

NORTHERN BRITISH COLUMBIAN ABORIGINAL MOTHERS:  
RAISING ADOLESCENTS WITH FETAL ALCOHOL SPECTRUM DISORDER

by

Mary Suzanne Johnston

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SIGNED: Mary Suzanne Johnston

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## DEDICATION

To my husband, John S. Johnston, P. Eng.

For his steadfast endurance, quiet encouragement, patience and love.



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## ABSTRACT

Northern British Columbian Aboriginal mothers raising adolescents with Fetal Alcohol Spectrum Disorder (FASD) face many challenges. This interpretive ethnography provides an understanding of how these mothers interpreted and responded to their adolescents' FASD. It affirms the experiences of Aboriginal mothers and acknowledges their life stories and those of their adolescent children.

The concepts of vulnerability, marginalization, and mothering, conceptualized within the theoretical perspectives of postcolonialism, provided the framework for this study. Postcolonial perspectives were particularly relevant to this research: the explicit aftereffects of colonialism on the well-being of Aboriginal women have shaped the worldview of mainstream society resulting in marginalization and stigmatization. A postcolonial perspective suggests that FASD is a problem compounded by colonization; until the underlying compounding issues are addressed, the incidence of FASD among Aboriginal people will continue to increase.

English-speaking Aboriginal women with one or more children between the ages of 14 and 18 years affected by FASD were recruited for the study. Appropriate measures were taken to ensure trustworthiness, verisimilitude, and legitimacy. Data collection included three sequential audio-recorded interviews with eight women over a specific time. Interview data were enhanced by document review, intervals of observation participation, and the examination of other historically and culturally relevant data.

The interpretive theory derived from the data, *Mothering from the Margins*, explains how Aboriginal mothers raise their adolescent children who have FASD. The

theory provides a perspective that enables nurses to view mothers with adolescents affected by FASD in an all-encompassing manner, and unifies the experiences of participants mothering adolescents with FASD. Aboriginal mothers of adolescents with FASD continue to experience societal blame and marginalization for consuming alcohol during pregnancy. This study extends the knowledge of how this blaming and marginalization experience plays out in the lives of both mothers and children. The findings debunk the stereotypical myth that Aboriginal mothers are not good mothers. In fact, the findings from this study demonstrate how, despite all the difficulties and challenges faced by study participants, they have demonstrated adaptability, confidence, and care in their mothering roles.

## CHAPTER I: INTRODUCTION

### Background

Fetal Alcohol Spectrum Disorder (FASD) is a major health concern for Canada's Aboriginal people (Tait, 2003). It is well understood that alcohol use during pregnancy can result in FASD. "There is consensus among scientific researchers, medical and social service professionals, paraprofessionals, and lay persons that FASD is one-hundred percent preventable . . ." (Tait, 2003, p. 121). Despite this, the incidence of FASD continues to rise.

Experts agree that accurately estimating the prevalence of FASD-affected children is difficult. Factors that may explain this include inadequate diagnostic capacity for FASD, inadequate access to professionals with the required skill sets, studies that are not representative of populations and sub-populations, and a lack of comparability among studies (Chudley, Conry, Cook, Loock, Rosales & LeBlanc, 2005). For example, Chudley et al. (2005) note that the worldwide incidence of FASD is estimated to be 9.1 cases per 1,000 live births. In Canada, it is thought that the incidence ranges between 1 and 9 cases in 1,000 live births (Stade, Ungar, Stevens, Beyanne, & Koren, 2006). In some Aboriginal communities in northern British Columbia, estimated rates of FASD are significantly higher than the national average, ranging between 25 and 200 cases per 1,000 live births (Caley, 2006; Chudley et al., 2005). Notably, research describing incidence rates among Aboriginal people is limited and there are questions about accuracy (Tait, 2003). Aboriginal authors themselves acknowledge that FASD is a

To date, existing studies on FASD have focused on diagnosis, etiology, and strategies for prevention. Despite the high incidence and the overwhelming impact of FASD, research has not focused on the subjective experiences of Aboriginal women mothering children with FASD. This study begins an important qualitative inquiry to address that gap.

#### Statement of the Problem

FASD has demonstrated a significant impact on affected individuals, who will likely experience complex physical, behavioral and cognitive difficulties over the course of their lifespans (Premji, Serrett, Benzies, & Hayden, 2007). Children with FASD are singled out based on recognition of associated characteristic facial abnormalities (e.g., short palebral fissures, smooth philtrum, thin upper lip). Such children often experience heart defects, cleft palates and lips, vision problems, seizure disorders, and kidney problems (Caley, Kramer & Robinson, 2005).

While these physical disabilities present challenges, it is the emotional, behavioral, social, and environmental challenges associated with FASD that may be more significant to childrearing (Caley et al., 2005). These disabilities manifest themselves in a variety of ways, and the frustrations of raising children with this condition are known and described in the literature (Gardner, 2000; Granitsas, 2004; Premji et al., 2007). Emotionally, children affected with FASD often experience attachment difficulties, depression, low self-esteem, and anxiety (Premji et al., 2007). Socially, their

development can be compromised due to difficulties with communication, an inability to maintain friendships, an inability to predict the consequences of behavior, and a lack of impulse control (Premji et al., 2007). Environmental factors may also alter the course of child development over the lifespan, and have the potential to exacerbate or mitigate the effects of prenatal alcohol exposure that results in FASD. For example, continued substance abuse by biological mothers, domestic instability, and foster placements may contribute to the development of further inappropriate behaviors of FASD-affected children (Premji et al., 2007). These inappropriate behaviors can result in disruptions at school, run-ins with the law, and increased social isolation.

Effective interventions that would assist mothers in rearing children affected by FASD have not yet been identified; assistance in managing these challenges and frustrations would be helpful to mothers in such circumstances. This study explored the beliefs and practices of Aboriginal mothers in northern British Columbia who are raising children with FASD in order to understand how they promote the well-being of their adolescent children.

#### Statement of Purpose

The major goal of this interpretive ethnography was to gain an understanding of the beliefs and practices of Aboriginal mothers as they promoted the well-being of their adolescent children who have FASD. This study sought to provide an understanding of how these particular mothers interpreted and responded to their adolescents' FASD. It was an attempt to affirm the experiences of Aboriginal mothers, to hear them tell their stories and those of their children. Understanding these issues from the viewpoint of

Aboriginal women will enable nurses and other health-care providers to anticipate and understand client behavior and to plan care that is as congruent as possible with existing values and lifestyles.

#### Research Questions

1. How do Aboriginal mothers understand and describe FASD?
2. How do Aboriginal mothers conceptualize and promote the well-being of their adolescent children who have FASD?

For the purposes of clarity in this study, I will refer to Aboriginal mothers who are raising children with FASD as *mothers* or *study participants*. The term *FASD* refers to the full range of effects caused by prenatal exposure to alcohol.

#### Significance of the Study to Nursing

Interventions helpful to mothers raising children with disabilities are widespread in the literature; however, specific nursing interventions helpful to mothers raising adolescent children with FASD are unknown. No existing studies describe nursing knowledge about this situation or what nurses can do to help mothers who are raising adolescents with FASD. Nursing interventions that help mothers manage the challenges they encounter in raising adolescents with FASD are needed. By understanding these childrearing challenges, nurses can help mothers to anticipate and be prepared for challenges they are likely to encounter. This anticipatory guidance will contribute to the improved overall health of children affected by FASD and will fill a gap in the nursing literature. Findings from this study will extend nursing knowledge about raising children with disabilities and generate knowledge specific to raising children with FASD. It is

anticipated that findings from this study will specifically apply to Aboriginal mothers in northern British Columbia, and may be applicable to other populations.

### Theoretical Perspectives

The concepts of vulnerability, marginalization, and mothering provided the organizing framework for this study, and were conceptualized within the theoretical perspective of postcolonialism. It is important to define postcolonialism by describing the concepts within its framework that are relevant to health and health research: race, racialization, culture and “othering” (Anderson, 2004).

Othering has been defined by Anderson (2004) as “an act of representation by which identity is assigned, human existence is categorized, people are characterized according to certain criteria, and experiences are homogenized” (p. 240).

Colonialism—“forced change in which one culture, society, or nation dominates another (Oregon State University, (n.d.))”— continues to shape lives, well-being, and life opportunities; it is an everyday reality for Aboriginal women (Anderson, 2004).

Colonialism has also been described as “a social process even more than it is a political process, where colonial strangers view Indigenous people as lacking culture and having little to offer in the way of social value...” (Laenui, 2000, p. 16).

The postcolonial theoretical perspective holds potential explanatory power by providing a framework for understanding the burden of history and how it shapes mothers’ present-day experiences (Browne, Smye & Varcoe, 2005, p. 22). Specifically, it facilitates the recognition of the “multiple burdens of Aboriginal women, such as childcare and over-surveillance” (Stout, Kipling, & Stout, 2001).

### *Definition of Postcolonialism*

Postcolonialism is a perspective derived from postcolonial theory and is “best conceptualized as a family of theories sharing a social, political and moral concern about the legacy of colonialism” (Browne et al., 2005, p. 19). These perspectives are particularly relevant to this research with Aboriginal mothers because of the explicit and obvious aftereffects of colonialism on the well-being of Aboriginal women in Canada (Browne et al., 2005). The intersection of historical, social, political, and economic inequities shapes the worldview of mainstream Canadian society resulting in marginalization and stigmatization of Aboriginal women (Browne et al., 2005; Smith, Edwards, Varcoe, Martens, & Davies, 2006). I believe that FASD is a problem compounded by colonialism. Until the root causes are addressed, the incidence and prevalence of FASD will continue to increase among members of the Aboriginal population.

According to Kirkham and Anderson (2002) “postcolonialism centralizes the issues stemming from colonial relations and their aftermath” (p. 3). Colonialism is best described as control by one power over a dependent people. This can take place when one group of people claims ownership of territory already occupied by another group and the more powerful of the two proceeds to govern the less powerful by imposing its own laws, customs, language, and values upon those they deem their inferiors (Etienne & Leacock, 1980). The result is a power differential within the colonized area. For Canadian Aboriginal people, this colonialism took the form of religious indoctrination, Western

models of education in residential schools, and enforced compliance to Western society's norms, rules, and ways of living (Kirmayer, Brass, & Tait, 2000).

### *Origins of Postcolonial Theory*

Postcolonial theory precludes a single conceptualization. It originates from the disciplines of anthropology, cultural studies, political science, sociology, and literary criticism (Browne et al., 2005; Mohammed, 2006; Prasad, 2005). Philosophic influences of postcolonial theory arise from the thinking of such individuals as Mahatma Gandhi, Edward Said, Homi Bhabha, Robert Young, and Arjun Appadurai (Prasad, 2005). Nursing scholars including Anderson (2002); Browne, et al., (2005); and Mohammed (2006) have contributed to the advancement of postcolonial theory in the development of nursing knowledge.

### *Postcolonial Concepts Important to Health and Health Research*

Anderson (2004) has identified race, culture, racialization, and "othering" and their interrelationships as being highly relevant to health and health research. Therefore, these concepts were used as a "theoretical springboard" for the literature review. To avoid a rigidly structured framework and to allow maximum freedom of data interpretation, these concepts were used to help increase understanding and sensitivity to the experiences of colonialism during the literature review (and throughout the research project).

### *Race and Racialization*

The terms *race* and *ethnicity* are often misused in the literature or used interchangeably (Ezenwa, Ameringer, Ward & Serlin, 2006). Kirkham and Anderson

(2002) note that *race* is thought to be a “social construction manipulated to define, structure, and organize relations between dominant and subordinate groups” (p. 4). Defining the term *ethnicity* is equally challenging; it is “considered to be a social concept designating a group of people within any given society” (Ezenwa, et al., 2006, p. 226). While the “biological component of race has been disproved, people continue to be grouped by physical racial attributes” (Kirkham & Anderson, 2002, p. 4). Denzin and Lincoln (2005) identify the concept and use of “race” as one of the current challenges in social science. They raise interesting questions: “What meaning does this term hold for us?” “Does any one person fit into a concept of ‘race’?” “What criteria can possibly be used that allow us to neatly slide persons into any one category or classification?” Denzin and Lincoln (2005) conclude that the term *race* is a linguistic category that represented somebody’s reality 50 to 100 years ago, but has little or no credibility today among academic researchers.

However, common applications of the terms *race* and *ethnicity* have the potential to reinforce historical notions of race and longstanding patterns of inequities (Kirkham & Anderson, 2002). For instance, they state that classifying people into cultural and ethnic groups is a racialized application of culture:

Culture has become a widely used metonym for difference within nursing scholarship, without an appreciation of the ways in which the concepts of culture and race operate in tandem, most often with race as the silent subtext to discourses of culture (p. 5).

Therefore, when we study cultural differences in beliefs and practices of Aboriginal people, we are ignoring how this emphasis on “difference” isolates and racializes the very individuals we study.

Furthermore, the term *racialization* suggests that a group of people is best understood as a biological entity within the realm of conceptions of culture and viewed through a lens of social, economic, and cultural differences (Browne et al., 2005; Kirkham & Anderson, 2002). Racialization is a “process of delineation of group boundaries and of allocation of persons within those boundaries by primary reference to (supposedly) inherent and/or (phenotypic) characteristics” (Kirkham & Anderson, 2002, p. 4). Racialization reinforces the stereotypical notions of Canadian Aboriginal people as having a culture of poverty, abuse and dependency (Browne et al., 2005). Racialization continues to perpetuate devastating effects of colonization on Aboriginal people in Canada, and continued their marginalization. For example, connections continue to be made between alcohol abuse among Aboriginal people and theories of racial susceptibility to alcohol dating back as far as the fur trade (Tait, 2003). Despite the fact that alcohol was a key trade item used by European traders to acquire furs from indigenous traders, the results of overuse were blamed on the “nature” of indigenous people (Tait, 2003, p. 19). In a recent review of the literature, Tait (2003) argues that while there may be individual studies that suggest differences in rates of metabolism of alcohol between aboriginal and Euro-Canadian people, other studies report no significant differences. There is recognition that a conundrum exists between ethnicity/race and

alcoholism, but my focus remains on the social, political, and historical contexts of Aboriginal mothers.

In addition, it is a common misconception that FASD is associated more strongly with ethnocultural background (Chudley et al., 2005). In fact, research suggests risk factors for prenatal alcohol exposure are more likely related to higher maternal age and lower education level, prenatal exposure to cocaine and smoking, custody changes, lower socioeconomic status and paternal drinking and drug use at time of pregnancy, reduced access to prenatal care and services, poor nutrition” (Chudley et al., 2005, p. S1). Nevertheless, today race and racialization remain a central aspect of everyday life for Aboriginal peoples, and the demeaning stereotype of the drunken Indian persists (Tait, 2003).

### *Culture*

Culture remains an important concept in the study of Aboriginal peoples. Rather than restricting culture to health beliefs and practices, a more encompassing view of cultural representation is appropriate for the postmodern world system. The process of cultural representation is now inescapably contingent, historical, and contestable (Clifford & Marcus, 1986). Culture can no longer be studied as a distinct entity; rather, the context in which it is set must be considered, and must include the interpretation of meanings behind beliefs, values and ways of knowing within a culture (Kleinman, 1980). Postcolonial theoretical perspectives provide an interpretative lens for understanding Aboriginal culture in this way. An interpretative perspective of culture that is reflective of

real-life situations mitigates the risk of conceptualizing culture as a distinct entity in ethnocentric ways that perpetuate colonial inequities.

### *Othering*

Anderson (2004) suggests that othering assigns identity, categorizes human existence, and homogenizes experiences. Browne et al. (2005) argue that othering “is founded on stereotyped identities where the projection of assumed cultural characteristics or identities is projected onto members of particular groups” (p. 21). The most significant example of othering in recent Canadian history is the residential school experience of Aboriginal people. “Residential schooling was enforced as a means of preserving the health of Aboriginal children who required protection from their ‘negligent and ignorant’ mothers.” (Kelm, 1998, p. 62, cited in Browne et al., 2005, p. 21). According to Browne et al. (2005) this context continues to shape practices of health professionals today where “gendered assumptions about Aboriginal mothers as negligent can unwittingly shape health professionals’ views of particular groups of patients” (p. 21).

The complexities of colonial politics, policies and practices have led to profound social and cultural disruption in Aboriginal communities, resulting in a colonial legacy where many Aboriginal women continue to be disadvantaged (Browne & Fiske, 2001). Continued colonization of Aboriginal people contributes to the distance that still exists between Euro-Canadian and Aboriginal people, affecting their very essence of being (Browne & Fiske, 2001). These effects are both far-reaching and profound for Aboriginal people, reinforcing their place among the world’s most vulnerable, marginalized from mainstream society to live, work, and play in a world set apart. Therefore, it is important

to define postcolonialism by describing the concepts within its framework that are relevant to health and health research: race, racialization, culture and othering (Anderson, 2004). Colonialism continues to shape lives, well-being, and life opportunities: the everyday reality for Aboriginal mothers (Anderson, 2004).

#### Summary

FASD is a major health concern for Canada's Aboriginal people (Tait, 2003). Supportive strategies aimed toward helping mothers face everyday challenges raising children with FASD are unknown. This study will enable us to understand how mothers manage challenges they encounter raising children with FASD, and how they promote their children's health. Findings will extend nursing knowledge in general about raising children with disabilities and generate knowledge specific to raising children with FASD in order to provide anticipatory guidance to mothers in preparing them for challenges they are likely to encounter. Additionally, findings will explicate how historical, political, and social contexts contribute to underlying issues that perpetuate the incidence of FASD.

## CHAPTER II: REVIEW OF LITERATURE

The focus of this chapter is to situate Canada's Aboriginal people living in northern British Columbia within an historical context, present the current working definition of FASD, and describe FASD prevention efforts to date. The current literature related to the theoretical concepts that provided the organizing framework for this research--namely, vulnerability, marginalization and mothering--was also reviewed.

Literature focusing on the current theoretical and empirical knowledge pertinent to postcolonialism, marginalization, vulnerability and mothering was broadly explored, as these concepts were deemed important to understanding how Aboriginal mothers raise adolescents with FASD. I specifically sought information that could inform my understanding of how Aboriginal mothers enact their mothering role within a postcolonial context, the challenges they encounter, and how they solve problems or develop strategies related to raising adolescents with FASD.

Online searches using CINAHL, ERIC, Medline, PsychLit, Canadian Provincial and Federal Government databases, as well as the Google search engine, were used to review pertinent journal articles. Literature included in the search was drawn from education, sociology, women's studies, and Canadian Northern Studies databases. Key search terms were *Canada*; synonyms for *Canadian Aboriginal people* (First Nations, Aboriginal, Métis, etc.); *Fetal Alcohol Spectrum Disorder (FASD)*; *Fetal Alcohol Syndrome (FAS)*; *Fetal Alcohol Effects (FAE)*; and *colonialism, postcolonialism, vulnerability, marginalization, mothering, chronic illness, school health, health status, health promotion, culture, indigenous knowledge, and indigenous practices*.

