risk making their identities knowable. This change was done to make the sample more representative of all workshop participants. These four individuals became valuable sources of information since their extensive experience with KSDPP helped fill in detail around the concepts that emerged from the other participants.

Theoretical sampling is a method for collecting and analysing data and involves selecting participants based on their ability to clarify emergent concepts.<sup>228</sup> Ideally each participant is selected after analysing the previous participant's interview in order to focus

questioning on developing the properties and dimensions of emergent concepts.<sup>228</sup> However, as Corbin and Strauss recognize this is not always possible.<sup>228</sup> Interviews in this study were conducted as participants were recruited in order to accommodate their schedules. Often participants wanted to be interviewed on their day of their recruitment. Frequently several interviews were carried out on the same day or took place a few days in a row. This did not allow time for analysis between interviews. To alleviate the risk of not getting enough information, participants were invited to talk about their experiences in the workshops at length and in great depth. In addition, the MSc nutrition student kept a list of emergent concepts that was updated during or after each interview for use in subsequent interviews to ensure all new topics were covered.

Corbin and Strauss advised theoretical sampling can be used when data have already been collected.<sup>228</sup> In this case and as in this study, theoretical sampling is performed sequentially for each interview text.<sup>228</sup> However, the risk of having under developed properties and dimensions of concepts exists.<sup>228</sup> As a result, a list of a few potential additional interviewees was prepared in case the need for more participants arose at the end of the initial analysis. Once the 18 interviews were analysed it was determined saturation had occurred since no new concepts emerged in the last few analyses and the relationships between concepts and their properties and dimensions were clear and developed in depth.<sup>228</sup> Thus additional interviews or analysis were unnecessary.

#### **Interviews**

First free and informed consent was sought from interviewees via the KSDPP Interview Consent Form (see Ethical Considerations, KSDPP Ethics Approval). Interviews were conducted on one occasion with each participant and were on average 54 minutes in length, but ranged from 23 to 141 minutes. It should be noted that the KSDPP Community Intervention Facilitator was not present at the interviews.

Interviews took place in one of several locations: a private room in the KSDPP office and when requested by participants' at their homes or work places when deemed acceptable to both the participant and the interviewer. The interviews were carried out in English because the interviewer speaks English. The majority of the population of Kahnawake speak English. Most people in Kahnawake do not speak the Mohawk

language fluently, though a Mohawk-immersion school was created in an effort to save the language and yearlong Mohawk language courses are available to adults.

The interviews followed the "interview guide approach." Semi-structured interviews were conducted using a list of topics to discuss. Specific questions were not designed in advance. The wording of questions was developed by the interviewer as the topics arose. <sup>91</sup> This allowed for a natural flow of conversation. <sup>91</sup>

The topics to guide interviews were developed in participation with community members to ensure relevance. The topics covered were developed with the assistance of the KSDPP Community Intervention Facilitator, Research Team and Community Advisory Board. These topics were conversation starting points. After asking a question based on a topic, the interviewer asked additional questions that flowed naturally from the interviewees' earlier responses. Probing for additional detail encouraged interviews to resemble a natural conversation where more depth of understanding of the interviewees' responses was possible. This helped to avoid "yes/no" or surface answers, which was important since we were searching for the meaning and perceptions of the participants' experiences in the workshops. In sum, a list of topics was prepared to guide the semi-structured interviews and more questions developed naturally based on the participants' responses to the initial questions.

The KSDPP Community Intervention Facilitator was also interviewed to gather her interpretation of how the participants experienced the interventions. She has been delivering workshops for KSDPP since November 2007 and has valuable insight. Dialogue continued between the researcher and the Community Intervention Facilitator throughout the research to inform the research and analysis processes.

The interview topics included general demographic topics, topics for questions that were asked of all participants, and some that were specific to those who took the cooking workshops or the physical activity workshops. The term, physical activity workshops, encompasses any or all of the following workshops: Fitness Program for Young Women/Mothers, Qigong, Yoga, Gentle Yoga and the physical activity portion of the Healthy Mind in a Healthy Body workshop. Note that the topics were designed to find out participants' perceptions of their experiences in the workshops. The focus was not to

try and measure specific changes in diet or physical activity as what we really wanted to find out was how participants perceived the workshops helped their lives and to find out what changes they made to their lives because of this experience.

# **Topics for Participant Interviews**

These topics were developed to find out how participants experienced the workshop, what lifestyle changes participants made and to uncover the meanings participants attached to those experiences and lifestyle changes.

- 1. Workshops attended.
- 2. Reasons for selecting the specific workshops.
- 3. Description of the workshop experience.
- 4. The meanings participants attribute to these workshop experiences.
- 5. Changes made to lifestyle. (Prompts for probing for detail could include changes in eating habits, types of foods cooked, cooking methods and exercise habits.)
- 6. Impact and meaning of these lifestyle changes.
- 7. Changes in feelings about food.
- 8. Changes in feelings about physical activity.
- 9. The support of friends and family and their response to the participants' lifestyle changes.
- 10. Teaching style of the Community Intervention Facilitator.
- 11. Interaction with other participants.
- 12. Benefits of the workshops.
- 13. Reasons for continuing or ceasing participation in the workshops.
- 14. Suggested changes to the workshops.

# **Demographic Topics for All Participants**

General demographic questions were asked to help develop a picture of who the participants were. They included:

- Age.
- Diabetes status.
- Diabetes status of immediate family (parents, siblings, partner or children).

## **Topics for the Key Information Holder Interview**

These questions were designed to find out how the Community Intervention Facilitator recruited participants and helped them maintain their attendance, her perception of the effects of the workshops on participants' lives and the cultural relevance of the programs.

- Recruitment of workshop participants.
- Methods for inspiring and motivating participants to make lifestyle changes.
- Perceived effects of the workshops on participants' lives.
- Uniqueness of the KSDPP workshops.

#### **Data collection**

Data were collected during the interviews via a Sony IC Recorder ICD-SX750 Linear PCM MP3 audio recording device and also included the interviewer's field notes taken during the interviews. During one interview a participant refused to have a portion of their interview recorded, but allowed notes to be taken.

## **Data Analysis**

The MSc Nutrition Student transcribed each recording into text using the word processor program Microsoft Office Word 2007 (Word) and then manually analysed the texts. In keeping with grounded theory, data analysis was started while data collection was still under way. <sup>228</sup>

In order to learn the methods of Grounded Theory the MSc nutrition student studied the text, "Basics of Qualitative Research, Techniques and Procedures for Developing Grounded Theory, 3<sup>rd</sup> Edition" by Juliet Corbin and Anselm Strauss. <sup>228</sup> To aid in properly employing Grounded Theory in this study, the MSc nutrition student prepared an analysis action plan using techniques from this text that was then reviewed by supervisory committee members and KSDPP Research Team.

Following the tenets of Grounded Theory each transcribed interview was read and examined for concepts. Concepts describe objects, actions or events that have similar properties.<sup>228</sup> In this study concepts are themes that emerged that were central to the individual's experience of the KSDPP workshops. Concepts were assigned codes which were terms that served to name the idea of the concept.<sup>228</sup> Coding is the process of

developing and naming concepts and their properties and dimensions.<sup>228</sup> Properties are the characteristics of concepts and dimensions are the individual variations in properties.<sup>228</sup> For example, the experience of feeling tension in the community and enduring a busy lifestyle were assigned the concept code stress. The feelings of tension and being busy were properties of the concept stress. The dimensions for example, would be the individual variation between participants in the manner in which a busy lifestyle was experienced.

A computer program was used to assist in the analysis of the interview texts. The Ethnograph version 6.0 (The Ethnograph) is a qualitative data analysis software program designed by Qualis Research.<sup>238</sup> The software does not analyse the data, but is a tool for organizing and coding data.

There were several benefits to using The Ethnograph for this process. First, it simplified the organization of coding since it associated codes with specific sections of interview text making it easy to search for codes or their associated text. The Ethnograph also provided a convenient way to track codes through code lists or trees. Second, it aided in the organization of memos by associating them with selected sections of interview text and they could be given headings and dated. Third, it provided a way of easily creating backed up copies of the data and analysis in the event of computer problems. This kind of tracking of the analysis was recommended by Corbin and Strauss.<sup>228</sup>

Memos are reflexive interpretations or analyses of the data written by the MSc nutrition student. They were written about emergent patterns and relationships between codes for each of the five interviewees. Memos that were similar between participants provided clues to finding out when concepts were really sub-concepts of a larger issue. They also provided a way of quickly recording multiple ideas which helped to avoid losing analytical thoughts. Corbin and Strauss' advice to focus on concepts and relationships instead of describing or summarizing the participants' experience in memos was followed as closely as possible. 228

An overall project file was created using The Ethnograph. Each transcript was formatted in Word to be compatible with The Ethnograph and loaded into the project file.

Corbin and Strauss recommended performing microanalysis which is open coding in minute detail, at the start of the analysis since it allows for identification of possibly important data for which the meaning is yet unknown, provides a good knowledge of the data, helps prevent the need to re-analyse data and makes later analysis flow more smoothly. Five interviews were microanalysed, which involved painstaking line-by-line examination of the interview data for emergent concepts that were then coded. At this stage all emergent concepts were coded. Codes that turn out to be not directly related to the research question can be dropped later.

