

Mount Saint Vincent University
Department of Applied Human Nutrition

A Voice To Be Heard.
**Social Barriers Impacting on Dietary Modification: The Experiences of Women of African
Descent with Type 2 Diabetes**

by
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Dedication

I dedicate this thesis to my aunts, Sylvia and Dorothy, who live with diabetes, as they have inspired me to pursue this topic of research.

Abstract

Although Nova Scotia has one of the highest populations of people of African descent in Canada, health research on this population is limited. Women of African descent have a high risk of developing type 2 diabetes, and are also at increased risk of experiencing greater difficulty with the physiological management of diabetes, which can lead to serious complications. While careful attention to dietary choices can help manage type 2 diabetes, social barriers often arise for women of African descent when considering food choices.

The purpose of this research was to examine the social barriers affecting dietary modification of type 2 diabetes experienced by women of African descent in the Halifax Regional Municipality. This qualitative study used the methodology of phenomenology to understand African women's experiences with type 2 diabetes. Purposive sampling was used to interview nine women in a face-to-face interview. Black feminist thought as a critical social theory was the theoretical framework used to guide analysis of the data.

Ten themes were identified as barriers in the literature and confirmed by the women in this study. Of the ten themes, the following four: (1.) Poverty/Low Socio-Economic Status; (2.) Role of Women in Families (Gender)/Family Relationships and Norms; (3.) Racism and its Effects on Health; and (4.) Cultural Meaning of Food/Taste of Food provided the largest amount of data. Although these four themes were identified as separate barriers, data from the women revealed that many themes intersected with one another, especially race, class and gender. Particularly, this study revealed that racism was a key barrier affecting African women's lives as they live with type 2 diabetes. This research highlights the importance of cultural competence. Cultural competence is required not only at the individual level, provided by the health care

professional, but also at the organizational and system level, to better meet the health care needs of African women living with type 2 diabetes.

Preface

The terms Black/Black women were originally used to describe participants of interest in the initial stages of this study. As a result, section 4.3 (Inclusion and Exclusion Criteria) and the documents in the appendices all use the terms Black/Black women. In addition, the researcher and participants often used the terms Black(s)/Black women during the interviews and member checking process. Therefore, some of the data in chapter 5 (Results), as well as some reported data during the member checking process in chapter 6 (Discussion) also includes these terms.

Elsewhere in the thesis, except when the term Black is used by other authors to describe a theory or ideology, the terms have been changed to African(s)/African women/women of African descent. These terms reflect identification with an ethnic group/heritage, rather than focussing solely on skin colour.

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Table of Contents

Title Page.....	i
Approval Page.....	ii
Dedication.....	iii
Abstract.....	iv
Preface.....	vi
Acknowledgements.....	vii
Chapter 1.0 Introduction.....	13
1.1 Significance of the Research.....	13
1.2 Research Question/Objective.....	14
Chapter 2.0 Literature Review.....	15
2.1 What is Diabetes?.....	15
2.2 Dietary Modification/Nutritional Aspects of Diabetes.....	16
2.3 Personal Interest in the Research.....	18
2.4 Social Barriers to Achieving Dietary Modification.....	18
2.5 Age.....	19
2.6 Political View as a Cause of Diabetes/Feelings of Losing Control.....	20
2.7 Lack of Support Within the Health Care System.....	22
2.8 Impact of Education on Diabetes Management.....	22
2.9 Poverty/Low Socio-Economic Status.....	23
2.10 Role of Women in Families (Gender)/Family Relationships and Norms.....	24
2.11 Racism and its Effects on Health.....	28
2.12 Current Diet.....	32
2.12.1 Cultural Meaning of Food.....	32
2.12.2 Taste of Food.....	33
2.12.3 Cultural Expectations of Body Weight Among African People.....	33
2.13 Summary of Social Barriers.....	35
2.14 Phenomenology.....	36
Chapter 3.0 Theoretical Framework.....	37
3.1 Introduction.....	37
3.2 Black Feminist Thought as Critical Social Theory.....	38
Chapter 4.0 Methodology.....	42
4.1 Research Design.....	42
4.2 Recruiting Participants.....	42
4.3 Inclusion and Exclusion Criteria.....	43
4.4 Sample Size.....	43
4.5 Research Instrument.....	44
4.5.1 Interviews.....	44
4.6 Data Analysis.....	45
4.7 Ethical Considerations.....	46

Chapter 5.0 Results.....	47
5.1 Description of Participants.....	47
5.2 Themes Identified in Interviews.....	48
5.2.1 Age.....	48
5.2.2 Political View as a Cause of Diabetes/Feelings of Losing Control.....	50
5.2.3 Lack of Support Within the Health Care System.....	52
5.2.4 Impact of Education on Diabetes Management.....	63
5.2.5 Poverty/Low Socio-Economic Status.....	66
5.2.6 Role of Women in Families (Gender)/Family Relationships and Norms...	74
5.2.7 Racism and its Effects on Health.....	81
5.2.8 Cultural Meaning of Food.....	94
5.2.9 Taste of Food.....	102
5.2.10 Cultural Expectations of Body Weight Among African people.....	106
Chapter 6.0 Discussion.....	113
6.1 Introduction.....	113
6.2 Poverty/Low Socio-Economic Status.....	113
6.3 Racism and its Effects on Health.....	116
6.3.1 Role of Women in Families (Gender)/Family Relationships and Norms..	117
6.3.2 Racism Regarding Cultural Competence.....	121
6.3.3 Racism Regarding Health Research.....	123
6.3.4 Racism Regarding Treatment by Professionals.....	125
6.3.5 Racism Regarding Internalized Oppression Leads to Mistrust/Not Asking Questions.....	128
6.3.6 Racism Among Africans/Assumptions.....	132
6.4 Cultural Meaning of Food/Taste of Food.....	135
6.5 Discussion Summary.....	139
6.6 Recommendations for Future Research.....	140
Chapter 7.0 Conclusion and Additional Recommendations.....	143
7.1 Recommendations Based on Barriers Analyzed.....	143
7.2 Poverty/Low Socio-Economic Status.....	143
7.3 Racism Regarding Cultural Competence.....	143
7.4 Racism Regarding Health Research.....	145
7.5 Racism Regarding Treatment by Professionals.....	146
7.6 Racism Regarding Internalized Oppression Leads to Mistrust/Not Asking Questions.....	147
7.7 Cultural Meaning of Food/Taste of Food.....	147
7.8 Summary and a New Understanding of Barriers.....	148
7.9 Limitations of the Research.....	151
Chapter 8.0 References.....	153

Appendices

Appendix A.....	160
Research Notice.....	161
Appendix B Interview Guide.....	162
Appendix C Study Information Sheet.....	164
Appendix D Consent Form.....	166
Appendix E Certificate of Ethics Approval.....	168

Chapter 1.0 - Introduction

1.1 Significance of the Research

Type 2 diabetes is a chronic disease that is associated with many complications which can be devastating. People of African heritage, as well as some other races such as Asians, Aboriginals and Hispanics, have a high risk of developing this disease. Dietary choices play an important role in controlling blood glucose levels, which is important in the proper management of diabetes. Effective glucose control is crucial in preventing or delaying the onset of complications; however, personal, as well as social barriers, often arise when restrictions are placed on food choices (Mahan & Escott-Stump, 2000).

Culture plays a large role in food and lifestyle choice; therefore, it is important to explore how this, and other barriers, influence dietary compliance in African women with diabetes (Fitzgerald et al., 1997). This area of study has not been well researched in the African population in Canada, or more specifically in the African Nova Scotian population; hence, the need for this type of research.

One of the main reasons for doing this research, aside from personal interest, is to contribute to the body of research on health related issues in the African Canadian community. From discussions with various individuals, I believe that this research will be valued among members of the African Canadian community. It is known that research on health related issues in the African Canadian community is limited and is needed. Health issues affect all of our lives as a society in general. It is documented that specific chronic diseases, (for example cardiovascular disease, diabetes, and cancer to name a few) are found in higher rates among African women (Enang, 2002). Given the seriousness of complications associated with diabetes, the role that diet plays in the management of diabetes (Mahan & Escott-Stump, 2000), and the

extremely deleterious effects on African women (Samuel-Hodge et al., 2000), it is important to research this area of health in relation to African women. By knowing what the barriers are to dietary modification, understanding can be gained as to how to help African women in culturally appropriate ways (Enang, 2002) with the dietary aspects of type 2 diabetes.

1.2 Research Question/Objective

What are the social barriers to dietary modification experienced by African women with type 2 diabetes in the Halifax Regional Municipality (HRM)?

Chapter 2.0 - Literature Review

Type 2 diabetes is increasing in incidence at an alarming rate (Satterfield et al., 2003). Globally, it is estimated that over 300 million people will have diabetes by 2025. In Canada by 2010, it is projected that 3 million people will have this disease (Canadian Diabetes Association [CDA], 2005). Type 2 diabetes affects more racially visible women (Kelly & Booth, 2004), and in particular African women, at a higher rate than other groups (Samuel-Hodge et al., 2000; Stover, Skelly, Holditch-Davis, & Dunn, 2001).

2.1 *What is Diabetes?*

Diabetes mellitus (DM), commonly called diabetes, is a disease in which the body cannot properly use insulin. Insulin is a hormone, secreted by the pancreas, which transports glucose into body cells where it is used for energy. In people with diabetes, insulin is not able to effectively transport glucose into the body cells. As a result, glucose remains in the bloodstream, causing high levels of glucose in the blood. Since glucose cannot get into the cells to be used for energy, the person often feels very tired. Over time, high blood glucose can cause serious damage to both small and large blood vessels, affecting the eyes, the nerves in the hands and feet, the kidneys and the heart (Mahan & Escott-Stump, 2000).

There are two main types of diabetes. In type 1 diabetes, previously referred to as Insulin-Dependant Diabetes Mellitus (IDDM), the pancreas has ceased producing any insulin, (or produces very little insulin). As a result, people with this type of IDDM must inject themselves with insulin daily. This type is usually diagnosed at a younger age, and used to be commonly referred to as Juvenile-Onset Diabetes. In type 2 diabetes, also known as Non-Insulin-Dependant Diabetes Mellitus (NIDDM), the pancreas usually still produces insulin; however, the body cannot use the insulin effectively. Since insulin is still likely present in the body, those with type

Type 2 diabetes do not necessarily need to administer exogenous insulin. The disease can often be managed with a change in diet and an increase in activity levels, and/or medication. However, diabetes is a progressive disease, and over time, people with type 2 diabetes often require the use of injected insulin in order to manage increasingly high blood sugar levels. Type 2 diabetes is often called Adult-Onset Diabetes, as in the past it was typically diagnosed after age 65, and the risk of being diagnosed with type 2 diabetes increased after age 40. However, there has been a great increase in the number of younger people diagnosed with type 2 diabetes. This is attributed to an increase in obesity and a sedentary lifestyle (CDA, 2005; Mahan & Escott-Stump, 2000).

Type 1 diabetes is not preventable; however, there are actions people can take to help prevent type 2 diabetes, or to postpone the age of onset (CDA, 2005). This is important because, as the disease is progressive over time, there is a greater chance of developing complications associated with diabetes, such as damage to the eyes, heart disease, kidney or renal disease, and ultimately limb amputations (CDA, 2005; Mahan & Escott-Stump, 2000). One of the most significant things a person can do to prevent type 2 diabetes is to exercise or increase their amount of physical activity. Other lifestyle changes such as healthy eating, maintaining a healthy body weight and not smoking can also be beneficial (CDA, 2005).

2.2 Dietary Modification/Nutritional Aspects of Diabetes

A diagnosis of diabetes (either type 1 or type 2) automatically means that greater attention must be given to one's diet. If the person cares about their health, they need to think about what they eat. Suddenly, what, how much and when they eat becomes increasingly important. Foods which contain carbohydrates are a primary concern since carbohydrates are ultimately metabolized into glucose and people with diabetes cannot process glucose normally (CDA, 2005; Mahan & Escott-Stump, 2000). This includes many foods such as all grain

products, dairy products, fruits and vegetables. Although all of these foods contain carbohydrates, there is a distinction between simple and complex carbohydrates.

Simple carbohydrates include the sugar in candies, jam, and simple sugars such as table sugar, and honey. Complex carbohydrates include foods containing starches such as breads, cereals, rice, pasta and potatoes. Some complex carbohydrates have more fibre than others, such as whole grain breads, whole wheat pasta, and brown rice compared to white bread, white pasta and white rice respectively. The higher fibre content of a food allows for a slower rise in blood glucose when these foods are eaten. As a result, blood glucose will likely be lower after a person consumes whole wheat pasta compared to the equivalent amount of white pasta (CDA, 2005). A person without diabetes who consumes carbohydrate containing foods will experience a transient rise in blood sugar levels; however, because their body is functioning properly, the glucose from foods will rapidly be absorbed by the body cells and will not remain in high levels in the bloodstream (Mahan & Escott-Stump, 2000).

In the person with diabetes, consuming these foods will also increase blood sugar levels; however, because they cannot properly use insulin, their blood sugar levels will remain high for a longer time as the carbohydrate (glucose) cannot get into the cells and will stay in the bloodstream (Mahan & Escott-Stump, 2000). Therefore, dietary modification is prescribed or suggested so that people consume a restricted amount of carbohydrate at any one time. They still require carbohydrate as this is a major source of energy. However, they now have to monitor the amount of carbohydrate consumed at any one time as too much may cause blood sugar levels to remain high for a long(er) period of time. Over time, this can contribute to blood vessel damage (CDA, 2005; Mahan & Escott-Stump, 2000). People with diabetes are also encouraged to consume meals that are spaced at regular time intervals (every 4-6 hours) and balanced in

carbohydrate, protein and fat content, as this balance is believed to help regulate blood sugar levels. Protein, fat and fibre help to slow down the rise in blood sugar levels compared to eating a meal composed of all, or mainly, carbohydrate (CDA, 2005).

2.3 Personal Interest in the Research

I have a keen interest in medical and health related issues, and particularly how nutrition influences health and disease. In my opinion, diabetes is a very intriguing disease due to the devastating effects of complications: both how severe they can be and how many parts of the body can be affected (for example the heart, kidneys, eyes, limbs) (Mahan & Escott-Stump, 2000). Although other diseases can affect one's life greatly, I often think about the many diet and lifestyle adjustments that a person with diabetes would need to make. They cannot eat certain foods without considering the possible effect on their blood sugar levels. The freedom to eat anything at anytime is something to be enjoyed, yet the person with diabetes must think about their diet more carefully if they want to stay healthy (Mahan & Escott-Stump, 2000).

As African people have a higher risk of developing this disease (Mahan & Escott-Stump, 2000), and as a person of African descent, I find this topic particularly interesting and it is a concern. As I have read literature discussing how seriously this disease can affect African people, and African women in particular (Samuel-Hodge et al., 2000; Stover et al., 2001), I have an increased desire to help people cope with their experience. By discussing what the barriers are for African women, this can be a step in that direction. Especially since there is not literature readily available about African people's health issues (Enang, 2002), I view my contribution to research in this area as desirable and advantageous.

2.4 Social Barriers to Achieving Dietary Modification

In Canada, there is a scarcity of scientific literature on diabetes in the African population,

due to a lack of research in this area. This may be due to the racist assumption that African women's health and disease experiences do not differ greatly from those of Caucasians who comprise the majority of Canadian society. Kelly and Booth (2004) indicate that more diabetes research is needed about racially visible men and women in Canada. As African Americans are present in greater numbers in the United States compared to African Canadians in Canada, there has been more research about African Americans and also more research about African Americans with diabetes (Liburd & Vinicor, 2003). I will include American literature reporting studies of African people which include mostly women, in order to describe the context for my research, namely the social barriers faced by African women with type 2 diabetes. I will also include literature on Aboriginals and diabetes as there is more literature on this ethnic group in Canada. In addition, I will include research findings that pertain to African women's experiences in Canada.

Many social barriers have been reported among African people, and specifically African women who have type 2 diabetes. These include age, feelings of losing control associated with a political view as the cause of diabetes, lack of support within the health care system, education, poverty/low socio-economic status, the expected role of women in families, racism, and their current diet. Many of these barriers intersect with one another, for example education and low socio-economic status. The social barriers are discussed in detail below.

2.5 Age

Although age is a physiological phenomenon and, as such, cannot be altered, it can be viewed as a social barrier. The middle adulthood years are often a time when women find themselves battling chronic diseases such as heart disease, diabetes, cancer and hypertension (Etowa, Loppie, Egbeyemi, Atwell, & Eghan, 2005). Although there are many factors to

consider in the development of chronic diseases, diseases can often be the result of women neglecting to look after their health needs and to care for themselves for many years prior to the onset of their disease. Excessive stress that is ongoing and/or prolonged over time can certainly play a role in the development of many chronic diseases. Maillet, Melkus, and Spollett (1996) presented an interesting variation between older and younger women in relation to the ease, or expected ease, of making dietary modifications. A younger woman (who had not yet developed diabetes, but was considered at risk), indicated that altering her diet would not be viewed by her as a cultural loss. This view contrasts with that of an older woman with diabetes, who suggested that altering her diet was difficult because she would be altering her cultural ways. Her diet was something she had done the same way for most of her life. This reveals that a woman's age may have an impact on her dietary management of diabetes in either a negative or positive way. Another way of explaining age as a social barrier is that a younger woman may not yet have faced the challenges of trying to change her diet as an older woman may have; therefore, it may be perceived that, for older women, dietary modification is a greater challenge (Maillet et al., 1996).

2.6 Political View as a Cause of Diabetes/Feelings of Losing Control

A common theme found among some Aboriginals is that they perceive diabetes to be primarily a disease of Caucasian people (Garro, 1996; Thompson & Gifford, 2000; Sunday & Eyles, 2001). They do not view diabetes as a personal health issue, but rather as stemming from political roots (Sunday & Eyles, 2001). They see diabetes as being imposed upon them as a result of Europeans taking over their land, resulting in a changed lifestyle (Thompson & Gifford, 2000). Interviews with Aboriginals in Manitoba revealed that some of them view diabetes as a

consequence of consuming less traditional, more processed foods, which stems from people of European ancestry moving into Native areas in Canada (Garro, 1996).

Many Aboriginals also reported that they feel they have lost control of their lives (Sunday & Eyles, 2001; Grams et al., 1996). Aboriginals traditionally view health from a holistic approach, valuing mind, body, spirit, soul, and links with the land and past cultural heritage. Since having diabetes is viewed as being imposed on them by political intrusions of European nature, this throws their life greatly out of order (Sunday & Eyles, 2001; Thompson & Gifford, 2000). Diabetes is seen as a lifelong and incapacitating disease and the emotional stress associated with this is viewed as a major barrier to controlling diabetes. This relates to the fact that Aboriginals feel they cannot personally control their disease, because they believe it stems from, and is maintained through, social/political means (Sunday & Eyles, 2001). A similar view is held by some African Americans. In the Sea Islands and mainland regions of South Carolina and Georgia, there are communities known as Gullah communities. These communities are known to exhibit the most preserved cultural traditions of any group of African Americans, due to the isolated nature of the islands which has resulted in interconnected communities. African women from these communities expressed that the increased tourism and destruction of land for business purposes has a detrimental effect on preserving their culture (Beoku-Betts, 1995), which is similar to the Aboriginals' view of feeling lost ties to their cultural heritage (Sunday & Eyles, 2001; Thompson & Gifford, 2000).

In the regions of Skidegate and Old Massett in Haida Gwaii (Queen Charlotte Islands), British Columbia, some Aboriginals, known as the Haida, believe that diabetes can be cured. The Haida speak about managing the disease in terms of taking political action. An example of such political action would be to increase access to social and health services (Grams et al., 1996).

2.7 Lack of Support Within the Health Care System

Among disadvantaged groups in Nova Scotia, main barriers to accessing health care include a culturally insensitive health care system, language barriers, as well as a lack of information of how diseases affect those of various ethnic/racial groups differently (Amaratunga, 2002). African women may perceive a lack of support from health professionals. Some African women reported a desire to avoid debilitating complications; however, they felt they were not getting enough educational, and general, support from their health care team, even when they informed them of symptoms experienced (Maillet et al., 1996). Women reported that they did not often, or ever, receive medical tests to detect complications, and if they did, they did not always have the procedures explained to them. As a result, these women did not always know which procedures pertaining to their disease were important, or why they were important (Maillet et al., 1996).

2.8 Impact of Education on Diabetes Management

Diabetic education is an important aspect of disease management. Nutritional management of diabetes is often an area that people find cumbersome. The importance of educating the patient has been well documented, as patients who are educated are better equipped to manage their disease (Assal et al., 1985; Funnell & Haas, 1995). There are a number of barriers to diabetic education. The facilities and personnel available determine the type and extensiveness of education received (Assal et al., 1985). In Nova Scotia, those living in rural areas may have limited access to resources and, therefore, may not receive adequate diabetic education (Atwell, 2001). In addition, nurses and dietitians state that they do not have enough time to adequately teach patients as well as update their educational training (Funnell & Haas, 1995). People also identify conflicts with scheduling and believing they already know enough as

reasons for not attending or continuing with diabetic education programs (Funnell & Haas, 1995). Another barrier is a lack of culturally sensitive diabetic programs (Funnell & Haas, 1995). Gilliland et al. (1998) mentioned the importance of collaborating and working with members of racially visible communities as part of the diabetic education program. This is because members of the community understand their cultural practices and the community will likely benefit from, and will value, having their community members be a part of the process and implementation of any diabetic education program (Gilliland et al., 1998).

2.9 Poverty/Low Socio-Economic Status

Low socio-economic status is a risk factor for poor nutritional status, which can negatively influence the risk of chronic diseases (Travers, 1996). Compared to the rest of the population in the United States, there is a high degree of poverty among African Americans (Bronner, Burke, & Joubert, 1994). The assumed cost associated with purchasing healthier foods can be a barrier as it creates difficulties in following a recommended diet (El-Kebbi et al., 1996; Maillet et al., 1996). Those with a lower socio-economic status may, therefore, have a low quality diet because they are not always able to purchase healthier foods which can sometimes cost more; for example, leaner cuts of meat and fresh vegetables and fruits are often very expensive (Ewing, n.d.). Indeed, a perceived higher cost of healthier foods is a barrier expressed by some African Americans (Horowitz, Colson, Hebert, & Lancaster, 2004). Some Aboriginals also describe the costs of healthier foods as a barrier, whereas others do not (Sunday & Eyles, 2001).

Lorde (1998) indicates that generally, racially visible women earn the least amount of money in the United States. For a poor African woman, race, class and gender all intersect to influence her life (Andersen & Collins, 1998). An African woman who is dealing with a chronic

disease, and who is poor, can be impacted greatly by her low socio-economic status. She may have limited resources for healthy food and live in an area where adequate health services are not easily accessed. Indeed, there are similar cases in Nova Scotia as some African Nova Scotians live in areas (such as the Prestons in Nova Scotia) which allow limited access to health care, information, and education (Atwell, 2001). African Americans realize the role that diet can play in their health; but, they sometimes do not have the necessities to adopt healthier lifestyles. For example, many are poor and also deal with illiteracy (Bronner et al., 1994), an example of another social barrier.

2.10 Role of Women in Families (Gender)/Family Relationships and Norms

African American families appear to have a cultural norm whereby family members help look after each other. This usually means that African American women feel the pressure to help others, despite enduring their health or other problems (Samuel-Hodge et al., 2000; El-Kebbi et al., 1996). This cultural norm is associated with the ideology of the Strong Black Woman (SBW) and many African women in Halifax identify with this association (Eghan, Bernard, & Etowa, 2004).