### Historical Background: Canada's Aboriginal People

The Canadian Constitution recognizes three groups of Aboriginal peoples: Indians, Métis, and Inuit; these are separate people with unique heritages, languages, cultural beliefs, and practices (Canada, 1996). First Nations people are the subset of Canada's Aboriginal people who have Indian ancestry and "while they share many values and beliefs, collectively First Nations peoples are culturally and politically diverse and geographically dispersed" (Clarke, 1997, p. 13). In this study, the term *Aboriginal* is used throughout to refer to those people who may be First Nations and are characterized as Indians within the constitution of Canada. Since the Aboriginal people living in Northern British Columbia are from a variety of First Nations cultures, Elders have suggested that the most accurate way to refer to the study participants is "Aboriginal."

#### *Historical Context: First Nations Peoples in Northern British Columbia*

According to Muckle (2006), First Nations people have resided in what became British Columbia (for approximately 10,000 years). Prior to European contact, traditional First Nations people lived in complex societies with strong political, social, economic, and spiritual institutions that functioned in harmony with their homeland. During pre-colonial times (up to about 400 years ago), First Nations people in British Columbia were known as complex foragers or hunter-gatherers. In the late 18<sup>th</sup> century, the fur trade brought changes to the population, economies, and social organization of First Nations people of British Columbia. These changes marked the beginnings of increased vulnerability as First Nations people experienced a loss of their cultural legacy, including both social and human capital (Muckle, 2006).

### *Population*

Records indicate that during the period between the mid-1700s and 1929, the population of First Nations people in British Columbia decreased by approximately 75% (Hopkinson, Stephenson & Turner, 1995; Muckle, 2006). Various factors contributed to this decline: diseases carried by Europeans to which First Nations people had no immunity; the introduction of firearms (contributing to both intended and accidental deaths); and the introduction of alcohol, which led to social problems, reduced fertility, and a consequent decline in the birth rate (Muckle, 2006).

### *Economies*

The fur trade altered traditional lifeways and relationships among First Nations settlements, particularly those pertaining to material culture, subsistence, and settlement patterns (Muckle, 2006). The enormous demand for fur increased hunting activity, while other traditional foraging activities such as fishing and berry picking decreased (Muckle, 2006). Furthermore, the establishment of coastal trading posts encouraged the relocation of First Nations communities closer to the center of trade activities, thereby increasing the number of coastal settlements and shifting power to those settlements that were suitably located (Muckle, 2006). The discovery of gold in the mid-1800s also contributed to changes in economies for First Nations people. Gold panning altered fish habitats, resulting in alterations to diet for First Nations people (Muckle, 2006). As a result, many First Nations people, realizing the value of gold, left their traditional work to become gold-seekers, thus further altering their own economies (Muckle, 2006). To sum up, traditional lifeways were forced aside.

### *Social Organization*

Social organization among First Nations people was complex, based on kinship, and featured rigid social stratification. Positions of leadership were established according to hereditary relationships and determined matrilineally (Boas, 1963; Muckle, 2006).

First Nations people were recognized by their affiliation to a house and/or a clan.

“Houses,” each led by a chief, comprised groups of related extended families sharing several cedar plank houses (Muckle, 2006), and clans were “groups of related houses from different groups within a nation or territory” (Muckle, 2006, p. 47).

Houses controlled access to resource locations and rights to hunting, fishing, songs, dances, and stories (Muckle, 2006). Clans, which were named after birds, fish, or animals, depicted relationships and kinship and provided their members with solidarity (Muckle, 2006). Most importantly, subsistence (including hunting, fishing, and access to resources) was strongly associated with settlement patterns and economic systems (Muckle, 2006).

Non-native settlement continued to alter the populations, economies and social organization of First Nations people; consequently, traditional subsistence activities were no longer carried out (Muckle, 2006). This resulted in the migration of First Nations people to larger towns established by colonial settlers and contributed to the “breakdown of kinship relations by enhancing their dependence on the settlers” (Boas, 1963; Muckle, 2006, p. 65).

According to the annual report of the Provincial Health Officer (British Columbia, 2007), First Nations people in British Columbia have experienced longstanding

inequalities in both health and social status. Trends shows improvement for some health indicators for First Nations people however there is a persisting and broadly based gap that cannot be explained by genetic risk alone. Causes are varied and rooted in socio-economic disparities and cultural disruption categorically attributable to inequalities resulting from colonialism, historical loss of cultural and political institutions, racism, residential school experiences, and geographic isolation (British Columbia, 2007). First Nations people are more likely to die before age 75 from all causes of death compared to other residents of British Columbia (British Columbia, 2007). What is most disturbing however, is the fact that the differences are marked for what are theoretically preventable causes. For example, external causes of death such motor vehicle accidents, accidental poisonings, suicides, homicides, are identified alongside causes like heart disease, cirrhosis, and HIV disease (British Columbia, 2007). Smye and Browne (2002) note that health issues in First Nations communities are rooted in socioeconomic and political circumstances that are a direct result of colonization and a long history of oppression.

Traditionally, Aboriginal womanhood was held sacred and maintained through a knowledge system of balance and harmony where women were spiritually powerful and held status in their communities (Moffitt, 2004). Today, Aboriginal women are portrayed as “drunken squaw, dirty Indian, easy, and lazy” (Anderson, 2000, p. 99, cited in Moffitt, 2004). For many, this depiction has become the identity of Aboriginal women in Canada (Moffitt, 2004), where the many challenges faced by these women are attributable to years of oppression, poverty, violence, and dependence on welfare that have arisen as a direct result of colonialism (Smye & Browne, 2002).

Browne and Smye (2002) note that the “colonial legacy of subordination of aboriginal peoples has resulted in a multiple jeopardy for large proportions of aboriginal women who face disadvantages and individual and institutionalized discrimination on the basis of race, class and gender” (p. 28). This context for First Nations women will change only when the remnants of colonialism are addressed by unmasking the social and structural forces that perpetuate oppression.

#### Definition of Fetal Alcohol Spectrum Disorder (FASD)

By definition, FASD is “an umbrella term describing a range of effects that can occur in an individual whose mother drank alcohol during pregnancy” (Caley et al., 2005). Chudley et al. (2005) describe these effects as including “physical, mental, behavioral, and/or learning disabilities with possible lifelong implications” (p. S1). Not until 1973 was FASD recognized as a definitive disorder and referred to as Fetal Alcohol Syndrome (Chudley et al., 2005). Since that time, this range of effects has become known as FASD, and, although not a medical diagnostic term, FASD is a diagnosis made within the framework of the medical model (Chudley et al., 2005). Numerous studies have noted the prevalence of FASD, particularly among Canadian Aboriginal peoples, Native Americans and Alaskan Natives. These studies focused exclusively on the epidemiological nature of FASD (Eriksson, 2007; Eustace, Kang & Coombs, 2003; Gardner, 2000; May et al., 2006; May & Gossage, 2001). While these studies tell us about the devastating extent of this condition, little is known about the impact FASD has on family dynamics, particularly in terms of mothers who are raising adolescents with FASD.

## FASD Prevention

Tait (2003) notes, “There is consensus among scientific researchers, medical and social service professionals, paraprofessionals, and lay persons that FASD and alcohol-related birth defects are one-hundred percent preventable and if pregnant women simply stopped drinking, babies with FASD will not be born” (p. 121). Initiatives targeted toward the prevention of FASD in Aboriginal communities and aimed toward reducing substance abuse have included work targeted at reducing maternal alcohol consumption during pregnancy, and implementing programs addressing the specific risk factors and known causes of FASD (Chang, Goetz, Wilkins-Haug, & Berman, 2000; Stade et al., 2006).

Despite efforts to prevent FASD, it remains a major health issue for Aboriginal people; the incidence of FASD continues to rise and women continue to consume alcohol during pregnancy (Krulewitch, 2005). Studies indicating success in raising awareness of FASD have been carried out; however, this knowledge has not translated into modified behavior (Stade et al., 2006; Murphy-Brennan & Oei, 1999; Walker et al., 2005). Consequently, efforts must be focused toward discovering successful strategies for raising adolescents already affected by FASD.

### Concepts of Marginalization, Vulnerability and Mothering

Concepts that form the organizing framework for study of Aboriginal mothers raising adolescents with FASD have been conceptualized within the theoretical perspectives of postcolonialism. The concepts of marginalization, vulnerability and mothering are not included in postcolonial theory, but I believe they are helpful in

understanding the everyday life of Aboriginal mothers raising adolescents with FASD. In addition, these three concepts provide understanding about the larger societal issues that define and structure the lives of Aboriginal mothers.

### *Marginalization*

Marginalization is the “process by which persons are peripheralized on the basis of identities, associations, experiences, and environments (Hall, Stevens, & Meleis, 1994, p. 25). It is a sociopolitical process resulting in increased vulnerability (Hall, Stevens, & Meleis, 1994). Marginalization is best conceptualized in terms of the multidimensional properties of secrecy, voice and Eurocentricism (Hall, 1999).

*Secrecy* refers to the access and control of information that protects the boundaries of one’s self and group. Marginalization facilitates secrecy within the marginalized group, hindering or preventing the dominant group from gaining inside knowledge and using it to their advantage against the marginalized (Hall, 1999). Many Aboriginal people are reluctant to talk about FASD, as it is a secretive topic that may reinforce stereotypes of Aboriginal women and their own helplessness.

*Voice* is the opportunity for individuals to express themselves and describe their experiences as being different from the dominant stereotypes (Hall, 1999). Within a marginalized group such as Aboriginal mothers, there is limited opportunity to be heard. Recently, Denzin and Lincoln (2005) identified “voice” as being a current challenge in social science research, especially in research methods where researchers attempt to create an abstracted reality. Because oppressive conditions are embedded in the everyday conditions of their lives, it is critically important that the voice of Aboriginal mothers be

heard. As the responsibility for rejecting stereotypes and defining themselves shifts to those who are living the Aboriginal reality, their voices have the potential to be powerful. But despite a thorough literature review, the voices of Aboriginal mothers who are raising adolescents with FASD cannot be found.

*Eurocentrism* is the ideology and interpretation of history that holds European values as superior to those outside the dominant society (Hall, 1999). Postcolonial contact with Europeans has contributed to intergenerational stress and historical trauma resulting from the loss of traditional lifestyles, languages, sacred places, healing traditions, and customs (Struthers & Lowe, 2003). It is clear that Eurocentrism is a key concept applicable to research with Aboriginal people.

Hall (1999) notes that resilience can result from the experience of marginalization in that individuals have capacity to develop durable strategies, support and skills that can aid survival. Again, it is important to note capacity is also dependent on circumstances and situations – what is useful in one circumstance may not prove useful in another. For example, residential school experiences and other such colonizing practices have contributed to the loss of culture and language, and even limited opportunity for parenting experiences. As a result, there is a generation of adults who have not been exposed to the benefit of protective factors that might insulate them from risk situations (Stout & Kipling, 2003).

### *Vulnerability*

Marginalized populations are also vulnerable populations; similarly, they are groups of people who are socially excluded, thus experiencing inequality in the

distribution of resources and power (Vasas, 2005). According to Spiers, (2000) “the adjective ‘vulnerable’ is defined as ‘to be able to be physically or emotionally hurt’ and ‘liable to damage and harm’ (p. 716)”. Aday (2001) suggests that vulnerability places one in “a position to be hurt or ignored as well as helped by others” (p. 1). Flaskerud and Winslow (1998) define vulnerability as having an increased susceptibility to adverse health outcomes.

Since the early 1950s, the concept of vulnerability has appeared in the nursing literature, with the frequency of relevant publications increasing over the last fifteen years (Flaskerud et al., 2002). Flaskerud and Winslow (1998) conceptualize vulnerability as increased susceptibility to disease, poor quality of life, and ultimately, premature death. They propose a conceptual model of vulnerability where the primary concepts of resource availability, relative risk, and health status are interrelated variables utilized in predicting adverse health outcomes among vulnerable social groups (Flaskerud & Winslow, 1998).

Conceptual interrelationships are integral to the model developed by Flaskerud and Winslow (1998). An inverse relationship suggests that a lack of resources increases relative risk, and that risk varies as a function of both opportunities and resources (Flaskerud & Winslow, 1998; Leight, 2003). Secondly, the relationship between relative risk and health status suggests the hypothesis that increased exposure to risk factors may lead to increased morbidity or mortality, leaving some groups more predisposed to risk at certain points in their lives (Flaskerud & Winslow, 1998, Leight, 2003). Finally,

Flaskerud and Winslow (1998) posit, “morbidity and mortality in a community may feed back into resource availability and further deplete availability of resources” (p. 71).

Shi and Stevens (2005) conceptualize vulnerability as a convergence of risk factors and emphasize determinants of vulnerability at both community and ecological levels. Their conceptual model of vulnerability includes individual and ecological risks that are influenced by vulnerability, thereby affecting health outcomes (e.g., physical, mental and social) at both the individual and population level. Risk factors include predisposing, enabling, and need attributes that reflect risks for poor quality of health care. A person's vulnerability status is determined by both individual characteristics and the environment in which the person lives, together with the interactions within that context of individual and environmental characteristics. This model also focuses on attributes of vulnerability for the population as a whole, rather than specifically focusing on vulnerable traits of subpopulations, and also stresses the significance of converging risk factors. Hence, the effects of experiencing multiple vulnerable traits may lead to cumulative vulnerability at any one time.

### *Mothering*

The social, political and economic context that contributes to the vulnerability of Aboriginal people extends to their experiences of mothering adolescents with FASD. Aboriginal children are born into a colonial legacy (Greenwood, 2005). Because there is such need to improve health for Aboriginal people in Canada and given that there is a link between childhood development and overall societal health, the concept of mothering lends theoretical strength to the need for research conducted with Aboriginal

women who are raising adolescents with FASD. Furthermore, the voice of previously silent groups--in particular, the voice of Aboriginal mothers--has not been heard (Dickson & Green, 2001; Nelson, 2002; Sawyer, 1999).

The concept of mothering is not clearly defined in the literature. For instance, mothering is defined as a “set of socially constructed activities involving nurturing and caring for people” (Arendell, 2000, p. 1192). Nelms (2005) suggests that mothering remains a continuous uphill struggle where women attempt to comply with the “perceptions of good mother” expectations (p. 3). However, stereotypes of Aboriginal women do not portray an image of good mothers (Anderson, 2000). Nelms observes that in many cases mothering is more related to child rearing than to anything else (2002). There is consensus among scholars that mothering involves nurturing and caring that is characterized by the practices of “being with” and “dwelling with” (Arendell, 2000; Hartrick, 1997; Nelms, 2000; Nelson, 2002). Since women typically do most of the work of mothering and are perceived to be natural caregivers, mothering has been primarily associated with women; however, not all women are mothers, and caring work is not the exclusive domain of women (Arendell, 2000).

In a metasynthesis of the literature on mothering other-than-normal children, Nelson (2002) identified four steps common to this experience: (a) becoming the mother of a disabled child; (b) negotiating a new kind of mothering; (c) dealing with the fact that many aspects of daily life will never be the same; and (d) the process of acceptance/denial (p. 520). This metasynthesis provides further information about the experience of mothering distinct children, such as those with FASD. These findings are

supported in a literature review, which examined approaches for helping families cope with chronically ill children (Meleski, 2002). Aboriginal mothers of children and adolescents with FASD are faced with societal blame for consuming alcohol during pregnancy. We know little of this experience or how it plays out in the lives of mothers and their adolescents.

Women's caring is framed in the literature as either burden or fulfillment (Nelms, 2005; Wuest, 2001). Despite the current theoretical understandings of caring/caregiving in relationship to mothering, there is little evidence in the literature to elaborate on how mothering actually fits into the complex reality of women's experience of caring. In particular, there is no literature describing the caring practices of Aboriginal women. Wuest (2001) suggests that caring is a way of being, rewarding, and sustaining. As well, the same author suggests that while purported to be growth producing, caring is symbolically laden with gender issues and images of stereotypical motherhood that may sometimes be unattainable and unrealistic models for mothers of adolescents with FASD.

The dimensions and strategies inherent in women's caring are intricately woven into the practices of mothering. Mothering experiences unique to Aboriginal motherhood are not well understood. Nelms (2005) describes the struggle of mothers who attempted to live up to the perceptions and stereotypes of being a good mother despite fatigue, self-doubt, and overwhelming emotions. When the postcolonial context of Aboriginal mothers is considered, the struggle of mothering must be even more complex and difficult. For example, blame is reflected in a study describing experiences of foster mothers raising children with FASD, in which Gardner (2000) found that some foster mothers express

anger toward birth mothers because of prenatal alcohol use. Aboriginal mothers raising adolescents with FASD may experience a form of chronic trauma similar to that of mothers who care for a child born with disabilities (Gardner, 2000). This chronic trauma may be related to a burden of shame related to alcohol use during pregnancy. This blaming and anger may be a singular phenomenon shared by society at large, which often blames mothers for drinking too much alcohol during pregnancy.

### Summary

Despite efforts to prevent FASD, it remains a major health issue for Aboriginal people; the incidence of FASD continues to rise, and women continue to drink alcohol during pregnancy. Little is known about Aboriginal mothers' experiences raising adolescents with FASD or the strategies mothers use to promote these adolescents' health. A postcolonial theoretical perspective facilitates our understanding of how the approaches used by Aboriginal mothers, and their experiences, might be influenced by the social and structural forces that perpetuate marginalization and oppression, including postcolonial concepts such as race, racialization, culture, and othering.

### CHAPTER III: METHODOLOGY

Chapter III presents a description of the preferred method of answering the research questions. The chapter includes: (a) an overview of ethnography and its origins; and a discussion of interpretive ethnography; (b) a description of the procedures followed to ensure the protection of human subjects; (c) a description of the sample and sampling strategies; (d) identification of data sources, including interviews and observation participation; (e) data collection procedures and analysis techniques, including data storage and management plans; and (f) criteria for ensuring validity.

How a nurse chooses to go about doing research depends on the questions asked: namely, how do we as nurses understand our patients' needs, and how can we provide nursing care that makes a difference in their lives? Therefore, a nurse-scientist must examine what it is he/she brings as a researcher to the knowledge production process, and select a method to accomplish this task. Similarly, in an ethnographic study, a nurse-scientist must examine what participants bring to the research process and ensure the selected research method will help illuminate how participants experience their world and tell their stories.

Interpretive ethnography is the method I have selected to examine Aboriginal mothers' experiences of raising children with FASD. The philosophical perspectives of interpretive ethnography inform the conceptualization of the study, its design and methods, the interpretation of its findings and its scientific merit or trustworthiness. Postcolonial theoretical perspectives will shape "participant inclusion, recruitment

strategies, generation of questions, data analysis, construction of results, and dissemination of research findings” (Mohammed, 2006, p. 101).