Some concepts, for example lifestyle change, were anticipated, asked about during the interviews and searched for in the data. However, the majority of concepts came directly from the data, for example the unanticipated code stress. In addition, in-vivo names were used to code concepts. In-vivo codes are those that use the participants' wording in the code name. <sup>228</sup>

The advice of Corbin and Strauss was followed to develop concepts by asking four types of questions of the data. <sup>228</sup> Sensitizing questions involved examining the data to find out what had really happened to the participant. <sup>228</sup> For example, what did the participant do at the workshop? Theoretical questions were those that helped identify process. <sup>228</sup> For example, how does stress relate to learning physical activity? Practical questions were those that helped develop the grounded theory. <sup>228</sup> For example, what is the overarching theme under which all other themes are subsumed? Guiding questions were those that came out of the research question and served to guide the entire research process. <sup>228</sup> For example, did the participants have transformative experiences? In addition, comparative analysis was used and is where constant comparisons are performed between participants in order to elucidate the properties and dimensions of codes. <sup>228</sup>

The properties and dimensions of codes were developed using several techniques including: investigating what participants meant when they used a word in an unusual manner<sup>228</sup>, when they showed emotions<sup>228</sup>, when words referred to changes in perceptions or experiences over time<sup>228</sup>, when they used similes or metaphors<sup>228</sup>, the "flip-flop" technique which meant imagining what the experience of a participant would be like if

the opposite of their experience had occurred<sup>228</sup>, "waving the red flag" which involved investigating the use of words that showed participants' had strong opinions for example the words "of course"<sup>228</sup>, and exploring negative cases which was where a participant's experience did not fit with the typical participant experience.<sup>228</sup>

The interviews were analyzed for context, process and consequence concepts. Context refers to the problems, events, circumstances or situations experienced by the participants when they began and participated in the workshops.<sup>228</sup> Process refers to the actions, interactions taken and emotions experienced participants as a result of the workshops.<sup>228</sup> Consequences were the outcomes of the processes that were experienced.<sup>228</sup>

Once the first five interviews were microanalysed, the coded text and memos were organized into summary documents and edited for clarity. These documents were then used to prepare diagrams for each participant. Diagrams are useful tools for showing how concepts relate.<sup>228</sup> For each participant, several diagrams were prepared in order to refine the context and process codes and their interrelationships. At this point codes not relevant to the context and process of the participants experience as it related to the research question were dropped from the analysis. This included codes regarding facilitators and barriers to participation which came out of the microanalysis coding process and do not relate to the research question.

Next summary diagrams were prepared that combined the experience of those participants who attended the same interventions. This was the beginning of rich explanation webs that would ultimately lead to the creation of a Grounded Theory. For example, three of these five women participated in the Yoga workshop. Thus the context and processes were mapped for the Yoga experience. This early mapping of the experience within each workshop helped the MSc nutrition student refine relevant concepts and to more easily identify these concepts in the analyses of the remaining interviews.

The detailed analysis of these five interviews by the MSc nutrition student facilitated her learning of how to apply Grounded Theory to interview data. It also helped to determine which codes were relevant to the research question and which were not, so

that the remaining analyses would not focus on irrelevant codes. Along with the early mapping of participants' experiences, this allowed the general open coding of the remaining thirteen interviews to develop more smoothly with less revisions required of summary documents and diagrams. Following the analysis of each of the remaining thirteen interviews, the data for each were compared and added into summary diagrams for each of the workshops. The workshop summary diagrams were then revised multiple times in order to refine the relationships between codes and properties.

Once the workshop summary diagrams were completed they were compared to determine the core category. The core category is the main concept that encompasses all other concepts and is the first step in theoretical integration (integration). The core category in this study was improved health. Integration is the development of a theory that answers the research question. It involved detailing the relationships between context, process and consequences with the core category. Integrative diagrams were used to develop the relationships around the core category. This reinforced the need to exclude excess information and develop clear relationships between codes. Thus the diagram was revised many times to facilitate integration. Sub-diagrams were prepared for the four transformative processes that lead to the core category.

In Grounded Theory, three types of theory can be developed: substantive, middle range and formal theories. <sup>187,228</sup> Substantive and middle range theories emerge from the data, but substantive theories apply only to a specific process whereas middle range theories may apply to several processes. <sup>228</sup> Formal theories are abstract theories that can be applied across different research projects. <sup>228</sup> In this study a substantive theory was developed that explains how the workshops enabled participants to improve their health and their community's health.

## Validity and Reliability

Internal validity has to do with how closely the study results match reality.<sup>239</sup> Several methods were used to strengthen internal validity including triangulation, member checks, peer examination, and participatory/collaborative modes of research.<sup>239</sup> The concept of triangulation was used in the development of this study by including a mixture of data collection methods: participant interviews and key information holder

interviews. Consistent trends appeared between the data collected from the different interview types. A member check was done via a meeting with a subgroup of participants including the Community Intervention Facilitator where results were presented to ensure the interpretation fit with how they understood their words and experiences. The interpretation needed to be checked to ensure that it gave voice to their experience. In addition the results of the study were reviewed with the Community Intervention Facilitator to confirm the theory fit with her experience with the Workshops. Peer examination was used via the academic supervisory committee and the KSDPP Research Team. In keeping with the participatory and collaborative style of this research the KSDPP Research Team and CAB reviewed the results. Internal validity was also improved by going back to the original interview data and comparing it to the grounded theory to ensure it fit and that nothing was missed. 228

The internal validity of this study was increased by three of LeCompte and Preissle's list of four factors including long-term data collection, that interviews allow for the direct collection of data, and that the researchers reflexive introspection is included in the research.<sup>239</sup> Internal validity was also improved by the researcher's sensitivity to the data, as defined by Corbin and Strauss (see section Research Approach, Qualitative Research).<sup>228</sup>

Reliability has to do with the repeatability of the research and as a result, is not applicable to qualitative research. <sup>239,240</sup> The point is not to search to find results that are repeatable in all situations, but instead to look for results that are positioned in a particular location and time. Consistency in work methods is a better aim for a qualitative researcher. <sup>239</sup> This was accomplished via research skill training and by performing precise work. <sup>239,240</sup>

External validity exists when the research theories uncovered from the data can be used in other contexts.<sup>239</sup> The results of this study may well be transferrable to similar Haudenosaunee and non-indigenous communities.

An initial limit of this study, was that we were relying on one key information holder to provide observations about the workshops. However the four study participants

also associated with KSDPP were able to provide valuable additional insight through their recalled observations of others' experiences and their own experiences at the workshops.

# 3.4 Organization and Procedures

The Supervising Professor, Dr. Katherine Gray-Donald introduced the MSc nutrition student to the CAB, Research Team and Community Intervention Facilitator. Starting in May 2009 the MSc nutrition student volunteered for KSDPP. During this time she assisted the Community Intervention Facilitator with for example, the setup before and clean-up after workshops, and by preparing PowerPoint presentations on healthy foods. Through this active participation she had the fortunate opportunity to get to know the members of KSDPP, several CAB members, and met many members of the community of Kahnawake.

The research idea for this thesis was designed with assistance from the Supervising Professor and the Community Intervention Facilitator. In keeping with the KSDPP Code of Research Ethics, the proposal for this study was put through the KSDPP review and approval Process for ethically responsible research.<sup>241</sup> First the proposal was submitted to the KSDPP Research Team for their review.<sup>241</sup> Once approved in principle by the Research Team, the proposal was presented to the KSDPP CAB<sup>241</sup> on two separate occasions for their review. Following the first presentation, KSDPP CAB members had questions and recommendations that were addressed and incorporated into the study design before the second presentation. Before the study could begin ethics approval was required. This is elaborated in the section of this report titled Ethical Considerations. Once a Certificate of Approval was obtained from the KSDPP CAB, this was added to the ethics application package submitted for approval to the McGill University Faculty of Agriculture and Environmental Sciences Research Ethics Board (REB). 241 With ethical approval from McGill University, a summary of the research proposal and copy of the KSDPP CAB and McGill University REB Certificates of Approval were forwarded to the Onkwata'karitáhtshera Health and Social Services Research Council (OHSSRC) of Kahnawake for their general information.<sup>241</sup>

The researcher attended KSDPP Research Team meetings and CAB meetings in order to provide regular updates on the progress of the research. As a student researcher

she was also included on the KSDPP Research Team. The KSDPP dissemination process included preparing: summaries of the research for the OHSSRC's records and a report to be published in the local newspaper in Kahnawake, a draft scientific article for the thesis supervisor in the form of the thesis manuscript, and the draft thesis for the community and McGill University. Once the researcher's degree requirements are completed in December 2011 the data will be returned to KSDPP and the KSDPP Summary of Research form will be completed along with the provision of the researcher's permanent contact information to the Research Secretary. 241

### 3.4 Ethical Considerations

# **KSDPP Ethics Approval**

The research proposal for this study was submitted to the KSDPP CAB for their Review and Approval Process for Ethically Responsible Research. Once a KSDPP Certificate of Approval was received ethics approval from McGill University was sought.

The KSDPP requires that free and informed consent be given by participants via the KSDPP consent form. <sup>241</sup> This form conformed to the requirements of the KSDPP Code of Research Ethics. <sup>241</sup> It included explanations of the research project, that the participant can withdraw from the study at any time and the potential benefits to the community. <sup>241</sup> Immediately before each interview, the MSc nutrition student introduced and reviewed the KSDPP consent form with the participant. The participants were invited to ask questions they had about informed consent before signing the form. This form also provided participants with the contact information for the KSDPP study Ombudsperson Dr. Treena Delormier, KSDPP Research Coordinator Judi Jacobs, thesis supervisor Dr. Katherine Gray-Donald, supervisory committee members Dr. Ann Macaulay and Dr. Richard Hovey, and the Chair of the McGill Research Ethics Board for the Faculty of Agricultural and Environmental Sciences.

As elaborated in the organization and procedures section of this report, every step and aspect of the research was submitted for approval to the KSDPP research team and the CAB. Findings and progress was reported regularly to the KSDPP via research team and CAB meetings. This was done out of respect for the KSDPP Code of Ethics and due to the importance of accountability to the community in the participatory research

process.<sup>230</sup> In addition approval was always requested from the CAB before any public opportunity to discuss this study.

# McGill Ethics Approval

Once the KSDPP Certificate of Approval was received, the research proposal was submitted to the Faculty of Agriculture and Environmental Sciences Research Ethics Board (REB) of McGill University for approval. Accordingly the work respected the Guiding Ethical Principles required by the Tri-council Policy Statement Ethical Conduct for Research Involving Humans which includes respect for human dignity, free and informed consent, respect for vulnerable persons, respect for privacy and confidentiality, respect for justice and inclusiveness, balancing harms and benefits, minimizing harms and maximizing benefits. The first principle, respect for human dignity, was met through sensitivity and respect to the participants feelings, opinions, culture, and experience. In addition, the researchers who worked on this project respected the Haudenosaunee philosophy of research which includes ensuring fairness, equality and accountability in the work and in creating results that are useful to future generations of Kahnawake. 241

Free and informed consent was met via the explanation in the KSDPP ethics approval section.