The ideology of the SBW is an image of women of African ancestry having an unlimited ability to survive adversity and every challenge (Etowa et al., 2005; Harris-Lacewell, 2001). She is like a “superwoman” (Etowa et al., 2005). The expectation that African women will take care of their family members and even extended family and community members, often results in African women putting the needs of others ahead of their needs. African women are expected to be the strong members of their families and communities and are expected to hold family and community life together. Although there is an expectation that women are the primary caregivers, African women are affected by the ideology of the SBW because they are expected to

be strong in the way they live out the role society places upon them. Not only are they women, they are expected to be Strong Black Women: expected to handle more in life, to work harder, and to prove themselves more. These are all examples of ways that the ideology of the SBW is deeply rooted in society and reflects oppressive and racist attitudes (Etowa et al., 2005).

Research with local African women reveals that the ideology of the SBW can be viewed as a myth and also a reality (Etowa et al., 2005). In terms of the myth of the SBW, some women believe they are not strong and often feel overwhelmed (Etowa et al., 2005; Harris-Lacewell, 2001). They feel the negative effects of the pressures and demands placed upon them. On the other hand, some African women believe that they are strong simply because of the life circumstances affecting African women, such as dealing with racism. African women deal with racism in addition to fulfilling the expectations of providing care placed on them. They have had to find ways of coping and they still survive, thereby making them *Strong Black Women* (Eghan et al., 2004; Etowa et al., 2005). Regardless of whether African women believe the ideology of the SBW is a myth or reality, many women indicated that this ideology is not something they can escape from. This is because within African communities, and even within the larger society, they are expected to care for everything and everyone, and be strong enough to handle the demands/responsibilities associated with that care (Etowa et al., 2005; Harris-Lacewell, 2001).

The ideology of the SBW can be viewed in a positive way in that African women are strong role models who have coped with hardships such as racism, similar to their ancestors overcoming enslavement; this is valuable to pass on to their daughters or other young African women (Etowa et al., 2005; Harris-Lacewell, 2001). In American research, an interesting phenomenon among African women had been observed; although their gendered role of caring for the family, involving food preparation, can be said to perpetuate dominating roles inscribed

by a patriarchal society, as a group, African women created roles within the family which are very important to themselves (Beoku-Betts, 1995). Their role is seen as unique; therefore, it is a role to be desired as an African woman. In addition, their role is viewed as extremely valuable for passing on information to their children as a way of preserving their culture, recognizing the struggles of African people and ways in which they have worked through these struggles (Beoku-Betts, 1995). Despite this role being desired, some African Nova Scotian women do speak of sometimes being tired of living up to the expectation of the SBW (Etowa et al., 2005).

The ideology of the SBW can also be negative because of the societal expectations placed upon African women, resulting in unfair treatment or demands upon them. For example, because African women are thought to be strong, they can be expected to work harder with no ill effects. Stereotypical beliefs about African women are held by greater society, leading to labelling African women as “strong” and “survivors” (Etowa et al., 2005). Shambley-Ebron & Boyle (2004) note that these labels result in the perception that African women do not need social programs (because they are “strong” and “survivors”). Labelling African women also results in a hostile health care environment (Shambley-Ebron & Boyle, 2004). The end result is that many African women do not seek care from the health care system (Atwell, 2001), which can lead to poor health (Enang, 2002).

It is important to realize that the ideology of the SBW is placed upon African women from within their families, churches and communities, and it is even expected by some African women themselves. This can be an unconscious or conscious expectation. The expectation that African women are strong and can handle anything can result in African women having difficulty in asking others, even close family members and friends, for help. It can also be hard for African women to admit that they do not feel strong and/or to verbally express their feelings

(Etowa et al., 2005). Qualitative research with African American women who have type 2 diabetes revealed that the greatest stressor for women is stress related to the expectation of providing support for their family (Samuel-Hodge et al., 2000). In addition, it is apparent that having diabetes may not result in more support from these women's family members. In some cases, women attempt to change their eating habits once they have diabetes, but feel they do not have enough support from their families (Maillet et al., 1996; El-Kebbi et al., 1996).

Interestingly, when African American women did receive help, they spoke of female family members and friends as their source of help. It is interesting that support came from other women and especially interesting that support came from their daughters (Samuel-Hodge et al., 2000). This revealed that expectations of women as nurturers and/or caregivers, which are similar to the ideology of the SBW, are deeply ingrained in society.

African American women indicated that the stress of care giving contributes to difficulty controlling their diabetes (Samuel-Hodge et al., 2000). Although the ideology of the SBW reflects local research in Halifax, Nova Scotia, a similar ideology appears to be present among African Americans. African American women identified the stress associated with the expectation placed upon them, to care for immediate and extended family, as well as African community members (Samuel-Hodge et al., 2000). One can make the connection, therefore, that African women may not receive additional support from family members, despite dealing with diabetes. Despite their health needs, African women care for their family and community members resultant of their conscious or unconscious expectations. Unfortunately, regardless of the positive aspects associated with the SBW, African women are often "taken for granted" (Etowa et al., 2005). Sadly, over time, the stress of living up to the expectation of the SBW and

care giving at the expense of their health needs can negatively affect African women's health: on an emotional, physical and even spiritual level (Etowa et al., 2005).

Research with Aboriginal community members showed that they may tend to be secretive about having diabetes, and do not want people (Sunday & Eyles, 2001), including family members to find out (Thompson & Gifford, 2000). However, research by Grams et al. (1996) reported that some Aboriginal community members believe it is better to talk with people about what they are experiencing in life, as a coping mechanism. For a group of Aboriginals in Australia, family responsibilities are seen as more important than dealing with diabetes. For example, if a family or community member needs to be taken care of, those with diabetes indicate that the regimens involved in managing diabetes, (e.g. checking blood sugar, taking medication) are seen as disruptive and, therefore, a barrier to their cultural way of life (Thompson & Gifford, 2000). This response parallels the similar view of African Americans, that looking after care needs of both immediate and extended family are expected roles that African women must live up to (Samuel-Hodge et al., 2000).

2.11 Racism and its Effects on Health

It is important to differentiate between terms that are commonly thought of as racism, namely prejudice and discrimination (Black Learners Advisory Committee [BLAC], 1994). It is also useful to include a definition of stereotypes.

Stereotypes are assumptions that are made about individuals or a group of people, devoid of considering the truth or finding out more information (Srivastava, 2007), for example, African men are violent. If someone is prejudiced, they hold a preconceived thought or attitude toward a group of people. Prejudices develop from stereotypes (Sharp, 2002). Discrimination involves taking action, based on a negative stereotype and/or prejudicial attitudes (Carvery & Bishop,

1994, as cited in Benton, 1997; Sharp, 2002). When members of a specific race believe negative stereotypes and/or prejudicial beliefs or attitudes about their race, this describes internalized oppression. As an example, research by Enang (2002) revealed that African women are stereotyped into categories viewed as negative; such as, a single mother, on income assistance, or unemployed. As a result, African women may experience insecurity and low self-esteem. These stereotypes are deeply embedded in society, so much so, that African women may also come to believe these stereotypes, and perpetuate these ideologies against other African women (Enang, 2002).

Racism requires a power dynamic, meaning that those who hold power in society (Caucasians) can use their power to dominate and oppress those of a group who lack power in society. When a group is oppressed, they are systemically treated unfairly by the dominant group in society (BLAC, 1994). Systemic racism describes racism that is less visible to the general public, because it is deeply embedded in societal structures such as in the social, economic, political and judicial spheres (Etowa et al., 2005; Bernard, 2004). Carvery and Bishop 1994 (as cited in Benton, 1997) provide a useful explanation of prejudice and racism:

On a personal level, anyone can be prejudiced toward anyone else based on any difference between them. However, prejudice based on difference in color does not become racism until you add social, political, economic, ideological and institutional power. A Black person in Nova Scotia can hate or be prejudiced against White people; but only White people can be racist against Black, First Nations, and immigrant people and other people of color. It is White people in Nova Scotia who have the advantage in business, the banking system, the court system, the school system, the media and all other institutions. (p.35-36).

Systemic forms of racism are less visible than overt, blatant examples of racial discrimination such as name-calling; however, they can be just as damaging and stressful. The belief in, and perpetuation of the ideology of the SBW is an example of the internalized oppression that Black women deal with today (Etowa et al., 2005).

The experience of racism is significant for all African women (Etowa et al., 2005) although each African woman's personal experience is different. African women in Halifax have discussed how racism has many negative consequences for their well-being and health (Etowa et al., 2005). Similarly, experiences of racism, and acts that have resulted in Aboriginals losing their land and close ties to their former communities, are viewed by them as contributing to their high rates of diabetes (Thompson & Gifford, 2000).

Results from local research on "Menopause and the Myth of the Strong Black Woman (SBW)" indicated that women often feel exhausted due to either internalizing or dealing with years of incidents of racism (Etowa et al., 2005). During middle adulthood years (40-65), women experiencing menopause revealed various symptoms which often left them feeling tired, confused, overwhelmed and out of control. Unfortunately, this is also the time in life when women often worry about the effects of racism on their children. African women often experience much exhaustion, resultant of challenging experiences of racism, which can affect their health emotionally and physically. Some women feel a sense of frustration and anger that racism will have the potential to affect their lives today and negatively impact the lives of their children (Etowa et al., 2005).

When one thinks about an African woman who is experiencing menopausal symptoms, the effects of dealing with racism, diabetes, (or another chronic disease), in addition to coping with the expected role of caring for other family and community members, it is evident that the

demands on African women's lives may certainly have a negative influence on their health. In a study conducted by Etowa et al. (2005), African women referred to racism as "a virus", stating that "When you think you have found a cure for a particular strain, it shows up in another form" (Etowa et al., 2005, p. 14). In addition to emotional exhaustion, due to racism, and dealing with other medical conditions such as menopause, women actually felt angry, overwhelmed and unable to put things from the past behind them. Over time, these negative feelings, if not dealt with appropriately, can negatively affect African women's health (Etowa et al., 2005).

Especially during the middle adulthood years, for example when African women are experiencing menopause, they feel that Caucasian physicians lack cultural competence and do not understand their experiences with racism and how much it negatively influences their health (Enang, 2002). Enang (2002) further states that many African women do not seek medical advice in Nova Scotia (either for standard, preventative tests, or for ongoing care while dealing with a condition), unless an emergency arises. This can result in increased risk of a disease, especially if the disease is not detected early; this increases the risk of complications associated with the disease and results in poorer disease outcomes (Etowa et al., 2005). Although it may be difficult to show a direct relationship between racism and negative health and disease outcomes, research from both the United States and Canada has shown that African women think about how they will be treated due not only to race, but also gender and class, and how this will affect their health (Enang, 2002). It is important, therefore, to consider a race and gender analysis in my research as many African women with diabetes will likely be in the middle adulthood years (Etowa et al., 2005).

2.12 Current Diet

In our society today, food not only provides us with nourishment, but plays a social role as well. Food brings people together. People eat for many reasons other than hunger. For example, one may eat based on emotion, such as when they are: bored, depressed, or upset, or may eat simply because food tastes good. Given that diabetes is a disease which has dietary implications, factors related to one's current diet, such as the cultural meaning of food, taste, and the cultural expectations surrounding body weight, can be important to consider in the dietary management of diabetes. Each of these factors is discussed in detail below.

2.12.1 Cultural Meaning of Food

Food plays an important role in Aboriginal culture. Haida people talked about food as healing to them and many get-togethers in their communities revolve around food (Grams et al., 1996). This is similar to many African Americans whose food can be described as soulfood, which has connections to the history of the enslavement period. Food was seen as a comfort to them, for the long laborious hours spent working. African Americans also believe that their soulfood is beneficial to their souls or spirits (Bronner et al., 1994). Others state that dietary change is very difficult because their traditional way of eating is so ingrained in their culture. They are used to eating certain foods or using certain cooking methods; they get used to particular tastes, and then find it difficult to change when a diagnosis of diabetes makes alternate foods/cooking methods necessary (Maillet et al., 1996; El-Kebbi et al., 1996; Fitzgerald et al., 1997; Samuel-Hodge et al., 2000). The effect this has on the person with diabetes can be deeper than simply making alternative food choices. For example, a study by Devine, Sobal, Bisogni, and Connors (1999) revealed that a newly diagnosed Puerto Rican (young) woman identified feelings of loneliness as she felt she was unable to eat the same food as others at a party. This

woman assumed she would be able to continue eating rice, (which she identified as a traditional food), but then discovered that this was not the case (Devine et al., 1999). Interestingly though, there is a need to properly educate people with diabetes regarding food choices since rice is an acceptable food. This woman's perception appeared to represent a perceived barrier to dietary management of diabetes, due to lack of dietary knowledge of appropriate food choices.

2.12.2 *Taste of Food*

Both African Americans and Aboriginals expressed difficulties in coping with the dietary changes which resulted from a diagnosis of diabetes. A Haida woman expressed how much she enjoyed sweets, and the feeling of giving them up was traumatic for her (Grams et al., 1996). El-Kebbi et al. (1996) noted that African Americans enjoyed foods sweetened with or high in sugar. Additionally, in studies by El-Kebbi et al. and Maillet et al. (1996), the majority of African participants indicated that they liked the taste of foods high in fat. African Americans found it difficult to restrict their traditional diets that included foods high in fat. A large number felt compelled to cook foods using traditional, high fat ingredients and discovered it was basically impossible to cook a meal for other family members as well as themselves (El-Kebbi et al., 1996; Maillet et al., 1996).

2.12.3 *Cultural Expectations of Body Weight Among African People*

Another barrier to managing diabetes among certain populations is a negative association with losing weight. One aspect of dietary modification for people with diabetes is weight management. Some studies have identified a pressure to lose a large amount of weight initially (rather than beginning with a smaller amount) (Maillet et al., 1996). There is an interesting phenomenon regarding some African women and how they view body weight. In contrast to the typical value of thinness in society today that is on the minds of many women, some African

women have a positive view of a heavier body and, as a result, do not appear to struggle with their body weight as a self-esteem issue (Snooks & Hall, 2002; Miller et al., 2000; Kumanyika, 1995). Some African American women who are overweight do not tend to see their weight as a health concern (Kumanyika, 1995); instead, having a certain amount of weight on their bodies is viewed as being healthy (Gore, 1999). Carrying extra weight is also considered by some to be beneficial from an economic and physiological perspective. Economically, when money to purchase food is limited, extra weight is viewed as a mechanism of ensuring survival. Physiologically, in the case of physical ailments and diseases, extra weight provides some protection (Kumanyika, 1995). Bronner et al. (1994) also noted that some African people think that healthy eating means eating food in large quantities, and this is associated with being strong and, therefore, healthy. Among some African cultures, it is more desirable for women to be overweight than to be at a normal weight or underweight. Many African American women believe body weight is a personal issue and that they should not be compared to standard weight charts and/or tables (Gore, 1999).

Although a heavier body weight is valued among some African cultures, some African women also realize that too much weight can negatively affect their health. However, when a heavier body weight is valued in their culture, it can represent a cultural barrier to managing either their risk for health conditions such as diabetes, or their dietary management of diabetes, once they already have this disease (Gore, 1999). Thus, even though obesity is recognized as a significant risk factor in the development of diabetes, in general, African American women may not view a higher body weight as a risk factor for this disease (Rajaram & Vinson, 1998). Furthermore, Gore (1999) notes that some women of African descent consider it acceptable to eat foods high in carbohydrates and fats. Women in Gore's study shared that they believe a diet

high in carbohydrates and fats is linked to the period of enslavement when slaves were given less desirable foods.

Another concern is the way body fat is distributed, as this is also a risk factor for developing diabetes (Rajaram & Vinson, 1998). Carrying extra weight in the abdominal area is known to be associated with insulin resistance (McNab & Ryan, 2003), which is described as the body's inefficiency to respond to changes in insulin levels (Mahan & Escott-Stump, 2000; McNab & Ryan, 2003). Insulin resistance is known in many cases to occur for years before a diagnosis of diabetes (McNab & Ryan, 2003). This is a concern as a greater waist-to-hip ratio is common among African American women (Rajaram & Vinson, 1998), thereby increasing their risk of developing diabetes.

2.13 Summary of Social Barriers

Both similarities and differences have been identified when comparing the experiences in the literature about Aboriginals and African Americans. These two ethnic groups share a history of oppression that continues to affect them today, and the literature has reported that each group experiences difficulties complying with recommended dietary modifications (Grams et al., 1996; Samuel-Hodge et al., 2000; El-Kebbi et al., 1996; Maillet et al., 1996). Some of these barriers are specific to experiences of African American women with diabetes. It is not known if similar barriers also exist for African women with type 2 diabetes in Canada. A lack of research (in Canada generally and Nova Scotia specifically) to understand African women's experiences of complying with dietary recommendations, may suggest that African women may not be receiving the care and support which is required (Liburd & Vinicor, 2003).

2.14 Phenomenology

A phenomenological design was used for this study. Phenomenology is a qualitative research method in which the goal is to understand the participant's experience of the phenomena being studied (Polgar & Thomas, 2000). Phenomenology is specifically interested in understanding the meaning behind the participant's experience (Donalek, 2004). This is not a study simply about African women with type 2 diabetes; rather, it is about these women's experiences, and what that means for them as they cope with dietary modification with regards to their disease. Research interviews are a common method associated with phenomenological research. Giving others a voice is a goal of phenomenology (Donalek, 2004). The phenomenological method was chosen as it allows African women to tell their stories about managing diabetes.

In essence, the voices/stories of the women I have interviewed provide the data for this study. This method is fitting for this type of research as there is a void in the literature pertaining to African women's experiences with diabetes in Canada. It will be welcomed within the African community as there is a lack of health research pertaining to African women's health in Canada specifically (Enang, 2002). By providing an account of African women's experiences, this research project diverges from the dominant view; which is the belief that everyone's health experiences with disease are generally the same as those of Caucasians. This study will be helpful for health professionals, as they will be able to use these findings to inform their knowledge about, and development of, educational and treatment plans for their clients of African descent with type 2 diabetes.

Chapter 3.0 - Theoretical Framework

The theoretical framework chosen for this research is critical social theory, specifically, Black feminist thought, as an example of critical social theory. I will begin by giving an introduction to feminism as it pertains to African women.

3.1 *Introduction*

Initially, feminists' efforts were geared toward giving women equal status with men; however, this occurred very much within the upper class. Hence this view conformed to a White, patriarchal, capitalist system and ignored the concerns of subordinated groups such as African women. As a result, many African women did not want to associate with feminism as it reflected a racist, classist ideology (hooks, 1984). Feminism is also structured around women uniting together to fight for equality. African women cannot be grouped in the same category as White women, as African women face not only gender oppression, but other forms of oppression, such as race and class (Shambley-Ebron & Boyle, 2004). Racial oppression has been identified as key by the majority of African American women (Collins, 1998; Shambley-Ebron & Boyle, 2004). Also, the interrelations of race, class and gender have been well documented (Collins, 1998, 2000; hooks, 1984; Shambley-Ebron & Boyle, 2004; Barbee, 1994) as important in considering how these forms of oppression operate together and negatively influence the health and, ultimately, the lives of African women. As White feminism is structured around the idea of unity (i.e. all women should unite to address gender oppression), the fact that African women identify difference is a threat to the power of unity in White feminism (Shambley-Ebron & Boyle, 2004). Therefore, Lourde 1998 (as cited in Shambley-Ebron & Boyle, 2004) notes that African women's ideas are classified as "other" [and]... "too 'alien' to comprehend" (p. 12). This is also

true for racially visible women, other than African women (Lourde, 1998, as cited in Shambley-Ebron & Boyle, 2004). This perpetuation of racist ideology, supports systemic racism.

It is necessary to examine the historical and present sociocultural context of African women's lives in order to understand why their position is different from that of White women, in addition to understanding how these contexts influence African women's health. Historically, African women were enslaved in the United States and although slavery is abolished, the psychological effect of their enslavement has a negative impact upon African women. Stereotypes formed by the dominant culture have been internalized by African women, which lead to false, unhealthy perceptions of themselves and leads to ill health. Living in a White, patriarchal, capitalist society, African women, by their race, gender and/or class, lack power to change ingrained/deeply embedded societal structures that keep them oppressed. Also, African women commonly remain in a lower socio-economic status (Barbee, 1994; Shambley-Ebron & Boyle, 2004), which negatively influences their health (Travers, 1996). Socioculturally, intra-racial discrimination, resultant of internalized oppression and described as members of the African race discriminating against one another, affects the health of African community members (Shambley-Ebron & Boyle, 2004).

3.2 Black Feminist Thought as Critical Social Theory

The data obtained in this study was interpreted using the theoretical framework of critical social theory. In particular, I will discuss the position of Black feminism as an example of critical social theory. I use the term *critical* as Collins (1998) uses it to define critical social theory, indicating that "What makes critical social theory "critical" is its commitment to justice, for one's own group and/or for other groups" (p. 276). Often, it is those who experience oppression who bring forth the viewpoint of a critical social theory. It is important to note that Black

feminist thought, as a critical social theory, is required because African women have historically been and continue to be an oppressed group in society (Collins, 1998, 2000). It is this similarity of group experiences that allows social theory to be critical and argue for equality for that oppressed group (Collins, 1998). Black feminism ultimately works for the eradication and/or change of the oppression of groups who have been classified as *other* or who do not fit the dominant powerful groups in any society. I chose this theoretical framework because African women as a group experience oppression. While as a group they are oppressed, it is important to remember that each African woman's experience can be different and that they are not necessarily a homogeneous group (Collins, 2000). Collins (2000) discusses ways in which various examples of oppression can be linked with one another; as an example, both gender and race can act to keep African women oppressed. Therefore, analyzing data from the point of view of this critical framework will aid in understanding African women's experiences and the barriers they face with regard to the dietary aspect of their experience with diabetes.

The viewpoint of Black feminist thought arose from the unique position of many African American women who were domestic workers in Caucasian homes (Collins, 1998, 2000). In the words of Collins (1998, 2000), these African women had an *outsider-within* position in that they gained insight into the lives of Caucasians, but could never have full privileges in terms of the power and status of being a White member of society. This position was influential in Black feminist thought coming to be regarded as oppositional knowledge, defined as "...knowledge developed by, for, and/or in defense of an oppressed group's interests" (Collins, 1998, p. 279). However, Black feminist thought as critical social theory does not stop at helping African women to cope with their oppression; it goes beyond and is active against oppressive societal structures. African women need to be given a voice and Black feminist thought is useful as it

values the experiences and realities of African women's lives. It also puts African women's experiences at the forefront (Collins, 1998, 2000), rather than ignoring completely or grouping together their experience with those of White women under the banner of feminism (Shambley-Ebron & Boyle, 2004). This is a historical pattern of traditional research (Barbee, 1994), which provides another example of systemic racism. African women need to be involved in research that considers their voices, stories and experiences. We need to hear and learn from African women about how their race, class and gender impacts on their life experiences, and, in this particular case, their experiences of type 2 diabetes.

Although African women differ in their experiences of oppression, as a group in general they are oppressed which shows the impact of the way that power is deeply embedded in our society. African women's experiences with racism and oppression are not all the same; however, as a group, African women do experience oppression that is deeply ingrained in societal structures, which is often hidden from the public (Collins, 1998; Eghan et al., 2004). While some African women have made their way into places associated with power (for example, educational institutions, professional corporations, et cetera), many African American women still live in poverty, suffer from illness, lack of employment, and have limited education. It is important to recognize that African women's critical social theory recognizes both individual differences among African women, and African women's experiences as a group. African women's experiences of oppression are instrumental in working for justice *together* as an oppressed group (Collins, 1998).