### Ethnography and its Origins

Ethnography is rooted in cultural anthropology and seeks to “explain both explicit aspects of a culture (what all members are aware of and take for granted) and tacit elements (outside of awareness)” (Hodgson, 2001). Ethnography is influenced by two traditions: (1) 19<sup>th</sup>-century British anthropologists and (2) the Chicago School of the 1960s (Madison, 2005).

During the mid-19<sup>th</sup> century, when anthropology was developed as an academic discipline, a form of traditional ethnography was implemented by colonists whose curiosity compelled them to study the “natives” (Madison, 2005). The Chicago School originated in the 1920s and included a combination of sociologists and anthropologists (Hammersley & Atkinson, 2003; Madison, 2005). These scholars have been credited with focusing fieldwork on the urban landscape, emphasizing pragmatism, and advocating the use of the theoretical perspective known as symbolic interactionism (Madison, 2005). The Chicago School played a significant role in laying the groundwork for interpretive ethnography. Notably, Denzin (1997, 2001, 2003) was credited with the recognition and contemplation of a subjective human experience as being important to interpretive ethnography (Madison, 2005).

Today, researchers continue to select from different types of ethnography, each having unique features. For example, traditional ethnography is a classic research method that provides a socio-scientific description of a people and a cultural basis for their

peoplehood (Spradley, 1980). A second approach, critical ethnography, “is a style of inquiry, analysis, and discourse embedded in conventional ethnography, and results in the production of transformative knowledge to affect social change” (Thomas, 1993).

Interpretive ethnography from a postcolonial perspective is yet another approach. It shares similarities with critical ethnography, but is distinguishable from the critical approach in that it focuses on disrupting the history of “race-thinking” and the structural inequities that have been brought about by histories of colonialism and ongoing neocolonial practices (Anderson, 2004; Denzin, 1997).

Regardless of the approach, an ethnographer takes, Boyle (1994) notes, “ethnography is always informed by a concept of culture,” and it is the theoretical perspective of the researcher that mostly influences the selection of an ethnographic approach (p. 160). Moreover, there are “hallmark characteristics of all ethnographies that must be recognized” (Boyle, 1994, p. 162). These are “holistic and contextual nature of ethnography, reflexive character, use of emic and etic data, and the end product referred to as ethnography” (Boyle, 1994, p. 162).

#### *Holistic and Contextual Nature of Ethnography*

According to Boyle (1994), ethnography is a labor-intensive project where the holistic representation of “other” must be contextualized within the data and is gathered through interview processes. Participant observation carried out during fieldwork completes the picture of the participants and enables the researcher to gain the holistic perspective.

### *Reflexive Character*

Reflexivity is a characteristic of ethnography that can result from an interface between participant observation and participant interviews, where the views of the participant and the observations of the ethnographer are melded together to produce what might be known as the “third dimension that rounds out the ethnographic picture” (Boyle, 1994, p. 166). This interaction contributes to knowledge construction. Denzin (1997) supports this notion and suggests methodological reflexivity involves moving beyond the standard version of ethnography to connect those original formulations to theories of the postmodern.

### *Emic and Etic Data*

*Emic* and *etic* are important terms found in the ethnographic literature; they are directly related to the idea of reflexive character, where the emic view is that of the insider/participant and the etic view is that of the ethnographer (Boyle, 1994). Combined, these perspectives contribute to the rich description that forms the ethnography of a given research project or situation. In this study, emic data will consist of mothers’ stories describing experiences raising adolescents with FASD, and might entail descriptions of challenges that arise in the everyday activities of schooling, relationships with peers and risk-taking behaviors common to the age group. Etic perspectives will situate these “here and now” experiences within the complexities of postcolonial politics, policies, and practices.

*End Product Referred to as Ethnography*

There is agreement among scholars that the application of qualitative methods such as ethnography may differ between the social science disciplines and nursing (Boyle, 1994). That being said, however, there is utility in drawing on “some cultural concepts and theories commonly used in anthropology to enrich both data collection and analysis in such ethnographic approaches” (Boyle, 1994, p.168). According to Denzin (1997), “any given practice that is studied is significant because it is an instance of cultural practice that happened in a particular place and time” (p. 8). Similarly, nursing brings its own socialization and science to the task and ultimately, knowledge that is useful for nursing and other health professionals (Boyle, 1994).

Arguably, the richest scholarship comes about when multiple perspectives are woven together to produce ways of knowing and seeing that push nursing as a discipline to move beyond the text of scientific inquiry (Anderson, 2004; Reed, 1995). Interpretive ethnography from a postcolonial perspective is a mode of inquiry that allows articulating, appreciating, and making visible the voices, concerns, and practices of research participants. Interpretive ethnography “takes ethnography to higher levels of analytic power, with the best thick description being analytically elegant” (Geertz, as cited in Morse, 1994, p. 193). According to Patton (2002), *thick description* is description that provides context and meaning; it goes beyond recording what a person is doing and beyond surface – it is context, emotion, and the web of social relationships that joins one person with another – it evokes emotionality and feeling.

### Procedures for Protection of Human Subjects

Before starting the research, I obtained human subjects approval from the Human Subjects Committee at the University of Arizona (Appendix A). I obtained informed consent during an initial meeting with each potential participant, where I described the study in detail to determine their interest in participating. I read consent forms aloud to each individual, encouraged and answered their questions, and left consent forms with them for further reading and consideration. Within a few days, I followed up with a phone call to determine if there were further questions. If, during this second contact, individuals indicated that they chose to participate, I scheduled appointments for the first interview. I obtained informed consent at the time of the first interview, and left participants with a copy of the signed consent. I advised all study participants that participation was voluntary and that they could withdraw from the study at any time. Confidentiality was maintained during the study and signed consent forms were stored at the Office of Research, in keeping with the regulations of the College of Nursing, University of Arizona. At the beginning of each of the three interviews, I also reminded study participants of their right to withdraw from the study at any time.

### Potential Risks for Participants

Although I tried to avoid risks in this study, I was aware of the potential that some interview questions might be stressful or upsetting to study participants. For instance, the topic of FASD might have evoked feelings of shame for study participants who may have consumed alcohol during pregnancy. In order to minimize this potential risks, I was sensitive to the feelings of the study participants and took plenty of time getting to know

each of them in order to help ensure the environment felt safe for them and that they had confidence and trust in my approach to their stories. I did not rush participants; rather, I carefully listened to their stories and made time for interaction both before and after each session to ensure each participant was comfortable with the process. No study participants expressed any concerns over the interviews or process and all described the experience as positive and enjoyable.

#### Potential Benefits for Participants

There were no direct benefits for study participants; however, they did have the opportunity to share their stories of childrearing with me and through that, process affirmed some effective approaches they had found useful, and that will be shared via this study, with the aim of benefitting other mothers. Mothers had the opportunity to discuss traditional approaches and mothering stories and their participation contributed to the findings. Through the development of a beginning interpretive theory, these findings explicated how historical, political, and social contexts contribute to underlying issues that perpetuate the incidence of FASD.

#### Sample and Sampling Strategies

Study participants were recruited from the interior of northern British Columbia from a well-known downtown center where participants were known to gather. Recruitment flyers (Appendix B) were displayed and handed out to individuals coming and going. In addition, word of mouth among participants led to other participants stepping forth to engage in the study. Furthermore, local health professionals provided information about the study to potential study participants. All study participants agreed

on their own initiative to have the researcher contact them about participating in the study. In this study a purposive sample of eight self-identified English-speaking Aboriginal women between the ages of 30 and 45, with one or more adolescents between the ages of 14 and 18 affected by FASD, were willing to talk about their experiences in raising these children, and gave their written consent.

Purposive sampling procedures were used to form this sample of Aboriginal mothers of FASD adolescents. This approach ensured that participants who had unique knowledge of the experiences and challenges under study were chosen. This research was not intended to be generalized beyond the phenomenon under study; rather it was intended to describe the ethnographic account and generate beginning interpretive theory within the context of discovery (Germain, 2001). While this primary selection approach was the ideal sampling method (where the researcher has an idea that the informants have the knowledge being sought), I also considered that I might need to employ secondary sampling strategies (Morse, 1991). If required, secondary sampling would have allowed me to expand the participant pool in order to compensate for interviews that provided less-than-adequate data (Morse, 1991; Patton, 2002). Because participants were volunteers, it was firstly necessary to determine if they met inclusion criteria. Secondly, it was necessary to dialogue with them to determine if they had the ability to provide the in-depth descriptions necessary to answer the research questions. All participants in this study who came forward proved to have the knowledge to convey their rich experiences.

An ethnographer must also sample within cases (Hammersley & Atkinson, 2005). There are three major dimensions along which sampling within cases occurs: (a) time, (b)

people, and (c) context (Hammersley & Atkinson, 2005). Time refers to those instances that the researcher may deem to be of particular interest, such as festivals or events of importance. Time was also important in the current study in terms of more day-to-day events such as the beginning and ending of the school day. Hammersley and Atkinson (2005) note that researchers must “sample the routine as well as the extraordinary” (p. 49). Since no research setting is socially homogeneous, it is necessary for the ethnographer to seek adequate representation of the people involved in the research (Hammersley & Atkinson, 2005). For my study, this meant that I included individuals who volunteered for the study because they had the rich experiences I wanted to explore. For this study, context also held significance to sampling within cases. For the purposes of this research, *context* does not refer to place; rather, it refers to the processes and activities within which the mothers engage in childrearing practices, such as a school-based setting where they are actually the learners. Sampling also included selection of events, activities, documents, newspapers and newsletters, festivities, and other data sources. For example, I attended classroom sessions on different occasions and in three diverse settings where all participants were FASD mothers, joining the women for their daily activity of baking, crafts, and schoolwork. Interaction between the mothers and their children often took place during the course of the day.

#### Recruitment

Study participants were purposefully recruited through word of mouth using previously established informal communication channels. Recruitment flyers (Appendix B), requesting volunteers, describing the study, and providing my contact information

were handed out and prominently displayed in the reception area of the Center and on bulletin boards in the rooms. I aimed for ten to twelve participants for this study.

Participants were chosen based on the inclusion criteria for this study, their knowledge and experience of the problem under study, and their willingness and ability to convey their rich experiences. This sampling procedure resulted in the selection of the final eight participants. I faced significant recruitment challenges in this study; Aboriginal mothers of FASD adolescents are members of a vulnerable population and therefore deserve the right to freely choose to participate in any research that includes them. Because I am a non-Aboriginal researcher, it was imperative that I work very hard to develop trustworthy relationships with key individuals within the community of Aboriginal women, so as to be viewed as an individual who would not unfairly exploit my subjects' willingness to participate. The women in my study were cautious and I was required to move at their pace of comfort to recruit participants and to complete the interviews with them.

#### Data Sources

The primary sources for data in this study were three in-depth interviews with each participant, observation participation, and field notes. A review of documents and the collection of historical and culturally relevant data also enhanced the interview data. Culturally relevant data included participation in activities at the center (such as classes and celebratory meals with the mothers), and other sources of meaningful data gathered from individuals who were engaged in providing various services for mothers who have FASD-affected adolescents.

### *Observation Participation*

In this study, observation participation is best characterized as “observer as participant”; I was involved in various meetings and community activities where participants were gathered (Germain, 2001). Some activities, such as support groups for FASD family and friends were held on a regularly scheduled basis. Other activities were more random, such as drop-in group activities at the center or Aboriginal Health conferences where participants gathered. This gave me an opportunity to immerse myself in local activities where mothers with FASD-affected adolescents gathered.

Germain (2001) characterizes the “observer as participant” method as being transparent, in that “the role of researcher is publicly known at the outset of the research project” (p. 290). This approach also affords the researcher fluidity to move about and be selective regarding participation and observation, as the research demands (Germain, 2001). During this observation participation, I had the opportunity to observe mothers with children interacting together with the broader culture during activities. In addition, I had opportunities to observe how mothers pass on traditional cultural knowledge during such events. For example, I attended a graduation ceremony where some of the mothers were recognized for their achievements in the classroom and received certificates of accomplishment. During this ceremony, some of the mothers’ adolescent children were present. At this time, I witnessed the importance that the mothers placed on the ceremony of receiving a recognition certificate from a formal program; it was clear that the most important part of the ceremony was the pride they took in being able to share this achievement with their children and other extended family members.

Field notes taken during observation participation and recorded over the course of the study served as a rich source of data for this study. Four types of notes were recorded during participant observation over the course of this research: (a) observational notes, (b) theoretical notes, (c) personal notes, and (d) methodological notes.

#### *Observational Notes*

Observational notes contain descriptions of what is observed in the context or field of the research, ideally, capturing everything the observer sees and hears (Patton, 2002). To ensure accuracy in this study, I recorded observational notes primarily in participants' homes and immediately following interviews. In addition, I made observational notes after being immersed in the field. As Wilson (1987) suggests, these observational notes are the "who," "what," "where," "why," and "how" of a situation and very little, (if any) interpretation needs to be offered while the notes are being captured (p. 262).

#### *Theoretical Notes*

Theoretical notes are derived from the observational notes and serve as the beginning points for analysis and interpretation of data (Wilson, 1987). According to Wilson (1987) the researcher will "infer, conjecture, and hypothesize to begin the analytic scheme" (p. 381). The researcher must be sure to provide descriptive observational notes so that the theoretical notes can be derived accurately (Patton, 2002). During the course of this study, theoretical notes were made at least weekly and incorporated into the ongoing analysis.

### *Personal Notes*

Germain (2001) recommends that researchers keep a record of feelings, biases, and introspections during participant observation to aid in the process of reflexivity in the data interpretation phase of the research. Wilson (1987) suggests that personal notes should include information about how the research is progressing and considerations of the researcher's role in the process; personal notes provide the context for data. It has been noted that engaging in research as a participant-observer can affect researchers on a personal level, and that personal note taking is a way to capture that growth opportunity (Loppie, 2007). Personal notes were made daily when the researcher was engaged in research-related activity over the course of the study.

### *Methodological Notes*

Wilson (1987) suggests that methodological notes are of value to record ideas or instructions regarding both useful approaches, and those approaches that were less than satisfactory. Methodological notes have the potential to shape the direction of research activities as a quality improvement measure. Therefore, methodological notes were reviewed and updated weekly. Methodological notes provided important direction on how particular questions were thought through, and how they were presented to participants in order to elicit important information. In addition, methodological notes were used to capture any issues related to secondary sampling activities.

### *Interviews*

At the beginning of the study, I met with each study participant in order to review the procedures for the protection of human subjects and to gain their consent. At this

time, I also collected demographic data (Appendix C, Part I). Three semi-structured, in-depth individual audio taped interviews lasting about an hour formed the basis of the data collection process; I asked each participant similar questions from an interview guide based on areas deemed important from the literature (Appendix C, Parts II, III, and IV). The guides served as springboards to begin the interviews within the subject area, leaving me free to build on the conversation, be spontaneous, and yet remain focused. Immediately following each session, I transcribed the interview.

The first interview with each participant was aimed toward building a friendly trusting relationship, and talking generally about caring for a child with FASD (Appendix C, Part II). The second interview focused on gathering information about the participant's health beliefs, practices, challenges, and childrearing experiences (Appendix C, Part III). The third interview filled in the gaps and served as an opportunity to clarify previously obtained information (Appendix C, Part IV).

#### Data Management

Interview data was managed using Ethnograph qualitative research software. Data collection and analysis occurred concurrently, as is consistent with ethnographic research. Data from participant observation was documented as field notes, and recorded according to category (observational, theoretical, personal, and methodological). Field notes were reviewed frequently, and changes made in the direction of inquiry as necessary.

To maintain confidentiality, I asked participants to select pseudonyms by which they would be identified in interview data. All audio-recordings and transcriptions were stored in a locked box in a locked cabinet in my home office. As required by the

University of Arizona, participant consent forms were filed in the Office of Nursing Research at the College of Nursing.

### Data Analysis

Data from many other sources, including field notes, observation participation, and interviews, completed the ethnographic record. Each source produced a different kind of data; analysis was completed as appropriate for each specific source. DeSantis and Ugarriza (2000) note that themes are extracted from the data through a process of logical analysis of all data sources. Scholars agree that themes unite a large body of data that may otherwise appear disparate and unrelated; they capture the essence of the meaning or experience under study (DeSantis & Ugarriza, 2000). Data analysis is a process that takes the researcher from the micro level of coding through to a macro level of overarching cultural themes.

Analysis of field notes included four types of recorded notes: (a) observational notes, (b) theoretical notes, (c) personal notes, and (d) methodological notes. Analysis of observational notes included such things as congruencies or discrepancies between what was being said and what was actually happening in the research setting. Field notes were documented after each encounter with participants, and whenever the researcher was in the research field. Observational field notes provided the descriptive information for the study findings and served to situate readers within the setting (Patton, 2002). Theoretical notes were maintained in an ongoing manner as analysis took place. As I noted observations, I used theoretical notes to infer document hunches, make conjectures, and generally speculate about details within the culture of the study. Theoretical notes also

proved useful in identifying gaps in the data. Information from my personal notes was also used as a reflexive journal, which I continued throughout the data analysis process. Similarly, I reviewed methodological notes in the context of the analysis to assess the impacts of any quality improvement activities undertaken during the course of the research. The content of field notes was discussed at periodic intervals with the Chair of my Dissertation Committee.

Analysis of the interview data involved following a series of inductive analytic steps, which was a process of constant comparative analysis. I listened to the recordings and then transcribed each interview verbatim. I also read the interviews several times in order to become familiar with the data and grasp them in their entirety.

Firstly, I broke every segment of data into data bits, coded them, and assigned a label describing the meaning of the data. In total, 99 codes were assigned to the data. Some examples of codes were *setting rules*, *guilt*, and *prejudice*. To ensure consistency in the assignation and meaning of assigned codes, I developed a codebook detailing the definitions of each code (Appendix E).

Secondly, using the Ethnograph software, categories were derived from the comparison and grouping of similar codes. I then abstracted codes into broader conceptual patterns of meaning and constantly compared them, making linkages with other conceptual categories. Data bits were compared with data bits, data bits were compared with categories, and comparisons were made across categories to illuminate both similarities and differences. These comparisons enabled me to see linkages and patterns in the data, resulting in a complete, internally consistent narrative (Janesik,

1994). I examined data closely to determine how colonialism manifested itself in the day-to-day lives of the mothers in my study, and to extrapolate the concepts of postcolonial theory, particularly race, racialization, culture and othering, as well as vulnerability and marginalization as manifested in mothering activities.

Thirdly, data bits that formed categories were grouped into themes that best explained how Aboriginal mothers understand and describe FASD, and how they conceptualize and promote the well-being of their adolescent children who have FASD. Finally, I identified an overarching cultural theme.