Respect for privacy and confidentiality was met through several methods. All interviews were performed by a health professional (the MSc nutrition student who is a Registered Dietitian) who followed professional rules regarding confidentiality.

The interviews were conducted in a private setting and the MSc nutrition student did not use participants' names during the recording of interviews. However, participants were able to use names and provide identifying information during the interviews. As a result, any potentially identifying information (i.e. names or events) provided in the interviews was either not transcribed or deleted upon review of the transcripts.

The MSc nutrition student assigned a unique code from a random number table to each interviewee that was used to identify the MP3 recordings and subsequent transcripts in order to ensure confidentiality. The interview data were kept separately from the list of participants and their assigned codes and this list was destroyed once data collection was complete. Thus anyone who views the transcripts or hears the MP3 recordings will not be

able to link the individual participants to the data collected except potentially by voice recognition. The only person that knew which participant provided which interview transcript was the MSc nutrition student. However, since random numbers were used to identify participants before the analysis began, the confidentiality of the analysis process was enhanced.

During the research process data were kept at the KSDPP office and at the McGill University Office of the Food Habits of Canadians data centre on password protected USB flash drives. The USB flash drives were encrypted using the computer program TrueCrypt 7.0a<sup>243</sup> and only the MSc nutrition student knew the password to open these files.

At the end of the research, all data will be returned to the KSDPP. Prior to this, any potentially identifying information (i.e. names or events) was cut out and deleted from the MP3 recordings via the computer program Audacity1.3.13-beta (Unicode).<sup>244</sup>

Since KSDPP owns the data collected, they may choose to use the MP3 recordings and transcripts for further analysis. Because any potentially identifying participant information was deleted before the return of data to KSDPP, privacy and confidentiality was maintained. However, if a community member is given permission by KSDPP to hear the audio recordings, it is possible the participants' voices could be recognized, which is unavoidable. It should be noted that, only the use of the data for research purposes would be allowed. KSDPP members are community researchers and KSDPP has been in research collaboration with McGill University and Université de Montréal since its inception in 1994. The KSDPP Research Team, currently chaired by Dr. Gray-Donald, consists of both university and community researchers bound by not only their university codes of research ethics, but also the KSDPP Code of Ethics. Also, the Mohawk of Kahnawake, as a community and as members of the KSDPP, are highly protective of data collected about them for research purposes due to a history of positivist "helicopter style" research. It is for this reason that all research projects conducted in the community must be registered with the Onkwata'karitáhtshera Health and Social Services Research Council (OHSSRC) of Kahnawake. Therefore, it can be considered that the data will only be used for research purposes once it is returned to KSDPP.

The participants' names and identifying information were and will be excluded from the thesis, results provided to the KSDPP Research Team, CAB and community of Kahnawake and any publications or presentations based on the study results.

All study researchers were required to consent signing the Research Team Member and Key Informant Confidentiality Agreement. This included the Community Intervention Facilitator because she contacted workshop participants to introduce the study and thus knew which workshop participants were potentially involved in the research.

Respect for justice and inclusiveness was ensured via the review processes with the KSDPP, CAB and the REB. Also this was done through ensuring the research was not exploitative via the participatory research process.

A potential foreseeable harm that could have occurred during the interview process was that participants could have been reminded of emotionally difficult subjects that could have resulted in emotional duress for the participant<sup>239</sup> and/or the interviewer. The MSc nutrition student was prepared to provide support to anyone who experienced this sort of stress by referring them to the appropriate health care professionals and/or community groups. A list of health care professionals, community groups and their contact information was prepared in advance of the interviews. However, no participants or the interviewer experienced this sort of duress and thus no referrals were made.

# 4.0 Manuscript

Understanding how workshops transform participants' lives by exploring their perceived experiences: the Kahnawake Schools Diabetes Prevention Project

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#### 4.1 Introduction

Obesity is a complex condition fuelled by an imbalance of energy intake and expenditure.<sup>245</sup> Obesity and sedentary lifestyles are major risk factors for the development of type 2 diabetes.<sup>46</sup> Postponing or preventing diabetes is possible with major lifestyle modifications including 150 minutes of moderate exercise per week while consuming a low fat and low energy diet.<sup>10</sup>

The Mohawk Nation are part of the Six Nations Iroquois or Haudenosaunee Confederacy. 50,235 Haudenosaunee means "People of the longhouse" in the Mohawk language Kanien'keha. 50,235 The Kanien'kehá:ka (Mohawk people) of Kahnawake, a Mohawk community near Montreal, Quebec, have a traditional food system based on agriculture, gathering, hunting game and fishing. Past and present colonizer society influenced their lifestyle such that over several hundred years dramatic decreases occurred in participation in traditional physical activities for example farming, consumption of traditional food and some cultural knowledge was lost. Diabetes in Kahnawake is increasingly prevalent. Between 1986 and 2003 diabetes rates in males 18 years and older increased from 6.0% to 8.4% and in females 18 years and older from 6.4% to 7.1%. These rates are higher rates than those for Canadians in general, 53 but lower than rates in other indigenous communities.

Kahnawake community members, health professionals, educators and academics created the Kahnawake Schools Diabetes Prevention Project (KSDPP) in 1994 in an effort to reduce the incidence of type 2 diabetes in their community. KSDPP follows a participatory research approach, where members from the community work actively with academic researchers as equal partners. Since 2007, a KSDPP Community Intervention Facilitator created several new workshops for adults including the Healthy Mind in a Healthy Body Workshops offered once a week for five weeks (a lecture series promoting positive lifestyle change that covered nutrition, traditional food, physical activity, diabetes prevention, mental and spiritual health), weekly gentle and standard yoga classes, Haudenosaunee Foods Cooking Workshops ("Cooking Workshops" featuring traditional foods) held intermittently at the discretion of the intervention coordinator, Fitness Program for Young Women/Mothers ("Women's Fitness Program"

which included a free Kahnawake Youth Center membership that included unlimited free access to the Center, weekly sessions at the weight and exercise room and one session with a personal trainer) and weekly qigong classes (which included meditation, breathing exercises and mild physical activity). The workshops were held in a variety of locations in Kahnawake and, when possible, were conducted by community members.

The majority of the literature on the effects of qigong or yoga classes aimed at treating or preventing type 2 diabetes, do not follow Western standards of scientific research and are methodologically questionable. 109,111-113,141,142 Studies of cooking 61,70,72, yoga 141,165,166,171,172,174,176-179,183 and qigong 112,113,123-127,130-135 classes and also physical activity interventions aimed at reducing type 2 diabetes in indigenous communities 83,94,97-101,103-106,108 have focused on measuring quantitative biometric and anthropometric values and met with varying degrees of success. Studies of cooking classes have also examined changes in food and nutrient intake. 60-63,65,66,68-70,72 For this study, a cooking class was defined as being a class where participants participated in the preparation of food. Classes where participants only observed the preparation of food were considered to be food or cooking demonstrations.

There is very little qualitative literature on cooking, yoga, qigong or physical activity classes in indigenous communities aimed at preventing type 2 diabetes. Pelican et al very briefly reported on positive changes in healthy cooking habits made by Indigenous cooks. Participants of a study on the effects of cooking classes given to Indigenous Australians with or at risk of developing type 2 diabetes experienced improvements in healthy eating knowledge, cooking skill and healthy dietary changes for example increased vegetable consumption. The same study also identified facilitators and barriers to healthy eating.

Qualitative literature on physical activity interventions aimed at preventing type 2 diabetes in indigenous communities is limited to exceptionally brief sub-sections of quantitative studies and focused on identifying elements of interventions that participants enjoyed and motivators for making healthy behaviour changes. 84,99,103

Qualitative studies of yoga interventions have identified motivators and barriers to performing yoga<sup>186</sup> and the likes and dislikes of yoga class participants and teachers.<sup>171</sup>

No qualitative studies were found that examined the effects of qigong interventions given to people with or at risk of type 2 diabetes.

The KSDPP Workshops have not been studied and needed to be explored to understand what effects they have on participants' lives. This qualitative study seeks to answer the research question: How do the KSDPP healthy lifestyle promoting workshops, as a process in which people participate, bring about transformative experiences that change how participants live their lives?

#### 4.2 Methods

## Enrolment criteria, sampling and recruitment

Participants were some of the adult, female Kahnawake community members (n=17 out of 21 contacted) who participated in KSDPP workshops from 2007 to December 2010. A key information holder was the Community Intervention Facilitator who instructs the Women's Fitness Program and the Cooking Workshops. Purposeful, criterion sampling,<sup>91</sup> was used to select those with repeat participation at more than one of the workshops in order to provide information rich cases. This included workshop participants who ceased participating in the workshops. The Community Intervention Facilitator used attendance records to prepare lists of potential participants and introduced them to the study by telephone. The principal investigator completed enrolment by telephone.

## **Data collection**

One semi-structured interview was conducted with each participant following an "interview guide approach" using a list of discussion topics. <sup>91</sup> Topics were developed to find out how participants experienced the workshops, what lifestyle changes they made following the workshops, and the meanings participants attached to those experiences and changes. General demographic questions were asked of all participants. Interview length was on average 54 minutes (range 23-141 minutes). Additional questions were asked of the Community Intervention Facilitator to examine her perceptions of the effect of workshops on participants' lives. Interviews were recorded with a Sony IC Recorder ICD-SX750 Linear PCM MP3 audio recording device. Identifying information was

deleted from the MP3 recordings via the computer program Audacity1.3.13-beta (Unicode).<sup>244</sup>

# **Data Analysis**

Interview recordings were transcribed into text using the word processor program Microsoft Office Word 2007. Interview texts were manually analysed following grounded theory<sup>228</sup> methods. The Ethnograph version 6.0 (The Ethnograph) designed by Qualis Research,<sup>238</sup> was used to organize coding and memos.

Post data collection theoretical sampling was conducted on the interview texts.<sup>228</sup> The first five interviews were microanalysed which involved detailed line-by-line open coding of all emergent concepts.<sup>228</sup> Memos were written to develop the meaning of concepts which are themes central to the participants' experience of the KSDPP workshops.<sup>228</sup> Subsequent interview texts were analysed and coded only for concepts relevant to the research question. Concepts were elaborated in terms of their properties, dimensions and whether they were related to context, process or consequences.<sup>228</sup> Summary documents of each participant's experience were prepared.