An important component of Black feminist thought is that it has been the result of the personal experiences of many African women from various walks of life. In this way, Black feminist thought is not only produced by those within academic circles; in fact, the racist

experiences of African women outside of academic circles are important because of their unique experiences which contribute to this theory. While the segregation of African people in schooling and housing in American society was a form of oppression, it created an opportunity for African women to come together and share their experiences and ways of coping and dealing with racism. Through sharing these experiences, some characteristics of Black feminism were created (Collins, 2000). The reliance of this framework on African women's stories is characteristic of qualitative methods of research (Polgar & Thomas, 2000). Participants' experiences are welcomed in the production of data, making Black feminism a useful framework for analyzing this qualitative study. While there are multiple forms of oppression at work in the lives of African individuals such as race, class, gender, and age to name only a few, African American women identified their race as the factor that stands out the most in their experiences of oppression, particularly in the United States (Collins, 1998; Shambley-Ebron & Boyle, 2004). Could the same be argued for African women in Nova Scotia? It would appear that way, as local African women indeed believe racism is alive and well in Nova Scotia, and have indicated that it has influenced their health negatively (Eghan et al., 2004). The work of Eghan et al. (2004) indicates that African women find the effects of racism particularly stressful during the years of middle age (40 to 65). This highlights the importance of considering a race analysis as many African women with diabetes will be in this middle age category (Eghan et al., 2004).

Chapter 4.0 - Methodology

4.1 Research Design

I have used a phenomenological design to interview African women who have type 2 diabetes. This was a somewhat difficult decision to make as I did not want to exclude people on the basis of their sex. Men and women will likely differ in their perceived barriers to dietary compliance, which is worthy of exploration (Mojonnier et al., 1980). However, much of the literature I have read has included more women (El-Kebbi et al., 1996) or only women, and the complications associated with this disease may affect African women to a greater extent, and in different ways, than they do males (Samuel-Hodge et al., 2000). Therefore, I am interested in learning about the barriers African women face in managing their diabetes from a dietary perspective. Also, due to the limited time frame/scope of a Master's thesis, I chose to focus solely on women.

4.2 Recruiting Participants

Consistent with phenomenological research, I was intentional in how participants were selected (Donalek, 2004), using purposive sampling. This involved focusing recruitment in places where I was likely to find participants of interest (Neuman, 2006), in this case, African women with type 2 diabetes. An example of such a place is the North End Community Health Centre (NECHC). I arranged to have notices posted at locations within African communities, for example, at the East Preston Family Health Resource Centre. The notice described my research, the type of participants I was interested in, and provided contact information (Appendix A). I also had an opportunity to connect with Cobequid Road United Baptist Church, predominantly attended by people of African descent. An announcement was placed in their church bulletin, which described my research. In addition, I recruited participants by discussing my interests and

intentions for my research among groups of African women in the community. For example, I had an opportunity to do this at a workshop on African women's health related/medical issues. This approach allowed African women to become familiar with me and the purposes of my research.

4.3 Inclusion and Exclusion Criteria

The participants of interest were defined as Black female adults age 20 and over who have type 2 diabetes. This age was chosen as recommended by a nurse at the NECHC (R. Fraser, personal communication, November 10, 2004). I included participants who were born either in Canada or another country, as long as they identify as Black. Including all Black women, regardless of place of birth will provide data that is richer with varying experiences. Excluded from the study were Black women who cannot speak English, and women with type 1 diabetes.

4.4 Sample Size

I did not require a large sample and planned to have between six and ten participants. This was an estimate as I planned on interviewing until no new concepts were gained, a point known as theoretical saturation (Adler & Adler, 1994). Based on similar type studies, I estimated that ten participants would enable me to achieve theoretical saturation. Due to limitations of time and the scope of a Master's thesis, I chose ten participants as the maximum number to interview. However, I was prepared to conduct more interviews if needed to achieve theoretical saturation (K.G. Davison, personal communication, November 2, 2004). I estimated that at least six participants was a reasonable minimum sample to achieve a variety of women's experiences. I ultimately interviewed nine women in total.

4.5 Research Instrument

4.5.1 Interviews

Participants took part in a face-to-face interview aimed to be approximately 1-1½ hours in length. Examples of questions that were used to guide the discussion in the interviews can be found in Appendix B. Although Collins 1990 (as cited in Denzin, 1997) speaks of the value of discussions among African women as a group, I believe such exchange was also valued among women, even in a one-on-one interview, especially with me, another woman of African descent.

Since I was interviewing participants and I wanted to make involvement in the study as easy as possible for them, I offered to do the interviews in the participants' homes. I also arranged to have interview sites available at familiar places within the African community such as the NECHC and the Black Cultural Centre (BCC). The date and time for the interview that was most convenient for the participants was arranged. I gave participants an oral and written explanation of the study along with a description of their roles and responsibilities (Appendix C). Participants were asked to sign a consent form (Appendix D) prior to the interview and were reminded that participation was voluntary and that they could withdraw from the study at any time. The purposes of the study were also explained to each participant, as well as procedures regarding confidentiality. Participants were asked to choose a pseudonym to represent and identify themselves in an anonymous manner. Each interview session was tape recorded with the participant's permission. They were each reminded that they had the option of turning the tape recorder off at any time. The researcher also made reflective notes after each interview noting information such as the surrounding atmosphere, body language, and other observations.

4.6 Data Analysis

I have provided an analysis which should enable readers to gain a sense of what it is like to have the experiences of the women I interviewed. An analysis with this effect can come only from speaking with the people involved (Collins, 1990, as cited in Denzin, 1997). Although I have identified a theoretical framework within which to analyze the data, the theoretical framework I chose guided, rather than dominated, analysis of the data in accordance with the phenomenological design (Donalek, 2004). As my theoretical framework takes a critical perspective, it is analogous to Denzin's (1997) view that when those who are experiencing barriers are allowed to tell about their experiences, all have an opportunity to share in these experiences. Scheurich (1995) notes the complexities of the data analysis process. I realize that I bring my thoughts, ideas, and opinions to this research topic, something that Scheurich also comments on. It is a challenge to let go of that and attempt to hear first and foremost, what these women had to say. It is suggested that, as researchers, we can indicate in our research that, although participants have provided their own experiences, it is not to say that their experiences will necessarily always be the same. My analysis of their experiences is also not the only correct way by which their experiences could be analyzed (Scheurich, 1995).

As much as possible, I want to let the participants' voice come out first, before academic theories or my reflections on the research process are applied to the data (Kirby & McKenna, 1989). This is characteristic of analysis of phenomenological research (Polgar & Thomas, 2000). The tape recorded sessions were transcribed verbatim into a computer after the interviews. Once interviews were transcribed, I gave the transcribed interviews to the participants and each was asked to review the transcript to ensure that it truly represented their point of view and experience. They were able to make any changes they wished. This is known as member

checking (Shepherd & Achterberg, 2003). Member checking was achieved for all but two participants. Attempts were made to connect with the two participants but there was no response. Any changes made by the participants were reflected in the final transcription of the interviews. Themes were identified from what the women said and interview data was coded and organized according to identified themes. As this was done for each transcribed interview, the pool of information became larger and themes were further divided into sub-themes. The researcher's reflective notes were also reviewed and, at times, considered to help understand the data. This process, beginning with a review of transcripts to identify themes, is known as thematic analysis (Polgar & Thomas, 2000).

4.7 Ethical Considerations

Ethical approval was granted by the University Research Ethics Board (UREB) at Mount Saint Vincent University before the study commenced. A copy of the approval form can be found in Appendix E¹. I have addressed the fact that participants signed a consent form after the study had been fully explained to them. All interview data, both audio taped and transcribed data, was kept confidential. Pseudonyms of participants were used throughout transcription, analysis and final reporting of data. Portions of transcribed data appear, as appropriate, in the results using quotes which do not identify the participants. Audio tapes and transcribed interviews were stored in a locked cabinet in the researcher's home². Once the research is completed, all tapes will be destroyed. Participants were welcome to keep their personal transcribed interview if they so chose, and were provided with a summary of the results of the study if they so wished.

¹ The form in Appendix E is the most recent copy of a renewal of ethical approval as the research was conducted over a period of time.

² Although the forms in Appendix C and D explain that audio tapes and transcribed interviews would be kept in the thesis advisor's office, it was deemed acceptable that these materials would be kept with the researcher for easier access.

Chapter 5.0 - Results

5.1 Description of Participants

Nine women were interviewed in total. Three women showed initial interest in being interviewed; however, they did not participate. There were scheduling conflicts for two women, and the third woman changed her mind after initially agreeing to be interviewed. Nine women were considered a satisfactory sample to obtain an adequate amount of data and reach theoretical saturation.

In order to give a context for the women who were interviewed, I will provide a brief introduction to each of them. The age of each woman is her age at the time of the interview:

Brianne is a 54 year old woman with diabetes that is controlled by insulin. She has three children, six grandchildren and was born in Nova Scotia.

Jane is a 64 year old woman from Ghana. Her diabetes is controlled by medication. She has six grandchildren.

Dawn is 58 years old. She has one daughter and one grandson. Her diabetes is controlled by insulin. She is from Nova Scotia.

Yvonne is 62 years old and has three children and one grandchild. She was born in Nova Scotia. Her diabetes is controlled by diet and exercise.

Makeda is a 42 year old woman whose diabetes is controlled by insulin. She was born in Nova Scotia.

Bonita was born in Nova Scotia. She is 63 years old and her diabetes is controlled by insulin. She has three children.

Grace is a 70 year old mother, grandmother and great-grandmother. She was born in Nova Scotia. Her diabetes is controlled by medication.

Grace S. is a 66 year old mother, grandmother and great-grandmother. She was born in Nova Scotia. Her diabetes is controlled by insulin.

Phia is a 60 year old woman whose diabetes is controlled by diet and exercise. She was born in Nova Scotia.

5.2 Themes Identified in Interviews

Following the order of social barriers identified in the literature review (chapter 2), I will present the data as themes identified by the women, corresponding to the order of social barriers identified in the literature review. Each woman's pseudonym has been used to indicate what she said. In areas of the interview where I spoke, my first initial, "D" was used. If any of the women discussed other family members by name, a pseudonym was also chosen for the family member to maintain anonymity.

5.2.1 Age

As described earlier, older women may have a harder time trying to change their dietary habits once diagnosed with diabetes (Maillet et al., 1996). This was indeed the case with Brianne and Phia when asked how they felt about having to change their way of eating:

Brianne: I feel very frustrated at times, very frustrated. And for the most part that I'm fighting a losing battle...having become a diabetic later on in life, I find that for me my eating habits are so hard to change and that's one of the things that I'm constantly fighting.

Phia: ...if I had known, as a young person, as a younger person probably, I would have gotten the habit of eating properly, you know, um, and I think that's the only regret that I

have because as you get older, even though you try it's not as, it's not as easy to [lose that weight]. It's, it's not as easy to, lose those habits either. You still have cravings for some of that, food that maybe you shouldn't have, yeah.

Maillet et al. (1996) mentioned the difficulty women may experience in changing their eating habits due to the view that they are changing their cultural, traditional way of eating; something they have done all their lives. Brienne identified with this finding:

Brienne: I have to make different choices and that's like training myself at this age. I have to train myself how to eat all over again basically because the food choices that I've been-you know used to, is what I've lived with all my life. Except now, it's like I gotta retrain my brain to think...okay, I can't have those four meat choices because that's not good for me. So, I gotta train my mind to think about something that's a little bit more healthier. Or, if I have those, if I have that choice that I have to have it without all that salt into it and take all that fat away, and odd as it may sound (chuckle), those are the things that our culture likes, so...

Brienne: ...it's just challenging because it's a whole different way of life for me. It's, it's a change of life for me. It's something that I have to um do, and I have to do gradually. It's gonna take, you know time, because you just can't take a whole lifetime and change just like that...

Although other women did not personally find it as difficult to adjust to dietary changes, they realized that it is an issue for some women:

Dawn: ...I can see it being hard, on some, type 2 diabetics, because type 2 diabetes doesn't, start right from the beginning, you - middle of life type of thing, and it's, you know, it's hard to switch over for some people...

Grace: ...and a lot just want to stay the way they were, you know uh, the way they've eaten all their lives...

5.2.2 *Political View as a Cause of Diabetes/Feelings of Losing Control*

Only a few women identified concerns that are similar to this theme. Although women did not specifically identify with Aboriginals who feel a lack of control regarding diabetes due to political and social issues (Grams et al., 1996; Sunday & Eyles, 2001), Brianne recognized that people with diabetes often feel as if they have lost control and have to give up everything:

Brianne: ...even myself at first, like when you hear the word diabetic, you're diabetic, it's like it's automatically almost like a death sentence, you give up everything, everything in life you gotta give up...

Brianne continues, noting the positive side of this:

Brianne: ... but I don't believe that. I think, everything is in, you know (pause) if you uh, you know, everything's in proportion. You know, of course you can't have, instead of

having all the candy, have a piece of it. I don't think you can just give up everything, and a lot of people feel that way, that you have to give up everything.

Garro (1996) discovered that some Aboriginals in Manitoba believe diabetes results from eating more processed foods. Brianne had a similar view:

Brianne: I mean, only until recently...I would say...our culture seems to be dying off earlier. Because I know back when I was younger growing up, my family ate something from their gardens and from, they raised their own pigs, raised their own chickens, whatever they did, all our grandparents...they lived to be 90 and 100 years old. And now it seems like our parents are dying off earlier. To me it's like it's triggered to all this modern medicine, as they say. A lot of it, I won't say all...but, some reason...I think it's the chemicals and that, anyway, yeah

D: Chemicals in the food you think?

Brianne: Yeah, yeah I do. Because I mean, look how long, and in my day, in my era when I was growing up as I said, (pause) yes, they had diabetes around, but you never heard tell of it. It's rampant now. You never heard tell of it like it is now. And not, (pause) even back then, not amongst the Black people, as much as you do now. No. And look what their diets consist of...like I said, they lived to be a hundred years old and they ate the greasiest of foods.

5.2.3 *Lack of Support Within the Health Care System*

A number of women had much to say about the health care system³. Although many had positive experiences with their doctors and other health professionals (such as dietitians and pharmacists, for example), they also identified with the finding that a lack of support and cultural sensitivity is present (Amaratunga, 2002; Maillet et al., 1996). As each interview came to a point that led me to inquire about the health care system, many women were clear in their response to this finding. I asked Makeda to comment (in general) about the treatment or advice she has received from health care professionals in relation to her diabetes:

Makeda: I'd say that some of it's been useful. Some of it has been uh, informative, uh, not particularly culturally sensitive though...I still think that there's a need to understand the disease, uh, as a culturally - as it affects other cultures within this country and how, how we treat it...

Grace also identified cultural insensitivity:

D: So would you agree that, because I've seen, in some of the literature too, like just the cultural insensitivity maybe

Grace: Very insensitive...mmm hmm... If you don't have the right doctor, you're in trouble.

Women provided more detailed examples of cultural insensitivity/lack of support:

³ Grace and Grace S are pseudonyms for two different women (see section 5.1 Description of Participants). Quotes from both women appear throughout the results and discussion.

Grace: I think health professionals have to learn, that Black people, in general, are *different*, in body type...

Makeda: ...for the most part, um, doctors don't fully understand, particularly uh (pause) in, in this province, um they don't fully understand the way um diabetics react. Or how, the way that, (pause) people of African descent, particularly with diabetes, can um, how the disease is not something that is particularly um (pause)...what's the word I'm looking for...we can walk around with a, with a high blood sugar count and not go hyperglycaemic. You know, um, when we hit a low, we hit a low. And I mean we hit a low, like a 2 or a 1. When we hit a high...you know, one of the things about being diagnosed with a 30 blood sugar was that they couldn't figure out how, we still walk because other body types, other folks of other ethnic groups may react very very differently, and be passed out in a diabetic coma. We're still functioning. We get up, we go to work, we drive, we do, we do all the things that we normally do, and they can't figure that one out. So, there's a whole lot of study I think that's still needed, at least in this country...

Grace: I think you know, the health care profession, have to be ready to listen to us, because these are our bodies you know. And uh, we know our bodies better than anybody. I mean I know my body better than anybody you know, so.

Grace S: I find that most of the, information you get, you have to be out there and get a lot of things on your own. On your own, uh, (pause) because...they don't seem to, like,

some doctors when they talk to you, they talk about your sugar levels and that type of thing; but, they don't really tell you how to eat or how to work with it or that type of thing. Um, they just, they just want your sugars low or a certain, rate and that's it. They don't know how you have to work to get to that point or whatnot. Because they use, uh, certain...for (pause)...you know say, an average, person but not everybody's average.

Yeah, so, sometimes, and a lot of things that work for another race, don't work for us. It's a big difference. And uh, even blood pressure, all those things are different with us. Yeah. So it's, it's hard for them, to really um, (pause) *understand us*. And same as in the States, their type of living, their type of food, is different from what we eat. So, and we're going by the American way. Yeah, and so, it's pretty hard.

D: Mmm hmm, mmm hmm. Do you find that um, like doctors or other health care professionals, do you find that they, recognize that there is that difference? Like, for, for Black, Black people or Black women or....

Grace S: No, I-I don't think they do. No...

A few women noted a lack of support due to a lack of explanation when using medications. Although Grace noted that her doctor became aware of a medication hazard for Black people, she highlights the important fact that doctors need to be aware:

Grace: ...they had me on medication, Avandia®. And um, that threw me into, almost, cardiac arrest, and put fluid on my lungs and um, and after, I ended up in the hospital, I

went back to the uh diabetic specialist, he said uh, 'Black people shouldn't be taking it'. This is not good for Black people and they...it was a new drug and they had, after they did the study, they realized it.....I mean, there's things that, you know, as my doctor says...there's medications we can't take. They've got to learn that. Uh, the Avandia® was a, you know, could have put me into heart failure...

Both Jane and Bonita identified that procedures relating to medications for diabetes were not initially well explained to them:

Jane: ... I started from Metformin and then they changed it to Avandia®. Whereby, I was taking 2 medications. And, then from Avandia® they changed it to Avandamet®, which is a combination of Avandia® and Metformin together. And, I was on for a while; but, the thing that I wasn't told like anytime I take the medication, I should eat. It wasn't explained to me that way. So, I figure that this is what's going to bring my blood sugar out...

Bonita: ...the doctor I went to he said 'well, uh, you gotta have, real good control'. And uh, so I went down from there. I went down, went from like blood work and, can't eat this and can't eat that. And, then the big thing that came on was drugs, came on and the needle...first the pills. And I-it seemed like, I still don't know if I had control of my, my diabetes; but, and I never-really never had understanding. I just, ate things what I wanted and while, you know, the pill is gonna control me, which, now I know it's a loss, the pill don't control diabetes. You gotta learn to work with it and control it...

Maillet et al. (1996) noted that even when women informed doctors about their symptoms of diabetes, women did not feel they received enough educational and general support. This is demonstrated by Jane's experience:

Jane: ...when they, I went for the treatment, the doctor didn't want to have anything to do with the diabetes. You know, no, he didn't want to have anything to do with the symptoms that I felt...

Women also identified insensitivity as it pertains to culture and diet. Makeda talks about the importance of food in the African Nova Scotian community:

Makeda: ...we plan food before we plan the function. And that's how important that is to us. There is very little that happens, in the African Nova Scotia community or in the African community period, that doesn't involve food. You know, even if you don't have a meal, even if you have a few cookies and a cup of coffee, you've got to offer something. And, there's a seeming lack of, fully understanding the cultural significance of having that kind of, you know, that kind of expectation. So that when you go to a function you know, you expect to have food.

Makeda notes that food is significant to many cultures:

Makeda: ...I think the sooner that, that the doctors and other health professionals realize that, you know, in a lot of cultures, that is a necessity. Um, and then talk to folks who have the disease, in that culture, um, in a different way. You know, there's-because the other, on the other side of it, you have the food guides for diabetes that now say well you don't necessarily have to give up sugar. You can have the occasional cup of tea with a couple teaspoons of sugar. You can have *a* hard candy, half a chocolate bar, 4 ounces of *a*, you know of *a*, a can of pop, or something like that, every once in a while. Doctors keep saying 'absolutely cut it out'. And dietitians are saying, 'no, have it in moderation'. And so, it sends mixed messages to people; so, it's very confusing.

Phia: I think one of the things that they *don't* do is that, they don't try to understand the history of a Black person. If you're going to give me directions, you need to understand what I eat and why I eat it, if that makes sense. Um, (pause) so yeah, they come from a perspective that, this is what you have to do if you're going to survive this; but, I think the part that's missing, that would help you is, 'listen I understand that this is what you're used to, but how can we maybe, taper that now to your needs'. So, instead of saying you *totally* have to forget about this, ok, let's look at what you were eating, so instead of that seasoned, nice seasoned, fried pork chop, maybe you can use half the seasoning, that you were using. Make sure it's not salty seasoning, and bake it. And so that, that's more receptive because, you're not taking, you're not totally taking away from me. You're not totally taking my culture or my heritage away from me food wise...Like they need to know, like even the indigenous Blacks, they like pigtails. So, a lot of the, it's so full of fat, it's not good for us. So, somebody coming in to teach me about diabetes, should be

aware of, that's some of the food we eat, and *explain*, 'you know, like if you eat this pigtail, this has', whatever it has in it, 'and it's going to affect you it's not good for your heart; but, maybe if you could scale that down and take all of that fat off , which doesn't leave much meat, but I'm just saying you know there's something that you can do.

Jane described that she needed to explain that her diet is different from the usual Canadian diet:

Jane: ...I went to diabetic clinic, and they are telling you what you should eat and what you shouldn't eat. So, in essence I had to explain to them look, I'm a foreigner, and we eat this. Here, they have a lot of potatoes and rice. But, other foods like...we have egusi. Egusi is like, eh, nut. We use peanut soup, peanut for making soup and stuff like that. So, that's what you have to find out...

Returning to the idea of not receiving enough educational or general support, as noted by Maillet et al. (1996), both Phia and Grace S. have experienced this:

D: What about the health care system? Like, for example, when you go to your classes or, when you've been to them in the past, what kind of, role do they play? How would you describe that...positive, negative or...

Phia: I think that they're pretty good. The only thing is that they don't really give you that, for me, I guess I, I need to see. And so, if I had um, and I, I know I need to purchase

the book that has recipes and whatever, you know. They don't really give you that menu that you can follow daily. So, I'm not one to sit down and say, 'ok, I'm going to make these menus out for the week'. But if, if it was made out for me, and I could go like say Monday and it had chilli, I would do that. And, I think they need to do that. I really do. Because, a lot of times you're saying to yourself 'well, you know what can I, what do I want to eat?' It's ok, you work with the, the portion control; but, you don't always want to be eating the same thing all the time. And also, you want to eat something that's appealing to you. So, I know that they have, um, diabetic books and whatever, cookbooks. And so, I need to get some of those.

Although Phia recognizes that a variety of meals suitable for diabetes are available in the cookbook, she still feels more education should be provided:

D: As you say, you feel like maybe, at the point of educating the person, it's good to provide it there. Because, right now for example, are you saying that they don't give you an actual meal plan?

Phia: Oh, no they don't.

D: They just give you guidelines?

Phia: That's right. They tell you, the times that you should eat. And, you know, you follow the Canada Food Guidelines and the portions and whatever; and, that's good. But, if you actually had *meals*, planned meals, you know.

D: Yeah, I've heard a lot of people, in general, like even people without diabetes, if they want to follow a meal plan, they want, the plan in front of them like Monday to Sunday at each meal.