Two themes were derived from the research data: (a) *Intergenerational Patterns*, and (b) *Adaptive Mothering*. Stretching the data further resulted in the derivation of an overarching cultural theme that conveys the message of the culture of Aboriginal mothers raising adolescents with FASD and encompasses the themes from which it was derived. That overarching cultural theme is identified as *Mothering from the Margins*.

#### *Mentorship Role of Committee Chair*

The Chair of my Dissertation Committee read a random number of interviews, reviewed approximately 50-80% of data coding, and regularly reviewed my codebook to assess coding and conceptual linkages.

#### *Ensuring Validity*

According to Patton (2002), the “credibility and legitimacy of qualitative inquiry can be strengthened by emphasizing criteria that have legitimacy within the qualitative traditions” (p. 544). Lincoln and Guba (1985) support this notion and suggest that trustworthiness is one process by which researchers can establish confidence in the

“truth” of their research findings. Using the constructs of credibility, transferability, dependability, and confirmability, I have outlined below how I established trustworthiness and ensured rigor in the research process.

### *Credibility*

One measure of the credibility of research findings is their “truth-value.” This exists when individuals who had the experience would immediately recognize it from the study’s description and interpretations (Lincoln & Guba, 1985). Patton (2002) notes that the credibility of a study can be gauged by the philosophical commitment of the researcher to the qualitative process, combined with procedures for rigorous data collection and analysis. I am committed to qualitative inquiry and interpretive ethnography as the best method to answer the research questions. Furthermore, to maintain the credibility of the findings, I carried out member checks and triangulation of data sources with each participant; as Patton (2002) notes, “triangulation of data sources involves checking out the consistency of different data sources within the same method” (p. 556). For example, participants were asked to review their transcripts (Sandelowski, 1993). In this study, I used triangulation to develop an understanding of incongruencies between what was said and what was observed. I also used ongoing member checks whereby data, analytic categories, and themes were tested with members of the population from whom the data was collected. Patton (2002) reminds us that triangulation can generate inconsistencies that have the potential to deepen understanding. Throughout the research process, I confirmed with the participants and other members of the culture group the truth-value of the developing categories, resulting themes, and proposed

relationships. I aimed to ensure the analysis was consistent with their experiences, and frequently confirmed with participants their views on how adequately the emerging themes represented their experiences.

### *Transferability*

Transferability or fittingness enhances the rigor of qualitative findings by ensuring that research findings are transferable to contexts outside the study situation. In this study, purposive sampling and thick description provided the basis for establishing transferable research findings. Sufficient details of the context of data, along with the findings presented, will enable other researchers to judge this study's applicability to other study contexts. Detailed descriptions of transferability are presented in Chapter V.

### *Dependability*

Dependability is a criterion of rigor relating to the consistency of research findings (i.e., other researchers using the data should be able to extrapolate similar findings) (Lincoln & Guba, 1985). An audit trail is one means by which research steps and decision-making in the analysis process can be made evident to others, making the process transparent and open to scrutiny. Figure 1 shown below represents the conceptualization of the codes, conceptual categories, and themes along with supporting documentation. In this study, creating records of all research activities, including participants; their interviews; and other data recorded and filed (such as field notes and coding processes) generated evidence substantiating dependability. This approach revealed the decision trail of interpretations and research decisions that forms part of the process. Throughout the research process, I used the Ethnograph software to develop and

maintain an audit trail of memos, notes, transcripts, and coding books. Dr. Joyceen Boyle, my mentor and Dissertation Chair, reviewed transcripts, codes, and emerging categories throughout the process; this dialogue led to a trusting and educative relationship with her.

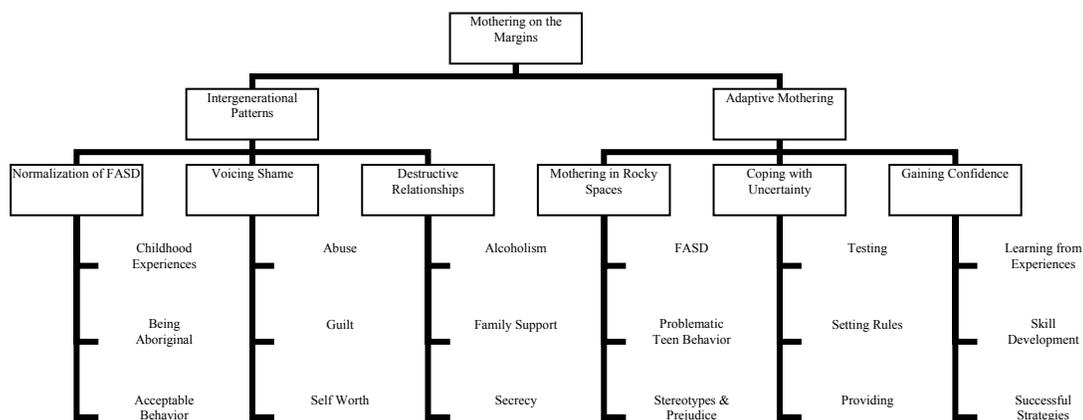


FIGURE 1: Illustration of Overarching Cultural Theme, Major Themes, Conceptual Categories, and a Selection of Codes.

A key aspect of interpretive ethnography is the appearance of truth: the quality of seeming to be true and telling a story that elicits a response of verisimilitude.

Verisimilitude is a means of judging research quality in ethnographic work.

Ethnographers include context, embeddedness, authenticity, and narrative truth in approach and methods (Denzin, 1997). How did this study establish verisimilitude? I aimed to present a text that has the capacity to reflect a true account--something that can be believed and verified by participants. After I completed the research, I asked participants to complete a final review to confirm the verisimilitude of the research findings. Of the eight women who participated, three agreed to review the final product; they confirmed that the study findings represented their experiences.

## Summary

Interpretive ethnography was an appropriate methodology to answer the research questions in this study. The theoretical underpinnings of this approach were described and the author's credibility as a researcher was affirmed. Processes undertaken to protect human subjects were described, a description of the sample and sampling strategies were provided, data sources were identified, and data management and analysis techniques were detailed. Criteria for ensuring validity were also included. Chapter IV presents a brief portrait of each study participant along with selected demographics.

## CHAPTER IV: STUDY CONTEXT AND PARTICIPANTS

Along with a discussion of nomenclature and selected demographic characteristics, this chapter presents brief portraits of the study participants.

### Demographics and Nomenclature

#### *Aboriginal Peoples in Canada*

As shown in Figure 2, the term *Aboriginal* as used in Canada generally refers to persons who may be North American Indian persons (Status or Non-Status Indians), Métis, or Inuit. Further, Statistics Canada (2008) (Catalogue no. 97-558 XIE) defines *Aboriginal* as follows:

Included in the Aboriginal identity population are those persons who reported identifying with at least one Aboriginal group; that is, North American Indian, Métis or Inuit, and/or those who reported being a Treaty Indian or a Registered Indian, as defined by the Indian Act of Canada, and/or those who reported they were members of an Indian band or First Nation . . . (p. 51)

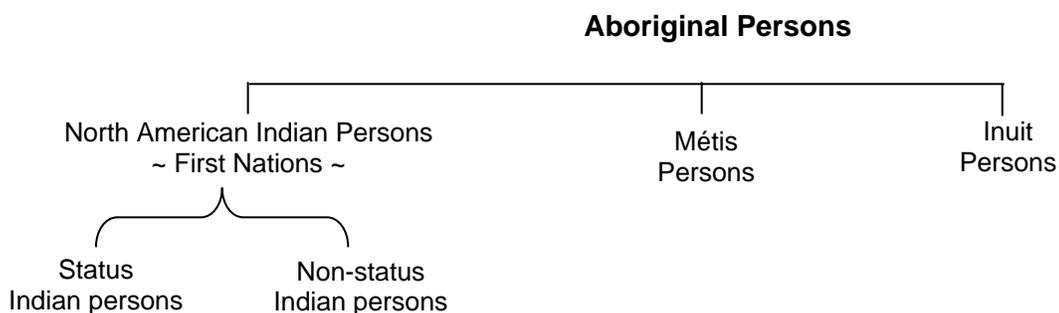


FIGURE 2: Aboriginal Persons in Canada

#### *Aboriginal People in Prince George*

This study sample was drawn from the City of Prince George including the larger Prince George Census Agglomeration Area (CA). According to Statistics Canada's 2006 census, in the City of Prince George, 8,045 out of 62,330 enumerated people are

Aboriginal, or 11.43% of the city's population. In the Prince George CA, 8,850 out of 73,765 enumerated persons are Aboriginal, or 10.71% of the population.

*Who is Included in the Aboriginal Population Figures?*

It is thought that the majority of the persons who are identified as Aboriginal in Prince George are First Nations (North American Indian). However, the contribution of the Métis population, who are also considered Aboriginal, is significant. A breakdown of Aboriginal peoples into First Nations, Métis, and Inuit is only available at the Regional District level. Geographically, the Regional District of Fraser Fort George is much larger than City of Prince George, but generalizations from the district to the city can be made reliably, as the population of the city comprises more than 73% of the total population of the Regional District.

TABLE 1: Table of Aboriginal Populations by Region and Identity.

Regional District in Northern BC	North American Indian Persons	Métis Persons	Inuit Persons	Multiple Aboriginal Identity	Other Aboriginal Identity
Skeena – QCI	7,360	290	10	10	315
Kitimat - Stikine	10,725	935	25	20	565
Bulkley Nechako	5,755	1,200	15	10	200
<b>Fraser Fort George</b>	<b>4,830</b> (50.1%)	<b>4,440</b> (46.1%)	<b>10</b>	<b>110</b>	<b>240</b>
Peace River	3,415	3,255	70	75	175
Stikine	470	10	0	0	15
Northern Rockies	820	350	0	0	10

BC Stats. (2008) *Fast Facts*.

### Study Participants

Eight self-identified Canadian Aboriginal women participated in this research study over a period of fourteen months. Age data indicate a diverse sample, with participants ranging in age from 30–45 years, with a mean age of 36.25 years. One

participant is married and living with her husband; three live with occasional common-law partners, and one mother, newly engaged to be married, lives with her fiancée. The remaining three are single mothers.

Income data indicate a wide range of earnings, with one woman earning over \$30,000 annually, three participants earning between \$10,000 and \$20,000, and the remaining women earning less than \$10,000. Education levels varied: one participant holds a diploma from a community college, one has a traditional high school completion certificate, two have high school equivalency certificates, and the remaining participants left school early. None of the participants have graduated from university. Six participants have at least one sibling with FASD. All but two of the participants have a parent or grandparent who has or had FASD, and of the eight participants, five have FASD themselves.

In total, the study participants have eighteen children and thirteen are between the ages of 14 and 18 with a mean age of 15.7 years. Of these, seven are male and six are female. The number of children in each family ranged between one and six. At the time of this study, one teenager had graduated from high school and completed a course at a local community college, nine were enrolled in school in special education classes, and three had dropped out due to drug and alcohol problems.

#### *Who They Are*

Brief portraits of each mother appear below, in alphabetical order. These portraits are not intended to capture all the details of who these women are. To maintain

confidentiality, each participant is presented individually using a pseudonym she selected, and identifying details of their lives have been altered.

*Amy*

Amy is an Aboriginal woman in her early forties who lives at home with her husband and three teenage children. Her daughter is the oldest and the boys follow closely in age. Amy grew up close to where she lives today, in a home with both parents, where she was the middle of three sisters. None of her siblings have FASD but and she does not think her parents or grandparents had FASD. Both parents are now deceased, and although her sisters live nearby, they are not in a close relationship. Amy graduated from high school and works independently in a home-based business. All three of Amy's children have FASD. Amy has been married for over twenty years and describes her relationship with her husband as being supportive and team-focused.

*Betty*

Betty is an Aboriginal woman in her early thirties who grew up in a home with her single mother and two sisters. Betty's mother has FASD and used alcohol and drugs during all her pregnancies. Because of her mother's behavior, Betty believes she has FASD. Betty is the eldest; over the years she has assumed an on-and-off parenting role with a younger sister who also has FASD and a serious drug addiction. Apparently, her middle sister does not have FASD. Betty lives with her fiancé and an infant daughter, and although she recently completed a Graduate Equivalency Diploma (GED), she does not work outside the home.

She receives a small disability pension and at some point hopes to go back to school to become an English teacher. Her teenage daughter from a previous relationship, who has FASD, does not live with her; rather, she lives with Betty's mother. Betty's teen has been in and out of rehabilitation for her drinking and a crack addiction, and another admission is pending.

Betty's infant daughter does not have FASD. Betty characterizes her current situation as "new beginnings" and is hoping for a chance to be a better mother this time around. She does not drink alcohol at all now, and has a dedicated caseworker who spends time with her. She describes herself as having a hidden disability with her own FASD, and although she refers to her earlier attempts at mothering as being "a failure," she states that she does not want to repeat the mistakes of her own mother this time, and is committed to success. Her fiancé is supportive of her in this role but does not encourage a continuing relationship with her teenage daughter; in fact, he discourages it.

### *Cindy*

Cindy is an Aboriginal woman in her mid-thirties who lives alone with her two teenage daughters, both of whom have FASD. Although she has never received a formal diagnosis, Cindy believes that she too has FASD. Cindy has a common-law spouse who lives with her sporadically when he is in town and not off working in the woods. Cindy describes him as a heavy drinker and does not condone his behavior around her daughters. She grew up as an only child in a small rural community and was raised by her maternal grandmother. In Cindy's early years, her own mother was coping with an

alcohol addiction, yet in recent years she has sobered up and has been back in Cindy's life. Cindy does not think her mother has FASD but she is not really sure.

A number of years ago Cindy relocated to a large urban center, where she has lived for the greater part of her adult life. Cindy has a high school equivalency diploma and is not able to find work; she receives income assistance. Cindy used alcohol during both her pregnancies and for some time afterward. She says it is expected behavior to drink and party where she comes from, even if you are pregnant. Both of her daughters were placed in foster care for a period in their early years; according to Cindy, this was related to her drinking behavior and absentee mothering.

Those were difficult times for Cindy, and although her own mother has been supportive of her in recent years, she does not live close by and only visits on occasion. Cindy spent time in rehabilitation herself and was able to have her daughters returned home, where they have been ever since. Cindy has a regular support network through caseworkers and Alcoholics Anonymous meetings, and says the meetings are her lifeline and source of support.

### *Donna*

Donna is an Aboriginal woman in her early forties and is the mother of six sons, all of whom are FASD-affected. Donna has one grandchild; she too is believed to have FASD. Donna is a single parent and lives on income assistance. Her mother and father both had FASD, as do Donna and her two brothers. Donna revealed that she is an alcoholic, as was her mother before her. Her mother left the family during Donna's early

years, and she spent some time in foster care. Donna reported that she experienced abuse in that environment and describes it as contributing to her drinking problems today.

Although she has attended special education classes for the past seven years, Donna has not been able to complete any schooling beyond grade five. She admits this is very discouraging and attributes her difficulties in this area to her inability to do math, which in turn is related to her FASD. However, Donna has a demonstrated talent as an artist and shows pride in her work.

Donna does not have a spouse and speaks little of the men who have fathered her children. None of the fathers has been present in her boys' lives, but her own father was a significant help in raising the boys until his death in the late 1990s. Since then, she has had some help from a cousin but that has been inconsistent, because Donna is unable to live up to the expectation of being sober that her cousin places on her.

Donna currently has one young teenager at home full-time, and some of her other sons live with her on occasion. She describes herself as being "worthless" and "not much of a person." Two of her sons are between the ages of 14 and 18.

### *Frances*

Frances, an Aboriginal woman in her early thirties, has a sixteen-year-old son affected by FASD. A single mother, she has lived in a large urban center for about twenty years. Her extended family lives in a town about two hours away. Frances says her mother is a heavy drinker and that her sister has FASD; she does not mention her father, other than to say he was never around much. She believes her mother and grandmother had FASD.

An unemployed woman on income assistance, Frances left school in grade seven and never completed high school. She continues to struggle with her own addiction to alcohol but does not believe she has FASD. Her son faces many challenges in life due to his FASD and has trouble fitting in with his peers; he does not attend school, although he remains registered, and has had several brushes with the law, one resulting in his incarceration in a group home for young offenders.

Frances struggles with guilt and shame about drinking alcohol while pregnant, and says that it took her a long time to admit that to herself. She feels she has made progress in working through her emotions about being Aboriginal, and about the abuse that is suffered by many in her home community, but she still struggles often with her cultural identity.

### *Grace*

Grace, an Aboriginal woman in her late thirties, is a single mother to an adopted sixteen-year-old son who has what she describes as severe FASD. Her two brothers, both of whom have FASD, live at home with her mother about two hours' drive away. Grace's father was killed several years ago in a car accident (he was driving under the influence of alcohol). Grace was injured in that accident and had to spend a few years away receiving rehabilitation. Grace believes her mother has FASD and often wonders why she herself does not. Grace graduated from community college with a diploma in early childhood education and is very proud that she has employment and is able to contribute her efforts toward helping women become good mothers. She has a dedicated interest in

working toward eradicating FASD in Aboriginal communities, and she desires to make up for the past mistakes of her own family.

*Ruby*

Ruby, an Aboriginal woman in her mid-thirties, has two teenage children, both of whom have FASD. Ruby also has FASD herself. Her son was born first, followed a few years later by her daughter. Both of her parents have FASD, as do her two brothers. Her father, who is deceased, left home years ago and had little influence on Ruby's upbringing. Her mother lives nearby, but because she is disabled she is not able to assist Ruby. After completing grade nine, Ruby left home and relocated to a large urban center, where she met the father of her two children. They never married, but lived common-law for a number of years until his work kept him away from home for long periods. He has since met another woman and taken up with her. Ruby has minimum-wage employment at a local big-box store and feels satisfied with that role. She reports that she makes enough to get by.

*Shannon*

Shannon is an Aboriginal woman who just celebrated her thirtieth birthday. She is a single parent of one teenaged daughter who has FASD. Both of her parents have FASD and her younger sister does as well. Although Shannon has FASD herself, she suggests it is a very mild form, and she believes she is able to cope pretty well. Although she admitted to drinking heavily in her youth and in the early years of her daughters' life, she has been able to be clean from drugs and alcohol for the past thirteen years. She has completed grade ten in school and is currently enrolled in upgrading classes in order to

obtain her high school equivalency certificate. Shannon has a live-in boyfriend at present time; the father of her daughter is not involved at all in her life or her daughters. She grew up in an urban center and although her mother mostly raised her, she spent a number of years in foster care due to her mother's absence for treatment of alcohol addiction. Her father has not been active in her life, and by choice she has very little to do with her mother or sister.

Shannon is unemployed and receives income assistance. Together with her boyfriend, they have enough income to get by, pay rent and provide for the necessities. Her daughter is attending special education classes and has been a successful student at that level managing to complete Grade 8 skills so far. Shannon believes that she has a good relationship with her daughter.