Extensive diagramming and constant comparisons<sup>228</sup> were performed to map and integrate<sup>228</sup> participants' experiences of the Workshops to produce a theory grounded in the data. Saturation was deemed to have occurred when no new concepts emerged and relationships between concepts and their properties and dimensions were clear and well developed.<sup>228</sup>

# Validity

Validity of the study results was achieved through triangulation via participant interviews, the key information holder interview and the observations of participants who were also associated with KSDPP; member checks with a subgroup of participants and the key information holder; peer examination via the academic supervisory committee and the KSDPP Research Team; and by following a participatory and collaborative research approach.<sup>239</sup> Internal validity was also improved by comparing the original interview data to the grounded theory to ensure a good fit<sup>228</sup> and through the researcher's sensitivity to the data, which was achieved through the principal investigator's experience, knowledge, background and a deep familiarity with the data.<sup>228</sup> Consistency

in work methods was accomplished via research skill training and performing precise work in keep with the tenets of grounded theory. <sup>239,240</sup>

## Research Ethics

The research followed the KSDPP Code of Research Ethics<sup>241</sup>, the Guiding Ethical Principles required by the Tri-council Policy Statement Ethical Conduct for Research Involving Humans<sup>242</sup> and respected the Haudenosaunee philosophy of research which includes ensuring fairness, equality and accountability in the work and in creating results that are useful to future generations of Kahnawake.<sup>241</sup> This study was first approved by the KSDPP Community Advisory Board via their Review and Approval Process for Ethically Responsible Research<sup>241</sup> and then by the McGill University Faculty of Agriculture and Environmental Sciences Research Ethics Board. Participants provided written consent and an ombudsperson (author Treena Delormier) was available to address any concerns.

### 4.3 Results

# **Participants**

The mean age of participants was 47 years (SD 15) and ranged from 25 to 69 years. The 17 participants interviewed had a total of 46 instances of individual workshop participation (mean of 2.7 workshops) which were distributed as follows: Qigong 5 participants, Gentle Yoga 5 participants, Yoga 9 participants, Women's Fitness Program 6 participants, Cooking Workshops 9 participants and Healthy Mind in a Healthy Body Workshop 12 participants.

The majority of participants were identified as having a traditional or Longhouse perspective. Longhouses were the traditional dwellings of the Mohawk people (Kanien'kehá:ka). Today the Longhouse is a centre for traditional ceremonies, political activity and has become a symbol for and is part of a way of life. One participant explained:

"...a Longhouse background... People that were tryin' to find the language. People that were tryin' to find culture and identity."... Longhouse people are people that are learning the language and trying to find roots in the community, who are

participants in the Longhouse way of life... A connection between the spirituality, the gardens, the earth, the dances, the cooking."

Having either a Longhouse or a Western philosophical perspective affected participants' perceived experiences of the interventions. Participants with a Longhouse perspective preferred the cultural elements of workshops. One participant with a Western philosophical perspective did not, although she recognized these traditions are valuable to those who practice them. For this participant, having a Western philosophical perspective meant believing in the scientific method and being sceptical toward other perspectives.

The Community Intervention Facilitator designed the Workshops to incorporate the Mohawk cultural multi-dimensional approach to health called whole health or in Mohawk, ionkwatákarí:te, which means "we are healthy". Thus the Workshops covered a variety of topics (including physical activity, healthy eating, Mohawk culture, spiritual and mental health) and were implemented in a variety of ways (for example lectures or hands-on activities). As a result the Workshops appealed to people interested in different kinds of activities and who enjoy learning in different ways. For example, one participant explained how she preferred the hands-on style of the Cooking Workshops and the Women's Fitness Program. She stopped attending the Healthy Mind in a Healthy Body Workshops because she felt it involved too much sitting and listening. Barriers to attendance were not investigated in depth because this was not a study objective. Some participants did not enjoy nor continue to attend interventions they started and cited reasons that were mainly logistical including the timing of the workshops, but also because of health problems, not enjoying the class size or lack of time to attend.

### **Overview: Theoretical framework**

A theoretical framework, shown in Figure 1, was developed that covered the experiences of all study participants. The main themes are shown linked together by arrows. Participants' personal challenges were acted on by experiencing the transformative processes that resulted from attending the KSDPP Workshops. Before joining the workshops, participants needed to first decide that doing something for oneself was acceptable. The bottom of Figure 1 shows how the transformative processes led participants to experience feelings of improved health and improved community

health. In the sections to follow, each of these themes are detailed in terms of their subthemes, properties and inter-relationships.

# Personal challenges experienced by participants

Participants related experiencing several personal challenges before joining a KSDPP Workshop. They felt they lacked traditional knowledge and healthy lifestyle skills and experienced stress, isolation and health problems.

Participants felt they did not know enough about the beliefs, values, customs, spirituality and cultural history of Kanien'kehá:ka in order to participate in cultural traditions. They felt unable to partake in or role model healthy lifestyles because they lacked skills including knowing how to cook, grocery shop for healthy food and how to perform physical activities. Health problems experienced by participants included the physical effects of illness, injury and aging (for example diabetes, cancer, surgeries, chronic pain, hip problems and arthritis). Some older participants felt isolated due to age related decreased mobility, a few women talked about being lonely and young mothers felt isolated at home with their young children.

Stress was experienced as tension, worry, burden and concern due to feeling overwhelmed with the busy tasks of daily living and external events or circumstances in the community. An example of community stress was the presence of the St. Lawrence Seaway:

"...It's a constant reminder of the governments imposing all kinds of things on us that...is not culturally or traditionally relevant to us. And so these are constant physical reminders of...the stress level that we're always under."

#### A difficult decision

Participating in a KSDPP workshop was perceived as doing something for oneself. In order to join a workshop, the women needed to first decide that taking the time to care for and do something for oneself was acceptable and valuable. This was a difficult decision, because, at the same time it was also a choice not to do something for anyone else. Participants had to overcome their senses of guilt and selfishness that came from feeling they were neglecting the people they usually care for by taking time for themselves. One participant captured this experience well:

"'Cause I'm always doin'! Look I'm makin' a cake for somebody. I'm makin' supper for someone, you know? I'm always doing that... And I can say that this [yoga] is for me. And that there's no other place I can say that, but there... It's like, to allow yourself to do that is a big thing when you're always doing stuff for someone else... At this point when I go there it's just for me, the hell with all of them and their problems! That's what I say too."

## **Transformative processes**

The Workshops provided opportunities for participants to enter into transformative processes, which enabled the participants to overcome, manage or cope with their personal challenges. The experiences of the participants were organized into four transformative processes: 1) food skills, 2) stress coping and physical activity, 3) cultural traditions and 4) community participation.

# 1) Food skills

The Cooking Workshops facilitated the transformative process of learning food skills, shown in Figure 2. The participants described how they learned to value cooking their own food, make healthy food choices and to cook healthy food that tasted good. Through these experiences, participants developed the confidence to cook and grocery shop for healthy food. A participant gave voice to this process in the quote below:

"...well it's different for me because I don't know about everybody else, but I don't know how to cook. [Laughs.] ...Well my friend she's making fun of me. She said, "Come on you gotta get your hands dirty," and stuff like that. [Laughs.] Like you have to touch the food and stuff like that. And it was kind of embarrassing. But then I did, I started to learn. I, even like, to wash potatoes when you're using just like the peelings on it. Like to really scrub it."

Another participant explained how the workshops affected her grocery shopping habits:

"'Cause I only realized after I did the workshops, ...how I was already just automatically changin' my grocery shoppin'. I guess I would just think back and

be like, "Oh yeah, okay. Okay I'm not gonna get that. I'm not gonna get this. I'm gonna get this instead."

These experiences, as shown in figure 2, led participants to cook healthy food for themselves, their family, friends and other community members, which gave them feelings of accomplishment and pride. They spoke both of their own and others' enjoyment and appreciation of the food. These feelings came together to create an overall sense of increased well-being. For the purpose of this study well-being refers to feeling good about oneself.

Participants came to value the importance of healthy eating, which changed how they felt about the way they and other people ate.

"'Cause it drives me nuts when, if I go to eat with other people, like my friends and their kids, they have just a slice of pizza. Like if we go to a buffet. A slice of pizza and they'll get some French fries on their plate. It probably wouldn't'a bothered me if I didn't take these workshops."

Participants became role models and advocates for healthy eating through the sharing of food. For this study, being an advocate means promoting a healthy lifestyle and its benefits to others. Role modeling refers to performing healthy behaviours that other people could potentially emulate.

A few participants knew how to cook before joining the Cooking Workshops and did not experience the above process. These women attended for the feeling of community participation explained in transformative process 5.

### 2) Stress coping and physical activity

The transformative processes of developing stress coping and physical activity skills are intertwined because they evolved together out of the Women's Fitness Program, Qigong and Yoga (gentle and regular) Workshops.

As shown in Figure 3, path 1, by performing and learning to do physical activities in the workshops participants developed the confidence to perform physical activities which led to a sense of accomplishment and pride.

Path 2 of Figure 3 illustrates how participants spoke of experiencing physical health benefits from the workshops including feelings of increased strength, flexibility,

balance, experiencing less pain and weight-loss. Because of the different types of activity in the Qigong, Yoga and Women's Fitness Program, the physical health benefits that occurred varied between participants. A participant described the moment when she realized her strength had improved:

"I moved this summer. And I had to haul, you know, quite a number of things. Boxes. Bins. You know, that kind of thing. And it occurred to me at some point that I was able to do those things... I mean I did attribute it to the yoga."

These physical health benefits often helped participants cope with their health problems. One participant with chronic pain explained:

"And then I was in a lot of pain. And the physiotherapist suggested different exercises, maybe five or six, and I couldn't do any of them. Every one of them caused me pain. ...But since I've started going to yoga, I don't take the medication every day."

Path 3 shows that in performing physical activity at the Workshops participants' minds became focused on the exercises and breathing. Although most participants did not feel that these Workshops provided a connection to spirituality, a few participants of the Yoga and Qigong felt that mental focusing was a spiritual experience that was compatible with their traditional spiritual beliefs.