Phia: So, if they had planned meals for a whole month, I don't have to eat exactly what they said on that particular day; but, at least I could see choices. Maybe I'll have this today; or, maybe I can do this with the chicken...

Grace S: They don't seem to, like, some doctors when they talk to you, they talk about your sugar levels and that type of thing, but they don't really tell you how to eat or how to, work with it or that type of thing. Um, they just, they just want your sugars low or a certain rate, and that's it. They don't know how you have to work to get to that point or whatnot; because, they use, uh, certain (pause) you know say, an average person, but not everybody's average...

Grace S. described that she took it upon herself, along with encouragement from dietitians, to find out more about foods pertaining to diabetes, such as label reading; however, she feels more should come from physicians:

D: And, would you say that that's something, that you found that you did on your own? Like you were naturally interested to, maybe, find out more about foods since having diabetes? Or is it something that maybe, a doctor or somebody else had encouraged you to do? Or, was it a little bit of both or...

Grace S: Well, I'd say, a little, a little bit of both. Well, not from the doctor, but from dietitians. Dietitians that started out you know, and then you're interested in reading different things and watching programs and different things. And, most of the things you do find out is on programs and, you know, things like that.

D: Is that um like, community programs or...

Grace S: Community programs, yeah. Yeah and any magazines I have, magazines and stuff like that. You get more information now than you ever had. Because even to care for yourself with diabetes, those are things that you have to just find yourself; because, most times, they [doctors] didn't teach it.

D: And how, if you were to describe your feelings about that...Do you find that that is something that's good for you, that you have to actually find the answers yourself. Or, do you sort of, feel like that should come maybe more from health professionals? How do you feel about that?

Grace S: I think that uh, more should come from them, the Health Department...

Phia comments more on the health care system in general:

Phia: I think what I find is doctors don't really check up on you, they don't follow up. I think, we need to understand that. When we go, we really need to tell the doctors how we're feeling, what we're feeling, what's working, what's not working. Because, in days of old the doctor, you know, you'd go back to him. He'd check you out, and that doesn't happen now.

D: Yeah that's interesting, do you think, well why do you think that is, do you think maybe it's just...

Phia: I think it's because, because our health care system is going down the tubes. I think it's more about money. The doctors don't have time to spend. Time is money. So, I can't spend half an hour, Phia, with you checking out, you know, whatever. Because, I've got to get that other patient in there. That's because the more patients I get, the more money that I can make. And so, it's called survival.

Upon member checking, Grace S. also mentioned that she finds that some doctors do not seem to make time for patients. She believes doctors should not be so rushed and should know more nutritionally to help patients.

5.2.4 *Impact of Education on Diabetes Management*

As stated in the literature by Assal et al. (1985) and Funnell & Haas (1995), receiving education about diabetes management is important. Women agreed with this and although they received education, as indicated by Grace S. and Brianne, Brianne identified that there are many in the Black community who have limited access, similarly noted by Atwell (2001):

Grace S: I think it's total education, knowing what's contained in our foods, what we're eating. I'm cautious about reading labels to see what's in the box; uh, what's in the package. So, I find that's a helpful thing. It's, knowledge. It's, it's really important.

D: So you feel that knowledge is good, right?

Brianne: I feel it is good. And, there's a lot of it there. But, still I know like um, even in my own community, there's uh, I'll say there's a lot of Black people I know, there's some who have diabetes and I know there's a lot that they're high risk, they don't get this information. A lot of them don't leave their homes, don't get it, and I feel this is where a lot of our culture's losing out. Because they miss so much information and there's so much out there to get. And they don't understand a lot of it. You know, by the time they realize how serious and bad the diabetes really is, they're already old. And, they've already gotten it and they're at a point where there's not much that can be done for them. And um, I really don't know how that info could be uh, put into communities, so that they stress just how important that this really is. Because, you know, you got a lot of uh

seniors, a lot of uh, you know Black families where the seniors are literally alone and don't have access to these things.

Brianne: There's a lot that doesn't have the support that I have. That's why I just bring it up; because, there's a lot of people that don't have the clinics and the little clubs to go to, the centres to go to, to get help. They may not even know about these places. I know there's a lot that don't. There's those who don't know that there's help out there. So, they're just dealing with it on their own, and it's very stressful. Yeah, it is very stressful.

D: Now, these programs that you go to, are they free?

Brianne: Uh, yes, most of them are, yeah. North End Clinic has programs that they have set up for people with diabetes. You can apply and ask about those. And, the Parent Resource Centre has sometimes, they have people come in, guest speakers. Yeah.

D: So, people who don't have access to those, sometimes it's just not knowing? Other times, would you say it's just hard for them to get there?

Brianne: It is, for some people, it is. Some people, even though they do know, they just can't, a lot of people, like the older people, can't walk to where they're at. And, they have no one to take them. So, they just miss out. They're just home, you know, so...

Unfortunately, some health professionals may not have time and/or resources to teach clients thoroughly, another finding in the literature (Funnell & Haas, 1995). Although Dawn was willing and able to seek information on her own, her experience reflects this barrier to diabetic education:

D: Would you say that there's anything that you feel that you don't understand when it comes to managing your diet and diabetes? Like anything that's not clear, or things that you wonder about?

Dawn: Uh, the odd time, I, like where measurements are concerned, uh, and how much I'm supposed to have. Like how much sodium I'm supposed to have per day. I read a lot of articles and things like that. I didn't get that information, now that I remember from the dietitian. Well, like how much salt I'm supposed to use. How much to break down...so many milligrams. How much is that in a teaspoon? Like, all this new, the new, well it's not new now; but, in my day it was only pounds and, and things like that. You know what I mean? So I really look. I read a lot of articles to find out information like that.

Funnell and Haas (1995) found that some people believe they know enough already as a reason for not attending or continuing with diabetic education programs. Jane acknowledged that, indeed, this may be the case for some Black people:

Jane: I will talk about an average Black person. They tell you your blood sugar is low. You go to the doctor. They tell you, some doctors know about diabetes, some people don't know about diabetes. And, then you don't go again, because you figure that you know what the doctor is going to tell you before you go. So, you have to seek and seek for answers, you know.

5.2.5 *Poverty/Low Socio-Economic Status*

It is well known that a low socio-economic status can greatly impact one's health. It was not surprising to find many women affected by this:

Brianne: I find that maybe up until a month ago, I always had my children living at home. And when you're a person of a low income and raising a family, it's very hard to uh, eat healthy, to be able to afford to eat healthy because you're the diabetic...

D: Would you say that you're able to purchase foods that help you manage diabetes?

Brianne: Not as much as I'd like to be able to. Because in order to do so, that way that the health plan wants us to eat as a diabetic, I would have to take away from something else in order to live that lifestyle, you know, so...

D: So when you say the health plan, is it Canada's Food Guide⁴?

⁴ Canada's Food Guide is now called Eating Well with Canada's Food Guide (Health Canada, 2007).

Brianne: Canada's Food Guide is what our nutritionist goes by. And, she does meal plans for us sometimes. You know, she'll write out different plans for us to try. And, even the ones that sometimes the nutritionist sets out for us, she'll try to do the one that costs the least but are still healthy for you. But, even those ones are still costly, so....

Brianne: I used to get tired of...when I first got diagnosed, I used to get tired of going to...I'd go to the hospital for different classes and things. And they would, yes would educate me on what I should eat, and how much I should eat, and this is what I should have, or not have this. I used to go to them all the time and get so frustrated because I would say, you know, it's easy for you to put a piece a paper and tell me this is what I should do. You do not know my situation, you don't have my finances, you don't understand that no, I can't just go to the grocery store and do this. You know, so, it's a choice you have to make. And if you're a parent who has children, unfortunately it's a choice you have to suffer for because of it, you know, so.

Although both Grace and Makeda can manage financially, they both identify the burden for women. Grace also mentions that it has affected her in the past while Makeda hints at the fact that finances do impact her choices:

Grace: ...a lot of our women can't afford a lot of fruit, fresh fruit and vegetables. So they don't, they don't get it. And so, that makes a big difference in how you eat. A lot of our women are at the poverty level and um, (slight pause) well I'm not rich...I'm on a fixed income; but, I really do try to make sure that we have the healthiest of foods, and the lean

meat. You know, if I'm buying hamburger to make spaghetti sauce or casseroles and that, you know, cause we eat a lot of casseroles and so, I try to make sure that that's, you know, lean, and the fat's drained from it and that kind of stuff. But, you know, I mean, if you don't have the money, you buy the regular hamburger which is really fatty. I think it depends on the financial situation of each person. Um, when my children were young and I became a single parent, we were there, so I know what that's all about. I know what it is like to, you know, live off bologna and I, try not to eat processed meats. So, you know live off of bologna and potatoes and soups, and stuff like that, the cheapest that was in the store and um, and I think that probably had a lot of effect on where I'm at now as far as diabetes. Because we were at the poverty level and um, and four children...it was very difficult, you know, to feed them. And um, you couldn't feed them on a healthy diet. You know, you just couldn't. So, it's a challenge, it's a challenge...

Makeda: It plays a major, major role, in diabetes. If one were to look at prices of, particularly fresh fruits, fresh vegetables...Yeah if you look at the, the cost of fresh fruits and vegetables, um, as cost of exporting increases, um, costs, of course increase at the grocery store level. Fixed income folks are not able to, to really afford, good *quality* fruits and vegetables. Most of the time you could buy you know, reasonably priced frozen vegetables. The cost of frozen vegetables is increased as well. You know, you have to make sort of those hard choices, around...given the price of meat, you know, a decent *cut*, of meat is very expensive. To buy chicken, chickens are very expensive...The cost of chicken is ridiculous. You can buy a chicken breast now and you're looking at, you know, to buy a family pack of chicken breasts, mortgage the house, you know. So, you

end up buying sort of lesser quality. Things like hamburger, and you don't buy the lean hamburger you buy the regular, you know. Lot less meat, lot more *fat*. You buy wieners, as opposed to, because in order to buy say a piece of pork steak or a piece of beef or chicken, and even to buy fish, is extremely expensive. By the diabetic food plan, you need to have a portion of protein, and even cheese is expensive to buy. We need a starch of some kind, be it rice uh, pasta or, potato. And then you need to have the vegetable. It is not an option because of price. So, it becomes um, economic status does hurt when you're trying to make those healthy food choices. If you're going to buy that stuff, then, you're buying it, but you may not end up eating it. You're gonna buy it for the kids, if you've got children. You know, I will do without, or I will do with less. The bulk of it's gonna go to the kids. That becomes a major health issue, when you have a disease such as diabetes. Even for myself, as a single woman, who, really has no *major* expenses...I don't have children, I don't have a home and mortgage...you still have to buy food. And even *I* look at the cost of food and say, 'oh my', although I *know I need* to eat more chicken, *less*, red meat, you know, I look at it and say, I can't do it because of how much it's going to cost me, financially. It's even *harder*, for someone who is a single parent, and has a limited income, is on either assistance or has to pay rent, feed and clothe a child, you know. The paycheck is what the paycheck is and it don't go no further. So, you're *limited* to be able to try and provide the *appropriate* food, and help treat your disease. Diabetes is becoming a huge problem for folks. It's lovely that doctors and folks talk about the need of more fresh fruits and more fresh vegetables...blah blah blah blah blah. It's lovely to say, but tell me how we're gonna get it in the hand of people who can't afford *to have it*, who can barely afford to get the medication. I don't know if anyone's ever mentioned

about the cost of diabetes, in and of itself. There's the cost of test strips, the cost of your medication. The cost may be a *little bit* cheaper if you're on insulin and, you know, depending upon whether or not...or if you're using a syringe, then you have those additional expenses. You know, just trying to get the insulin. Although insulin is almost 80 years old, in terms of when it was produced, the cost of insulin has not decreased. Huge huge, huge issues, for folks. Provincial government once upon a time did have a plan, that allowed, assisted, diabetics, with being able to get at least the diabetic supplies at reduced cost. If such a plan were to be back in existence, it would free up, more money. People could make better choices in terms of the foods that they buy, because they have a bit more money to spend on food. You don't have to worry about, you know, if it comes down to a choice between buying that bag of apples or that package of insulin. Of course the choice is always gonna be the vial of insulin; *but*, if you're getting some assistance with the cost of that, you know, the cost of that is *minimal* to you. Then, that means you can get that bag of apples, and these two things can work hand in hand.

Although Yvonne can buy what she needs, her experience and thoughts reveal that low incomes are common among Black women/families. She notes that if she had not had former financial support in life, she also would have found herself as a Black woman, facing a financial burden:

Yvonne: I think it probably would be, an issue because um, (pause) we don't all have those good jobs with good pensions right? So yeah, and if he [her husband] didn't leave me a pension it would *definitely* be a problem; because, I'm not getting much of a

pension when I retired. Because, I haven't been there that long right, to make a good pension, so...

D: Why do you think it might be that way for Black women or Black families? That they are in that position of it being hard financially. Any comments on that?

Yvonne: Well I think, I don't know about the young people today because our young people are getting educated, and getting better jobs; but, in my day, James [her husband] was very fortunate, he got hired and it was a very good union, very good pension plan. But, a lot of people didn't have trades, per say. So they, probably like, maybe just jobbed around and then when there's retirement time, there's no pension, or very little pension. And things are expensive, insulin's expensive. I have a sister-in-law who's on insulin. It's expensive, you know. And, if you have high blood pressure and you gotta pay that because, you don't have um, the coverage or the, you know the medical plan, and that's money. You know, that's money. And people make choices. Do I get my medication or do I eat? Do I pay the rent or whatever...

Both Brianne and Phia pointed out that more action is needed to help people in need:

Brianne: Well, for me to speak for myself as a Black women, to sum up everything with me and diabetes would be at my age, a middle-aged Black woman and being of low income, I find it's very stressful financially. I just feel that there needs to be more means I guess for people like myself and others in this category, more means to be able to live

the right way, with more healthier choices. I have to add this too; because, it's not just for the Black culture. I'm talking about the financial, this is for anyone, any race, any colour, anyone dealing with diabetes and dealing with it on this level. It's just to me, it's just added, (pause), it's just extra...uh, uh, what's the word... it's just something that people who's already sick don't have to deal with. Having those extra stresses makes your health more deteriorated. So, if lower income people had means and sources and not having to worry about that there, that would be a help, you know. That would help them in their health situation. Yeah.

Brienne: I think more money is needed for people with these kinds of conditions. I mean if that's what we need to do is to eat healthy and buy healthier choices, well we need the means to do that. Stress adds so much, when you're a diabetic and you're stressed, you know, it just does something to your whole body. And so, when you're stressed about taking that money you had to pay a light bill because you had to go buy some food, well that's stress. So you know, all those things add up. It may not sound like a lot to some people, but it is when you're living it, it's an awful lot, yup.

D: Any concerns about purchasing foods that help you cope with diabetes? Is that an issue that is there sometimes? That, maybe you can't get the foods that you want?

Phia: I think the only issue is that sometimes they're expensive. Yeah, and that's an issue because sometimes you don't always have the finances to be able to buy the proper food. And I think there should be something done, I don't know what, but yeah. I bought this

skinless chicken, and *it is absolutely wonderful*, you know; but, it's expensive. It's extremely expensive. So, it's not like you could just run to the store and buy that every day. You can't. You know, it's almost, to me, it's so expensive it's like a delicacy. And, you treat it as such. I just think that if you want to manage it, especially if people are on disability or seniors, who are on, limited budgets, they need to make things available for them.

D: So, right now, are certain medications and things covered through any type of health plan or through Medicare?

Phia: I don't believe that they are. I think that the Pharmacare, I think the seniors get Pharmacare. They still have to pay, uh, a certain amount of money up front. And, then for about I guess several months, their medications aren't that expensive; but, they're still expensive.

Dawn's experience highlights another interesting finding:

D: If I were to ask you what you see as a challenge, or what would be the most challenging thing in terms of managing your diabetes, in terms of diet what would you say? It can be a couple things or it can be one thing, whatever you...

Dawn: Uh the most challenging, well one of the most challenging things is getting out to the grocery store. And then I have to, either get a taxi, which is costly, 12 dollars, because

I can't, I do have a bus pass; but, then again you can't buy a month's supply of groceries and, carry it on the bus. So, therefore, I would have to get a taxi. My circulation isn't good; so, therefore, I have to buy a very expensive pair of boots, up towards a hundred dollars. I have to wear, my hands, I have to wear a good insulated pair of gloves, a good warm coat, those could be expensive.

D: Ok, so not so much diet; but, more just other-

Dawn: Not diet, but supplies...

5.2.6 *Role of Women in Families (Gender)/Family Relationships and Norms*

Many women identified with the societal expectation placed upon women in families, and were aware of the ideology of the SBW and the influences that this ideology places upon women. The following examples show women's experiences as primary caregivers, which results in neglect of their health needs and/or putting the needs of others ahead of their own:

Jane: The mother-you have an important role to play in the family, you know. Because you have to decide what is best for your children. So, in other words, you know, you are a protector for your husband becomes a child [laughing/chuckles]. You still become a mother, you know. And so, you have really important role that is, you reach a stage where I think you have to take care of your own self. Don't wait 'til you get sick before you take care of yourself. Which really, my body was running down, but I didn't have

time to stop and think. You know, because I figure that oh, everybody eat, you know, me I don't eat. I don't care. You see...

D: Yeah, that seems to be very common among women.

Jane: Yeah, very common. You know and you should take care of yourself even if your kids, you have smaller kids and they're eating, you should grab something...

Jane: Although my kids were away at that time, they were here a bit, you know. The thing is that when you have a family grown up and they are gone, you look after them with all your cash. And when it comes to the time of taking care of yourself you think you know, you should go out there and make more money, so you live comfortably, right. So, diabetes or no diabetes, doesn't help. You know, you don't think about the diabetes and its symptoms and its complications. So, you work, and then sometimes you find that even you're still thinking about the children. So, in other words, you carry this stress. Which I call it burden. And then the burden turn to depression.

D: So, like you said, it doesn't matter if you have diabetes or not, the priority is still looking after your family, right. So, it's like an extra burden then, if I have this disease and I still have to look after my family. Ok, so it's like a burden right

Jane: Yeah, yeah.

Grace S: I looked after children first and whatnot. And sometimes you're busy. You didn't realize you weren't eating. And uh, you wait for such and such a time and you grab something quick - a piece of toast, or a cookie, and a cup of tea. And you didn't realize you weren't eating properly. And uh, that was the thing I had to adjust to, eating on time, and your medication on time. That was a big adjustment.

Makeda: With Black women (slight pause) we've always been the ones to make sure that everyone else got, before we did. Anything healthy to be had in the house, in terms of what we were preparing for dinner, then, that went to kids. The milk went to the kids, if there was a limited amount of milk...if the choice comes down to the kids getting the good stuff and we take the leftovers, that's what we do. And, we still do to this day. Um, you know, I've seen myself come home and my niece and nephew be at the house, and my mother will say 'well I only have a certain amount of uh, stuff left, for dinner tonight'. And I'll look at it and I'll say, 'feed the kids, I'll go pick up something', and then off I go to the nearest fast food restaurant.

Grace: I think we are Strong Black Women. I think Black women are strong. Um, we have went through a lot of struggles. I went through the struggle of bringing up four, four young children all by myself. I worked two jobs and I went back to university. I did all that. I'm looking back now and saying 'how did I do it?' But, I did it.

D: I've also heard people talk about like there's this idea that the women are strong; but, also that sometimes, that can also be, like a myth. In the sense of that, people think that, oh they can handle so much and then they don't look after their own health.

Grace: Yup, and that's a problem too; because, they handle everybody else's problem but their own. I'm very guilty for that, in the past. And now it's me, [Grace chuckles] you know, but I have to be. I always say with her [referring to her daughter] being sick, I have to be good for her, *for me* in order to look after her. And if I'm not healthy, then I can't look after her. So, you know, it's really important; but, we do, we look after...Black women look after everybody, *everybody*. You know, we bring up our grandchildren, you know, I brought up my grandson. We do all that. You'd never believe in the later years we put people in nursing homes. You *never, ever* put anybody in a nursing home, you know? There was always a grandparent in the house. So, we have been strong for them. We have been the caregivers, providers, everything...

Phia: Sometimes it can have a negative impact, because as a Strong Black Woman you think, listen I can endure anything. So you're feeling something different, and you don't bother going to the doctor because you think listen, all I gotta do is just take something at home and that will fix it. So that's sort of like the Strong Black Woman. And also not having time for yourself. You have time for everybody else and you don't take time for yourself. So you miss out on a lot of things. Yeah so, when you're feeling tired and it could be a sickly tired, you may be thinking well, I'm only tired because I've done all of this type of stuff, and so you don't really take care of yourself as a woman. So I think that

has a negative impact. Maybe if you sort of didn't have that expectation or if you didn't have that expectation of yourself, you might see a sign, that hey, something's wrong with me and you would go to the doctor sooner...

Grace S. suggests a historical context for the role of the SBW:

Grace S: In a lot of families, it's only the mother there. Because the man, some of the men have their role, (slight pause) and, maybe the women take their role, I don't know. And so they feel there's no place for them. Or they don't take the responsibility. So the women say 'I'm a Strong Black Woman' because they're pulling the whole load by themselves. So, they're pulling the whole load doesn't mean that they're strong. They're pulling it because they have to pull it, you know. And they're doing the best they can. But I think that comes from way back, when (slight pause) the man was taken away. And the woman had to fend for the family plus she worked in the fields. She did *everything*. That's the Strong Black Woman because she had to do it *all*. She couldn't have the help of her family, because most of the time her children were taken away to work in the fields, you know. She was doing what she had to do to survive.

I had an opportunity to ask Grace if she thought that the societal expectations of women's roles within the family are different for Black women:

D: Do you find that it's different from other cultures? Or do you know of any examples of how, it really is different, because some people might say well 'all women do that' right. But do you find that it is actually different for Black women?

Grace: Yeah, I think it affects differently. I think it's different. I think uh, Black and Aboriginal women have a lot in common because we, do a lot I think. I don't think White women would put up with the stuff that we do. Ah my, I don't think all women do that.

Upon member checking with Grace S., I mentioned that it seems as if Black women want to preserve an image of strength to the world and so not admit to the world that they need help. I asked Grace S. what she thought about this statement. She commented that, as a Black woman, if you ask for help, even within the Black community, it can be perceived as being weak:

Grace S: And I think that's one of the problems with us, as Black women. (Slight pause) I think sometimes, our pride stands in the way of *a lot of things*. And, we're strong, against our own; (pause) but, we're out there in the world and we don't say too much, yeah. And when we do, our own don't want you to say too much either. So, there's a lot of oppression. We don't stand together.

Grace S. described who she would call a Strong Black Woman: someone who can take charge of what is going on in her life and can take care of themselves and not be ashamed to ask for help; also someone who is happy with herself and knows who she is.

Grace S: I hear people say, about, uh, Strong Black Woman. I've heard women say 'well I'm a Strong Black Woman'. And, I look at the person that's saying it, and I look at their life and I thought, well you're not very strong. It's how you look at strong. You know, because you're controlling everything doesn't mean that you're strong. It takes that person that (slight pause) will accept help and need help. Everybody has to play their part. The strong person's breaking down, and they're trying to handle everything, and that's not the way it should be in a family, you know.

Although most of the women I interviewed found that their family members were supportive, Phia provided some interesting comments regarding the support of others:

Phia: There's an educational process that has to go on with your family members. And sometimes they're not where you are, in terms of...I think that um, they have their own struggles, and sometimes you know, I guess none of us realized the severity of the illness.

D: Ok, would you say it's almost the kind of thing where you don't realize the severity of it until you're actually living with it?