#### Summary

Chapter IV presented a brief discussion of nomenclature and selected demographic information on the study participants, along with brief descriptions of the unique circumstances of their lives.

In Chapter V, I will present the findings of the study and describe the themes that were derived from these data. Chapter V will conclude with a description of the overarching cultural theme of this interpretive ethnographic study.

## CHAPTER V: FINDINGS

Chapter V presents results of the data analysis after a total of 24 in-depth interviews with Aboriginal mothers. Analysis focused on answering these research questions: (a) How do Aboriginal mothers understand and describe FASD? and (b) How do Aboriginal mothers conceptualize and promote the well-being of their adolescent children who have FASD?

The analysis was informed by data from personal interviews with each study participant, contextualized with field notes taken during periods of observation participation and recorded over the course of the study. The experiences of the researcher during this process were documented as personal notes, and included reactions to the interviews and data. Theoretical notes were recorded throughout, considered during interpretation and analysis, and used to identify any gaps in the data. Demographic information was also collected and considered within the context of the research environment. Other sources of meaningful data were gathered from individuals who were engaged in providing various services for mothers who have FASD-affected adolescents.

Two themes were derived from the data, representing an abstracted level of analysis: (1) *Intergenerational Patterns*, and (2) *Adaptive Mothering*. Further theoretical analysis resulted in the development of an overarching cultural theme, *Mothering from the Margins*, conveying the culture of study participants raising adolescents with FASD and encompassing the above-mentioned themes. Each of these themes and the overarching cultural theme will be fully described and discussed in this chapter. Figure 3, shown below, represents the conceptualization of the codes, conceptual categories and

themes along with supporting documentation. Direct quotations from the participants are used to portray the richness of the data, illustrate aspects of the themes, and substantiate the theory development.

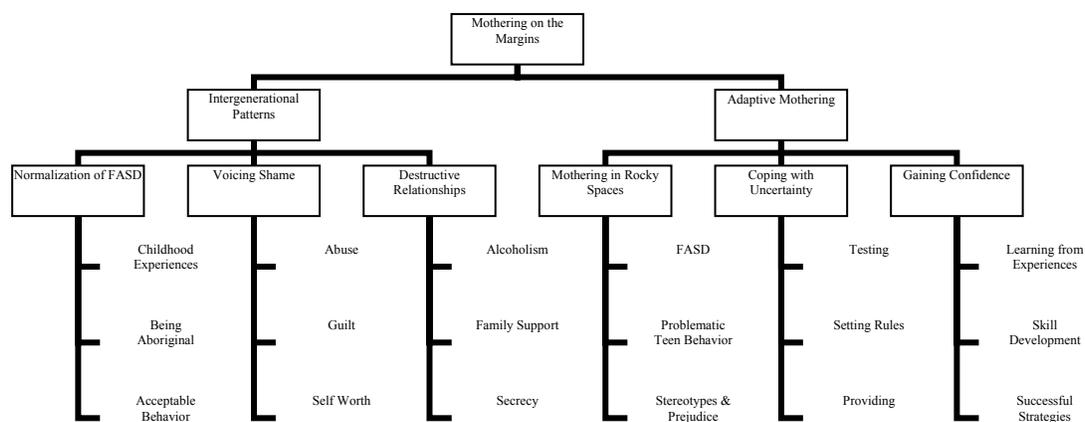


FIGURE 3: Illustration of Overarching Cultural Theme, Major Themes, Conceptual Categories, and a Selection of Codes.

### Major Theme – Intergenerational Patterns

*Intergenerational Patterns*, the first major theme derived from data analysis, includes the context in which participants live out everyday situations and experiences that are influenced by their tribal and family history. It is best defined as the behavioral patterns and responses taken up by individuals that are transmitted over generations. This theme implies that while the appearance of FASD in itself is intergenerational and related to the abuse of alcohol during pregnancy, the theme of *Intergenerational Patterns* resides in the more complex context of a colonist world that exists well into the seventh generation of Aboriginal peoples. Aside from having FASD-affected children and grandchildren, more than half of the study participants (N=8) reported they too had

FASD, and six had at least one sibling with FASD. All but two of the participants had a parent or grandparent affected with FASD.

*Intergenerational Patterns* become apparent when behaviors appear repeatedly over generations and are exhibited in a wide variety of ways. *Intergenerational Patterns* may exist for many reasons; in the case of the participants, the root causes might be related to the historical and collective emotional injury Aboriginal peoples have experienced as a result of colonialism. This injury manifests itself in many behaviors, including the abuse of alcohol, which leads to FASD, among other problems. According to the participants, they ignored and suppressed this trauma because there was little support for dealing with the associated feelings that remain unresolved and passed down through generations. All of the participants commented that what they believed to be normal when they were children is passed on now to their own children and grandchildren. For example, individuals pass on unhealthy ways of behaving that they use to protect themselves from their pain of trauma, such as abusing alcohol, and these behaviors are modeled for their children, sometimes without those same individuals even being aware of the dynamics involved.

The theme of *Intergenerational Patterns* is derived from three conceptual categories of meaning: (1) normalization of FASD, (2) voicing shame, and (3) destructive relationships. Because context is so important to these findings, a description of context is integrated into the discussion of each conceptual category within the themes.

*Category: Normalization of FASD*

*Normalization of FASD* is the first conceptual category that contributed to the theme *Intergenerational Patterns*. Normalization of FASD is best understood as the way behaviors and ideas come to be accepted as normal through repetition, ideology, or cultural norms, to the point where they become “natural” and have the appearance of being expected or taken for granted within a given context. One participant acknowledged this notion in her matter-of-fact comment as she revealed some of her family history and childhood experiences. In talking about her parents, she says, “Lots of FASD, my mother drank. I think my Dad had FASD too. Yeah, he was a drinker too.”

Another participant says, “I think they both have FASD [referring to brothers].” Still another participant admits that her father was drinking when he was killed in a car crash when she was a young girl. She was in the car with him and the accident left her with a brain injury. She states, “I do have a brain injury from an accident in early years, wrecked up in a car crash . . . my father was drinking and driving; he was killed.”

Drinking alcohol is the norm, it is expected behavior and when normalized, everyone just accepts it as being a part of life. The same participant adds, “Everybody does it.” Another comments as follows:

But no one really told me that my kids would be retarded. My first girl looked okay when she was born, and then I had the second. I didn't think the drinking would matter. Men expect to party in the village and that is just the way it is. Partying meant drinking, smoking, and having sex.

Study participants described how their childhood experiences influenced their behavior as they played out their role as mothers of adolescents with FASD. One participant states that in her world, FASD was "normal" and people assumed that because her son has FASD, it was likely her drinking that caused it. They were not aware that she was an adoptive mother. She states, "I struggle with being a First Nation mother of a FASD teenager, and I do not have FASD. Where I come from FASD is normal, accepted, and in many other communities too."

The *normalization of FASD* fosters an environment where drinking alcohol during pregnancy is not all that unusual. Another participant reinforces this belief, saying, "It is expected, the drinking. Not everyone who drinks gets FASD." Yet another participant, referring to how these views are reinforced within her culture, says, "How I parent is based on what I have learned."

In the lives of the participants, FASD is normalized and is viewed as "something that just happens." It can happen to anyone; it is the expected norm.

#### *Category: Voicing Shame*

*Voicing Shame* is the second conceptual category that contributed to the major theme of *Intergenerational Patterns* and is best defined as speaking of a painful emotion caused by a strong sense of guilt and unworthiness. This category includes the feelings that study participants shared about their personal circumstances including the guilt some participants expressed because of their alcohol drinking behavior. Coupled with a lack of self-worth for many of the participants, these feelings manifested themselves in their expressions of shame. Although it may seem contradictory to describe drinking behavior

as causing feelings of shame when it is normalized and accepted, it is important to note that for some participants it was years before they were able to make the connection between drinking alcohol during pregnancy and having a baby affected by FASD. One participant's testimony brings this to life:

Okay, I was bringing my son to daycare. He attended that daycare for four years. It took me that long to hear what the girls [staff] at daycare were saying. I think it was when he [her son] was about oh, 18 months, that they said there might be something wrong with him. I ignored it; denied it, really. He was doing random stuff, almost like temper tantrums. It took me a long time to even think about it, to even admit that,--yes, I drank. He was fussy, he cried lots. It was really not until he was about four that I agreed to have any testing of him. The staff said to me, "What do you think? Here are the behaviors." Then I said, "Yes, maybe he does have FASD." I did drink; I know I did that when I was pregnant.

One participant spoke to her own burden of guilt and shame as she described her own behavior when raising her small son. She now believes that her behavior may have contributed to his problems. Apparently, when her son was a toddler, she engaged in what she now refers to as "risk behavior," taking her small son to places where activities included drinking and partying. She explains:

I know when he was a baby I took him places he never should had been. I knew I should not have taken my child in some of those places, but at that moment, it met a need of mine. Like a man. Being with a man was more important to me sometimes than taking care of my baby and keeping him safe. I never knew really

what that looked like. I think that did not help him. I just didn't really know – too young, I guess.

In describing how she learned her son had FASD, another participant states, “I tell you, I am ashamed of myself, but I cannot help it. I still drink. I really feel bad about doing it. I tried to stop but I just can't. It is just too hard.”

Some of the participants described how ashamed they were of what they had done, or believed they had done, to contribute to their children’s problems. One participant says, “Not many people talked about it. Fetal alcohol is a shame thing where I come from, and not something that is talked about too much.”

Another, reflecting on how she feels responsible for her son’s problems, says, “I suppose, I think what I really feel is that I am to blame for my son. I have to live with what I have done to my son, every day.”

In the same vein, another participant says, “My sons mean a lot to me. It is my fault they are drinking and messed up. Everyone is drinking and messed up, I would say. It is just the way it is.”

For participants in this study *voicing shame* was subjective and formed part of their self-identity. It affected all aspects of their being.

#### *Category: Destructive Relationships*

*Destructive Relationships* form the final conceptual category of the theme *Intergenerational Patterns* and describe how participants’ relationships have a detrimental effect on their well-being and contribute to their further emotional injury. Destructive relationships are best defined as relationships that are unhelpful and harmful.

All participants admitted that they had problems in their relationships with family members; similarly, relationships between mother and child were often painful and contributed to suffering for both. In one instance, one participant described her destructive and sometimes abusive relationship with her grown sons, all of whom are FASD-affected. She states,

And they said all kinds of stuff, things that I know they don't really mean, things that they said, but they were mad. Then sometimes, I get along with them real good, and then they come and stay and then sometimes they won't leave for a while till they get stuff straightened out.

Another participant remarked on how she had hoped her family might have been able to support her as she raised her children under such difficult circumstances. In fact, it turned out that she could not rely on family for any help at all. She says,

Well, and when you are thinking of family you just, it is not the word *assume*, it's . . . maybe *hope*. I hoped I might have gotten some help from them. I guess I expected family to try to help, right? But it doesn't always work that way.

All of the participants in this study talked about how unhelpful their relationships with family members were, in particular when it came to obtaining support. One participant states, "I never had a babysitter in my life. It was me. I had no help at all. [Husband] tried to help me, but he didn't get it either. I was depressed, tired and depressed."

Sometimes participants became very frustrated with unhelpful relationships and took this frustration out on their children. In describing a time when she became

exasperated with the lack of support from her family, one participant spoke of how she lost patience with her daughters and spanked them. She remembers as follows,

And just nobody, well, nobody, helped me. Everyone said they would, but nobody came. So yes, I spanked my daughters when they were bad. I was tired, fed up, and had no help. So child protection can judge me all they want. I never beat my kids.

Another spoke with sadness when describing her feelings about her relationship with her sixteen-year-old son and her inability to muster the emotions she feels believes are necessary to foster a good relationship, saying, “I never really understood that except that I felt alone, I have no one that I can really love. I tried to love my son, but down deep I do not think we have much of a relationship at all.”

Alcoholism experienced by some participants and their children further fuelled the destructive relationships for participants with family members and with their children. These relationships were often fraught with pain, abuse, and feelings of being let down. One participant describes her story about her relationship with her father: “Sometimes he would be drinking and rowdy and just blow. He never ever hit me but I lived scared that he might. You never knew when it [abuse] was going to happen. We never talked about it.”

Another participant speaks about the destructive relationships she had with her own family and even though she has distanced herself from them, her unease with this strategy is evident in her words:

It was the car accident that killed my father that took me to a larger center for rehab, and I was able to stay away from the village. If not for that, I think I might have been the very same as most of the people there today. I distanced myself from my family. It is painful, it is hard, but for me it was the right choice, so far. I think that is why I want to make a different life.

This sentiment is echoed in the comments of another participant who briefly considered moving back to her home community:

Well no, I think about going back home, packing up and moving there, but just the odd time, because if I went back there is really nothing there for me. For me, it does not meet any needs. I think there is too much guilt and anger about where my family has been over generations and I just don't want to do that, so I totally just go over to the other side. I don't go back; I just mask the feelings.

Destructive relationships chipped away at the participants' sense of self, resulting in injury, hurt and physical and emotional abuse. Destructive relationships were unhelpful and damaging to the participants as they carried out their mothering roles.

### *Conceptualization of Intergenerational Patterns*

*Intergenerational Patterns* is an abstract theme that describes how participants understand and describe FASD. It is a powerful underlying foundation that establishes the context where FASD is normalized. *Intergenerational Patterns* supports the notion of how participants explained the normalizing effect of FASD, both in their mothering roles and their families. Based on the participants' accounts of their lives, as well as their relationships with their parents and siblings, it is evident that the behavior resulting in

FASD is known and has been exhibited for several generations within each familial context.

By definition, a *pattern* is something regarded as a norm: “everybody does it.” In this study, both the internal patterns (voicing shame) and external patterns (destructive relationships) characterized by the participants indicated that a pattern has emerged across each mother’s role. Collectively, they created *Intergenerational Patterns* generated from the study data.

#### Major Theme – Adaptive Mothering

The second major theme derived from the data, *Adaptive Mothering*, was generated from these conceptual categories: (1) mothering in rocky spaces, (2) coping with uncertainty, and (3) gaining confidence. *Adaptive Mothering* is defined as participants adapting to the unpredictable needs of their adolescents with FASD in ever-changing environments. *Adaptive Mothering* illustrates how participants face numerous challenges in raising their children with FASD. Participants demonstrated varying skill levels in mothering under difficult circumstances and in coping with uncertainty. However, for the most part, participants managed to learn from their experiences and began to gain confidence in their childrearing abilities. The participants are at different stages of *Adaptive Mothering*. Their desire to mother is not diminished in any way by some of the acts of mothering that they describe as being inappropriate. These instances are viewed, for the most part, as insights that prompted learning opportunities.

*Adaptive Mothering* is also influenced externally by discriminatory judgments held by mainstream society toward the participants as they struggle to be the kind of mothers they perceive the larger society expects them to be.

*Category: Mothering in Rocky Spaces*

*Mothering in the Rocky Spaces* describes the experiences participants grappled with in raising adolescents with FASD. This category is best defined as facing and responding to the special and difficult challenges of mothering FASD children on a day-to-day basis. Participants found themselves having to adapt to meet those challenges. In capturing the essence of that context, one participant created the name for this category: “I don't know the goalposts or boundaries with these kids. It is the rocky space in between that is my life.”

All the participants described examples of how FASD manifested itself in the lives of their adolescents. One mother describes the magnitude of her son's problems as a result of FASD and how they lead to trouble succeeding in school:

Let me list it for you: there are memory problems; he can't express himself properly with language; he has attention deficit and no social skills. He can't get cause-and-effect stuff and he has sensory issues. He is really sensitive to stimulation around him – hypersensitive.

Most challenging for many of the participants was the fact that FASD can be a hidden disability: not all individuals who have it share the marked physical characteristics attributed to FASD. As a result, members of mainstream society expect behavior from

adolescents with FASD that is typical of so-called “normal” kids. One participant describes her frustration with such experiences with her son:

He often can present well in the public eye, right? People see him for an hour and they think he has it all going for him. Well, it is his choosing, but in the safety of home or the environment where he feels safe to let it all out, I see a different picture.

She went on to describe how he often lashed out at her in anger and frustration once he returned to his safe haven at home. The point she was making, of course, was that no one else really knew just how he behaved at home or how problematic his behavior was for his mother.

In the words of another participant, “There is just no getting better from FASD. Even if one is challenged only a small amount, there are still challenges. People don't always see it, but it is there.”

Another participant describes her ambivalence about her son's school performance, while questioning herself as to whether he should even continue:

Never going to happen [high school graduation]. So where he is, in the special program, is just good for him. If he got a certificate from the high school the world would expect him to know stuff, right? So I like it better that he does not have it. He has tried to work, he tries hard. He works hard, but he can't last longer than a couple of days. So for him, keeping the expectation low helps him to cope. I wrestle with that.

All the participants in this study described their mounting frustration with their adolescents' behavior as a result of FASD. One participant said that she could spend hours teaching math to her daughter only to find that even though she grasped the concepts at the time, the next morning it was as though she had never heard it before: "You know how FASD works; the electrical impulses go the other way. When it hits a blank spot, it is like these kids never heard it before. Honestly, I just don't know. This is just so hard."

Another participant displayed her frustration as she described how her son gets frustrated and angry and acts that out:

Even if things are going along okay, right out of the blue he can get frustrated with something, something he was supposed to do or remember and he forgot, and then he thinks of it. He has big anger toward himself . . . no patience with anyone, really. He gets steamed up in a store if he has to wait, volatile.

Echoing this sentiment, and then going on to describe how short-term help or interventions do not really help at all, another participant says, "He needs lifelong support, not one-off stuff like short-term. FASD is different, it changes. That is what makes life so scary. What will the needs and demands be tomorrow?"

Describing the instability and chaotic home life as she attempts to raise her sixteen-year-old son, this same mother speaks of her worries and fears when her son loses his temper:

Yeah, let's say a different opinion can lead right down the path to a full-blown violent outburst from him--him storming out or worse, staying and just ransacking

the house. The best thing is that he storms out. But I am scared when that happens too, because I know someone will bear the brunt of his anger.

And when speaking of how her adolescent son tries to fit in with a peer group, another participant states the following:

I think he is just disconnected. Disconnected from me too, and he does not really know why he is not fitting in. He is the way he is because he has FASD. He cannot do things like other kids his age, because he does not have the skills or the wherewithal to figure it out. He didn't learn to tie his shoes until he was eleven. Before that it was Velcro. But, hey, I celebrated with him when he did tie them!

External factors outside the participants' control contributed to the challenges of mothering in rocky spaces. All the participants described experiences in trying to raise their adolescents with FASD that included some or all of the following: interactions with the police, problems in school, problems with trying to get jobs, and problems with friendships. One participant recalls the following,

He is on the streets mostly . . . the crack shacks. Some of those street gangs always take advantage of him. The police call me and tell me he got in a fight and is holding. There is always something. He is just 16.