Participants found it difficult to think about much else while actively focusing. This included not thinking about sources of stress such as personal problems, tasks of everyday living or worrying about how classmates perceived participants' ability to perform the physical activity in the Workshops. The Community Intervention Facilitator echoed the sentiments of Workshop participants with her words:

"The yoga classes and the qigong were very centering and focusing. Where you're gonna take your mind out of a stressful day. Leave that there because now you're focusing on just movement. ...And the more you get into this yoga like breathing and just exercising and focusing on your body, the more you learn how to break away from a stressful situation."

At this point paths 2 and 3 merged when participants experienced positive feelings of calm mind, increased energy, patience, feeling relaxed, less stressed and better mood. One older participant explained how having more energy affected her life by giving her more time to do things for herself:

"Well, what I notice right after the class, I can go shopping. ...I went shopping after yoga. Then I went to the movies and that's not like me. I only do one or two things a day. But that day I did three. And I never went to bed till like eleven o'clock!"

The combined effect of experiencing these positive feelings was that participants developed a sense of readiness to confront sources of stress in their lives.

"It [the Women's Fitness Program] just like makes you feel more ah capable and able... It gives like a energy push like. I can do that! I can take that on today!"

When they confronted their sources of stress, participants felt it was easier to decide how they truly thought and felt about their problems and could then make better decisions.

A participant explained how she found this process empowering:

"...If you have something difficult in your life and whatever, you feel powerless, but when you do certain exercise, like I did a weight training and this [Yoga] and if it involves power, then you got some power somewhere."

The Yoga and Qigong techniques became tools participants could use for relieving stress during physical or emotional crises. A participant explained how she used the breathing techniques from Yoga to help her cope with acute pain after surgery:

"I couldn't even cry it hurt so much. So then I just did, from the yoga, the deep [breathing], ...'Cause I didn't even wanna know, did they make an incision? Or did they, were they able to do the robotic? But okay, I says oh God just do that deep breathing through my nose. And I fell asleep."

The figure concludes with three more outcomes: participants experienced improved well-being, continued the same physical activity after the Workshops ended or

found new ways to be physically active, and they role modeled and advocated for physical activity and stress coping skills for their friends and family. For example, a woman who attended the Women's Fitness Program explained how the benefit of stress relief impacted her well-being:

"Major, major stress relief at the gym... It [the Women's Fitness Program] really does help you relieve a lot of stress and you feel good after you leave. I'm like yeah, you did something for yourself. You feel good about yourself."

A Yoga participant explained how she became a role model to her friends:

"Well I only live with my husband, but my girlfriend said, "Gee, ever since you're taking yoga, you're doin' all kinds of things." I said, "Yeah, it really, really works." She says ah, "So now a lot of girls wanna take yoga!" [Laughs.]"

## 3) Cultural traditions

Figure 4 shows the transformative process of learning cultural traditions experienced in the Cooking Workshops and the Healthy Mind in a Healthy Body workshop. At these workshops participants learned to prepare traditional foods and about traditional medicines. Some women received spiritual guidance that fit with their traditional Mohawk spiritual beliefs. Other women felt the mix of mysticism and philosophies presented did not mesh with their traditions.

Learning and participating in these activities that their ancestors would have carried out gave participants opportunities to experience feelings of connection with their ancestors, history and spirituality. The Community Intervention Facilitator spoke about the importance of feeling these connections:

"To me, I like cooking with our cultural foods because that's what our ancestors ate. And that's our foods. And I don't want it to be just a memory. Corn, beans and squash as a memory, like a ghost. Like, you know, talking about something that happened in the past. I want when you say corn, beans and squash you mean it, because you've tasted it. You prepare it. You eat it. ...It lives in you. 'Cause we are, what we eat. We are our foods. So if we can learn that, there's a connection between the foods and our ancestry."

Often the experience of connection was accompanied by a sense that this was an opportunity to regain traditional knowledge lost due to the effects of colonization.

"Because we lost so much. And nobody realizes how much they don't know. They really don't realize how much they don't know. They think they know enough, but they don't. And then when you finally know some things, you're like, "Wow! Really? That's where I come from? That's what we did? And I'm doin' it now!" ... Even though everything was taken and gone. And we could still do it because people still know."

Participants felt that having the opportunity to experience these connections with their traditions informed their sense of identity which led to a sense of increased well-being. This participant explained how cooking with squash for the first time, made her feel:

"That was the first time I ever actually used squash... Yeah. In soup and 'cause...before that I never actually did it myself. I never even touched it or washed it or nothing like that until she did it with us... It makes me happy. [Laughs.]"

The participants became role models through sharing traditional knowledge and food with family and friends. The Cooking Workshops gave this granddaughter a special opportunity to participate in her culture with her grandfather:

"I loved that. ...I was so happy 'cause I was able to take leftovers [traditional cornbread] home. And I brought my grandfather a plate. And I'm like, "Here Baba." And he's like, "Oh my goodness! I didn't have this since my mother was alive." Yeah! So it was really nice 'cause I was like kind'a showing him that like I'm trying [to learn her traditions]."

Mothers wanted to share their new knowledge with their children to help them develop their own sense of identity. This mother explained:

"Because I didn't have anybody to make me learn my way...And as I got older I didn't know what I was... So, I don't want them [her children] to be lost."

### 4) Community participation

As shown in figure 5, the Women's Fitness Program, the Cooking Workshops and the Healthy Mind in a Healthy Body Workshops gave participants opportunities to experience the transformative process of community participation. Spending time only with family and friends did not provide a feeling of community participation. This participant's words show her excitement about the opportunity for community participation via the Workshops:

"When I got a little more information about it [the Cooking Workshops] I really was anticipating to come 'cause my daughter would be watched and I could cook and I could hang out with my friends and I could be out. You know? Be out! Be a part of the community again. Not at home doing nothing."

At the workshops participants shared with friends and other women they did not normally see. Sharing meant talking about the workshops, commonalities and their lives. They enjoyed laughing, having a good time, participating and learning together and also learning from each other. A sisterly, family atmosphere developed between participants at the workshops:

"One day when I went they were all cutting vegetables and they were laughing and telling stories and the kids were right in front of them and their hands were going. Kids were putting stuff into bowls. One mother was feeding her baby and changing diapers and washing. And then somebody would hold the baby while she did something. ...It looked like a family gathering rather than a workshop."

As shown in figure 5, this led participants to develop a sense of group belonging and feelings of improved well-being. As one participant explained:

"It was a fun gathering. We're all there in the kitchen you know. Some were cutting this. Some were cutting that. And we were all joking around. It was fun."

# Theory of improved individual and community health

The transformative processes showed changes in four different aspects of individual health (bottom of figure 1 and figure 6). These included improved intellectual,

spiritual, emotional and physical health. An additional aspect of health, community health, was influenced by the other four aspects of individual health.

Intellectual health was improved through learning new skills and knowledge in transformative processes food skills (Figure 2), stress coping and physical activity (Figure 3) and cultural traditions (Figure 4) and by sharing with other participants during process 4, community participation. Participants spoke about feeling satisfied to have learned something new.

Spiritual health was improved for some participants by having opportunities for spiritual experiences and by receiving spiritual guidance in the transformative processes stress coping and physical activity (Figure 3) and cultural traditions (Figure 4). The Community Intervention Facilitator explained that having good spiritual health is necessary for maintaining good overall health:

"Because if you're happy in the mind and happy in the spirit you're not gonna be out there looking for...a big donut or something."

Emotional health, defined as how participants felt about themselves, was improved via the stress coping skills learned in transformative process 2 (Figure 3), through the development of feelings of confidence, accomplishment, pride that occurred in transformative processes food skills (Figure 2) and stress coping and physical activity (Figure 3), and improved well-being that arose in all four processes. A participant described the Workshops' emotional impact:

"I really love the Community Intervention Facilitator's workshops. I do. They make you like, I don't know what the word would be... They do. They just make you feel good about yourself. You know, just flat out, that's the bottom line. They make you feel good."

Physical health was improved via the physical health benefits including coping with health problems and continued physical activity that occurred via transformative process 2 and also through consuming healthy food via transformative process 1.

By improving the intellectual, spiritual, emotional and physical health of community members it can be said that community health was improved. Community

health was also improved through the role modeling and advocacy for healthy lifestyles performed by workshop participants who underwent transformative processes 1, 2, and 3. For example when the Women's Fitness Program ended, a participant explained how she returned to the gym, convinced her mother to join and in the quote below she explained:

"I was thinkin' about myself at first. But then after a while I was thinking like, oh my god you know I want my mom to be involved with me you know? But then I'm thinking about my auntie. ...Like she has diabetes and we've been tryin' to get her to come. My mother especially. She's been tryin' to get her to come to the gym too."

#### 4.4 Discussion

Mezirow's transformative learning theory suggests that people perceive the world through a frame of reference that includes assumptions about how the world and life work, mental habits, beliefs and points of view. Frames of reference are used to understand and give meaning to life experiences, to guide actions and can be changed by transformative experiences like those from the KSDPP workshops. Transformative learning is a process where new knowledge leads to a transformative crisis or many small transformative experiences that result in a changed frame of reference. New knowledge is then acted on from the revised frame of reference. The participants of this study experienced transformative learning that resulted in improved health.

For many Indigenous people the medicine wheel is a symbol for harmony and connectedness at the universal or individual level. The four quadrants represent individual elements including the spiritual, physical, emotional and intellectual self. Traditional thinking indicates that people who live a balance between these elements are thought to be happy, productive and capable of sharing, caring, trusting and respecting others. When the balance is maladjusted it is traditionally thought to result in poor health. The productive and capable of sharing thought to result in poor health.

During the analysis of this study data emerged showing transformations in participants' perceived physical, intellectual, spiritual and emotional health. The medicine wheel was selected as the theoretical model for this study (Figure 6). Although it is not an

original Mohawk tradition, the medicine wheel was used in health promotion by a physician<sup>247</sup> from Kahnawake and is an accepted model used in many communities.