Phia: Exactly, until you actually-until it actually affects you, and you understand when your sugar's low and all of those type of things, you don't have the energy...and the importance of eating right and the fact that you can lose limbs and worrying about open sores. Until you're actually in that, like I've got this and I've got to be careful of those things, I don't think you really take it seriously.

Phia: I find people don't give you that, you know you say listen, I've got diabetes; but, they just, whatever we got cooked that's what you have to eat. And so to me it's, almost like a lack, uh, a lack of respect, right, for who you are. So *you* have to, while you're at their place, manage your thing. And what happens is that, if you only want a little bit to eat, they become offended. So you know you've gotta make this decision, 'do I eat a lot, and then not eat as much tomorrow'. So yeah, I find that...

5.2.7 *Racism and its Effects on Health*

Although her experience with the health care system was quite positive overall, Jane commented on a finding consistent with local research about Black women not seeking help (Atwell, 2001; Enang, 2002):

D: So would you say that among Black women, they tend to not want to seek that help?

Jane: Yeah, you know, the help is there, the health care system is good. But you have to you know...They are sitting down at home and they want the answers, and I think that's one, number one key.

D: If health care professionals came to their house, do you think they'd be receptive to that?

Jane: No, the person has to be ready. You know they have to be ready, in the sense that you know, the social worker come to the door, first negative way is, 'Oh, he's coming to my door to check whether I have a boyfriend or something'. Certainly, they figure why you want to know their business...So, if there is, like there's something like the health care society-the doctors can go and find out, they're thinking that they're nosying around because it was a Black person.

D: Ok, so they would feel like they're being intruded upon?

Jane: Exactly, they have the illness and this illness is going to kill them. And if it's going to kill them, whose business is it? I'm not going to the doctor. It's attitude.

Depending upon the flow of the interview, I asked the women if they thought that members of the Black community/Black women are more receptive to Black health professionals. In other words, if a Black person or Black woman had a Black health professional attending to them, is the end result a positive or better experience in the health care system. The women's responses varied:

D: Would they be more receptive if the health care professional was, let's say if it was a Black doctor or a Black dietitian, or somebody that shares their cultural background or race. Do you think that would make a difference or no?

Jane: No I don't think it would make a difference.

D: Do you think if people, um, maybe, saw health professionals that shared their cultural background or maybe, shared their race, like maybe Black, health professionals, would that help? Do you think or not necessarily?

Bonita: I think it would, really it would. Like if they, had, if they went someplace like if you get them [Black women] to go.

D: I've heard that some people say too like you said it's to get them to go. So then it's like, well how do we get that information? Maybe, for example, they like to know, 'ok I have a doctor who shares my cultural background or whatever right? But, it's still hard for me to get out to that, doctor's office, right?' So it's like, how do we get the information to them? And some people have said, 'well maybe we could take it to them, take it to their homes, or maybe we could, you know, do home visits or something'. So do you think that might be another way to do it?

Bonita: It would. It would be a way. Because, I tell you, for one thing, some of the Black don't want to go and listen to a White doctor telling ya about your Black, uh, your culture. If they have a doctor come and tell you, you know, that the Black people this and the Black people that, first thing they're gonna say that they're prejudiced. But the man is only there, or a woman, the doctor, to help them, telling them about their culture. But a lot of people don't want to hear, ah, Blacks inherit this and Blacks - they don't want to

hear that. Some people it's different now. Some is great. Some of them, you know, don't mind; but, I find the older type, they're ready to fight...

D: And do you think, it would be also beneficial to have, I've heard some people say that they, they feel like, you know, if they had maybe a Black doctor or some other sort of Black health professional right, that they would feel more comfortable. Do you think that's true?

Grace S: Yes.

D: Is that true for you?

Grace S: Yes.

D: And, and people in general?

Grace S: Well (pause) I can ask, but then a lot of things they [the doctors that do not understand our culture] don't know. But, somebody that understands (pause) the culture and somebody that understands (pause) some of the, the things that we, *suppress*. If they would understand that, and, they're out there working and they know what they're up against each day too so they can identify with what you're saying. Because sometimes you just say something 'oh no, I-I didn't find it that way'. So, they, you know, because

they don't even see that. They don't even think that way. They don't even know where you're coming from. So, it's really, it helps, yeah.

Phia: I think if you get a doctor who is not of your culture or race, but who is culturally competent, then it doesn't make a difference. It's when you get the doctors and nurses that are not of your race and they are not culturally competent, that's when you need to have someone who understands your history, where you came from or whatever. Now, there's a slight possibility you could get somebody of your own culture that is not culturally- you know what I mean? So, I think that we need to be careful. For me, I need someone who is culturally competent.

D: Ok, regardless of whether they share your race or not.

Phia: Yeah. That's what's important to me. Because if I insist that I, I need somebody from my own culture, that excellence of a cultural competency, it's gonna stop. You know what I mean? I need you, when I walk in, it doesn't matter what you look like, you need to have that connection with me, you know? Because the reality is, you know, if there's no one that looks like me, does that mean that I'm not gonna get the care that I need. That's not acceptable.

D: Like maybe we're not always gonna be able to have people that share our race, or cultural background. But the key is, do they understand where I'm coming from. Right?

Phia: And we need to make sure, that, you know...we need to make sure that these professionals are, following those cultural competency guidelines.

D: And being trained that way right?

Phia: Exactly.

Both Grace and Grace S. had much to say about racism and the resulting effects on Black women/people⁵. Yvonne also commented about experiences in the past, which have affected the class or social standing of Black people today:

D: You mentioned like back in that time, maybe, there was just not a lot of trades that people were getting into and not as much education. Any comments on why you think that was the case back then? What the difference might be today or, any?

Yvonne: Well, uh [Yvonne sounds like she's trying to think] a lot of people just had to go, (pause) go to work. They couldn't stay in school. A lot of kids just...I had a couple of cousins who um, when I looked around, they weren't in junior high with me and they weren't in high school, they were out working, you know.

D: Even at that young age?

⁵ From this point forward in this section on Racism and its Effects on Health, many of the women's quotes are from Grace and/or Grace S. This is simply because Grace provided much insight regarding racism, in part due to her profession in the health care system, and Grace S. shared much in regards to racism. As previously noted, Grace and Grace S. are pseudonyms for two different women.

Yvonne: Yeah, they were out working. Yeah, they were out working so um, like their fathers or mothers might have said you know, come from large families, and, you have to go to work. So, you don't have a choice, right. And you, well you get into, you get into domestic work or construction labour, whatever right. And, so there wouldn't, necessarily be any, benefits.

D: One reason maybe why people don't want to ask questions of health professionals is because, do you think people feel inferior?

Grace: They do. They do, because a lot of us, a lot of the people don't have education. The older people don't and some of the young ones don't either. But the older women, a lot of them don't have education, uh, so, they feel inferior...*I mean, most of these older people can't read or write...*

Grace S: Because there are people up there that, (slight pause) maybe can't read and understand, and, lots of times too, uh, if there's programs out there in the community, we need places where we can go, where all these things are explained to people. The senior's group, the youth group, and start at a young age, you know. I notice that they're starting at the schools now, where they're putting in the cafeteria's and things like that and it's getting, out there. And, I find that in the smaller communities, rural communities, we're the last ones to see them things, you know.

D: The rural communities are the last to get it, right?

Grace S: That's right.

D: Any comments on why you think that is, like is that (pause) mmm...

Grace S: Well, (sigh, pause) I-I think too, (pause) in some of the smaller communities, rural communities, (slight pause) I think we don't talk enough. Mum's the word, you know. We don't say, and we don't ask for things that we really need. And if she asks you something, well, you talked too much. We're the last to get it, you know, and uh, I think we need to be more forceful with our needs.

D: Do you think if more people did speak up, or did talk about what the community needs are, do you think that would begin to happen? Or, do you think that there may be...

Grace S: They're just coming in slowly and we have to let them know that we're here. Yeah, you know. (Slight pause) Because, most of the small communities, I don't know, we're the last to get everything...

D: And do you think that makes people, feel a certain way?

Grace S: It does, yeah. It makes you feel inferior. Yeah. And so, that's why they don't, they don't ask questions or that type of thing, you know. If you ask for something, well...

D: So, to those communities of people, they may feel, you know, maybe we're being discriminated against, do you think?

Grace S: Well they are, they are, yeah, yeah. We don't say it too much but that's the truth...

D: Yeah, ok, ok; but, again you feel like once people do start to speak up, you think that governments or politicians would listen? Is that generally how you feel?

Grace S: I hope so. They talk at election time. But, you know, they come in the communities, they can find the people during election time, acting like they're all interested. And then you don't hear or see them anymore. We need, (slight pause) um, I think we need more Black people in politics.

Grace: I think there needs to be in depth study on Black people and diabetes. I really do. I, I think that we have, this is a province where we have the largest indigenous Black population in Canada. And we are the least studied and um, the least to know about our own health...I think the health professions need to take a lead in doing some research.

Upon member checking, Grace S. said that in Nova Scotia/Canada, Blacks are still laid back, not saying anything and under the thumb of oppression. Grace S. stated that she feels that as a Black person, doctors do not want a Black person to question anything. It is as though the patient is a subject:

Grace S: Sometimes we don't ask questions. And then some of them don't expect you to ask. They know, and they're controlling your body.....Well, I don't know, it's just...But (pause) I find now that, (slight pause) some of the doctors and nurses are just, um (pause) take it for granted, and they think 'well you ask too many questions' or that type of thing. They don't want you to be in the know. That's what I find. They sort of brush you off, you know. They don't want to answer your uh, you know...You're under me and you know...And that's what I, I don't care for, yeah. Because you have to help yourself. And (slight pause) lots of times, you tell them things before it's happening. They're describing the way that looks, not the way you are, yeah. So, you're running around with something wrong, and you might run around for months going back and forth, back and forth, and back and forth. And then, but just what you said, it, you know, because, they have the way well, 'I've never had a patient had that happen before', you know, so...

D: Yeah, that can be frustrating I'm sure.

Grace S: *Very...very* frustrating. Or, I find too if you have diabetes, if you go to the doctor for, say if you're not feeling well, they want to know about your sugars. Of course, that's important too; but, they always think it's your diabetes, you know. [Grace S. starts to chuckle] One time if you were Black, you went for something and they thought you were pregnant. You know, never look at the point - what you're telling them...

D: So, it's like they're making assumptions.

Grace S: Yeah, assumptions.

D: They're not really listening to...

Grace S: listen to what, we're saying, yeah.

Grace S. also said (during member checking) that the doctors are not taking you at face value. The doctors think it should be "as the standard/by the book". They are not really believing what you are telling them. Half of the time she thinks they do not want to listen.

D: You hear this term, client-centered or patient-focused care, right? You feel there needs to be more of that.

Grace S: Yes.

D: Yeah, ok. So in terms of what you've experienced then, with health professionals, or doctors, or whoever, um, (pause) and in terms of how you feel about what you described, how does that affect your willingness then, to follow through with, you know, recommendations or changes that they might suggest? (Pause) Does that make sense?

Grace S: Yeah, (sigh). At times, it makes you not feel very confident. Because if they're not listening to you, if they're not hearing what you're saying, are they diagnosing you properly?

Grace S. also commented (during member checking) that in general, among older Black men and women, there is a trust issue. It is as though prejudice is always in the back of their minds and so they are almost ashamed to ask questions and challenge the authority.

Grace reflects on the experience of Blacks in Nova Scotia:

Grace: Nova Scotia Blacks have really had a rough, rough ride. They were put on the worst land, rocky land out in the Prestons and, left there to die, and, cold in the winter. But, we survived it. We survived it, you know. And uh, we're strong people. We are strong people and we better, make sure, we better, you know, thank God for that strength that we have, because we are strong people...

Grace also provides insight on an interesting phenomenon among immigrant women from her experience:

D: Would you say, in your profession in the health care system, would you say that, have you seen um, where it may be different for women who were born in Nova Scotia or grew up here, compared to women who come here-

Grace: Ohh yes, oh yes, treated a lot different... ..They're treated like they're angels or something coming in and we're treated like, we've been here forever and treated like dirt, you know.

D: Oh really? Is that what you find?

Grace: Yeah...yeah, they say, we don't know what we're talking about or, whatever, and *they* treat us different, most times.

D: You mean the immigrant women treat...

Grace: Yup, yeah, yeah. They think we shouldn't be complain-we should be further along [in education and economics for example]. But they don't know the devastation and the racism that we suffered, and we really suffered racism, *continue* to suffer racism. In the school system, we couldn't even get an education in this province until in the 60's, ah, integrated education, you know? I went to a segregated school and teachers didn't have much more, than I had, you know. So, it's been a rough ride for us as a people. So I, I can see the mindset of a lot of our people, you know. They almost have a slave or passive mentality; but, we've gotta get away from that and move on now, because, it is a new day and so, we've got to...

5.2.8 *Cultural Meaning of Food*

Foods traditionally consumed within our culture have an influential role on our dietary choices; this is true for many women:

Jane: ...like Africans seem to cook food with oil, a lot...

Phia: We were used to eating foods that had flavour; so, you had salt...pickled pigs feet. So, you're talking about all that fat and gristle; but, you never thought of it when you were growing up, right?

Makeda: A lot of the choices I make are very cultural, also very, very personal in terms of, of family and how we eat and have been socialized, culturalized, and stuff. So there's, you know, a kind of thing around food and how, how we choose food, how we choose to, to socialize...

Makeda: Culturally, Black people do a lot of baking and um, there's always a church function, or a community function that involves some squares. And, it's really hard for people to fully understand, that, you- yes you can have these things, but, you've got to watch the way you bake them now, because there is such a high incidence of diabetes in the community...

Brianne: I find too like within our culture, we do have different eating habits. I don't know how to explain it, but we do. We just do. Like a lot of our eating habits is not found, you know, in the nutritionist's office on her idea of a diet.

Brianne: From the culture that I come from and the food choices that we've always made, and I think, not trying to quote history or anything, but I think it does revolve back to the slavery days when we always had to have the poor choices of things. Like um, today, when I look at the health system today and everything that I'm used to and everything that I like, is everything that I'm not supposed to have...

Makeda: Culturally, (pause) in the Black community we tend to eat a lot of fatty, fried foods. I think like from enslavement on, they ate the things that we like. Corn, and that kind of stuff. There was always stuff that was fried. It was quick and, and not as, not so nutritious.

D: So um, any, ideas or insights as to why you think a lot of Black women do tend to eat, more or any (slight pause) any?

Grace: I think it's just our culture.

D: Just our culture, eh?

Grace: Just our culture. A lot of uh, a lot of fried foods. I go to my friend's house... and, you know, I'm served fried food and I'm thinking 'Oh...do I have to, do I have to eat this?' It's always fried. Very rarely, is there baked unless it's a roast or something you know. Um, everything is fried. And, they don't fry it in olive oil, or canola oil. It's, you know, it's the cheapest oils. And, *and they see nothing wrong with it* you know. Yeah, and, I see the, the way they eat you know. Two plates of foods and, big plates. I don't know how they-I don't know where they put it...

D: I've heard some of the other women that I've interviewed, as well as I've seen some literature, say that maybe it has a tie back to years ago with our ancestors...sort of going back into the days of slavery. That, maybe, they looked forward to their food as like, an extra special treat.

Grace: Yeah it was. It was an extra special treat.

As also noted by many in the literature (El-Kebbi et al., 1996; Fitzgerald et al., 1997; Maillet et al., 1996; Samuel-Hodge et al., 2000), women identified difficulties with altering their cultural dietary habits due to diabetes:

Brianne: Yeah, this is ah, this is something that I've always, uh, diabetes concerning Black people, not just women, Black people in general. And, that is that I find that our culture, we've always been, I guess, for health reasons you could say, we've always, uh....we've always eaten the wrong things. I'll put it that way [chuckle], because our-our

menus, our diet, well, my diet, I can't speak for anyone else, but my diet consisted of, boiled dinners and all the greasy foods, like you know the fried chickens and all the pastas and baked macaroni and cheeses. Things that like you know, is not really healthy. So, I find that um, becoming a diabetic and, going to see my nutritionist at the clinic, the menu that they plan for me is things that is just, not, you know, wasn't normally, of the norm for my diet, you know. Because we eat lot of fat, grease, salt. Salt, I-I'm having a struggle trying to get rid of the salt. I've-I've slowed down; but, it's hard.

Jane: [Laugh] Saying it and doing it is two different things.

D: Yeah, that's the challenge, right?

Jane: Yeah.

D: What would you say is the, um, if you had to highlight the main challenge in terms of the diet, or nutritional aspect of it?

Jane: The nutritious aspect. You know, some people, you know, say, some doctor say 'oh have your breakfast', you know. And have your good breakfast to an average person is eggs and bacon and toast and jam and all this. And a cup of tea on top of it. But, they're not thinking about having cereal, you know. Something like oatmeal is really good for lowering your blood sugar. So you think about the nutrition, um, your milk that goes with the oatmeal, that's even wholesome. And, if you can eat this one, eat a

proportion out of it, not the whole bag of oatmeal. ...If somebody come and tell you 'watch what you eat', you'll be mad, you know. Because the person is telling you, you don't eat right. Maybe you go and buy French fries with the gravy and then the French fries has the fat, and the gravy has the fat, and you think, I'm eating healthy...

D: So the hardest thing you would say is the diet?

Jane: Yeah, the diet and everything that you know, the dietary discipline...

Makeda: We've been untreated for so long, that naturally making that adjustment is very, very difficult. We simply just don't make the adjustment well. Uh, that's because we've been told to take certain things...we're not prepared to take out of our diet.

Makeda: *I know*, that I need to pay *close* attention to my diet. So that using my diet, I can reduce my body weight, to reduce my dependency on insulin. I know it's up here. *It's here, it's in the brain*. It's getting the rest of the body to follow, [Makeda chuckles] follow the brain, you know. And, it's getting me to make, you know, it's me making those, those *appropriate* choices. You know, it's like, ok, you know, yeah, I got it. [Makeda chuckles slightly] You know, it's-it's now, it's, we have to go beyond *getting it* to now enacting. And, part of that enacting, is making those dietary choices.

Bonita provides detailed information on the types of feelings she experiences:

D: So, how would you say that you cope with that? Or, how do you feel about having to reduce, or avoid, or eliminate those foods you like? Like for example, you said you like the boiled dinners, right. So how do you feel about that, knowing that you can't? Is it difficult maybe coping with something that, you know, I can't have this because it's salty? Or, yeah, just wondering how you feel about it? How do you cope with that?

Bonita: Well, really, personally, sometimes it makes me mad. Like really well, something, sometimes, when I go to buy the groceries, can't eat this, can't eat that. Diabetes can't eat this. You can't eat that. And, I said gee it gets on your nerves, and that's, my opinion. That's - I'm *always* saying that...

D: So, it's more like the main meals.

Bonita: Yeah.

D: The boiled dinners and stuff. Then, sometimes that's frustrating knowing that, you know, you feel like 'oh I can't eat this, can't eat that'.

Bonita: Yeah. And the ice cream is another one. Now, I can eat ice cream, I love ice cream. Mmm, half a cup of ice cream, and, have no more. And then, and then the ice cream, you gotta start counting because with...like the fat's in it, and the sugar. And you gotta, and I'm only allowed to have so much intake a day. So, if I don't, if I don't have to take it, I don't bother with it because there's too much counting.

D: Right. So, would you say then that maybe it's just easier to not bother.

Bonita: Yeah.

D: Because you find, it's cumbersome, right?

Bonita: Yes

D: To keep track? All the time?

Bonita: Yeah, yeah. Because I gotta count the sugar intake. You got, um, in the, in the ice cream, a half cup of ice cream, and um, and you gotta count, well, now, now what did I have today. That was so much sugar. And, then what did I have today that was so much fat intake. Can I have the ice cream, so like that...

Bonita: Your favourite foods is really when you're going out is on the list [the menu]; but, that's my biggest fault with the diabetes, is like when you're going out. You can't go out with a crowd. (Slight pause) If you do go out with them, you gotta, (slight pause) eat a certain amount. We went up and if I got uh, uh, ribs and ah, and fries, which I'm not supposed to really have, you're only allowed the few, and I, well I ate fries yesterday, and, no way I'm gonna continue. It tastes so good. I'm gonna have them tomorrow; but, I can't. If you fall off, right back on...

D: So, you find in general you're able to do that. If you have an off day, for example, you're able to get right back on track.

Bonita: Yeah, yeah.

D: Ok and that's what they recommend that you do.

Bonita: Yeah, yeah that's what she [dietitian] recommends.

D: Ok, and you find that relatively easy to do.

Bonita: Oh it is, yes...yeah, very easy for me.

D: Ok, good, and would you say, maybe you find it easy because you think of your health. Is that why, do you think?

Bonita: Well I, I'm a worrier, like always worrying and all. And like you said, my health, true. I *know* that you're not supposed to really have it; and, she [dietitian] told me she said 'well French fries, ah, she said uh, like you can't have them every day'. She said if I go out, once in a while and we're not talking about every day out; well, you know I had French fries today and, and it bugs me, I can't have that tomorrow. So, like I worry about the least little, thing like I eat. And, I'm oh I'm not supposed to be eating that...

5.2.9 *Taste of Food*

All of us can identify with foods that we enjoy because of how they taste. Many women discussed how taste affects their food choices; namely foods high in sugar and/or fat. This results in great difficulty with controlling portion sizes, which is an important factor in dietary management of diabetes:

Phia: When I went to the classes, I realized that a lot of those foods had fat. I mean you eat pork chops and, you know, when they fry the pork chops, the fat on the edge used to taste so good. ...Portions, that was our big thing, because when our parents put out uh, a plate of food, you had a plate of food; but, your body doesn't need that much. Then when you learn about the starches and the sugars and whatever, which, we didn't have that. I don't think our parents even knew about that. So, you know, I try to reduce my portions. And that's, sometimes that's hard for me; because, the food that I like, it's hard not to go back for that second serving, yeah.

Grace: I guess, as a Black woman, I mean a lot of our Black women eat a lot of fat. And um, and they eat heavy portions. I've seen that at conferences, I've seen that at church settings and dinners and stuff. And uh, (slight pause) a lot of fried chicken and things like that. I've really made a change in my life, but a lot of women are still in that, because Black people love their fried food. I mean it's just one of those things, we grew up on it you know, fried foods...

Grace: Yeah I think, I think we all like our fat now, you know. [Grace and D start to laugh]

D: Sure, it makes things taste better right?

Grace: Does it ever. It really does taste better.

Grace: I think, um, we could do better at how we prepare the food, you know. But we tend to prepare it the quickest way. Just throw it on the stove frying pan cooking...

Makeda: For my family, you know sweets are our downfall. We have (pause) massive sweet teeth...We eat a lot of meat, fatty content foods.

Makeda: Um, we love our fried foods. We love our high fat meals and that kind of stuff, the dips and all that kind of stuff...

Makeda: Often times I hear a lot of diabetics talk about, how difficult it is to, around holiday times, as we're heading into, the Christmas season...

D: If you had to identify like, the main challenge, in terms of managing diabetes...