As the children grew into their adolescent years, the problems mothers encountered became increasingly challenging. One participant spoke of her son's involvement in working as a drug dealer despite her repeated attempts to help him to understand that activity would likely lead him into trouble. She states, "Yes, he sold

drugs. These kids! I do not know if he cannot learn from other people's examples, or that he does not want to.”

Another participant shared her views on her son’s choice of friends, describing him as being too trusting and a poor judge of character:

He gravitated toward the low life. It does not matter where he is--he gravitates to low life. That is why I won't take him out of that support program because of the stress it causes at home. I have told him that it is up to him, who he wants to go with--the druggies or me.

When sharing her frustration with her daughter’s school failure and subsequent lying about it, one participant states the following,

She just got into trouble a lot at school and had to be in detention and then she just flunked out. It does bother me that she is that way. More than anything, she frustrated me, her lying about everything, and lying to my face.

Describing an experience where her daughter was arrested for shoplifting and placed on probation, the same participant notes, “. . . she just seems to walk into trouble even if she is not looking for it. She is short-tempered, frustrated easy, and follows whatever someone tells her to do.”

Realizing how little her daughter understood about consequences when shoplifting, this same mother expresses her frustration in these terms: “I don't think she puts two and two together there. She is headed for trouble, some might say. I think that is one thing I know in all of this.”

Another participant echoed her concerns over her teenage daughter's relationship with a boyfriend. Worried that her daughter is not a good judge of character, she states, "This relationship is headed for problems. They are drinking for sure, maybe more like drugs. She is with that boy day in and day out! Oh, I just know there is trouble there and I can't do much about that."

FASD has also been associated with negative stereotypes regarding Aboriginal peoples and alcohol abuse. Participants believe this prejudice is leveled directly at them. They frequently encountered barriers to services they felt were grounded in stereotypes and prejudice. One participant captures this sentiment in this dramatic example:

Natives are always stereotyped, even worse than anyone really. No one wants to hang around with us. At school way back, I remember there were black kids and they were cool, Filipino kids and they were okay, but bring home a native and whoa! Natives were just Indians, right? Not cool. It is not cool to be a native here. You know that man that left his baby to die on the ice a while back? Native, right? He was drinking and he took the kids out and he forgot them . . . left them, and that baby died on the ice or in the snow. I think the other one was okay, You know, right away it is said, "Native people can't look after children. See? That baby froze to death in a snow bank and her Daddy was too drunk to know it." White people forget their kid in the back seat of their minivan in the summer and leave the window sealed up tight and the kid dies. Suffocates, right? But you know what? What a shame. He is an exception, it was a tragic accident. The native guy is not the exception, he does the expected.

Another participant says:

So if you look like this [points to self], you're Aboriginal . . . it is probably [sic] that you have an addiction, likely housing issues; it is a package. And then you get the stuff that goes with the package. Welfare. Maybe you will lose your kids. Likely your kid will be FASD and that is just it. Normal for us. You know. I think we have lost our individuality as a people. There is no compassion; it is all about pigeonholing us into a group of services, and really, it does not matter what works or not, it is just the fact that you are getting a service.

In summary, *Mothering in Rocky Spaces* illustrated how participants have adapted to the behaviors and challenges presented to them on a daily basis by their adolescent children. These challenges include acting out and emotional volatility, the fact that FASD can be a hidden disability, difficult interactions with school and friends, the lack of hope for improvement, and dealing with external pressures such as the larger culture's preconceptions.

*Category: Coping with Uncertainty*

*Coping with Uncertainty* describes the activities that participants undertook to attempt to gain predictability in their day-to-day lives of raising adolescents with FASD. Uncertainty is experienced as a multidimensional process with characteristics of unpredictability, unfamiliarity, and inconsistency. In order to cope with uncertainty, participants developed household rules and safety routines. Some even redesigned their houses so that life would be more manageable.

Participants shared the view that mothering adolescents with FASD is not a linear process where growth and development (from the time the participants learned their children had FASD, to the present day) can be predicted from experiences of so-called “normal” children. One participant describes it best, saying, “There is no map.”

Another says, “If my kid had diabetes or something, I would get a fact sheet, right? There is no fact sheet for FASD. It is different for a two-year-old than a twelve-year-old and a fourteen-year-old. It changes all the time.”

When speaking of the need for predictability, one participant describes her early years mothering her FASD-affected son:

I think that . . . truly, I had trouble meeting his needs when he was a baby. I needed to know what the baby needed and I never could know that. Once he could talk, then I knew what was wrong easier. I thought when my baby cried, he was hungry, so every time he cried I fed him, but I never thought way back then that he needed a diaper change maybe or something. I came from a place where I tried to have predictability and I couldn't.

Coping with uncertainty demands a measure of ingenuity on the part of participants. One helpful strategy participants described was setting firm rules for their children's behavior. Although there were differences among individuals, all participants use this strategy as a way of coping with uncertainty. These rules came into play when the children were young, and as the children developed and matured, the rules shifted in response to new demands.

When speaking about how she had to do her weekly shopping with her three small children in tow, one participant described how she used rules to get through that activity, saying:

I devised this system where when you pull into that parking lot at the shopping mall you cut the motor of the car, you stop. And if the kids aren't quiet you tell them, "We are not getting out of this car until we are quiet, okay?" Then it gets quiet – then you go over the rules. Okay, what happens if you do this and this in the store? And so on; that worked pretty good for me. I needed to do it every time because they never remembered.

Another participant talks about how she established rules of behavior for her daughters for school nights: "The rules are the rules. Going to bed on school nights, doing homework, no smoking, that kind of thing."

When speaking of her need for rules around her adolescent son's behavior and her realization that she needs to incorporate some flexibility into her rule enforcement, one participant shares the following,

He does have to stick to the rules. I can't just have him totally out of control. I don't mean black-and-white-to-the-point-of-ridiculous rules, he would never be able to manage within that. I mean decency things. There are no rules, really, for FASD. People say we need to set rules for our families and I do that. But . . . geez, I don't want to make it so hard that he can't live here. I mean rules that are normal, like pick up your stuff, don't smoke in bed, don't have kids in when I am

not here and don't lie to me; if you did something, tell me. I will forgive him every time because I love him.

Not all participants had success with the rules they established, as their children did not always follow, understand, or remember these rules. One participant speaks of how she struggled to get her daughter to live by the household rules: “I try to get her to obey the rules of the house; she knows there are certain rules to follow, but it doesn't always work that way.”

Although she found it frustrating that her daughter did not stick to the rules, this participant made decisions about which rules were the most important to the smooth running of the household, and would then enforce those. Sometimes, however, enforcing a rule would result in a disagreement and anger and the best decision might be just to “let it go.” She states, “And so for me, the rules are important but I think you have to really choose those rules carefully, make them few, and pick the ones that count.”

One participant described how she remodeled her house to put in larger windows, allowing her to watch her children from all angles of the house when they were outside playing. The new windows helped her cope with the uncertainty of where her children were and what they were doing: “My policy has always been if you can foresee what is going to happen you can prevent a lot of it beforehand. Hence, this house has 24 feet of living room window. Sometimes even the dog would know when they were going to get into trouble out there.”

To help them cope with uncertainty, participants also sought information about their children's FASD. This information seeking often resulted in formal testing to make

a determination or diagnosis of FASD. Although a diagnosis paved the way for participants to receive assistance money for their children, it also brought the potential for damaging labeling for both the mothers and their children. Some participants sought testing readily, while others took longer to decide to have their child evaluated.

Eventually, however, all participants had their children tested for a diagnosis of FASD.

One participant describes her experience as follows:

I didn't want to test the girls, not at first; I knew there was something wrong, though. They didn't talk much, cried and had temper tantrums a lot. They are still a handful. I know FASD is pretty common at home; something we just get from what we do . . . I went to some groups with other mothers and we got to talking about stuff like kids and drinking . . . in the classes there. Then I knew I had to get them tested.

Another participant described her efforts in trying to obtain a firm diagnosis of FASD so her son could qualify for disability and have some means of future income. At the same time she was worried that having done that, her son would be stigmatized by society:

Teachers told me in school to test him. Here's the deal: if he was diagnosed with FASD there would be more help for him over the long run, but more ridicule from people. He might get more help, the right help, and he might stay in school. The sad part is, it is better to have ADD or ADHD: at least your mother did not drink. Because that is what people say.

Similarly, another participant notes, “And if you do not get the right testing and a proper diagnosis, you always struggle to get the services that are needed and the recognition of disability.”

All participants expressed worry about their adolescents’ futures, stemming mostly from their inability to predict a normal trajectory for them, such as graduation from high school, attending university, and securing employment and lasting relationships. One mother talked about how she felt conflicted about her hopes that her daughter would leave home and become independent, and yet worried that her daughter would never establish independence:

I want her to be independent. That is my goal. I don’t want her home until I am 85 or 95. And I have told her that. Any parent with a normal viewpoint on parenting wants their child to be independent, but I know my child.

And in another statement, the same mother reveals one of her specific worries: “She can’t even make toast. No way would I risk her being in a place with a stove and no supervision.”

At the time of this study, one teenager had graduated from high school and completed a course at a local community college, nine were enrolled in school in special education classes, and three had dropped out due to drug and alcohol problems. From the participants’ point of view, testing served to bring some certainty. With that certainty was the reassurance that with a formal diagnosis of FASD, there would be a way of obtaining financial aid. More than anything though, for participants, testing was mostly about

finding out for sure if their child had FASD. Acceptance of FASD helped them cope with uncertainty to some degree.

All participants had a source of income. Of the eight participants, one was employed in a home-based business and made what she referred to as a “decent” living. One other had employment and received minimum wages, barely putting her over the poverty line. All other participants received assistance from government programs, and as a result, lived close to or below the poverty line. Being able to provide for their families was a central and important issue for participants. All participants expressed worries about their children’s futures. As one participant asked, “What does the future hold for my daughter?”

In pondering that question, the same participant notes,

I think about the future lots and one day the light bulb went on for me. I am my Mom. My Mom never got out of poverty. She drinks, lives in a hut . . . I just think about my Mom and where she is, and I see me. I want a different future for my girls.

And with a tired sigh, one participant described a pressing worry that keeps her awake at night: “The reality for [daughter] is that she needs constant support from me. I think she always will need it. But I worry about what will happen to her when I am gone.”

In summary, participants developed approaches to assist them in *Coping with Uncertainty* to varying degrees; all participants are gaining predictability, familiarity, and consistency as they carry out their mothering roles. Since mothering adolescents with

FASD is a nonlinear process coping with uncertainty was a necessary adaptation for participants in this study.

*Category: Gaining Confidence*

*Gaining confidence* describes how participants obtain the skills and abilities they believe are necessary to be confident mothers. Confidence is defined as having belief in yourself and your abilities. Past experiences with destructive family relationships left participants believing that they had missed out on opportunities to learn mothering skills. Therefore, they were unsure about their own abilities to mother their children. In speaking about how this made her feel, one participant said, “I felt betrayed by my own mother.” This participant meant that she was angry with her own mother for leaving her and deserting her. She believed that if her mother had stayed and raised her, she herself would be a stronger, more capable mother.

Almost all the participants were raised in families where one or both parents (if present) had FASD, and five participants have FASD themselves. These experiences have significant effects on the participant’s lives, contributing to their lack of confidence to be what they referred to as “good mothers.” In telling her story, one participant described how she felt very unsure in her mothering role and how this eroded her confidence: “The nurse visited and I was on welfare too. My [social] worker said I was having trouble looking after them. I didn’t know what to do.”

Part of gaining confidence as mothers included learning from previous experiences, even if those experiences did not leave participants feeling proud of

themselves. In describing the circumstances that led to her daughters being taken into foster care, one participant says,

It was a long time ago. I got them back and kept them ever since. It was just for a break, I was having a hard time then . . . that is quite a while ago as the girls were just getting going in school.

This same participant admitted that her confidence in her mothering abilities was shattered by that experience. Slowly over time, she is regaining it. However, this participant viewed the continuing supervision by child protection workers as a vote of non-confidence in her mothering skills. She admitted that she learned from the experience and understood that her children required supervision; still, it was a devastating experience for her:

They will never really have trust in me as a mother, right? I failed once and I just get one chance. Now I will be watched forever, right? That is my world. One chance, and if you screw up it's a life sentence: watched forever.

Another participant described a visit with her family physician that served to reinforce her lack of confidence: "The doctor said, "There is absolutely nothing wrong with this child. Nothing." I was so exasperated and so tired--and I had twins two and a half years old at home. "Fine," I said to him. "Maybe look at it this way: maybe there is something wrong with me."

Furthermore, the lack of confidence allowed for intrusion of further self-doubt as the participants tried to develop necessary mothering skills, such as meal preparation. One participant was very frustrated with her inability to prepare meals for her family. She

told me that for her, having FASD made following a recipe awkward. Her inability to do math left her unable to follow the preparation instructions:

I can't follow a recipe to cook anything 'cause I can't do math and can't figure that out, measuring and stuff is not my thing. Frozen stuff and food from cans, now that I can do. I can bake a potato. My Mom would try to teach me to cook, she would say, "go cook something." I would try, but just get frustrated and give up.

Another participant described how her own experiences in foster care left her without a mother to learn from, saying, "I was in foster care for a while--not much learning about cooking, just getting by."

The same participant further described some of her frustration as she tried to learn the skills that could help her to become a more confident mother: "I'm frustrated. I have been coming here to this program myself for so long. Seven years and it makes me just feel stupid. I haven't learned much yet."

Despite the struggles to gain confidence, almost all participants were able to describe some of the successful strategies they now used that helped them gain confidence in mothering their adolescents with FASD. One participant talked about how she learned from the experience of teaching her son to cross the road safely:

And another thing these kids cannot get, is they cannot transfer the learning from one context to another very easily. I mean, like this: I teach him to look both ways before he crosses the road out front and he does it all the time. But when I take him somewhere else he just darts out, like at his Grandmother's house, two weeks

ago. She lives on a busy highway . . . he just knows that he wants to get across the street to the store and off he goes, across the street flying, no looking either way for traffic. It was like he never heard it before. This is what mothers need to know.

Another participant spoke of how she has developed a game out of helping her thirteen-year-old gather his clothes together to get dressed in the morning: “Well, I stay sequential . . . first we do this, and then we do that. This way he is able to be successful and that means a lot. I feel good about that.”

Additional comments offered by another participant illustrated how she realized just how her son learns best: he just needs a creative and patient approach:

Just understanding that they won't comprehend stuff as fast, like materials at school, like normal kids, I know I didn't either. But if you tell them they can do it, then they'll do it, just at a slower pace . . . and it is hard for me as a mother, 'cause I think, “My kid is delayed,” and I get impatient. And I think that is a major challenge and I think mothers should look at that and let the kids do stuff on their own and not push them. I needed to look at that differently, I think.

Another participant described how she maintained a quiet and peaceful home environment that she knows minimizes her son's anxiety:

Structure, consistency, a peaceful place at home for him to be relaxed: those are key. I try to really understand his hypersensitivity: if he is getting anxious, I discretely shut the environment down. That way I do not inflame the anxiety he is experiencing that often leads to a violent outburst. This calms him.

Through putting what they have learned into action, participants gained increased expertise in mothering skills and abilities. Even more importantly, they were able to share some of their success with other mothers in some of the learning environments they found themselves in together. One participant summed up her feelings of increased confidence by saying, “. . . our kids, if they make it, when they make it in this world, will make it solely because of the effort we put in as mothers and putting it all into them.”

As participants gained increased expertise they also gained confidence in their abilities to mother. One participant shared a rule she lived by: “. . . the one thing I know I will do is to tell my kids that they are of value and worth something--every day!”

In summary, gaining confidence meant learning from their past experiences and developing new skills to create successful strategies to mother their adolescents confidently. Participants believed they had missed out on opportunities to learn mothering skills and were unsure about their own abilities to mother their children. As participants gained increased expertise they also gained confidence in their abilities to mother.

### *Conceptualization of Adaptive Mothering*

*Adaptive Mothering* gives meaning to the unpredictable nature of mothering adolescents with FASD and provides insight into the skills mothers need to be successful. *Adaptive Mothering* is an iterative process that occurs throughout mothering in rocky spaces, to coping with uncertainty, to gaining confidence in their skills and abilities to mother. Mothers typically develop skills and abilities through mentoring from their own mothers or other significant mother figures.

For the mothers in this study, those mentoring opportunities were absent for a variety of reasons. Almost all of the participants were raised in families where one or both parents (if present) had FASD. Even more challenging, four of the participants have FASD themselves. Others were raised for a time in foster homes, where individualized mentoring and support did not occur. Despite this, participants undertook activities where they could learn skills and through these experiences, they gained confidence.

### Mothering from the Margins

*Mothering from the Margins* is the overarching cultural theme derived from these data. According to Spradley (1979), a cultural theme is tacit knowledge implied within a culture to interpret experiences, behaviors, and meaning in a cultural context. *Mothering from the Margins* unifies the exclusionary and isolating experiences of the participants and provides a vehicle for understanding and interpreting them (Spradley, 1979). Participants are living within a sociocultural context where as mothers, they are not connected to or integrated with mainstream society. Each of the two major themes is inextricably linked to the cultural theme of *Mothering from the Margins*.

All participants are influenced by their history as they mother in rocky spaces, cope with uncertainty, and gain confidence as mothers. *Mothering from the Margins* was implicit in all experiences of participants as they described how stereotypes and prejudice manifested in their daily lives as they mothered their adolescents with FASD. From the time that normalization of FASD was recognized as a factor that influenced not only their childhood experiences, but also their present-day mothering, participants were very much aware of being on the margins of mainstream mothering. The realization that they were

treated differently from others came to them in a variety of different ways. Yet the participants were able to adapt to the challenges and showed this strength in their mothering. They provided for their children as best they could under difficult circumstances, and often with limited resources.

Although clearly today their mothering is still lived out on the margins, a compelling story has been told where participants faced difficult circumstances in mothering their adolescents with FASD, yet showed determination, strength, and hope for the future. *Mothering from the Margins* is the overarching cultural theme that best depicts their lives.

#### Summary

Chapter V provided results of the data analysis along with a full description of the major themes derived from the data representing an abstracted level of analysis. Further theoretical analysis resulted in the development of an overarching cultural theme, described here as Mothering from the Margins, to convey how this sample of Aboriginal women raise their adolescents with FASD.

Chapter VI presents a discussion of the findings related to the research questions and presents the interpretive ethnographic theory. The chapter will include a discussion of implications for nursing, an identification of the limitations of the study and concluding remarks.