As shown in Figure 6, participants experienced improved physical health. In the food skills transformative process participants reported making healthy food and food choices which is consistent with studies of cooking classes that found improvements in healthy food intakes and eating habits. 60-63,66,69,70,72,73 Participants also reported experiencing improved physical health from physical activity. This is consistent with studies of yoga and qigong that found significant improvements in participants' physical health 110,135,142,160,163,164,249-251 though some of these results may be questionable due to methodological issues. For example, studies of qigong and yoga interventions were found to have small sample sizes and poor descriptions of randomization, blinding and methodological procedures. 111,141,142 Studies of physical activity interventions in North American Indigenous communities have met with varying degrees of success showing significant improvements in biomarkers (for example weight loss), 97,98,103 no changes in biomarkers, 97,100,103-106 undesired increases in biomarkers (for example increased body fat) and qualitative research found participants felt stronger, healthier and more mobile. 99,186

Many participants continued to be physically active once the KSDPP workshops ended. Another study of a physical activity intervention with Indigenous Americans did not result in significant changes in post intervention leisure physical activity. A yoga intervention for diabetes prevention and treatment resulted in participants integrating elements of yoga into their daily lives by, for example, performing yoga stretches, meditation or breathing exercises daily. Reference on the physical activity and the provided physical activity and the provided physical activity and the physical activity and physical activity. A yoga intervention for diabetes prevention and treatment resulted in participants integrating elements of yoga into their daily lives by, for example, performing yoga stretches, meditation or breathing exercises daily.

As shown in figure 6, intellectual health was improved through learning new skills during the first three transformative processes. This included cooking skills, which is consistent with studies of cooking classes. <sup>60-63</sup>, <sup>66</sup>, <sup>71</sup>, <sup>75</sup> In transformative process 2, participants learned physical activity skills. Changes in intellectual health have not been studied in Indigenous North American populations participating in diabetes prevention interventions.

In transformative process 3, cultural traditions (Figure 4), participants learned Mohawk cultural traditions. Most physical activity interventions in indigenous communities were designed to be culturally relevant by including for example traditional values, physical activities, methods of learning, seasonal and cultural foods, and incorporating print material and art featuring Indigenous people. 83,84,95-97,99,100,102,103,105,106,108 It appears that culturally relevant health promotion interventions are designed so that participants may better relate to the material and thus be more likely to adopt healthy lifestyle advice. This has not yet been shown in the diabetes prevention literature. The KSDPP workshops were designed to contain cultural content. In this study we found participants improved their sense of personal-cultural identity due to the connection they felt with traditional material in the KSDPP workshops. It may be that this improved sense of identity is important for improving the adoption of healthy lifestyle advice.

Intervention design should recognize the importance Indigenous people place on spirituality and its relationship to health. 83,95,96 It is not surprising that some participants felt the KSDPP yoga and qigong workshops were spiritual experiences since they are types of meditation considered to be spiritual pursuits. Some physical activity diabetes prevention interventions in indigenous communities have included elements of traditional spirituality in their design, but none have investigated their effects on spiritual health. Tuture studies of diabetes prevention interventions may want to examine whether Indigenous people experience a better balance in other areas of health if spiritual health is improved.

Emotional health was improved by the KSDPP workshops (Figure 6).

Participants' improved confidence to cook is consistent with some studies, 62,63,73-75 though others have not shown changes in cooking confidence. 62,63 KSDPP workshop participants' improved confidence to do physical activity is consistent with another study. 106

The transformative process of community participation was important for participants who felt isolated. There is little literature regarding the social elements of diabetes prevention workshops in indigenous communities. Social isolation and lack of

social support were found to be barriers for nutrition related health behaviour change.<sup>82</sup> Cooking classes were social experiences that informed the motivation to attend, peer support, enjoyment of the class and improved self worth.<sup>60,62,67,73</sup> Unlike the present study, Abbott et al found that following a healthy diet could be socially isolating.<sup>60</sup>

A growing body of evidence from longitudinal studies shows depression, anxiety, emotional stress, anger and hostility as potential factors in the development of type 2 diabetes. <sup>196,205,208-213</sup> The diabetes risk for a group of American Indigenous people was found to be significantly associated with psychological stressors. <sup>222</sup> In our study, physical activity was found to lead to the development of stress coping skills, which was an emotional health benefit of the KSDPP workshops. Similarly, a heart disease prevention intervention with Indigenous Alaskans found women significantly increased their use of physical activity to decrease stress. <sup>106</sup>

Paths 2 and 3 of transformative process 2, stress coping and physical activity, that evolved out of the yoga, gigong and Women's Fitness Program, are very similar to a theory of the biopsychosocial effects of gigong. 136 Chow and Tsang suggested the psychosocial effect of qigong is mind regulation developed through relaxation, clearing the mind, and mindfulness practice to avoid contemplating stressors in a non-competitive environment which could help calm, reduce anxiety and improve coping with illness and pain. 136 One of the goals of voga and gigong meditation is clearing the mind of thought to increase awareness of the present moment. 109 This fits with the KSDPP participants' experience of not being able to think about sources of stress while focusing their minds on activities performed. The outcomes of meditation are feeling relaxed, better mood and compassion. 109,253 The participants of a gigong intervention for rural women found participants reported feeling more energy to do activities, less stress, relaxation and that they could accomplish goals. 135 These effects are similar to the KSDPP participants' experience of positive feelings, shown in Figure 2. The feeling of being ready to accomplish goals is comparable to the KSDPP participants' readiness to confront sources of stress.

Chow and Tsang also suggested the physiologic effect of qigong may be physical fitness and improved mood, <sup>136</sup> which is quite similar to path 2 of the KSDPP stress

coping and physical activity transformative process. Both the psychosocial and physiologic pathways of Chow and Tsang's theory led to an improved sense mind-body well-being. <sup>136</sup> Improved well-being was also experienced by the KSDPP participants.

Well-being was improved in all four transformative processes (Figures 2 to 5) of the KSDPP workshops. Minimal literature was found on physical activity and cooking class interventions that reported an effect on well-being. Sawchuk et al found no effect of a randomized physical activity trial on well-being. Castagnetta et al reported a qualitative finding that participants receiving a diet intervention experienced a feeling of well-being. 64

Typically the centre of the medicine wheel represents the Creator or the individual.<sup>247</sup> The centre of the theoretical model in Figure 6 is community health. The external portions of the medicine wheel represent aspects of the individual while the centre recognizes the individual's belonging to and influence on the community.

KSDPP workshop participants influenced community health by becoming role models and advocates in the first three transformative processes. The KSDPP workshops participants' decided it was acceptable to choose to do something for themselves before they joined a workshop. They were concerned that by joining a workshop they were neglecting others. Through the workshops they learned new skills to help themselves be healthier and then they role modeled these skills to others.

A few studies of physical activity interventions in indigenous communities and cooking classes have found evidence of participants' role modeling and advocating for healthy lifestyles and inspiring others to make healthy changes. <sup>64,74,83,101</sup> The Zuni Diabetes Project went a step further for participants who had lost weight and developed blood glucose control, by encouraging them to become stronger role models via leadership training. <sup>101</sup> It is important to design interventions to create role models and advocates for traditional and health knowledge because as in the present study, participants become sources for this knowledge and encourage others directly and indirectly to pursue a healthier lifestyle.

One of the limitations of this study was that only women were invited to participate. With one exception, the Healthy Mind in a Healthy Body workshop, the

KSDPP workshops were attended by women only. It is possible the experiences were different for men who attended the Healthy Mind in a Healthy Body workshop. With one exception, all participants of this study had a Longhouse perspective. People with different perspectives may not experience the same transformative processes. All participants self selected to join the KSDPP workshops and could be somehow different from the general population. The experiences of the workshops may be difficult to replicate since they were led by a charismatic community member with strong leadership qualities who also has a Longhouse perspective.

### 4.6 Conclusion

To the best of our knowledge this is the first study to use in depth qualitative research to examine Indigenous women participating in cooking workshops and physical activity interventions in North America. This study shows how culturally relevant health promotion interventions can bring about healthy changes in the physical, intellectual, spiritual and emotional aspects of the daily lives of participants which may aid in the prevention of diabetes. The results may be used to enhance existing or create new interventions in Kahnawake or to develop health promotion and diabetes prevention programs in other communities.

A benefit of the whole health approach to creating workshops was that by providing a diversity of programs with in depth coverage of a range of health topics, participants with different interests or perspectives could be reached. The practical implications of this study include that workshop subject matter and advertising should emphasizes and nurture 1) the positive value and importance of choosing to do something healthy for oneself via joining a workshop; 2) the development of the transformative processes found in this study. Future workshops with Indigenous people should be designed to impact and evaluate all four elements of the Medicine Wheel of individual health and to nurture the development of role modeling by providing leadership training.

### 4.7 Acknowledgements

This study was supported through a Master's Fellowship provided to the principle investigator by the Anisnabe Kekendazone – Ottawa Network Environment for Aboriginal Health Research (NEAHR) that is funded by the Institute of Aboriginal

Peoples' Health, Canadian Institutes of Health Research. The principal investigator would like to thank KSDPP, the community of Kahnawake, the supervising professor and supervisory committee for their support of and contributions to this study.