Makeda: It's uh, it's quantity. And types of foods in a lot of cases, you know. These figures come, because we tend to eat a lot. Portions...when you're at home, you know,

even if it's something that is inherently healthy, I usually eat a chicken stir fry, and you're having that with rice. A normal serving should be half cup of rice with, with the stir fry. Well, you know, the half cup of rice doesn't look like it's enough on the plate. So, that half cup of rice becomes a cup and a half of rice. [D and Makeda laugh]. And then, you need to put some soy sauce on that. So that's like, even if it is the light, well the light of course you're gonna have three-quarters of a bottle because, you need that salty taste with it. [Makeda chuckles] You can't-you can't taste it when it's only *half* a bottle. Or, if um, if you're at home and you're having like a burger and French fries, normally you go for a burger, you buy one burger, one order of fries, and then a drink. That's it. But, when you're at *home* and you're *barbecuing*, um, one burger can easily become three to four. Of course, all of them have to be loaded with cheese, and pickles and ketchup and barbecue sauce and mustard and mayo and, everything else. You know, they become, they're works of art. [Makeda and D chuckle] And you eat about four of those. Um, (pause) you know normally a spoonful of salad would suffice; but, no the spoon has to be, not heaping, (slight pause) it has to look like Mount Kilimanjaro...You got these two huge mountains of macaroni and potato salad. [Makeda chuckles] So, you know, (slight pause) it's that, it's portion control that's become the major problem. If I go to eat a meal, and I'm eating chicken dinner; then, one chicken breast on the plate is fine. When I'm home, it's two chicken breasts, you know. I will cook up both chicken breasts. I'll look and I figure, (slight pause) that ain't gonna be big enough for supper tomorrow night; so, I might as well eat that tonight with, with the other one. And then, tomorrow night go buy a whole new package of chicken, and start the whole process all over again. But yeah, it's that portion control, that I think is the biggest, it's the biggest problem. On

top of portion control, it's all the extras that we tend to add. All the condiments and stuff. Well, you can't have white rice without putting some soy sauce, you know. If you use light soy sauce because you're controlling the salt, um; but, you know, you want that sort of salty soya taste. Then, you're going to use pretty near all the bottle in order [Makeda chuckles] to get that taste. As I say (slight pause) if you go out to a function, and you're having hot dogs and hamburgers, one hot dog, one hamburger. But when you're home and you're barbecuing, that dozen wieners ends up on the barbecue. Although there's only three people in the house. [Makeda chuckles] Somewhere along the line, you're gonna eat four hot dogs, and you know, complete with buns, and everything else. So that's like eight pieces of bread, four wieners, which are not exactly the best protein in the world for you anyway. And, you know, your fat intake is increased, your salt intake increased. You've got all those complex carbs, and then, you go and lay down on top of all of that. [Makeda laughs] That's it, you're doomed, [Makeda laughing] you're just doomed. So, yeah...That's the biggest challenge is trying, is trying to, to eat at home, like you would if you were out. And, for the most part, we tend, and this is, people in general, *tend*, to do that. We tend to, 'oh well I'm out, I guess I'm gonna have me a lovely meal', you know. Or, I'm home and I've cooked up this big turkey dinner, so once I've had my initial serving, well, there's still some meat on that leg. There's still gravy in the pot. Some stuffing. And we tend to go for all that. We tend to go for, for the extras and never the turnip and the squash and the low-cal vegetables. It's always the turkey, the stuffing, the gravy, and the cranberry sauce...So, you know, that's, I think that's the biggest challenge we've had. Maintaining, *reasonable*, portions and still feeling (slight pause) full, in the end.

D: Still feeling satisfied right?

Makeda: And feeling satisfied. ... from a cultural standpoint...We're so used to having those fried foods you know, deep fried food like, deep fried okra, and all that kind of stuff, fried chicken, fried fish...You order fish and chips...well of course...one piece is not enough, that's an appetizer. You *want* those large portions, and we tend to look for those large portions and give ourselves larger portions...

Jane: Like an average Ghanaian, or an African, would, you know, cook this rice with sauce. The sauce is ok, but our fruits and vegetables...Somebody come and bring you a big cake, a fat cake, 'oh, I'll have that one for dessert'.

5.2.10 *Cultural Expectations of Body Weight Among African People*

In regards to a heavier body weight among African women being valued (Snooks & Hall, 2002; Miller et al., 2000; Kumanyika, 1995; Gore, 1999), some women were aware of this view:

Brianne: Well, a lot of older people, you hear a lot of older people used to say if somebody bigger got sick, oh, that's good because at least they have something to fight with, you know. They're the person that can afford it, if they have to lose a little bit of weight and all that, yeah.

Makeda: We're big boned and, and that's that. We've adapted to that, you know.

Jane: My mother was a big woman. When I was growing up, I was very thin. And then, the same mother told me that, you know, you look so thin, just put on a bit of weight. With the intention that, if you put on a bit of weight and you get some illness or something, instead of being in cancer, you know, because cancer can really make you go down, in weight.

Grace has heard of this view; but, she believes it is a myth:

Grace: I've heard women say 'well, if I got the weight on I can fight off disease'. That's crazy. You don't need that weight on to fight off disease you know. You're fighting off diseases with your immune system. And, you need to um, (pause) I don't say you need to be skinny. I mean I don't intend to be...I mean I'm happy with the weight I've got. But um, I-I, I really don't think you have to weigh three, four hundred pounds to be healthy, to, to fight off disease. I think that's crazy. I, you know, I, I really do. And I, I um, (slight pause) I think about when my daughter was diagnosed with her condition; she wasn't, she was skinny you know. And I mean, a lot of skinny people are dying of heart attacks and everything else. So, it's nothing to do with, you know, your weight. So, but I, I really don't think that, should be an issue of fighting off, you know. And, I know I hear that all the time. I hear from our women. Oh yeah I hear it all the time. 'Well, I gotta keep this weight on because I gotta fight off, I need something to fight my...' And that, that's a real myth they have. It's a myth, yeah.

Phia: Um, I think in our culture it was valued. And I think it was, it was seen as women of strength. Um, and it was also accepted that it's a part of the culture you know. Um, I don't know how else to put it but, you know, people talked about you know...the big butted, the curse of the Black woman, you know what I mean? And, big breasts and-and, and I think, most of the older women that I saw were, were very, were very sturdy looking. And-and, they call it fat now; but, in those days they were sturdy looking. They were strong. It meant strength...

Bonita noted that a heavier body weight among Black women (and men) is common:

Bonita: A lot of Black people, uh like, women and men, real heavy...

Brianne and Phia provided some insight regarding the prevalence of this phenomenon today:

D: Would you say that that's still common in your culture or not as much?

Brianne: Not as much. Not as much. Because I find now in our culture, um, (pause) a lot of people, a lot of the younger generation and that, are now trying to be more health wise. Like they try to exercise a lot more. And, they want their children to be more healthy. Because they witnessed their grandparents and parents go through this here diabetes thing to the point of losing their limbs and losing their lives. So, the younger generation now, I find, is on a more healthier, is on a more healthier road...

D: Do you think it's still that way, today?

Phia: I think it's...questionable now, because of all that we learn about health. Um, you know carrying too much weight is going to affect your heart. And, I think there is, there's a difference now. Except, you still see strong sturdy older, Black women and they look, they look healthy. They don't look, you know like something's wrong. Um, (pause) yeah I think it's-it's still valued; but there's, there's, a question brought. You know, are they really healthy? Are they really strong?

A few women did not see a positive view of a heavier body weight within their culture:

Dawn: I-I've never, I've never heard of it in the, in the, per se, for just the Black woman. But, I mean years ago, I, I read back in Queen Victoria and them days, the men preferred the heavier set woman; but, as to, just for a Black woman, I never ever...never heard that...no.

Yvonne: I've heard it. I can't say that I've ever (pause) known anybody who actually felt that way; but, I've heard people say that because somebody's heavy, they should be able to withstand whatever illness or whatever. I've heard people say 'oh you're all right because, you've got weight that you can afford to lose', that type of thing, right? So, but I, I can't say I've seen any evidence - proof of such a thing.

D: Ok, so you can't, you haven't seen any of that in - among people that you've grown up with, growing up here.

Yvonne: No.

D: Ok, but you've heard of it.

Yvonne: I've heard it, yeah. I-I think I heard it more as I, when I, grew up and after I got married than when I was young. I didn't hear it, actually you know, growing up, when I was young, the people were smaller.

Grace S: Years ago, not many women were that big. All this fried food yeah, yeah, you get - and, and we're walking less. Now people are sitting and driving and that type of thing...

During member checking, Grace S. said we eat the same today and are not as active; therefore, we're bigger today.

Women provided interesting comments when asked how body image personally affected them:

D: How do you personally feel about body image?

Brianne: Well, I know now that the reason I have diabetes is not because I'm overweight. I'm overweight and I know that. And now, I'm more cautious and I really try to manage my weight more so now, and especially because of the diabetes. Because even when I put on weight now, I can feel the difference in my own body. So, I try to stay consistent or try, you know, I'm trying to lose at the same time. But yeah, I'm more cautious of it.

Makeda: My view of body, of body image for managing diabetes, is not about how the body looks. For me it's, um, I need, to manage the weight in order to manage the disease. ...If I can, for me it's like, get rid of this, and, I'm not overly concerned about um, you know, how the body, the body looks. I would want to get rid of this [points to body part] because this is, indicative of the fact that I'm overweight. And that I can't, I need fewer pounds on my frame, in order to control the illness that I have.

D: Ok, and so, for you, um, do you have any comments in terms of your view of body image? How that plays a role in you managing your diet or diabetes?

Phia: Well, I think that I, I, um, I'm not happy with my body weight. I can remember as a young girl I used to, and I don't expect to look like a young girl, but, if I could get myself into proportion. I don't mind being stocky, but I just wanted to be like a healthy weight. Not something that looks sloppy, you know what I mean? That type of thing, that's important to me.

As noted by Gore (1999), there is a contrasting view of valuing a heavier body weight, versus being concerned about weight due to increased risk of health issues, resulting in a possible barrier for some women. I discussed this with Phia and she had this to say:

Phia: I think it's what you see. I think of that because when I think of my adoptive mom she was built...I guess I'm built sort of like she was; but, she was a very *stoic* woman. Very, uh, regal, looking woman. And I don't think there's anything wrong with that, you know. Um, and yeah they were in the days when you had the girdle. But, when she dressed she looked *regal*. You know what I mean? And I still...her presence was very... when she walked into a room, you know what I'm saying? She, it was her presence. Um, and, and when I think of it now, it was - she was a woman of strength, you know? Um, but you didn't *see* that, maybe, her weight and stuff maybe, there was a problem with her health...You know so, if I look like her, then that's fine; but, again, getting the education I am about health and how weight affects you and whatever, I know that some of my excess weight is not good. That's not stoic. That's not regal, you know. Yeah, so, you can find the balance. And I think the thing is finding the balance... ..Because you see two things; you see that, ok, I do have maybe that stoic, whatever, but then, you know the reality. Is it stoic or am I really overweight? Am I really too fat, for my, you know, yeah...

Chapter 6.0 - Discussion

6.1 *Introduction*

Several themes/barriers to dietary modification have been identified throughout this study. The following four showed the greatest effect in terms of the amount of qualitative data: Poverty/Low Socio-Economic Status; Racism and its Effects on Health; Role of Women in Families (Gender)/Family Relationships and Norms; and Cultural Meaning of Food/Taste of Food⁶. It was incredible to see the volume of data. This made it difficult to choose, among so many meaningful quotes, the quotes that would capture a rich experience of meaning for African women; a goal of phenomenology (Donalek, 2004). I will structure the discussion around the four above mentioned barriers to dietary modification, providing an analysis of the data provided by the women interviewed.

6.2 *Poverty/Low Socio-Economic Status*

It is known that diabetes is increasing in incidence in epidemic proportions (Satterfield et al., 2003). Knowing that this disease affects so many people and that the financial cost is great, Makeda pointed out the need for government to intervene and put programs in place to offset the high cost of this disease. She continued, saying that a provincial government plan to get diabetes supplies at a reduced cost should be reintroduced:

Makeda: Diabetes is becoming a huge problem for folks. It's lovely that doctors and folks talk about the need of more fresh fruits and more fresh vegetables...blah blah blah blah blah...but tell me how we're gonna get it in the hand of people who can't afford, *to have it*, who can barely afford to get the medication. I don't know if anyone's ever

⁶ Cultural Meaning of Food and Taste of Food were discussed separately in the literature review. In the discussion, I have combined them since the women's quotes identified within these two themes/barriers are similar.

mentioned about the cost of diabetes, in and of itself. There's the cost of test strips, the cost of your medication. ...You know, just trying to get the insulin. Although insulin is almost 80 years old, in terms of when it was produced, the cost of insulin has not decreased. Huge huge, huge issues, for folks. Provincial government once upon a time did have a plan, that allowed, assisted, diabetics, with being able to get at least the diabetic supplies at reduced cost. If such a plan were to be back in existence, it would free up, more money...

In addition, Brianne pointed out that, the stress of being concerned about finances in order to buy basic healthy food is unacceptable.

Brianne: When I first got diagnosed, I used to get tired of going to, I'd go to the hospital for different classes and things. And they would, yes would educate me on what I should eat, and how much I should eat, and this is what I should have, or not have this. I used to go to them all the time and get so frustrated because I would say, you know, it's easy for you to put a piece a paper and tell me this is what I should do. You do not know my situation, you don't have my finances, you don't understand that no, I can't just go to the grocery store and do this. You know, so, it's a choice you have to make. And if you're a parent who has children, unfortunately it's a choice you have to suffer for because of it, you know, so.

Brianne: I mean if that's what we need to do is to eat healthy and buy healthier choices, well we need the means to do that. Stress adds so much, when you're a diabetic and

you're stressed. It just does something to your whole body. And so, when you're stressed about taking that money you had to pay a light bill because you had to go buy some food, well that's stress.

As noted by Brianne's physical symptoms associated with stress, stress further hinders a person's diabetes, which negatively impacts overall health. It is known that too much stress is harmful to one's health. Brianne demonstrated that not only does stress affect her physically, but also mentally. Brianne noted that these stresses are for anyone who is considered low-income and dealing with diabetes. Although it is true that low-income can affect all women who live with diabetes, of particular concern for the purposes of this research is the effect low socio-economic status has on African women. Grace discussed this:

Grace: A lot of our women can't afford a lot of fresh fruit and vegetables...a lot of our women are at the poverty level...

Yvonne reflected on the fact that when she was growing up, many Black people in her family did not have the opportunities to get good jobs and/or a good education:

Yvonne: I had a couple cousins who um, when I looked around, they weren't in junior high with me and they weren't in high school. They were out working you know...so um, like their fathers or mothers might have said you know, come from large families, and you have to go to work. So you don't have a choice. And you, well you get into, you get

into domestic work, or construction labour, whatever. And so, there wouldn't necessarily be any benefits.

Historically, African Nova Scotians were not provided equal access to education⁷ (BLAC, 1994). This reflects a continuous cycle that keeps many Africans in a lower position in society, preventing them from attaining a higher paying job and/or a job with benefits. Race, class, and gender are interconnected hegemonic structures that are deeply embedded in society from years past. As just raised by Grace, these factors still negatively influence African women's health today.

6.3 Racism and its Effects on Health

There are many points worth discussing which relate to the effects of racism on African women's health. Although the ideology of the SBW is discussed within the barrier of Role of Women in Families (Gender)/Family Relationships and Norms (in chapter 2), the issues raised by this ideology also point to the effect of racism and internalized oppression. Therefore, for the purpose of this discussion, I will include Role of Women in Families (Gender)/Family Relationships and Norms within the barrier of Racism and its Effects on Health. As such, the following six areas will be discussed under the barrier of Racism and its Effects on Health: (1.) Role of Women in Families (Gender)/Family Relationships and Norms; (2.) Racism Regarding Cultural Competence; (3.) Racism Regarding Health Research; (4.) Racism Regarding Treatment by Professionals; (5.) Racism Regarding Internalized Oppression Leads to Mistrust/Not Asking Questions; and (6.) Racism Among Africans/Assumptions.

⁷ African Nova Scotians attended separate schools (many of which had no heat or running water) which delivered substandard curriculum compared to the curriculum delivered in common schools for White children (BLAC, 1994).

6.3.1 *Role of Women in Families (Gender)/Family Relationships and Norms*

As noted earlier by Samuel-Hodge et al. (2000), African American women indicated that the stress of care giving contributes to difficulty controlling their diabetes. Many African women fall into the roles associated with the expectations of caring for the family, which can cause them to neglect their health needs (Etowa et al., 2005). Jane's experience, below, revealed a similar finding which was present among the African women interviewed:

Jane: The mother-you have an important role to play in the family, you know. Because you have to decide what is best for your children. So in other words, you know, you are a protector for your husband becomes a child [laughing/chuckles]. You still become a mother, you know, and so you have really important role that is, you reach a stage where, I think you have to take care of your own self. Don't wait 'til you get sick before you take care of yourself, which really, my body was running down, but I didn't have time to stop and think...you know, you don't think about the diabetes and its symptoms and its complications.

In addition to the roles of women, that are ingrained in society, the African women interviewed had much to say about the ideology of the SBW and the role that African women are expected to keep in family, church, community and society in general (Etowa et al., 2005), as stated by Grace:

Grace: Black women look after everybody, *everybody*...we have been the caregivers, providers...everything...

The ideology of the SBW is important to consider in terms of how it influences African women's lives. When Grace S. suggested a historical context for the role of the SBW, she explained during member checking⁸ why African women ended up taking on this role. In her words she says:

Grace S: ...I think that comes from way back, when, (slight pause) the man was taken away, and the woman had to fend for the family, plus she worked in the fields. She did *everything*. That's the Strong Black Woman cause she had to do it *all*. She couldn't have the help of her family because most of the time her children were taken away to work in the fields, you know. She was doing what she had to do to survive.

It is well recognized that historical and cultural experiences deeply impact people of African descent (Barbee, 1994; Shambley-Ebron & Boyle, 2004). Grace S. reported that during the enslavement period, African men and children were taken away from the family. As a result, the women had to work the fields and also do everything else. This shows that the effects of the enslavement period still affect the lives of Africans today, even though this form of oppression has been abolished. This is an example of how oppressive, hegemonic structures are deeply embedded, and still affect the lives of African women. Discrimination and overt acts of racism may cease, however this demonstrates how powerful oppressive acts are and the toll it takes on African women's health, physically, mentally and emotionally. This is significant to consider for

⁸ Member checking is described as the process whereby participants are given the opportunity to verify interview information (Shepherd & Achterberg, 2003).

these African women living with diabetes, as the stress they experience also has a negative impact on managing their disease and overall health.

Another important point, in regards to the ideology of the SBW, is the perpetuation of oppression that is present within some African women. Although there are negative implications to the ideology of the SBW, there also appears to be a phenomenon whereby African women want to show the world that they are indeed strong and do not want to be perceived as weak. This is an example of how stereotypical beliefs about African women that are held by society, such as the label of being strong, are internalized by African women. The fact that African women may unconsciously believe this stereotype reveals that expectations of African women being strong are deeply embedded in society. This is yet again, another example of an oppressive, hegemonic structure in society (Eghan et al., 2004; Etowa et al., 2005).

Indeed, African women (on a whole) are strong, because they have endured many struggles. Although this can be a positive characteristic, a problem arises when African women believe that they have to be strong and prove their strength to others, both among themselves, and outside the African community. Believing this stereotype and feeling a need to prove their strength even when they do not feel strong, is a result of the powerful influence of this ideology that affects African women negatively (Etowa et al., 2005).

As mentioned previously in section 5.2.6, Grace S. reported during member checking that asking for help, even within the African community, can be perceived as being weak. Furthermore, internalized oppression can promote a sense of competition among members of the African community. Internalized oppression can cause division among African women resulting in a lack of support for each other, as stated by Grace S.:

Grace S.: And I think that's one of the problems with us, as Black women. (Slight pause) I think sometimes, our pride stands in the way of *a lot of things*. And, we're strong, against our own; (pause) but, we're out there in the world and we don't say too much, yeah. And when we do, our own don't want you to say too much either. So, there's a lot of oppression. We don't stand together.

It is clear, then, that oppressive societal structures can also work against African women to keep them oppressed when African women continue the cycle of not voicing their need of help. Nonetheless, although these structures are present, some African women do realize that there are negative implications to the ideology of the SBW, and that it affects them. Some African women pointed out that negative implications must be challenged and changed; and this change can start within one woman recognizing the need for change, and choosing to think and act differently. Examples include African women redefining their view of being strong, as well as educating the younger generations to not think and act in ways that can lead to ill health and well-being, as indicated by Grace S. and Phia:

Grace S.: I hear people say, about, uh, Strong Black Woman. I've heard women say 'well I'm a Strong Black Woman'. And, I look at the person that's saying it, and I look at their life and I thought, well you're not very strong. It's how you look at strong. You know, because you're controlling everything doesn't mean that you're strong. It takes that person that (slight pause) will accept help and need help. Everybody has to play their part. The strong person's breaking down, and they're trying to handle everything, and that's not the way it should be in a family, you know.

Phia: I think instead of feeling that we have to be Strong Black Women, I think we have to be sensible women. I think we need to understand and know our bodies. We do need to know, when it's changing. We need to be more aware the older we get. I think that we need to be aware but more importantly, we need to raise our young women to be alert. Let's not let them get to our age and they have to go through all of this. I think that if we start at a very young age eating properly, knowing the things that can affect us, positively and negatively, and taking care of our bodies, then as we get older we don't have to worry so much.

6.3.2 *Racism Regarding Cultural Competence*

It is necessary to take a moment to discuss the concepts involved in the idea of cultural competence. Cultural competence is a term that can have numerous definitions. Basically, when health professionals are culturally competent, they have learned to adapt their thinking and be open to the cultural influences of ethnic groups that are not their own. Health professionals need to be aware of their biases and assumptions, and realize how their biases and assumptions influence those they are caring for. Professionals also need to realize that although they may gain knowledge, i.e. information about an ethnic group's culture, people who are members of any ethnic or cultural group are individuals within that group. Therefore, not all aspects of the culture may apply to an individual (Srivastava, 2007). For example, just because someone is of African descent, this does not mean that they embrace all aspects of their ancestral culture. Cultural competence then, is about gaining knowledge, but also being able to take knowledge and apply it in culturally appropriate ways across varying circumstances and interactions (Srivastava, 2007).

In the next chapter, the conclusion, I will describe steps that can be taken toward gaining cultural competence.

Phia's comments summed up the key issue regarding a culturally sensitive health care system:

Phia: I need someone who is culturally competent.

D: Ok, regardless of whether they share your race or not.

Phia: Yeah. That's what's important to me. Because if I insist that I need somebody from my own culture, that excellence of a cultural competency, it's gonna stop. You know what I mean? I need you, when I walk in, it doesn't matter what you look like, you need to have that connection with me, you know? Because the reality is, you know, if there's no one that looks like me, does that mean that I'm not gonna get the care that I need. That's not acceptable.

Phia noted the importance of professionals being culturally competent, regardless of their race or cultural background. It is important not to make assumptions because someone is of African heritage that they know about the cultural influences of their African client. Nor can we insist that only African professionals are required to help those in the African community. Ethnic matching is the term used to describe the belief that members of a certain race, ethnicity or cultural group are best served by health professionals of the same race, ethnicity or cultural group. In some cases in the literature, clients have benefitted from ethnic matching (Srivastava,

2007). It is also evident from the various responses of the African women I interviewed regarding this issue, that some African women do feel more comfortable with professionals of African descent. In Nova Scotia, it has been noted that ethnic diversity is not well reflected among health professionals (Enang, 2002). However, we must be careful to not assume that ethnic matching will solve the problem of lack of cultural competence. Also, not every person of African descent will automatically feel more comfortable with a health professional that shares their African heritage. Every professional should be trained to be aware of, and open to, discussing the cultural influences of the clients they are helping, as also noted by Srivastava (2007). During member checking, Grace S. commented on the fact that the researcher is a Black woman, coming into the Black community as a Black health professional, with good intentions of trying to help the community. Regardless, there may still be a barrier because I am not from Nova Scotia and I do not necessarily understand the culture in the rural Black communities of Nova Scotia. This means that any health care professional, especially those working in rural African communities in Nova Scotia, or with any person who has a different cultural background, must take the time to get to know and understand the culture of the community in which they are working. Again, more specific details as to how this can be done will be explained in the conclusion, chapter 7.