## CHAPTER VI: DISCUSSION AND CONCLUSION

Chapter VI presents a discussion of the interpretive ethnographic theory along with findings related to the research questions, their importance, and contributions to the literature. The chapter will include a discussion of implications of the research for nursing, an identification of the limitations of the study, and concluding remarks.

### SAY THESE WORDS

**“ The white man will teach your children to read  
printing, and to be like themselves”**

*Gilbert Sprout, 1868*

**Say Tseshaht, Hupacasath, Ahousaht,  
Nuu-Chan-Nulth.  
Say canoe, salmon,  
baskets made of spruce root, cedar.  
Say Potlach, feast.  
Say Reservation. Say tuberculosis. Smallpox. Alcohol.  
Say the children.  
Raised with the sacred,  
the ravens, the seasons of the moon,  
to honour the earth, the elders.  
Say residential school.  
The men who came in gunboats,  
to take the children.  
Say hunger. Say death.  
Say the dark things without names.  
Say these words.**

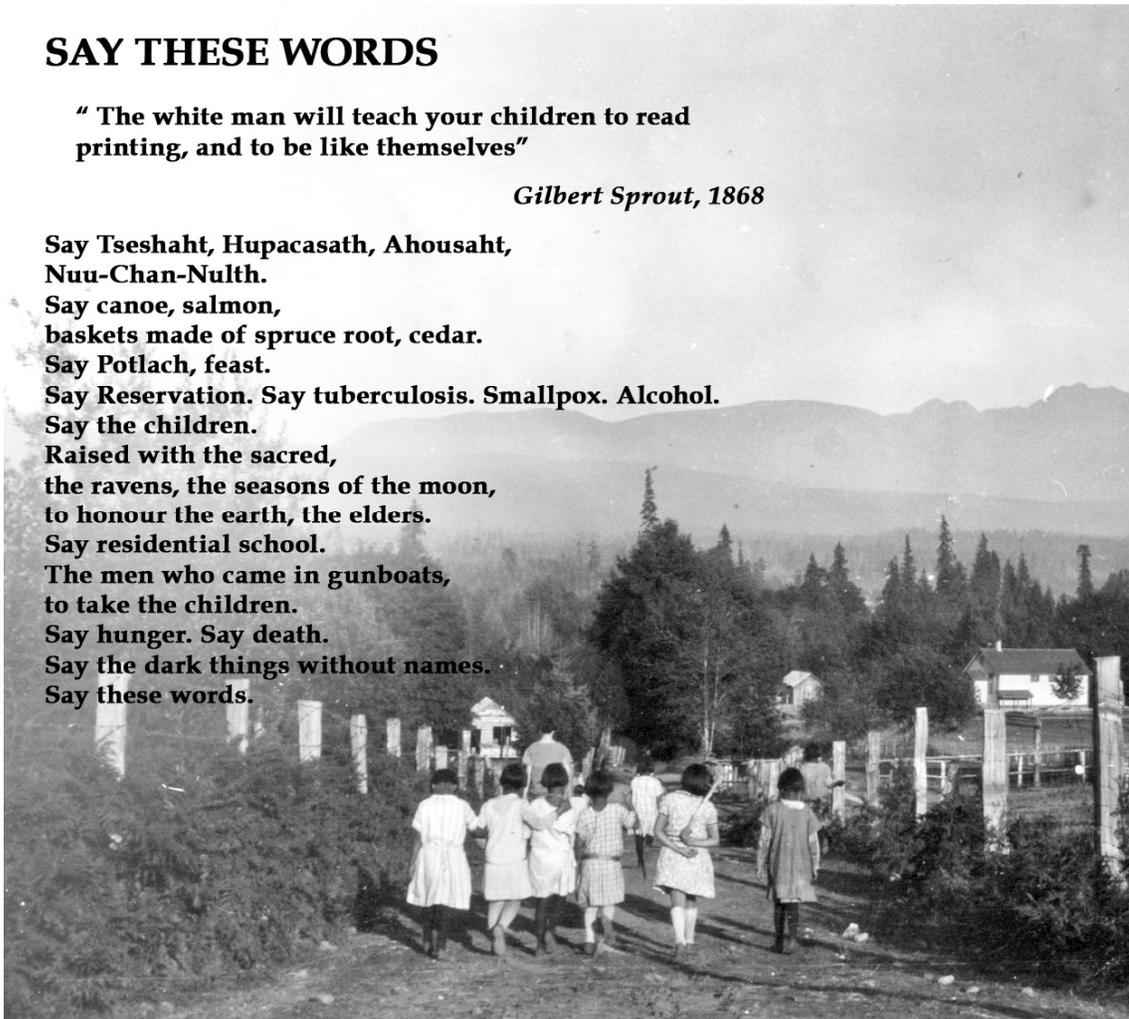


FIGURE 4: This Poem Captures the Negative Effects of Colonialism

As illustrated in Figure 4, (Wendy Morton, personal communication, June 8, 2008), Aboriginal people have faced many challenges, both past and present, as a result

of colonialism. The goal of this interpretive ethnography was to understand the beliefs and practices of Aboriginal mothers as they promote the well-being of their adolescents with FASD. Two research questions guided this inquiry, specifically: (1) how do Aboriginal mothers understand and describe FASD? and (2) how do Aboriginal mothers conceptualize and promote the well-being of their adolescent children who have FASD? The concepts of vulnerability, marginalization, and mothering conceptualized within the theoretical perspective of postcolonialism provided the organizing framework. The data were closely examined to determine how these concepts were manifested in the day-to-day lives of the study participants. I answered the research questions by bringing an interpretation of how these concepts influenced participants as they enacted their mothering role.

#### The Interpretive Theory – Mothering from the Margins

The interpretive theory derived from this research explains participants' beliefs and practices relating to mothering adolescents with FASD. Their mothering is lived daily from the margins and is framed within a postcolonial context of prejudice and stereotypical notions of Aboriginal motherhood. Because of the legacy of the residential school experience that impaired normative styles of parenting (Stout & Kipling, 2003), generations of Aboriginal people have grown up without opportunities to learn child-rearing skills. For study participants, this deficit was compounded by poverty, unemployment, isolation, and lack of education. Intergenerational patterns of destructive behaviors, most frequently alcohol abuse, influenced all participants. These behavioral patterns naturally spilled over into their mothering, thus perpetuating the mistakes made

by their own mothers. Despite this, study participants demonstrated ability in understanding and adapting to the challenges they faced. They grappled with uncertainty yet overtime, they gained confidence in their mothering skills.

As an interpretive theory, *Mothering from the Margins* is useful in understanding the everyday life of Aboriginal mothers raising adolescents with FASD. This theory provides a useful way for looking at the issues that define and structure the lives of Aboriginal mothers and was reflected in the lives of study participants. All participants in the study were pushed to the margins of society on the basis of their Aboriginal identity and their behavior. The resulting marginalization resulted in their increased vulnerability as they grappled with childrearing challenges. Mothering in ordinary circumstances is challenging. For study participants, it was not any one isolated event that solidified their position on the margins; it was a combination of both circumstances and history. Factors including historical trauma, destructive behaviors, and stigmatizing conditions such as FASD added layers of complexity to their mothering roles. Raising adolescents with FASD in these circumstances required an adaptive approach to mothering.

For the participants, FASD is viewed as normal; according to their accounts, having a child with FASD is not unusual. Many participants related that Aboriginal people are reluctant to talk about FASD and the behaviors that cause it because FASD reinforces negative stereotypes of Aboriginal women. This secretive approach hinders opportunities to illuminate the issues that exist between Aboriginal and non-Aboriginal people because the very information that might prove helpful remains unknown. Through negative stereotypes, images of Aboriginal motherhood remain linked to alcohol abuse

and inappropriate mothering. These images continue to be manifested in prejudices endured by participants, and only serve to widen the distance between Aboriginal and non-Aboriginal people. For example, when participants sought care in local emergency rooms they were always asked first if they had been drinking, as opposed to being asked the nature of their emergency. Browne et al. (2005) observed that assumed cultural characteristics (such as alcohol abuse, in this case) are projected onto all members of a group, resulting in actions driven by stereotype and prejudice. The results of this study reinforce Browne's observations and concerns.

My study findings support the observation by Flaskerud (1998) that many indigenous women are marginalized by virtue of their race. Because of their marginalized position, the participants do not have the opportunity to reject the negative stereotyping that defines them to outsiders. According to the participants, there are no opportunities for Aboriginal women to be heard. This interpretive theory brings a powerful voice to participants by providing explanations beyond race regarding the importance of understanding the context in which participants' mother and how this context perpetuates the incidence of FASD. By allowing participants to be heard, this theory sets them on the road to overcoming boundaries that have created assumptions about their mothering.

This theory contributes to the body of knowledge substantiating the need to reject damaging stereotypes and describe the strengths of Aboriginal mothers by offering new insights into their world. It makes visible the life experiences of Aboriginal mothers from the margins and in keeping with Anderson (2002), this allows greater understanding of the context of suffering of those we care for as nurses. Some participants still live with

the frightening experience of having child protection workers monitor their mothering skills. For participants who experienced it, having their children removed to foster care because of inappropriate mothering had a devastating impact. These mothers were often left wondering how they would be able to muster the skills and behaviors needed to have their children returned. Some were successful in meeting those goals; when their children were returned to their care, they were able to develop appropriate mothering skills. Others were not successful; their children were permanently removed from their care.

Currently in British Columbia (B.C.), an “Aboriginal child is about six times more likely to be taken into foster care than a non-Aboriginal child. Of all B.C. children who are in care, 51% are Aboriginal--yet Aboriginal people represent only about 8% of B.C.’s population” (Auditor General, 2008, p. 18). Disturbingly, this figure is rising. On average, Aboriginal children spend seven months longer in care than non-Aboriginal children (Auditor General, 2008). To make matters worse, Aboriginal children in foster care fare worse than non-Aboriginal children in care, experiencing “higher rates of illness, injury and death by all causes (including suicide); slower academic progress and a lower rate of high school graduation; and higher rates of incarceration and of eventual dependence on income assistance” (Auditor General, 2008, p. 18) Today there are more Aboriginal children in foster care than were ever in the repressive and harmful residential schools of the last century (personal communication, Prince George Aboriginal Health Center, 2008).

This interpretive theory, *Mothering from the Margins*, explains how marginalization contributes to the participants’ vulnerability. According to Shi and

Stevens (2005) a person's vulnerability status is determined by both individual characteristics and the environment in which the person lives, together with interactions within that context. For participants in this study, the interpretive theory offers an explanation for their increased vulnerability. For example, being marginalized to the edges of society contributes even further to isolating contexts within which participants live. The high rate of Aboriginal children in care reflects intergenerational patterns where isolating contexts and historical disadvantages experienced by Aboriginal people continue to manifest themselves today. Aboriginal children are still being born into this colonial legacy. Aboriginal mothers who have children with FASD face societal blame for consuming alcohol during pregnancy. They can relate to the stigmatizing effects of being on the receiving end of stereotypical caricatures of “the drunken squaw.”

The interpretive theory also adds strength to Hall's (1999) notion that resilience can result from experiences of marginalization, in that individuals have the capacity to develop durable strategies, supports, and skills that aid survival. Study participants talked about losing the opportunity to learn mothering skills from their own mothers. Their own experiences of mothering taught them what they know, and through a trial-and-error approach, they developed successful strategies, gaining confidence and implementing successful mothering skills.

The first major theme, *Intergenerational Patterns*, explicates how Aboriginal mothers understand and describe FASD. Study findings indicate that all the participants observed that they were at risk of passing to their own children and grandchildren behaviors they believed to be normal from their own childhood experiences. More than

half of the participants had adopted the unhealthy behaviors of their parents and grandparents, such as drinking alcohol during pregnancy, a root cause of FASD. The participants came to view drinking during pregnancy as normal and accepted behavior. This view appears rooted in their early childhood experiences, when they were raised in unhealthy families; families where they saw their own mothers (as well as other family members) abusing alcohol.

These study findings are consistent with the work of Braveheart (1999) who found that generational alcohol abuse among members of the Lakota Nation contributed to a lack of clarity around norms, such as not using alcohol during pregnancy. Further, these same tribal members reported that being raised in unhealthy families left them feeling inadequate and confused about their parenting roles. Braveheart (1999) further notes that the accumulation of trauma such as that experienced by participants in my study during early childhood, results in historical trauma not only during their lifetimes, but also across generations. It is through the stories and oral traditions of Aboriginal people that historical trauma is passed on to new generations; therefore, the burden of this trauma continues (Chamberlain, 2000; Dodgson & Struthers, 2005; Stout & Kipling, 2003).

Drinking alcohol contributed to the experiences of mothers in the study. Feelings of shame and guilt voiced by participants were often triggered by realizing that the alcohol they consumed during pregnancy resulted in their children's FASD. However, two participants who were adoptive mothers also expressed feelings of shame consistent with the participants who drank during pregnancy. Salmon (2007) suggested that while it

is a known fact that FASD is attributed to drinking alcohol during pregnancy, it is the denial or lack of consideration of the context in which it occurs that is most ingrained. This is why it is so challenging to disrupt the damaging intergenerational patterns.

Claes and Clifton (1998) note that many residential school survivors developed destructive behavior patterns in an attempt to cope with their trauma. These effects tend to ripple outwards to families, communities, and across generations (Stout & Kipling, 2003). Morrissette (1994) also described a relationship between residential school attendance and residual negative effects on parenting. Smith, Varcoe and Edwards (2005) note that the residential school experience has intergenerational impacts on parenting and turning around these impacts is necessary to improve future generations. Although participants in my study were not residential school survivors, they witnessed the destructive behaviors these survivors used to cope with their trauma. Study participants expressed how the normalization of such behaviors and feelings of shared trauma resulted in their taking up similar destructive behavior that was, in turn, viewed as acceptable.

The second major theme, *Adaptive Mothering*, describes how Aboriginal mothers conceptualize and promote the well-being of their adolescent children who have FASD. It explains how participants respond to the unpredictable needs of their adolescents in ever-changing environments by managing challenges, coping with uncertainty, and gaining confidence.

Study findings conceptualize how participants strive to meet society's expectations of motherhood, yet fall short of the mark. Participants spoke about the significant difficulties they experienced in raising their children, including challenges in

promoting their children's well-being, protecting their children from harm, and providing for their futures. Society's preconceptions and stereotypical notions of Aboriginal mothers have had a significant impact on how these mothers fared in this regard. This is corroborated by Krane and Davies (2007) in a study that focused on understanding mothering in the context of a shelter for battered women. Their findings indicated that even in such difficult circumstances, notions of motherhood are subject to idealized constructions, remaining elusive for many women in this context. For example, Krane and Davies (2007) stressed that the understanding of context along with the emotional complexities and challenges faced by these mothers is very important. Likewise, Nelms (2005) noted that society's altruistic images of stereotypical mothering are unrealistic and that women's desire to be "good mothers," even when faced with overwhelming challenges, is strong.

In my study, findings reinforce the assumption that postcolonial perspectives continue to shape how the larger society views Aboriginal mothers. These views consist of prejudicial beliefs that perpetuate negative attitudes and behaviors toward study participants as they struggle with raising their adolescents with FASD. Despite this, participants mustered incredible adaptability in their quest to promote the well-being of their children and their desire to be viewed as good mothers.

Findings from this study highlight the challenges of rearing adolescents with FASD and indicate that the experience is fraught with unpredictability and is at times frightening. Some participants' children were affected with FASD's full range of physical, mental, and emotional symptoms. For others, FASD remained a hidden

disability: the telltale physical characteristics were absent, leaving mothers to manage the emotional and mental effects of aberrant behavior that was viewed by others. Regardless, all study participants experienced what Nelson (2002) identified as being common to the experience of mothering “other than normal” children. For instance, becoming a mother of a disabled child involves recognizing the specific disability and understanding how to manage a mothering role that is different than expected. Nelson (2002) described how managing the many aspects of daily life in such a case was challenging; similarly, participants in my study expressed being overwhelmed at managing the challenges of childrearing. Although the process of acceptance/denial as identified by Nelson (2002) was not articulated in this study’s findings, it is an area that may be of interest for further research.

Findings also highlighted how frustrated participants became as they raised their FASD-affected adolescents. Oftentimes, these frustrations stemmed from that fact that their children were not able to develop positive social relationships, not able to fit in with other teens, exercised poor judgment in friendships, and performed poorly in school. Gardner (2000) found that those fostering children with FASD experienced many of the same frustrations as the participants in my study. For instance, most parents in Gardner’s (2000) study reported their adolescents had little understanding of the consequences of their behaviors or their impact on others, and shared similar worries about their teenagers’ lack of judgment.

In keeping with a postcolonial prejudicial view, the blame for children being born with FASD is placed squarely on the shoulders of mothers. Gardner (2000) found that

even foster parents expressed anger toward birth mothers for having harmed their unborn children. Salmon (2007) suggested the notion that FASD is associated only with prenatal alcohol exposure is a common misconception. Rather, alcohol consumption during pregnancy is associated with numerous factors, not the least of which are abuse, lower socioeconomic status, and aspects of colonialism (Salmon, 2007).

Another important study finding illustrated the challenges participants faced when trying to gain predictability, familiarity, and consistency in mothering their adolescents. All participants described the importance of developing approaches that could assist them in coping with uncertainty; setting rules for their adolescents was a common approach. This is supported as an effective technique in earlier findings of Wuest (2000) who found that mothers implemented strategies such as setting ground rules in order to manage family care demands.

My study had findings similar to those of other studies, where mothers found it very helpful to obtain information about their child's illnesses so they could assume an advocacy role for their child's health (May, 1997; MacDonald, 1996). This information helped mothers to cope with the uncertainty inherent in raising their children, because it gave them an active role to play in managing their children's conditions. Conversely, participants in my study described how frustrating it was to try and obtain information from health professionals, and how difficult it was to obtain accurate diagnoses of FASD for their children. Participants were not viewed as part of the care team. According to the participants, they encountered systemic barriers such as long waitlists and biased social workers that made getting a timely diagnosis extremely difficult. Moreover, they were

afraid of perpetuating negative stereotypes for their children; for example, “If you have FASD, your mother is a drunk.”

Aside from their uncertainty in mothering their children, participants described how they also gained confidence from those experiences. Participants exhibited numerous strengths, such as developing routines and protocols for their children to aid them in becoming successful in day-to-day activities; for example, getting dressed on their own, riding the school bus, being wary of strangers. They discovered best approaches to capitalize on their adolescents’ learning styles and through such activities, developed an understanding of how best to support and guide their children in completing schoolwork. Participants showed courage and insight during the interviews when they admitted that they did not know or were not comfortable with their mothering skills. In their own family histories, admissions of not being able to mother one’s children had led to devastating consequences, such as residential schools.