Figure 1: Theoretical Framework

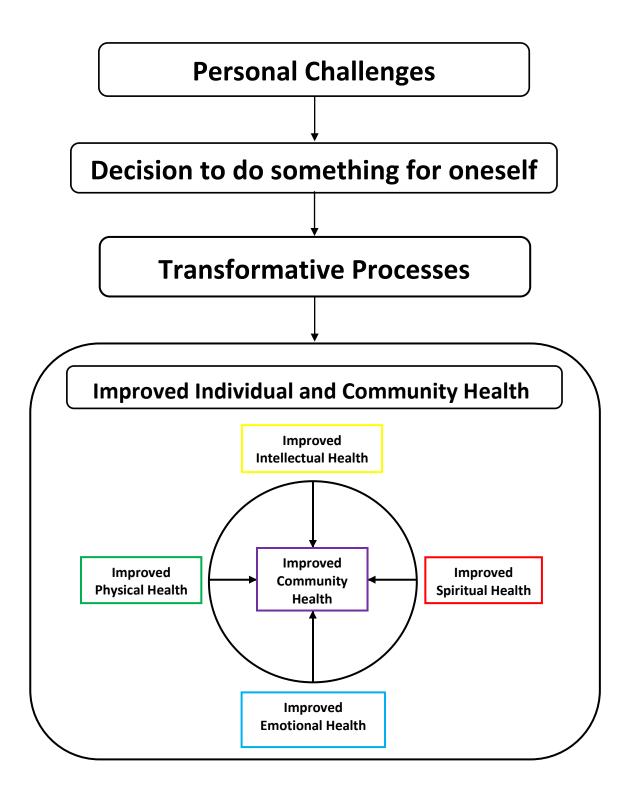


Figure 2: Transformative process 1) Food skills
Haudenosaunee Foods Cooking Workshops

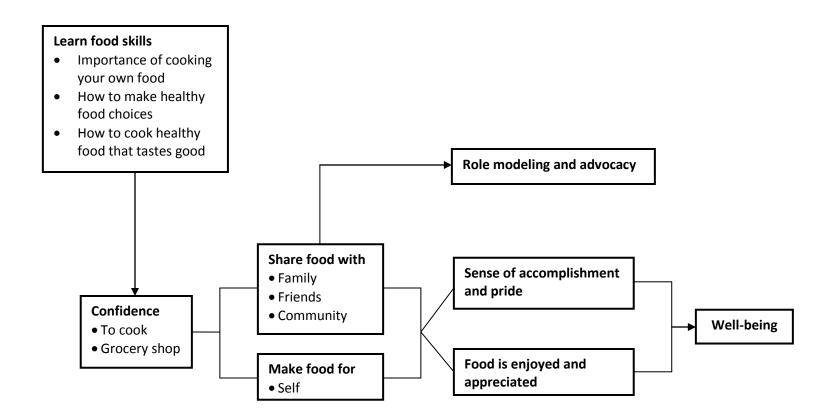


Figure 3: Transformative process 2) Stress coping and physical activity
Qigong, Yoga and Fitness Program for Young Women/Mothers Workshops

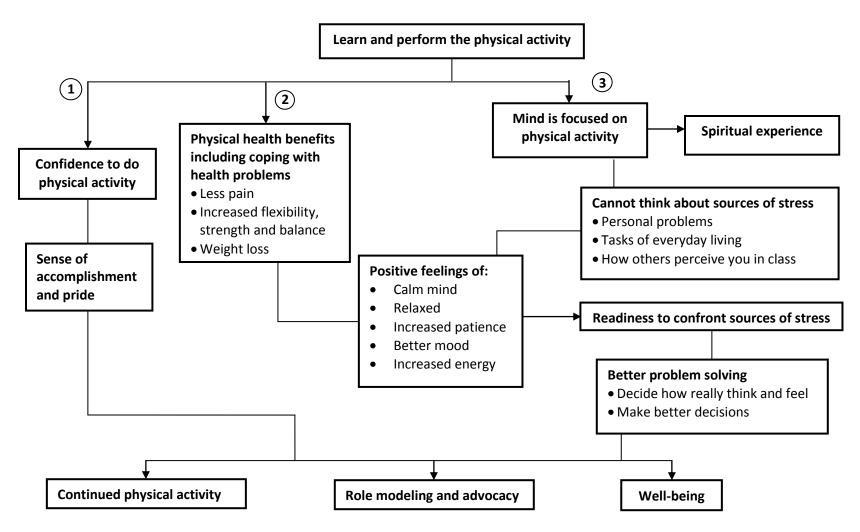


Figure 4: Transformative processes 3) Cultural traditions
Haudenosaunee Foods Cooking Workshops and Healthy Mind in a Healthy Body Workshop

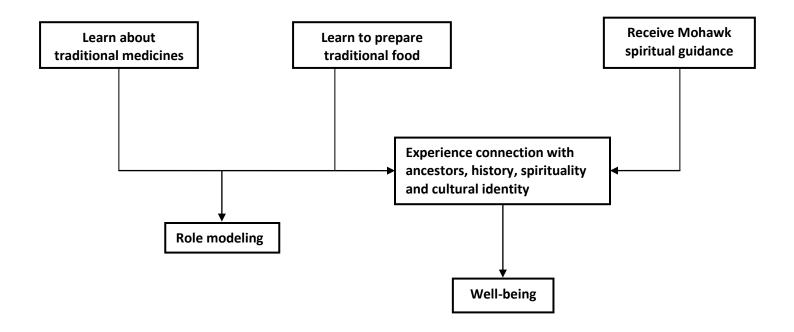


Figure 5: Transformative processes 4) Community participation

Fitness Program for Young Women/Mothers Workshops, Haudenosaunee Foods Cooking Workshops and Healthy Mind in a Healthy Body Workshop

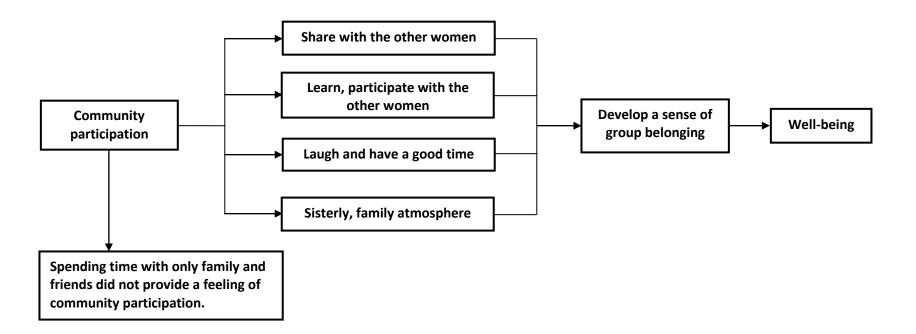
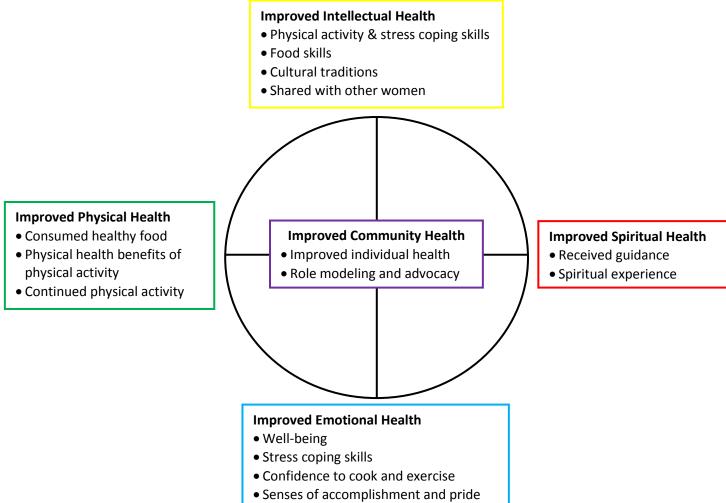


Figure 6: Theory of improved individual and community health



#### 5.0 Conclusion

To the best of our knowledge this is the first study to use in depth qualitative research to examine Indigenous women participating in cooking workshops and physical activity interventions in North America. This study shows how culturally relevant health promotion interventions can bring about healthy changes in the daily lives of participants and changes in their physical, intellectual, spiritual and emotional health which may aid in the prevention of diabetes.

The qualitative research method was selected as the most appropriate way to answer the research question. Using grounded theory we were able to explore participants' perceptions about their experiences in the KSDPP workshops and the meanings and impacts they associated with these experiences. This method did not impose limits on the kinds of experiences that could be investigated. Using open-ended interview questions we were able to learn about different types of anticipated and unanticipated changes participants' underwent. Grounded theory allowed us to find deep insights into the participants' subjective experiences. This method was helpful for uncovering un-anticipated changes in participants' lives and finding patterns in participants' experiences and behaviours.

In addition, qualitative research does not impose a hypothesis to be proven or disproved by data.<sup>227</sup> Instead, we developed a grounded theory that emerged from the data that explained how the health of participants and their community were impacted by the KSDPP workshops.

Participants of the KSDPP workshops influenced community health by becoming role models and advocates for healthy lifestyle change. The participants' needed to decide it was acceptable to choose to do something for themselves before they joined a KSDPP workshop. They were concerned that by joining a workshop they would be neglecting others. Through the workshops the participants learned new skills to help themselves become healthier and then they role modeled these skills to others. Future workshops in Kahnawake and possibly elsewhere could emphasize that making this difficult decision is an opportunity to develop the many different healthy lifestyle skills outlined in Figure 6, for example stress coping and physical activity skills. It could be emphasized that

attending workshops results in a positive impact on the health of other people through participants' role modeling and advocating for healthy living, for example through sharing healthy food and encouraging others to be physically active.

Qualitative research results are not meant to be generalizable to all populations. <sup>91</sup> The results of this study are specific to women living in a Mohawk community close to a large urban centre. Their lives, culture and experiences may differ greatly from the lives of other Indigenous people. However, attempts could be made to replicate this study to examine whether findings are applicable to other populations. Also, the results of this study could be used to guide the development of research questions investigated in studies in other communities.

A benefit of the whole health approach to creating workshops was that by providing a diversity of programs with in depth coverage of a range of health topics, participants with different interests or perspectives could be reached. Participants experienced four transformative processes, which impacted the four elements of their health shown in the medicine wheel: physical, intellectual, spiritual and emotional. Future workshops with Indigenous people should be designed to impact and evaluate all four elements of the Medicine Wheel of individual health and to nurture the development of role modeling by providing leadership training.

Doing this study gave me the chance to develop expertise in developing, implementing, analysing and writing a qualitative grounded theory study. I value having these skills as I can take them with me from the academic sphere into my future work.

I also had opportunities to develop other forms of expertise. I learned how a community based participatory research project functions. Already I have given invited presentations to national and international audiences on my knowledge and experience of working with this type of research approach. The greatest lesson I learned through this process was that it takes time to build trusting relationships to do research with indigenous communities. The participatory research approach by nature takes longer than other types of approaches. It includes consulting all parties involved to receive their feedback on all aspects of the research. The benefit of taking the time to work together is the creation of a study that will have results with the potential to actually impact the

community with whom the study was developed. As a researcher, this is the most important outcome to me – that my work will be meaningful and useful to the people with whom I worked. I feel I have accomplished this goal.