6.3.3 *Racism Regarding Health Research*

The following quote from Grace indicated an important gap in health research:

Grace: I think there needs to be in depth study on Black people and diabetes. I really do...this is a province where we have the largest indigenous Black population in Canada.

And we are the least studied and um, the least to know about our own health... I think the health professions need to take a lead in doing some research.

Although there is a lack of health research among the African population in Canada (Enang, 2002), the complexities of this issue are evident when the quotes from the following women are compared:

Grace: ...I think research needs to point to Black people in general on their health. And start having some people in clinical trials and, that sort of stuff in order to, to see...because we're not in clinical trials *in anything*, we need to be part of the research process...

Makeda had a different view:

Makeda: ...we have been, hard done by, scientific studies, over the years. We tend not to believe...scientific studies...we have often been victimized by science, we tend not to believe...the research...

By comparing the views of these two women, it is clear that not all are keen on health research, or see the value of it. However, the key is to find a way to include African women in research in a culturally appropriate way, so they can see the benefits of health research for African women. During member checking, Grace provided insight as to how this can happen when she said that doctors need to be involved in appropriately explaining to African women the

benefits of clinical trials, and the need for them to be included in more clinical trials. This will be discussed further in the conclusion.

6.3.4 Racism Regarding Treatment by Professionals

The following quote from Grace S. reveals a serious concern regarding treatment by health care professionals:

Grace S.: I find now that, (slight pause) some of the doctors and nurses are just um (pause) take it for granted, and they think ‘well you ask too many questions’ or that type of thing. They don’t want you to be in the know. That’s what I find. They sort of brush you off, you know. They don’t want to answer your uh, you know...You’re under me and you know... And that’s what I don’t care for, yeah.

The client’s needs and concerns are overlooked and even ignored. Clients can walk away feeling unimportant and uncared for due to just being brushed off, which can result in a lack of trust in health professionals:

Grace S.: Yeah, (sigh). At times, it makes you not feel very confident. Because if they’re not listening to you, if they’re not hearing what you’re saying, are they diagnosing you properly?

I was very surprised when Grace S. said the following:

Grace S: ...one time if you were Black, you went for something and they thought you were pregnant... you know, never, look at the point-what you're telling them...

This quote further exemplifies not only the assumptions that doctors make, but also reflects prejudicial attitudes/racism by negatively stereotyping Black women as promiscuous or very sexual (Collins, 2000; Barbee, 1994). As a result, if they go to the doctor feeling unwell, the assumption is that they must be pregnant. Grace S. commented during member checking that she believes this view is still prevalent today.

Another example of an assumption is when doctors and/or nurses assume that if a client with diabetes feels unwell, their blood sugar level must be elevated. Grace S. shared a statement directed to her by a nurse: 'sugars must be up' (Interview 8, p.12). During member checking, it was confirmed that the nurse assumed Grace S.'s blood sugar was elevated without checking her blood sugar. This is the assumption without truly considering and investigating why the client feels a certain way. Grace S. and I discussed during her interview that when this assumption was voiced to her, it sounded accusatory. This in turn could cause someone to internalize the message that they are to be blamed for their symptoms, which can lead to feelings such as guilt, inferiority and powerlessness. Although it is true that if a person eats food that is high in simple carbohydrates, their blood sugar will rise possibly causing physical symptoms, the key issue here is that assumptions should not be made and voiced to the client as in Grace S.'s experience. During member checking, Grace S. commented that nurses who are not used to looking after Black patients, will let the patient know that they are not used to providing care for a person who is of a different race. Grace S. provided an example of such a comment: "Your skin is tough". Grace S. said that some Black people do not know how to deal with comments such as this and

therefore mistrust health professionals. Grace S. went on to say that comments like this are unnecessary as she does not need anyone to remind her that she is different. She also mentioned that similar comments have been said to her numerous times; however she does not allow them to bother her and is willing to speak up. Yet for someone who is not assertive, this presents a very real concern that clients are not being treated appropriately by some health professionals.

It is a concern that treatment, such as just described, occurs on numerous occasions. This clearly shows why African women may not want to seek health care unless absolutely necessary. Sadly, this can lead to negative health outcomes (Enang, 2002). Whether or not a client is assertive, a comment such as described is unacceptable and an example of a stereotype that can be internalized. By pointing out to clients that they are different, or as indicated in section 5.2.7 by Grace S.'s experience with doctors and/or nurses: ...'I've never had a patient had that happen before', this emphasizes that African clients do not fit within the norm. As previously noted, Shambley-Ebron & Boyle (2004) discussed the notion of White feminism which is structured around the idea of unity (i.e. all women should unite to address gender oppression). Therefore, when African women identify a different experience, this is viewed as a threat to White feminism. This concept can be applied to Grace S.'s experience. While indeed African people's symptoms can be physiologically different, it is the emphasis on African people's symptoms and experiences as *too* different, and cast in a negative light that is problematic. Nurses/physicians emphasize the difference in a negative way which comes out in voiced assumptions and as a result, African clients are too difficult to understand, rather than taking the time to learn about the differences and work together to help the African client. As pointed out earlier in the results (section 5.2.7) the problem is that Grace S. commented that some doctors think experiences and symptoms should be "as the standard/by the book". The fact that doctors/nurses can make

statements, such as ‘I’ve never had a patient had that happen before’, emphasizes the point that everyone is not the same, or “as the standard/by the book”, and reveals the need for culturally competent health care.

6.3.5 *Racism Regarding Internalized Oppression Leads to Mistrust/Not Asking Questions*

Grace S. also commented (during member checking) that in general, among older Black men and women, there is a trust issue. It is as though prejudice is always in the back of their minds and so they are almost ashamed to ask questions and challenge the authority. Grace S.’s comments show how years of dealing with systemic racism and internalizing negative stereotypes has resulted in (1.) a lack of trust and (2.) feelings of inferiority to the point where self-esteem/confidence is shaken, and African people feel almost ashamed to even ask questions, especially of someone in a position of authority. This further reiterates the point made earlier in chapter 2 in the section on racism (section 2.11), that those who hold positions of authority/power in society can exert that power over other groups to keep them oppressed (BLAC, 1994). This can happen on either a conscious or an unconscious level. Grace S. said that if a Black person came into the community with (health) information, members of the Black community may not trust that person’s knowledge and/or authority. Members of the Black community tend to wonder if the information presented by another Black person, is really true and/or trustworthy, even if that Black person is from within their community. Whereas, if a Caucasian person came into the Black community, Black people are more apt to listen to that person and not question them. In these situations, Caucasian professionals are trusted more (than Black professionals) because Caucasians have the power of influential authority in our major societal institutions, in this case, the medical profession (Carvery & Bishop, 1994, as cited in Benton, 1997).

Although we would like to think that African people are not seriously affected by years of internalized oppression, Grace S.'s comments reveal that African people may mistrust members of their community when authoritative knowledge is brought forth and/or they have a position of authority. Due to years of believing negative stereotypes and prejudicial attitudes which leads to internalized oppression, African people come to believe that they are inferior and struggle with insecurity/low self-esteem/lack of confidence. This belief is held so deeply, that it can affect their view of their whole culture, community, and race. Africans believe negatively about themselves and other Africans, either within or outside their community (Enang, 2002). As a result, they do not trust themselves or other African people in general. Rather, they trust Caucasian professionals and therefore do not even question their authority or ask them questions because, as African people, they feel inferior. The following quote from Grace reveals this:

Grace: A lot of our, women and... men particularly, but more of our women too, *don't ask questions*, um, ...see we grew up very passive, grew up that whatever, whatever the, clergy said, whatever the doctor said, whatever the school system said, it's ok, and *it's not ok*, it's not ok, ...until we start asking questions...

Grace went on to explain one reason why people do not want to ask questions; they feel inferior due to the fact that many, particularly a lot of older women, are uneducated. This shows the complexity of the issues facing African women. The lack of equal access to education has resulted in feelings of inferiority, which is again another example of how African women are deeply affected by being kept in a lower position in society, due to not having the same opportunities as Caucasians. Grace goes on to say:

Grace: ...that's a, real barrier there, you know, we don't ask questions. We need to, and um, and I think you know, the health care profession, have to be ready to listen to us...

Grace's comment shows that we need to work together. African people need to be willing to ask questions, and health professionals need to be open to, listen to, and learn from Africans about the differences in their culture. This is not always an easy task, as the negative effects of years of oppression can take a long time to heal and Africans may not be willing to open up and ask questions.

Although Grace S.'s comment, at the beginning of this section, indicated that in general older Black people are almost ashamed to ask questions, she further clarified the following points during member checking. She believes there is a more prevalent view that when a Black person comes into the Black community, older Black people are more likely to open up and ask questions. This view contrasts to younger Black people, who are more prepared to ask questions today and will ask even a White professional who comes into the Black community. From this, we see a difference in age. If African people do end up asking questions, older Africans will more likely ask questions of another African person, rather than a Caucasian person, that comes into their community. This shows that older Africans appear to feel more comfortable asking questions of members of their race. In contrast, a younger African person is more likely to ask questions in general, regardless of whether an African or Caucasian professional comes into their community. This is a sign of positive change and reflects the fact that the younger generation has had more opportunity, compared to their ancestors, to become educated and therefore, may feel less intimidated and inferior. It can be inferred that for some older African Nova Scotians, age

and lack of education intersect as barriers to forming trusting relationships with those in positions of authority.

The effect of age also reflects, in my opinion, why it was sometimes difficult to recruit African women for this study. Many African women with type 2 diabetes are within the older age category and although they may be more comfortable asking questions, they may still not be comfortable opening up to others, even other African people. For example, I am an African woman in a position of authority who may be viewed as an “outsider” to the community. Additionally though, I believe that some African women welcomed the opportunity to discuss issues with me in a personal interview. I believe this was the case especially because I am an African woman who wants to hear African peoples’ voices. I also seek to provide research on health related issues among members of the African community in Halifax, as this is clearly lacking (Enang, 2002). Bonita also mentioned during member checking that she thought it was easier for me to talk to Black women because I am a Black woman.

While we cannot assume that a person of African descent will automatically feel more comfortable with a health professional of African descent (Srivastava, 2007), it is important that professionals provide culturally competent care and, as mentioned by Enang (2002), that greater ethnic diversity is reflected in our health care system. If African community members see more people from their ethnic background/race among health professionals in their communities, this may be a step towards the recognition of positive change among people of their race, and the belief that members of their race can overcome obstacles, hold positions of authority and make a positive difference in their communities.

6.3.6 Racism Among Africans/Assumptions

The following dialogue with Grace shows an interesting phenomenon that is worthy of discussion. I inquired whether or not she thinks that indigenous African women are treated differently from immigrant African women:

D: Would you say, in your profession in the health care system, would you say that, have you seen, um, where it may be different for women who, were born in Nova Scotia or grew up here, compared to women who come here-

Grace: Ohh yes, oh yes, treated a lot different... .. They're treated like they're angels or something coming in and we're treated like, we've been here forever and treated like dirt, you know.

D: Oh really? Is that what you find?

Grace: Yeah...yeah, they say, we don't know what we're talking about or, whatever, and *they* treat us different, most times.

D: You mean the immigrant women treat...

Grace: Yup, yeah, yeah. They think we shouldn't be complain-we should be further along [in education and economics for example]. But they don't know the devastation and the racism that we suffered, and we really suffered racism, *continue* to suffer racism.

In the school system, we couldn't even get an education in this province until in the 60's, ah, integrated education, you know? I went to a segregated school and teachers didn't have much more, than I had, you know. So, it's been a rough ride for us as a people. So I, I can see the mindset of a lot of our people, you know. They almost have a slave or passive mentality; but, we've gotta get away from that and move on now, because, it is a new day and so, we've got to...

These comments by Grace provide both insightful and surprising information. What surprises me is that (1.) immigrant women would receive better treatment than African women native to Nova Scotia (because my assumption is that immigrant women would also experience racism) and (2.) that immigrant women believe that African Nova Scotian women should be further along and should not complain about the racism they have experienced. Of course, this is one woman's opinion and any number of immigrant women may disagree with Grace's comment. However, the fact that Grace made such a strong comment using words such as "Ohh yes, oh yes, treated a lot different" and "we've been here forever and treated like dirt", is worthy of further exploration. Upon member checking, Grace made a comment in regards to immigrant women having better opportunities for their race in their home countries, and they do not realize that similar opportunities have not been available in Nova Scotia due to racism and the rough road experienced by African Nova Scotians. Hence, immigrant women think Black women native to, or who have lived in Nova Scotia, should be further along in terms of education level and economics. Immigrant women would also say that African Nova Scotians do not know what they are talking about when they discuss the effects of racism. Once Grace explained this, I had a

better understanding of why immigrant women may feel that African Nova Scotians should not complain and be further ahead in terms of their position in society.

Shambley-Ebron & Boyle (2004) discuss the concept of intra-racial discrimination. The views held by immigrant women toward African Nova Scotian women is an example of this; such views also represent ignorance on the part of immigrant women explained by the fact that they have not known and lived the experiences of African Nova Scotians. This shows the importance of being aware of our assumptions as individuals. We cannot assume that we know and understand another group's culture and experience, even though we may share the same race. Immigrants that come into Canada from other countries must not assume that life for people in Canada means no discrimination and equal opportunity. Likewise, African Nova Scotians must not assume that immigrant women's experiences in their home countries are either better, or more difficult than the Canadian experience. The key is to allow women a chance to tell their story so that other people can better understand their true experiences. Short of living the experience ourselves, if women honestly share their stories, we can learn about other cultures.

Of course, one can turn Grace's comment around and say that immigrant women have not necessarily had better opportunities in their home countries. How do we know unless we have lived their experience? The importance of using phenomenology in this qualitative study is evident as it provided women with a voice, captured their experience, and provided important data to analyze; as noted, this is a goal of phenomenology (Donalek, 2004). This lived experience though, can be interpreted in various ways (Scheurich, 1995), thus showing the complexity of the issues that impact women of African descent.

Being aware of assumptions is also relevant for researchers (Scheurich, 1995). As a researcher I must remain open and not allow assumptions to enter into the research process. This

obviously is a challenge as it was very easy for me to assume that as women of African descent, African immigrants would understand the experiences of African Nova Scotians. As a result of that assumption, Grace's comments took me by surprise. It is evident that our biases are often deeply embedded within us at an unconscious level. Putting forth qualitative research of this type, which gives African women a voice, is valuable in informing and educating professionals, as well as society, about issues that may not necessarily have been evident; yet these issues are important to consider as influential barriers pertaining to the health of African women.

6.4 Cultural Meaning of Food/Taste of Food

The following quote by Phia highlights a gap in terms of health professionals adequately providing culturally competent care, by not taking time to understand which foods are eaten and why:

Phia: ...they [health professionals] don't try to understand the history of a Black person. Um, if you're going to give me directions you need to understand what I eat and why I eat it...

As a woman of African descent, Brianne explains the important influence of traditional cultural diets, speaking of ties to slavery, which was found in the literature by Bronner et al. (1994) and Gore (1999).

Brianne: ...I think it does revolve back to the slavery days when we always had to have the poor choices of things, like um today, when I look at the health system today and

everything that I'm used to and everything that I like, is everything that I'm not supposed to have...

Makeda also mentions ties to slavery in section 5.2.8. Both Brianne and Makeda, among other women in the study, go on to discuss the difficulty of making dietary changes due to their diagnosis of diabetes:

Brianne: ...I find that um, becoming a diabetic and, going to see my nutritionist at the clinic, the menu that they plan for me is things that is just, not, you know, wasn't normally, of the norm for my diet, you know. Because we eat lot of fat, grease, salt. Salt, I-I'm having a struggle trying to get rid of the salt. I've-I've slowed down but, it's hard.

Makeda: We've been untreated for so long, that naturally making that adjustment is very, very difficult. We simply just don't make the adjustment well. Uh, that's because we've been told to take certain things...we're not prepared to take out of our diet.

It is well known that dietary management of diabetes is something that people have difficulty adjusting to. As noted earlier in the literature review, those who are educated are better equipped to handle the dietary management of diabetes (Assal et al., 1985; Funnell & Haas, 1995). These women inform us of a very significant challenge. It is significant that their cultural, traditional diet is still influenced by ties to the enslavement period. As previously mentioned, Barbee (1994) and Shambley-Ebron & Boyle (2004) note the perpetual impact of enslavement on African people. The comments referring to enslavement reveal how powerful historical and

cultural influences are, even though enslavement has been abolished. Furthermore, these women's quotes reveal ignorance on the part of health professionals regarding the power of historical and cultural influences. Health professionals may not consciously ignore this influence, but it is still important to consider. Health professionals and society in general may think that since slavery is a thing of the past, it no longer affects those of African descent, and may simply not realize how strongly this act of oppression still affects Africans today.

Another interesting comment relating to the influence of slavery was made during member checking with Grace S. She believes that from back in the past, African women in general, are an excitable group of people. She went on to say that even emotions like fear and stress as a result of the days of slavery, accounts for higher blood pressure among African women.

Education can help the client with diabetes, but as these quotes reveal, it is essential that help is provided in a culturally appropriate way. Otherwise, these women fall through the cracks of the health care system and do not get the appropriate help that they need. Again, assumptions must not be made. Jane's comment shows how unconsciously assumptions can be made:

Jane: ...some doctor say 'oh have your breakfast', you know, and have your good breakfast to an average person is eggs and bacon and toast and jam and all this...

Jane reminds us that a good breakfast can mean different things to different people. If assumptions are made and health professionals are not taking the time to explore what an African woman may have for her traditional, cultural breakfast, African women may come away with a false perception of beneficial dietary guidelines that are appropriate for their diet. Instead, what

they need are culturally appropriate dietary guidelines that will help them manage diabetes. Given that dietary management of diabetes is so important to positive health outcomes while living with this disease, it is essential that these women get the help they need in making the adjustment. Phia offers a simple way:

Phia: ...I think the part that's missing, that would help you is, 'listen I understand that this is what you're used to, but how can we maybe, taper that now to your needs'. So instead of saying you *totally* have to forget about this, ok, let's look at what you were eating, so instead of that seasoned, nice seasoned, fried pork chop, maybe you can use half the seasoning, that you were using. Make sure it's not salty seasoning, and bake it. And so that, that's more receptive because, you're not taking, you're not totally taking away from me. You're not totally taking my culture or my heritage away from me food wise. So is there a compromise, and where there's no compromise, ok, because I can see well I can still, do the pork chop, maybe I can't have it as big or I can't have two but I can still have one...they need to know, like even the indigenous Blacks, like they like pigtails. So, a lot of the, it's so full of fat, it's not good for us. So, somebody coming in to teach me about diabetes, should be aware of, that's some of the food we eat, and *explain*, 'you know, like if you eat this pigtail, this has', whatever it has in it, 'and it's going to affect you it's not good for your heart; but, maybe if you could scale that down and take all of that fat off, which doesn't leave much meat, but I'm just saying you know there's something that you can do.

Phia explains that health professionals/dietitians need to be aware of what a person's traditional diet consists of. Phia uses the word compromise, which suggests working together where possible, to fit traditional foods that the client eats within a healthy meal plan, and explaining to the client how this can be done. Dietitians demonstrate a culturally competent approach when they, for example (as Phia describes), explain to the client how to include the pork chop or pigtail within their meal plan, rather than telling the client that pork chops or pigtails should not be consumed. Dietitians need to encourage clients to inform them about their traditional diets, and then work collaboratively with the client to consider how these foods can be tapered into the meal plan to encourage a healthy diet.

6.5 Discussion Summary

All women provided rich data; they had a lot to say, which is indicative of deep, varied and meaningful experiences. It was a valuable experience to interview these women and allow their voices to be heard. It was also a valuable learning experience for me – these women taught me about their culture, provided an in-depth look at their day-to-day life and struggles as women of African descent living with diabetes, and even provided some words of wisdom considering their life experience.

Considering the vast amount of data, I found that in many cases, the women's voices provided themes that intersected. In other words, in many cases, the themes could have fallen within more than one barrier. This indicates that the issues that African women face, with diabetes (or other health issues), are complex. As noted by Collins (1998), many women of African descent still suffer from low socio-economic status, illness and have limited education. Indeed these issues affect the lives of the African women I interviewed. The women also had much to say about racism therefore confirming that a race analysis is important to consider in

this research. Together these women show that although their experiences are different, they are united as a group in that they are commonly influenced by hegemonic structures, yet they can work together toward overcoming their barriers (Collins, 1998; Eghan et al., 2004). By allowing their voice to be heard in the research, they are given a chance to tell their story and suggest ways to cope and change. In these ways, Black feminist thought as a critical social theory was useful as a theoretical framework to aid in analyzing the data.

6.6 Recommendations for Future Research

It is clear that health related research in the African community is limited (Enang, 2002). Specifically, health research is needed on diabetes in those of African descent. The women's voices speak clearly when asked about recommendations in general and/or recommendations for future research:

Phia: ...we need more, uh, stats, we need to know, what, what causes these things, why there's so much illness in perhaps one community, than there is in another, the biggest thing is that we need to get Capital Health on board, to help us get those statistics, (slight pause) yeah, that's the biggest recommendation, yeah.

Grace S.: ...I would like to see more studies, on information on Black women, Canadian women, and uh, um, also, on different medications, yeah uh, because a lot of research has been done on diabetes, but we don't hear much...

Grace: ...I think research needs to point to Black people in general on their health. And start, having some people in clinical trials and, that sort of stuff in order to see...because we're not in clinical trials *in anything*, we need to be part of the research process...

Makeda also mentioned in section 5.2.3 that diabetes has a different physiological effect on people of African descent. Her comments are suggestive of the fact that more research is needed on how diabetes physiologically affects African Canadians:

Makeda: ...one of the things about being diagnosed with a 30 blood sugar was that they couldn't figure out how, we still walk because other body types, other folks of other ethnic groups may react very very differently, and be passed out in a diabetic coma. We're still functioning. We get up, we go to work, we drive, we do, we do all the things that we normally do, and they can't figure that one out. So, there's a whole lot of study I think that's still needed, at least in this country...

By including African women in clinical trials relating to diabetes research, we can discover possible answers to the effects of diabetes medications on African women, and how the disease physiologically affects African women compared to women of other races. In regards to the comment made by Phia, the easiest way to obtain statistics for those in Nova Scotia is via information on individuals' health cards through Medical Services Insurance (MSI) (S. Davis-Murdoch, personal communication, September 4, 2009). This process has not been in place, however, as professionals, we need to advocate for more statistics to be obtained.

I plan to publish a summary of this study in an academic journal, and discuss other aspects that are beyond the scope of this thesis. An additional important part of completing this research is to take the results back to the African community. I plan to discuss a summary of the research results at various events within the African community so that the results do not stay solely within academic circles. In fact, one of the women I interviewed told me about a seniors group that she participates in, and that they would welcome the opportunity to hear about this research. I plan to connect with this group, as well as speak at events within the African community, such as workshops run by the Health Association of African Canadians (HAAC) and the United African Canadian Women Association. During the fall of 2007, when most of the interviews took place, I attended Cobequid Road United Baptist Church. The pastor was helpful in introducing me to the congregation and providing notices about my research. I look forward to connecting with these people again and informing them about the research results. By doing this, African women's experiences have a chance to be heard among the larger African community, and ways of coping and working together for positive change to overcome barriers can be discussed. It is also important that this information is not kept solely within the African community. By collaborating with HAAC and organizations like the Canadian Diabetes Association (CDA), who have already established a partnership with HAAC, the experiences of these women will be shared and made known to members outside the African community. In this way, professionals and society in general will realize the experiences of these African women, which in turn can lead to further research and help with planning how best to help African women with type 2 diabetes.