Participatory research has provided me the opportunity to further develop my career in Indigenous peoples' nutrition and research because of the friendships and connections I made with KSDPP Research Team, Community Advisory Board and Intervention Team. Through a member of the Research Team I was invited to be a research assistant for a project on fish consumption through the Northern Contaminants Program of the Tulita Renewable Resources Council in Tulita, North West Territories.

To aid in the return of results to KSDPP, I will be preparing a summary of the practical applications of this research to give to the KSDPP Research Team, Community Advisory Board and especially the Community Intervention Facilitator so she may implement them as she sees fit. The KSDPP Community Advisory Board may want to use the results of this study to inform new workshops. The results will be returned to the community of Kahnawake through the publication of results in the local newspaper and possibly also on local radio and television programs. The results will be submitted (and hopefully published) in a scientific article so they may be used or adapted in other indigenous and non-indigenous communities for the development of other diabetes prevention and health promotion programs.

It is often difficult to recruit participants for studies in indigenous communities where people already feel overly examined by researchers. I had the unusual situation of having eighteen participants and several more potential participants at the end of data collection for this study with KSDPP. I attribute this to 1) the friendly relationship and trust I developed with the Community Intervention Facilitator by volunteering for her and developing the study with her; and 2) the time I spent visiting the KSDPP workshops so that I would be familiar to participants.

Eighteen participants is an unusually high number for a qualitative research study due to the large amount of data generated by that many interviews. As a result, there is the potential to re-analyse the data from the perspective of new research questions. Future plans for the data are tentatively arranged around 1) a hermeneutic retelling of the results,

2) an examination of the facilitators of healthy behaviour change, 3) the importance of culturally relevant interventions, and 4) the effect of the lay health worker, the Community Intervention Facilitator. Through working with KSDPP's Research Team we recently (in 2011) received funding from the Aboriginal Diabetes Initiative of the First Nations and Inuit Health Branch of Health Canada to continue analysing these data to characterise the practices involved in providing culturally appropriate interventions.

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# 7.0 Appendix A: Interview Forms



## KAHNAWAKE SCHOOLS DIABETES PREVENTION PROJECT

P.O. Box 989

Kahnawake Mohawk Territory, via Quebec, J0L 1B0

Research Team Member and Key Informant Confidentiality Agreement
Understanding how workshops transform participants' lives by exploring their
perceived experiences: The Kahnawake Schools Diabetes Prevention Project.

The purpose of this research study is to understand how the KSDPP healthy lifestyle promotion workshops may bring about experiences that change how participants live their lives. The workshops include Healthy Mind in a Healthy Body Workshops, yoga classes, Haudenosaunee Foods Cooking Workshops, a Fitness Program for Young Women/Mothers and chi gong classes. The study findings will be shared with the KSDPP intervention team and the community before they are published locally, nationally or internationally. Results will have the potential to enrich the current KSDPP workshops and will add to our understanding of community approaches to changing health attitudes and behaviours.

 Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g. recordings, transcripts) with anyone other than the Research Team members and the Principal Investigator.
 Once data are denominalized (all identifying data removed) and analysed some direct quotes will be used in the research reporting as we will portray the words of some participants.

- 2. Not divulge the names of study participants, nor confirm or deny the participation of individuals in the study in order to protect their anonymity.
- 3. Keep all research information in any form or format (e.g. recordings, transcripts) secure while it is in my possession.
- 4. Give all research information in any form or format (e.g. recordings, transcripts) to the Principal Investigator when I have completed the research tasks.
- 5. After consulting with the Research Team members, erase or destroy all research information in any form or format regarding this research project that is not returnable to the Principal Investigator (e.g. information stored on a computer hard drive) upon completion of the research tasks.

Print Name

Signature

Date

Principal Investigator

Print Name

Signature

Date

Date

If you have questions or concerns about this study please contact:

Principal Investigator: Jayne Murdoch (Tel.: 438-321-7445,

Email:jayne.murdoch@mail.mcgill.ca).

Jayne is a master's of science student at the School of Dietetics and Human Nutrition at McGill University, under the supervision of Dr. Katherine Gray-Donald (Tel.: 514-398-7677, Email: katherine.gray-donald@mcgill.ca), supervisory committee members Dr. Ann Macaulay and Dr. Richard Hovey, Judi Jacobs the KSDPP research coordinator (450-635-4374) or Treena Delormier who is the KSDPP ombudsperson for this research project (450-635-4374). This study has been approved by the KSDPP Community Advisory Board and the Research Ethics Board of the Faculty of Agriculture and Environmental Sciences of McGill University.



## KAHNAWAKE SCHOOLS DIABETES PREVENTION PROJECT

P.O. Box 989

Kahnawake Mohawk Territory, via Quebec, J0L 1B0 Tel.: (450) 635-4374 Fax: (450) 635-7279

### **Interview Research Consent Form**

Understanding how workshops transform participants' lives by exploring their perceived experiences: The Kahnawake Schools Diabetes Prevention Project.

This research project is part of the Kahnawake Schools Diabetes Prevention Project (KSDPP). KSDPP has been involved in promoting diabetes prevention in the community of Kahnawake for the last 16 years. The main aim of the KSDPP is to prevent type 2 diabetes through promoting healthy eating habits, physical activity and a positive attitude. Using a "whole health" approach, KSDPP created workshops for adults including Healthy Mind in a Healthy Body Workshops, yoga classes, Haudenosaunee Foods Cooking Workshops, a Fitness Program for Young Women/Mothers and chi gong classes. The purpose of this research study is to understand how the healthy lifestyle promoting workshops may bring about experiences that change how participants live their lives. The study findings will be shared with the KSDPP intervention team and the community before they are published locally, nationally or internationally. Results will have the potential to enrich the current KSDPP workshops and will add to our understanding of community approaches to changing health attitudes and behaviours.

You are invited to participate in a face-to-face interview, or possibly a series of 2 interviews, with the researcher, who will ask questions about your experiences in the KSDPP workshops. In particular she will ask about what the workshops were like; changes in lifestyle and feelings about food and physical activity; and the meanings you attribute to these experiences and changes. She will also ask about the support of other people; the benefits of the program, and why you attended and/or stopped attending the workshops.

The interviews will last about 1 to 1½ hours. The interview will be conducted at your convenience, at the KSDPP office, in the home office of the KSDPP Community Intervention Facilitator Elaine Delaronde, in your home, or another location that you prefer. The interviewer will ask your permission to audio record the interview using an MP3 audio recording device. Audio recording will help the interviewer to access all the ideas from the interview once it is finished. If you are uncomfortable at any time during the interview you may ask to have the audio recording stopped.

This study has been approved by the KSDPP Community Advisory Board and the Research Ethics Board of the Faculty of Agriculture and Environmental Sciences of McGill University.

## **Confidentiality**

All of the information that will be collected will be kept strictly confidential. As a result, any information that could identify you, your family or friends will be excluded from the results provided to the KSDPP Research Team, Community Advisory Board, community of Kahnawake, the researcher's master's of science thesis and any journal publications based on the results of this study. We may use a quotation from what you have said to support an important idea. However, neither your name, title nor any organizations to which you belong will be attached to that quote.

The recorded interviews will be transcribed (typed up) and any information that could identify you, your family or friends will be removed or changed from the transcribed document to ensure your confidentiality. Every precaution will be taken to ensure that none of the information given during the interview will be linked to your name or the name of a member of your family or friends. Recordings of the interview will be stored on password protected USB flash drives in a locked filing cabinet at the KSDPP office and at McGill University. During the study, only the master's of science student Jayne Murdoch will have access to the recordings and transcripts. Since the KSDPP owns the data collected, they may choose to use the MP3 recordings and transcripts for future further analysis. It should be noted that, only the use of the data for research purposes would be allowed.

## **Risks**

The potential risk associated with your participation in this study is minimal. Although unlikely, during the interview process, it is possible that you could be reminded of an emotionally difficult subject that could result in emotional duress. If this happens, support will be given to you by providing you with the contact information for the appropriate health care professional and/or community group.

#### **Contacts**

If you have any comments or concerns, or need any additional information, you should contact Jayne Murdoch (Tel.: 438-321-7445, Email: jayne.murdoch@mail.mcgill.ca). Jayne is a master's of science student at the School of Dietetics and Human Nutrition at McGill University, under the supervision of Dr. Katherine Gray-Donald (Tel.: 514-398-7677, Email: katherine.gray-donald@mcgill.ca), supervisory committee members Dr. Ann Macaulay and Dr. Richard Hovey, Judi Jacobs the KSDPP research coordinator (450-635-4374) and Treena Delormier who is the KSDPP ombudsperson for this research project (450-635-4374). Jayne has been volunteering for the KSDPP since May 2009 as an assistant to Elaine Delaronde and Judi Jacobs.

#### **Freedom of Consent**

Please read the above description of the study. Your participation in the research is voluntary. You may refuse to participate or withdraw from the study at any time. You have the right to answer only those questions with which you are comfortable. This will in no way affect you or your family's present and future care in any education, health or social service agency inside or outside Kahnawake.

#### **Statement of Consent**

I have read the above description of the study. I have had the opportunity to ask questions about it, and I consider that I have been fully informed. I understand that I may refuse to participate or that I may withdraw at any time without affecting my present or future care. I also understand that all information about me will be kept strictly

confidential. I understand that m my legal rights.	y signature on the consent form	n does not waive any of
I agree to be audio-recorded.	YES NO	
I accept to give permission to t in the research results and I ur to me.	-	•
YES NO NO		
I accept to participate in this st	tudy.	
Name of participant	Signature of participant	Date
I have explained to the participan	nt the terms of the consent form	n for this research project.
I have clearly explained that she	he can add other conditions re	lating to her/his
participation in this study at any	time. I will provide a signed co	opy of this consent form to
the participant.		
Name of researcher	Signature of researcher	Date
Principal Investigator Jayne Murdoch McGill University		

A copy of this consent form will be securely kept at the KSDPP research office. If you have questions about your rights as a research participant, or if you would like to verify the ethical approval of this study, please feel free to contact: Chair McGill Research Ethics Board, Faculty of Agricultural and Environmental Sciences c/o Macdonald Research Office at 514-398-8716, or by e-mail research.macdonald@mcgill.ca.