Chapter 7.0 - Conclusion and Additional Recommendations

7.1 Recommendations Based on Barriers Analyzed

In the following sections, I will discuss pertinent implications regarding the barriers analyzed in the discussion and provide recommendations for the future.

7.2 Poverty/Low Socio-Economic Status

Low socio-economic status was a major concern pointed out by many women. Even if not affected by low socio-economic status currently, women identified that this was a major concern in the past, or that it affects other women in the African community (and those in society in general). Based on the analysis of how poverty affects African women's lives, more economic resources need to be provided for African women and others in society living with diabetes, as the financial cost of this disease is great. I would recommend that the cost of supplies be covered completely. Experiencing diabetes is stressful enough in and of itself. Individuals should not have to be concerned about how they are going to buy supplies to help manage their disease. These supplies are considered basic health care needs for those living with diabetes, and being unable to afford the supplies is unacceptable. Dietitians need to advocate on behalf of those who cannot afford basic healthy food, as well as those who require supplies to help manage diabetes. Dietitians can do this by becoming involved in organizations designed to lobby for food security, such as the Nova Scotia Nutrition Council, as well as collaborate with organizations such as the CDA, to help those who need diabetic supplies.

7.3 Racism Regarding Cultural Competence

Regarding this section in the discussion, section 6.3.2, the following are suggestions for steps that health professionals can take toward becoming culturally competent:

As mentioned earlier, health professionals need to be aware of their biases and assumptions. They also need to examine what they see as significant and valuable, but also be willing to consider why they feel a certain way, either positively or negatively, toward an issue, person or group. It can be helpful to engage in self-reflection and reflect on why a certain belief is held (Srivastava, 2007).

Health professionals need to be willing to learn not only about, but from other cultures. Similar to when professionals network to broaden their connections, health professionals can involve themselves in what is known as cultural networking, by looking for ways to connect with members of another culture. This can include colleagues who share various cultural backgrounds. The specific purpose should be to gain knowledge regarding a culture or group's beliefs about health and disease, and their way of seeing the world (Srivastava, 2007). By doing so, health professionals can increase their understanding of another culture's perspective, which may differ from their own. Health professionals can also seek out information by examining literature as well as electronic resources that are specific to the culture or group they are helping. Health professionals can gain general knowledge about a certain ethnic group's cultural practices, but must realize that people are individuals within a larger cultural group (Srivastava, 2007). Professionals can engage clients to discuss what is significant in their culture, as a way of providing a safe environment and helping the client to feel comfortable. By providing this opportunity to clients, professionals can compare what they have learned about a culture in general, to what is specifically important for the client in any given situation. Professionals must then be able to tailor their general cultural knowledge to what is culturally relevant for the individual they are caring for in the given setting (Srivastava, 2007).

Another suggestion is to hold community forums where, for example, members of the African community are invited to share their cultural heritage with health professionals. These forums should be held within African communities in order to provide ease of access for community members. Professionals can do this by consulting with organizations such as HAAC and the CDA, who already have a working partnership established.

Although not yet mandatory, cultural competency training is available through the Nova Scotia Department of Health. For example, a group of dietitians can choose to be trained together. It should be mandatory that all health professionals undergo cultural competency training. In addition, this training should be implemented in professional programs in universities, community colleges, and programs in which health professionals are trained. As Mount Saint Vincent University has a professional program in nutrition and dietetics, cultural competency training should be a required course (S. Davis-Murdoch, personal communication, September 4, 2009). In addition, the mission/vision of Dietitians of Canada should reflect cultural competency guidelines. Ensuring that clients receive culturally competent care means that guidelines are not only implemented at the individual level via the health professional, but also at the broader level, within organizations and society in general (Srivastava, 2007).

7.4 Racism Regarding Health Research

In the discussion, section 6.3.3, Grace raised an important point about the fact that there is limited health research pertaining to the African population in Nova Scotia. Why is there limited health research on the African population when Nova Scotia has one of the highest populations of people of African descent in Canada (Eghan et al., 2004)? Why was it so difficult for me to find pertinent Canadian literature on African women and diabetes for my literature review? As health professionals, we must move away from the racist/exclusionary assumption

that Africans' experiences of health and disease can always be categorized within the experiences of Caucasians, who are considered the norm in society. While doctors and other health professionals are undergoing cultural competency training, they should also be trained to inform African women appropriately about the benefits of including them in health research. African women need to be encouraged that they are valued members of society with unique health needs that are worthy of exploration. Grace's earlier comment in section 5.2.3 regarding the study that revealed the harmful effects of Avandia® for African people, is an example of a study that doctors can use to explain to African women the benefits of research. As HAAC has been instrumental in advocating the need for more health research, doctors and other health professionals can partner with HAAC to help inform African women of the benefits of including them in health research.

7.5 Racism Regarding Treatment by Professionals

At the end of section 6.3.4, I pointed out that Grace S. commented that some doctors think that everyone's experiences should be, in her words, "as the standard" or "by the book". Her comment further acknowledges what was similarly noted in the previous section, 7.4, namely that African's experiences with health and disease are often categorized to fit society's standard group, Caucasians. (Considering this viewpoint, it is not surprising that there is limited health research pertaining to the African population in Nova Scotia). Professionals need to acknowledge that there are differences between ethnic groups, and then take the time to find out about the differences and act appropriately. A step in the right direction is for doctors and other health professionals to engage in appropriate cultural competency training. They can do this by contacting the Nova Scotia Department of Health (S. Davis-Murdoch, personal communication, September 4, 2009).

7.6 Racism Regarding Internalized Oppression Leads to Mistrust/Not Asking Questions

In section 6.3.5, I raised the point that Africans and health professionals need to work together; however, it may be difficult for some Africans to be open about their experiences and be willing to ask questions due to the negative effects of internalized oppression. However, when professionals are trained in cultural competence and learn how to help Africans in a culturally appropriate way, this can be a step in the right direction. It is important to acknowledge the African client's cultural differences and be willing to hear their views and beliefs about their particular situation (Srivastava, 2007). In addition to engaging clients to discuss what is significant in their culture (as mentioned earlier), health professionals can ask questions in an appropriate way. Examples of such questions could be:

“What do you think caused your illness?”

“Are you treating this condition yourself in any way?”

“Do you have treatment preferences you would like me to include in your care plan?”

(“A Cultural Competence Guide for Primary Health Care Professionals in Nova Scotia”, 2005, p.15-16).

These questions promote a sense of openness to the client and can help clients to feel welcome and valued.

7.7 Cultural Meaning of Food/Taste of Food

As mentioned in section 6.4, dietitians need to be aware of different cultural foods and how they influence a person's dietary choices. By having a greater understanding of cultural foods and cooking methods, dietitians can be better equipped to help the client modify their diet to help manage diabetes. Rather than assuming that Eating Well with Canada's Food Guide (Health Canada, 2007) will be applicable to African clients, dietitians need to be willing to

explore an African client's dietary choices and habits. This can be done by taking the time to investigate a client's culture, as well as talking to the client about their cultural diet, to provide culturally competent service. In some cases, the traditional Canadian diet may be relevant to women of African descent. For example, both Dawn and Yvonne were born and raised in Nova Scotia and their diet patterns and choices reflect the traditional Canadian diet. The key is to not make an assumption. Although Phia was born in Nova Scotia, her dietary patterns *do not* reflect the traditional Canadian diet. Dietitians need to be willing to explore each client's cultural dietary choices, and then where necessary, work within the client's dietary preferences to create a healthy meal plan for managing diabetes.

7.8 Summary and a New Understanding of Barriers

As noted throughout this study, health research is limited in the African Canadian community (Enang, 2002). In conclusion, this study was a worthwhile project to explore as it contributes to the limited amount of research in both Canada and Nova Scotia, regarding the health of people, specifically women, of African descent.

The research question has been answered; indeed, social barriers to dietary modification exist for African women living with type 2 diabetes in HRM.

Not only were African women given an opportunity to tell their story and have their voice heard, but also, the data provided by these women has provided a new understanding of the barriers identified in chapter 2 (literature review). It was clear that barriers such as poverty, race, and gender intersected with each other, as much of the data provided by the women could have fit within more than one barrier. The new finding however is that although the barriers intersect with one another, the majority of the data points to the issue of racism. As a result, it becomes evident how much internalized oppression affects many aspects of African women's lives, all of

which in turn, negatively affect their health. Etowa et al. (2005) also found a link between experiences of racism and negative health effects. Based on the analysis in the discussion (chapter 6), I will provide two examples of how the “cycle” of racism can affect African women.

In this first example, as revealed by various comments from the women in this study, due to internalized oppression some African women feel inferior. As a result they do not ask questions or ask for help, and also mistrust the health care system. By not asking questions or asking for help, they have less control over their health, which increases their risk of poor health. They are also at increased risk of being labelled as non-compliant, too difficult to deal with, or unreachable. This in turn can cause African women more stress, which again can lead to ill health and poorer disease outcomes, specifically, greater difficulty managing their diabetes.

The BLAC Report on Education Redressing Inequity – Empowering Black Learners (BLAC, 1994) highlights the complexities of the African Nova Scotian experience. Unequal access to education has resulted in lower education levels and decreased quality of job opportunities. Therefore, another example is that due to racial oppression, African women had limited opportunity to get an education and obtain a high paying job. This has led to increased poverty levels, therefore limiting African women’s access to healthier food choices. They may also have limited resources to obtain diabetic supplies, which in turn, can result in poor management of diabetes. Therefore, African women may experience increased stress in their lives, which can also contribute to poorer diabetes management and overall ill health.

In one sense, the fact that the effect of racism is a major point of this research is not surprising. As mentioned earlier in chapter 3 (theoretical framework), racial oppression has been identified as significant by African American women (Collins, 1998; Shambley-Ebron & Boyle, 2004), and I knew that including a race analysis in this research would be important. However I

must admit that I was still surprised as to how much the issue of racism affected these African women's lives, so much so that it has been difficult to keep the issue of gender and race as separate areas for discussion. Although I kept the issue of gender as a separate section in the literature review (chapter 2), it became evident as I analyzed the issue of gender roles and the ideology of the SBW, that the major effect this ideology has on African women, is due to women either consciously or unconsciously believing this form of internalized oppression. Therefore, for the purpose of the discussion (chapter 6), it was best to include the issue of gender and the ideology of the SBW, within the barrier of racism. Much of the discussion points to the issue of cultural competence, which I did not anticipate discussing in as much depth prior to analyzing the data and writing the discussion. This reveals that racism is significant since a culturally insensitive health care system was highlighted by a number of women. In fact, all four themes analyzed in the discussion relate to racism. Even dietary patterns, reflected in the combined themes Cultural Meaning of Food/Taste of Food, are closely tied to the effects of racism for many of these African women.

As mentioned in chapter 3 (and similarly in the previous paragraph), African American women believe that racial oppression is the most notable form of oppression, particularly in the United States (Collins, 1998; Shambley-Ebron & Boyle, 2004). Near the end of chapter 3, I asked if the same could be said for African women living in Nova Scotia and mentioned that it appeared that way from research by Eghan et al. (2004). Indeed it can be said that this research also reveals that racial oppression was most significant for the majority of the African women interviewed in this study. Although not all women openly discussed racism, it can be inferred that the impact of African women's race in society was important for most of the women interviewed. In other words, although they did not all speak explicitly about racism, the impact

of systemic racism (i.e. poverty, unequal access to education) on the lives of most women was evident. This research has been valuable for me in that I have gained a greater understanding of the complex issue of internalized oppression, and how it deeply affects African women's lives, including in subtle ways.

7.9 Limitations of the Research

A number of limitations to this research study can be identified. Firstly, the theoretical framework and data analysis process used represent only one way of interpreting the data. The utilization of another framework and process of analysis would have, conceivably, yielded different findings and conclusions (Scheurich, 1995). Secondly, due to the limited sample size, this study cannot be generalized to the larger African community of women in HRM. The experiences and opinions of the nine women interviewed do not represent that of all women of African descent in HRM. Thirdly, the limited experience of the researcher as an interviewer may have impacted the researcher's ability to probe efficiently; this could have potentially led to different responses from the research participants.

Finally, as discussed by Shepherd & Achterberg (2003) and Scheurich (1995), the research process is always impacted by the biases the researcher brings to the process. I will provide two examples. First, given my background in nutrition, I am aware that I bring certain biases and judgements to the research, particularly in terms of how participants comply with a diet suggested for any disease. It was a challenge to hold back these biases and judgements while conducting this research and interviewing the women. However I believe that my feelings (i.e. understanding nature), surrounding the difficulties of coping with a changed diet, helped me to better understand the women's experiences and empathize with them.

A second example of researcher bias is that as a woman of African descent, I assumed that race was an important issue for these women. There was an expectation that the women would discuss the impact of their race on their food choices and diabetes management. As a result, this may have led to a particular tone of voice and/or intonation when I asked certain questions during the interview. Participants may have perceived this as leading and may have been influenced to respond in a certain way. Nonetheless, despite the fact that I may have led them with my tone of voice, not all women discussed the impact of their race on their food choices and diabetes management.

Chapter 8.0 - References

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Appendix A

Diabetes in the Black Community



- Are you a Black woman who has diabetes?
 - Are you over 20 years of age?
 - Were you diagnosed when you were an adult?
- If so, are you interested in talking about the difficulties you experience with your diet/eating habits in a one-on-one interview for a research study?

To leave a message, please call 457-6555, enter mailbox number 1002 and press the pound key (#)

Appendix B – Interview Guide

The purpose of the study will be explained to the participant at the beginning of the interview. The researcher will also explain that there are no correct or incorrect answers, and will remind the participants that they can refuse to answer any questions they do not wish to respond to or may stop the interview at any point. Confidentiality will be reviewed in addition to the informed consent form. The researcher will ask for the participants' permission to tape record the interview and will remind participants that they can ask to have the tape recorder turned off at any point.

- Introductory Question: Tell me something about yourself
- Diabetes History: How did you first come to know that you had diabetes? When were you diagnosed?
- Tell me about a typical day – what would you eat?
- Which foods are usually consumed in large amounts in your culture?
- A.) Have you been told to reduce, avoid or eliminate any of these foods because of diabetes? If yes, which foods, and have you been told why?
- If you have been told to reduce, avoid or eliminate any of these foods and have *not* been told why...
 - why do you think this happened?
 - how do you feel about this?
- How do you feel about having to reduce, avoid, or eliminate these foods?
- Tell me about how you have been doing with your diet in coping with diabetes?
 - 1.>Are you able to purchase foods that help you manage diabetes?
 - 2.>How does your role in your family affect your food choices/diet?
 - 3.>What role does the health care system play in your food choices/diet?
 - 4.>How does your race/how does being a Black woman play a role in your food choices/diet?
- What do you see as a challenge in managing diabetes through dietary choices? What do you attribute these challenges to? Note: If participants cannot think of anything to say for this question, I will mention points 1. 2. 3. & 4. and A.) as possible challenges and then ask if they would identify any of these as challenges. If you outlined challenges, what do you attribute these challenges to?

● Please comment on the treatment/advice you have received from health care professionals in relation to your diabetes.

● Tell me how you feel about the treatment you have received. To what extent and in what ways, (specific examples) do these feelings affect your willingness to follow diet restrictions/changes?

● Are there things you feel you do not understand about managing your diet and diabetes? If yes, what are they?

>How does your economic status play a role in managing your diet and diabetes?

>How does your role as a Black woman in your family affect your concerns?

>Would you say that a higher body weight is viewed as desirable in your culture?

>How does your view of your body image play a role in managing your diet and diabetes?

● Tell me about the ways that you cope with diabetes?

>Which support systems do you depend on?

>Do you feel you have support from your family? Please tell me more.

Appendix C – Study Information Sheet

Study Title:

Social Barriers Impacting on Dietary Modification Experienced by Black Women with Type 2 Diabetes.

Researcher:

Deborah Bruhier, BScAHN (Mount Saint Vincent University, MSVU), MScAHN (candidate)
Graduate Student, Applied Human Nutrition
MSVU, Halifax NS

Supervisors:

Janette Taper, PhD, Professor of Applied Human Nutrition, MSVU
Felicia Eghan, PhD, Assistant Professor of Family Studies and Gerontology, MSVU
Winnie Benton, MSW, RSW

Introduction:

You are welcome to take part in the above mentioned research study as part of a Master of Science in Applied Human Nutrition thesis. It is important that you understand the purpose of the study, and what your participation will involve should you decide to participate, including any risks and benefits, and what is expected of you. The information is detailed below. Your participation is completely voluntary. If you have any questions or concerns prior to or during the study, please contact the principal investigator or a member of the supervisory committee. If you would like to speak with someone who is not directly involved in the research, please contact the Chair of the MSVU University Research Ethics Board, Dr. Stephen Perrot, at 457-6337.

Purpose of the Study:

To examine the barriers to dietary modification of type 2 diabetes experienced by Black women.

Study Design:

This study will uncover the experiences of Black women with type 2 diabetes as it pertains to dietary choices and the social barriers that are present in their lives. Black women who have type 2 diabetes will be recruited to participate in a face-to-face interview. Once 6-10 Black women have agreed to participate, the recruitment process will cease.

What Participation Involves:

If you choose to participate in the study, you will be asked to participate in a face-to-face interview with the researcher. The interview will take place in either your home, the North End Community Health Centre, or the Black Cultural Centre, wherever is most comfortable for you. The interview will be at a time and on a day that is convenient for you and will last approximately 1-1 ½ hours.

The interview will be tape recorded with your permission and the researcher may take notes during the interview. You may ask to have the tape recorder turned off at any time during the interview, and you may choose to end the interview at any time if you feel uncomfortable. Your name will not be directly associated with any material you provide in the interview. The researcher is the only person who will know the real identity of each participant.

Upon completion of the recorded interview, it will be transcribed and then returned to you so that you can review it to ensure it is an accurate representation of your information. You will have the opportunity to add any information to, or remove any information from, your interview. This process will involve a second meeting which will take approximately 30-45 minutes. Any quotes from your interview which may be used in the researcher's thesis or in professional publications will not be directly associated with your real name.

Potential Harms:

There are minimal risks associated with participation in this study as it will consist of an interview. However, you may find some of the questions difficult to answer or they may cause you to reflect on negative experiences. You never have to answer any questions that you do not want to and you may choose to end the interview at any time.

Potential Benefits:

There are not direct benefits to you as a result of participating in the study. The information gained may allow others to understand the barriers that Black women face with their diets while experiencing type 2 diabetes. This study may also highlight ideas for future research.

Withdrawal from Participation:

Your participation in this study is completely voluntary and you may choose to withdraw from the study at any time. If you choose to withdraw from the study, your tape-recorded or transcribed interview will not be used in the study and will be destroyed.

Confidentiality:

Your name will not be identified with any information that you provide at any stage of the interview, or in the discussion or written description of the results. Only the researcher will know the real names of all the participants. All information will be stored in a locked cabinet in the thesis advisor's office at Mount Saint Vincent University and will be destroyed after the appropriate time as per the University Research Ethics Board (UREB) regulations.

Contact Person:

If you have any questions about your involvement in the study, please contact the researcher Deborah Bruhier at (902) 457-6555, 1002, #.

Appendix D - Free and Informed Consent Form (for Student Researchers)

Social Barriers Impacting on Dietary Modification Experienced by Black Women with Type 2 Diabetes. / Ms. Deborah Bruhier

I am a *graduate student* in the Department of Applied Human Nutrition at Mount Saint Vincent University. As part of my master's thesis, I am conducting research under the supervision of Dr. Janette Taper. I am inviting you to participate in my study, *Social Barriers Impacting on Dietary Modification Experienced by Black Women with Type 2 Diabetes*. The purpose of the study is to examine the barriers to dietary modification of type 2 diabetes experienced by Black women.

This study will involve a face-to-face interview where we will discuss how you feel about your diet in relation to type 2 diabetes. The first interview will be approximately 1 ½ -2 hours in length. With your permission, I would like to tape record our interview as this is the easiest way to record information discussed. If you wish, the tape recorder can be turned off at any time during the interview. I will then type the taped interview and return the typed interview to you so that you can review it and make any changes or add additional information. This will involve another meeting which will take approximately 30-45 minutes. The information gained in this study will be used to help describe the experiences of Black women with type 2 diabetes specifically in terms of diet and social barriers. The results will be presented orally at various community events and published in a research journal.

There are minimal risks associated with participation in this study as it will consist of an interview. However, you may find some of the questions difficult to answer or they may cause you to reflect on negative experiences. You never have to answer any questions that you do not want to and you may choose to end the interview at any time. There are not direct benefits to you as a result of participating in the study. The information gained may allow others to understand the barriers that Black women face with their diets while experiencing type 2 diabetes. This study may also highlight ideas for future research. Your participation is completely voluntary. You may withdraw from this study at any time without penalty.

Participants will be asked to choose a pseudonym to represent themselves during the interview. Only the student researcher will know which pseudonym corresponds to each participant. When direct quotes from the interview are used in the written results, the pseudonym will be used and quotes will not be identifiable to any participant. No individual participants will be identified without their permission. All information gained from the interview will be stored in a locked cabinet in the thesis advisor's office at Mount Saint Vincent University, and will be destroyed after the appropriate time as per the University Research Ethics Board (UREB) regulations.

If you have any questions about this study, please contact me, Deborah Bruhier at 457-6555, 1002, #, or my thesis advisor, Dr. Janette Taper at 457-6256 or

janette.taper@msvu.ca. This research activity has met the ethical standards of the University Research Ethics Board at Mount Saint Vincent University. If you have any questions or concerns about this study and wish to speak with someone who is not directly involved with this study, you may contact the University Research Ethics Board, by phone at 902-457-6350 or by e-mail at research@msvu.ca.

By signing this consent form, you are indicating that you fully understand the above information and agree to participate in this study.

Participant's signature

Date

Researcher's signature

Date

By signing below, you are indicating that you consent to having the interview tape recorded.

Participant's signature

Date

Researcher's signature

Date

One signed copy to be kept by the researcher, one signed copy to the participant.

Appendix E – Certificate of Ethics Approval



University Research Ethics Board

UNIVERSITY RESEARCH ETHICS BOARD

Certificate of Research Ethics Clearance
[Renewal]

Title of project: *Social Barriers Impacting on Dietary Modification Experienced by Black Women with Type 2 Diabetes*

Researcher(s): Deborah Bruhier
 Supervisor (if applicable): Dr. Janette Taper
 Co-Investigators: n/a

File #: 2007-004

The University Research Ethics Board (UREB) has reviewed the above named proposal and confirms that it respects the *Tri-Council Policy Statement* and the *MSVU Policies and Procedures: Ethics Review of Research Involving Humans* regarding the ethics of research involving human participants.

This certificate of approval is valid one year from the date of issue. A final report is required within 30 days of expiry. Researchers are reminded that any changes to approved protocol must be reviewed and approved by the UREB prior to their implementation.


 Dr. Michelle Eskritt, Chair
 University Research Ethics Board (UREB)

June 5, 2009
 Effective Date

[Expires: July 18, 2010]

Renewal is contingent upon submission to the UREB of a written request for renewal accompanied by a satisfactory annual ethics report thirty days prior to expiry.