In summary, when woven together, the two themes of *Intergenerational Patterns* and *Adaptive Mothering* unify the experiences of mothering adolescents with FASD and represent my interpretations of the participant’s lives, as explained in the theory I have entitled *Mothering from the Margins*. Beyond this, Aboriginal mothers of adolescents with FASD continue to experience societal blame for consuming alcohol during pregnancy. This study extends the knowledge of how this blaming experience plays out in both the lives of mothers and their children; moreover, the findings actually begin to debunk the stereotypical myth that Aboriginal mothers are not good mothers. In fact, the findings from this study demonstrate how, despite all the difficulties and challenges they

face, study participants have demonstrated adaptability and confidence in their mothering role.

#### Implications for Nursing

The knowledge generated from this research has implications for nursing research, theory, and practice.

#### *Implications for Nursing Research*

This interpretive ethnography encompasses a postcolonial theoretical framework and provides a foundational study that will inform future research with Canadian Aboriginal mothers. Further research undertaken with this population must always include the work of building trusting relationships, and the recognition that the women who participate in the study are the experts. In addition, researchers are responsible for ensuring that findings are shared with participants and policy-makers in order to help illuminate the issues and remove the oppressive systems that allow FASD to destroy the lives of children and mothers.

The interpretive theory will lead to further investigations into gaining a better understanding of Aboriginal mothers as they raise their children. From this vantage point, similar topics could be explored with other indigenous populations. As a caution, the goal of such research should be aimed toward “promoting ways by which differences are valued, diversity is honored, and an understanding of behaviors and responses from within the cultural heritage is fostered rather than adding to further marginalization of Aboriginal women” (Meleis & Im, 1999).

Findings from this study suggest that critical theories such as post-colonialism generate nursing knowledge about raising children with disabilities and deepen the understanding of challenges mothers face as they raise their adolescents under difficult circumstances. This research has also provided the basis for further studies to focus on screening tools for specific and early detection of FASD, so as to create opportunities for earlier interventions for mothers in similar circumstances. In addition, this study provided evidence that there are specific strategies mothers use to manage their adolescents' behaviors; these strategies and the strengths of mothers must be investigated further. Research focused on developing these strengths could be based in the development and testing of culturally competent strength-based interventions that could lead to the development of further skill building in parenting adolescents with FASD. Finally, and most importantly, understanding the context of mothering for Aboriginal mothers provides important information for researchers to consider when doing research.

#### *Implications for Nursing Theory*

The interpretive theory *Mothering from the Margins* explains how Aboriginal mothers raise their adolescent children who have FASD. Post-colonial theories provide a viewpoint that will encourage thinking about these situations differently. The theory provides a perspective that enables nurses to view mothers with adolescents affected by FASD in an all-encompassing manner, and also has applicability and transferability for other similar studies, especially those with Aboriginal peoples. By acknowledging their position within the sociocultural context, this interpretive theory also provides a

foundation for further development of interventions focused specifically on Aboriginal mothers.

### *Implications for Nursing Practice*

On a practice level, this study provides a theory that explains what it is like for Aboriginal mothers to raise teenagers who have FASD, what their struggles are, how they meet challenges, what is helpful, and what is not. Understanding these concerns forms a basis for good clinical practice when dealing with such situations. Similarly, this study is a step towards developing nursing interventions that could prove useful for mothers raising adolescents with FASD. Practical strategies such as those identified by participants can be applied to everyday situations. These strategies, translated into nursing interventions, can be shared with other mothers as they manage the challenges they encounter in raising their children. Through this understanding, nurses can help mothers anticipate and be prepared for the challenges they are likely to encounter in childrearing. This anticipatory guidance will contribute to the mothers' ability to manage childrearing challenges, resulting in improved overall health for their children.

Finally, nurses are well positioned within the health care system to take a leadership role in working to reduce health disparities between dominant cultures and marginalized Aboriginal women. By showing leadership in developing culturally competent care, structures, and policies, nurses can lead by example to make a difference in Aboriginal mothers' experiences with the health care system. Furthermore, nurses hold a responsibility for advocating on behalf of individuals and diverse communities particularly when faced with practice situations where prejudice and negative

stereotypical behavior is exhibited. Again, using a post-colonial framework to approach clinical practice expands the repertoire of interventions available to the nurse. Practice is not limited to administering developmental tests and counseling; rather, nursing interventions such as pinpointing the effects of colonialism and lobbying for change in the system must occur at the macro level.

This section presented the interpretive theory that was derived from this study. In addition, this section presented the integration of the literature, linkages to theoretical perspectives, and the implications for nursing research, theory, and practice. The next and final section will present the limitations of the study and concluding remarks.

#### Limitations of the Study

The most significant limitation of this research was the length of time required to build trusting relationships with potential participants. Aboriginal mothers raising adolescents with FASD are members of a vulnerable population, and accessing the population presented challenges. I had developed a trusting relationship with a local agency where Aboriginal mothers gathered, and once I met with potential participants and they got to know me, they willingly shared their stories and encouraged others they knew to participate. This study was also limited by the geographical boundaries from which the sample was drawn. If I had expanded the boundaries to include the entire north-west area of the province, there might have been additional recruitment opportunities. However, given time and travel limitations, this was not feasible.

### Conclusions and Summary

This study used an interpretive ethnographic method to gain an understanding of the beliefs and practices of Aboriginal mothers as they promoted the well-being of their adolescent children who have FASD. The interpretive theory *Mothering from the Margins* advances the current understanding of how Aboriginal mothers struggle to promote the well-being of their adolescent children with FASD and how they interpreted and responded to their adolescents' FASD. This theory makes a significant contribution to advance science and our current understanding of Aboriginal mothers in northern British Columbia raising adolescents with FASD.

APPENDIX A: HUMAN SUBJECTS APPROVAL

THE UNIVERSITY OF  
**ARIZONA**  
 TUCSON ARIZONA

Human Subjects Protection Program

1235 N. Mountain Avenue  
 P.O. Box 245137  
 Tucson, AZ 85724-5137  
 (520) 626-6721  
<http://www.irb.arizona.edu>

Mary Suzanne Johnston, BN, MN  
 Advisor: Joyceen Boyle, BS, MPH, PhD  
 Nursing  
 P.O. Box 210203

July 17, 2007

BSC: B07.256 NORTHERN BRITISH COLUMBIAN FIRST NATION MOTHERS: RAISING ADOLESCENTS WITH FETAL ALCOHOL SPECTRUM DISORDER

Dear Mary Suzanne Johnston:

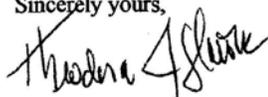
We received your research proposal as cited above. The procedures to be followed in this study pose no more than minimal risk to participating subjects and have been reviewed by the Institutional Review Board (IRB) through an Expedited Review procedure as cited in the regulations issued by the U.S. Department of Health and Human Services [45 CFR Part 46.110(b)(1)] based on their inclusion under *research categories 6 & 7*. As this is not a treatment intervention study, the IRB has waived the statement of Alternative Treatments in the consent form as allowed by 45 CFR 46.116(d)(2). Although full Committee review is not required, the committee will be informed of the approval of this project. This project is approved with an **expiration date of 17 July 2008**. Please make copies of the attached IRB stamped consent documents to consent your subjects.

The Institutional Review Board (IRB) of the University of Arizona has a current *Federalwide Assurance of compliance, FWA00004218*, which is on file with the Department of Health and Human Services and covers this activity.

Approval is granted with the understanding that no further changes or additions will be made to the procedures followed without the knowledge and approval of the Human Subjects Committee (IRB) and your College or Departmental Review Committee. Any research related physical or psychological harm to any subject must also be reported to each committee.

A university policy requires that all signed subject consent forms be kept in a permanent file in an area designated for that purpose by the Department Head or comparable authority. This will assure their accessibility in the event that university officials require the information and the principal investigator is unavailable for some reason.

Sincerely yours,



Theodore J. Glatke, Ph.D.  
 Chair, Social and Behavioral Sciences Human Subjects Committee

TJG/rkd  
 Cc: Departmental/College Review Committee



Human Subjects  
Protection Program

1235 N. Mountain Ave.  
P.O. Box 245137  
Tucson, AZ 85724-5137  
Tel: (520) 626-6721  
<http://www.irb.arizona.edu>

01 May 2008

Mary Suzanne Johnston, BN, MN  
Advisor: Joyceen Boyle, BS, MPH, PhD  
Nursing  
PO Box 210203

RE: **PROJECT NO. 07-0537-02** NORTHERN BRITISH COLUMBIAN ABORIGINAL  
MOTHERS: RAISING ADOLESCENTS WITH FETAL ALCOHOL SPECTRUM DISORDER  
[NEW TITLE]

Dear Mary Suzanne Johnston:

We received your 25 March 2008 Request for Amendment Form [received 04/04/08] and accompanying revised Informed Consent Form and recruitment flyer for the above referenced project. The purpose of the amendment is to change the project title from NORTHERN BRITISH COLUMBIAN FIRST NATION MOTHERS: RAISING ADOLESCENTS WITH FETAL ALCOHOL SPECTRUM DISORDER to NORTHERN BRITISH COLUMBIAN ABORIGINAL MOTHERS: RAISING ADOLESCENTS WITH FETAL ALCOHOL SPECTRUM DISORDER; and to subsequently revise the consenting document and recruitment flyer to match this change. Approval for this change is granted effective 01 May 2008 and reflects the current expiration date of **17 July 2008**.

The Institutional Review Board (IRB) of the University of Arizona has a current *Federalwide Assurance* of compliance, *FWA00004218*, which is on file with Department of Health and Human Services and cover this activity.

Approval is granted with the understanding that no further changes or additions will be made either to the procedures followed or the consent form(s) used (copies of which we have on file) without the knowledge and approval of the Institutional Review Board. Any research related physical or psychological harm to any subject must also be reported to the appropriate committee.

A university policy requires that all signed subject consent forms be kept in a permanent file in an area designated for that purpose by the Department Head or comparable authority. This will assure their accessibility in the event that university officials require the information and the principal investigator is unavailable for some reason.

Sincerely,

Elaine G. Jones, PhD, RN, FNAP  
Chair, Social and Behavioral Sciences Committee  
UA Institutional Review Board

EGJ:maa





Human Subjects  
Protection Program

1235 N. Mountain Ave.  
P.O. Box 245137  
Tucson, AZ 85724-5137  
Tel: (520) 626-6721  
<http://irb.arizona.edu>

### Continuing Review Determination

**Investigator:** Mary Suzanne Johnston

**Project No. :** 07-0537-02 (Previously: B07.256)

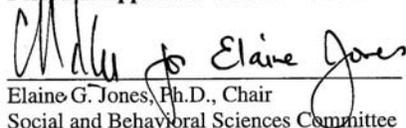
**Project Title:** Northern British Columbian First Nation Mothers: Raising Adolescents with Fetal Alcohol Spectrum Disorder

Project Status	
<input checked="" type="checkbox"/> Enrollment in Progress or Still Planned	<input type="checkbox"/> Data Analysis Only
<input type="checkbox"/> Enrollment Closed: study procedure/intervention ongoing	<input type="checkbox"/> Concluded
<input type="checkbox"/> Enrollment Closed: follow-up only	<input type="checkbox"/> Study Not Begun

**IRB Comments:** N/A

Documents Approved Concurrently:	Documents Reviewed Concurrently:
<input type="checkbox"/> N/A	<input checked="" type="checkbox"/> N/A
<input checked="" type="checkbox"/> Consenting Instruments: Consent Form (vrs. date: 5/1/08) Re-consent: <input type="checkbox"/> All <input type="checkbox"/> Current Only <input checked="" type="checkbox"/> Not Required	<input type="checkbox"/> Investigator's Brochure
<input type="checkbox"/> Protocol Amendments	<input type="checkbox"/> Progress Reports
<input type="checkbox"/> Protocol	<input type="checkbox"/> Study Related Problems
<input checked="" type="checkbox"/> VOTF signed 5/16/08	<input type="checkbox"/> Protocol Deviation
<input type="checkbox"/> Other:	<input type="checkbox"/> Other

**Period of Approval:** 7/17/08—7/17/09

  
Elaine G. Jones, Ph.D., Chair  
Social and Behavioral Sciences Committee

Expedited Review  
 Full Committee Review  
 Facilitated Review  
Date Reviewed: 6/27/08

Arizona's First University – Since 1885



**Reminder:** Continuing Review materials should be submitted 30 – 45 days in advance of the current expiration date to obtain re-approval (projects may be concluded or withdrawn at any time using the forms available at [www.irb.arizona.edu](http://www.irb.arizona.edu)).

APPENDIX B: PARTICIPANT CONSENT FORM

APPROVED BY UNIVERSITY OF AZ IR  
 THIS STAMP MUST APPEAR ON ALL  
 DOCUMENTS USED TO CONSENT SUBJECTS  
 DATE: 7-17-07 EXPIRATION: 7-17-08

## INFORMED CONSENT FORM

### NORTHERN BRITISH COLUMBIAN FIRST NATION MOTHERS: RAISING ADOLESCENTS WITH FETAL ALCOHOL SPECTRUM DISORDER

#### **Introduction**

You are being invited to take part in a research study. The information in this form is provided to help you decide whether to take part. Study personnel will be available to answer your questions and provide additional information. If you decide to take part in the study, you will be asked to sign this consent form. A copy of this form will be given to you.

#### **What is the purpose of this research study?**

The major goal of this interpretive ethnography is to gain an understanding of the beliefs and practices of First Nation (FN) mothers as they promote the well-being of their adolescent children who have Fetal Alcohol Spectrum Disorder (FASD). This study seeks to provide an understanding of how these particular FN mothers interpreted and responded to their adolescent's FASD. It is an attempt to affirm FN mothers experiences, to hear them tell the stories of themselves and their children.

#### **Why are you being asked to participate?**

You are being invited to participate because you are an English speaking First Nation woman between the ages of 30 and 45 and have experience mothering one or more adolescent children between the ages of 14 and 18 who have FASD. You may be willing to talk about your experiences in raising children with FASD.

#### **How many people will be asked to participate in this study?**

Approximately 10 - 12 persons will be asked to participate in this study.

#### **What will happen during this study?**

We will meet four times. The first meeting is set so that we can get to know one another a little. I will use that time to explain the study and obtain your consent and you will be asked to fill out some general information about yourself and your child. We will use this time to schedule our first, in a series of three meetings where I will interview you. Each of these interview meetings will be a little over an hour long.

During these interview meetings I will focus on gathering information about your health beliefs, practices, challenges, and childrearing experiences. The final interview will focus on filling any gaps, clarifying previously obtained information, and giving you the chance to add any final thoughts.

#### **How long will I be in this study?**

You will be enrolled in the study for about three months time in order to allow for the researcher to complete the three scheduled interviews. Your participation will take about 4 hours of your personal time.

**Are there any risks to me?**

The things that you will be doing have minimal risk. Although I have tried to avoid risks, you may feel that some questions I ask will be stressful or upsetting. If this occurs, you can stop participating immediately. I will provide you with contact information for individuals who may be able to help you with these problems.

**Are there any benefits to me?**

There are no direct benefits to you, however, you will have an opportunity to share your story of childrearing and through that process may discover some of the effective approaches you have found that might be useful to others. You will have the opportunity to discuss your traditional approaches and your mothering stories. Furthermore your participation will contribute to the development of nursing interventions that may help other mothers to manage challenges they encounter in raising children with FASD.

This study will enable nurses to gain understanding of challenges from your viewpoint to enable nurses and other health care providers to anticipate and understand client behavior and to plan care that is as congruent as possible with already established values and lifestyles.

**Will there be any costs to me?**

Aside from your time, there are no costs to you for taking part in the study.

**Will I be paid to participate in the study?**

No.

**Will audio recordings be made of me during the study?**

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**Your Signature**

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\_\_\_\_\_  
Name (Printed)

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date signed

**Statement by person obtaining consent**

I certify that I have explained the research study to the person who has agreed to participate, and that he or she has been informed of the purpose, the procedures, the possible risks and potential benefits associated with participation in this study. Any questions raised have been answered to the participant's satisfaction.

Mary Suzanne Johnston  
Name of study personnel

\_\_\_\_\_  
Study personnel Signature

\_\_\_\_\_  
Date signed

APPROVED BY UNIVERSITY OF AZ IRB  
 THIS STAMP MUST APPEAR ON ALL  
 DOCUMENTS USED TO CONSENT SUBJECTS.  
 DATE: 5/1/08 EXPIRATION: 7/17/08

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## INFORMED CONSENT FORM

### NORTHERN BRITISH COLUMBIAN ABORIGINAL MOTHERS: RAISING ADOLESCENTS WITH FETAL ALCOHOL SPECTRUM DISORDER

#### **Introduction**

You are being invited to take part in a research study. The information in this form is provided to help you decide whether to take part. Study personnel will be available to answer your questions and provide additional information. If you decide to take part in the study, you will be asked to sign this consent form. A copy of this form will be given to you.

#### **What is the purpose of this research study?**

The major goal of this interpretive ethnography is to gain an understanding of the beliefs and practices of Aboriginal mothers as they promote the well-being of their adolescent children who have Fetal Alcohol Spectrum Disorder (FASD). This study seeks to provide an understanding of how these particular Aboriginal mothers interpreted and responded to their adolescent's FASD. It is an attempt to affirm Aboriginal mothers' experiences, to hear them tell the stories of themselves and their children.

#### **Why are you being asked to participate?**

You are being invited to participate because you are an English speaking Aboriginal woman between the ages of 30 and 45 and have experience mothering one or more adolescent children between the ages of 14 and 18 who have FASD. You may be willing to talk about your experiences in raising children with FASD.

#### **How many people will be asked to participate in this study?**

Approximately 10 - 12 persons will be asked to participate in this study.

#### **What will happen during this study?**

We will meet four times. The first meeting is set so that we can get to know one another a little. I will use that time to explain the study and obtain your consent and you will be asked to fill out some general information about yourself and your child. We will use this time to schedule our first, in a series of three meetings where I will interview you. Each of these interview meetings will be a little over an hour long.

During these interview meetings I will focus on gathering information about your health beliefs, practices, challenges, and childrearing experiences. The final interview will focus on filling any gaps, clarifying previously obtained information, and giving you the chance to add any final thoughts.

#### **How long will I be in this study?**

You will be enrolled in the study for about three months time in order to allow for the researcher to complete the three scheduled interviews. Your participation will take about 4 hours of your personal time.

**Are there any risks to me?**

The things that you will be doing have minimal risk. Although I have tried to avoid risks, you may feel that some questions I ask will be stressful or upsetting. If this occurs, you can stop participating immediately. I will provide you with contact information for individuals who may be able to help you with these problems.

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This study will enable nurses to gain understanding of challenges from your viewpoint to enable nurses and other health care providers to anticipate and understand client behavior and to plan care that is as congruent as possible with already established values and lifestyles.

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Name (Printed)

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Name of study personnel

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 DATE: 7/17/08 EXPIRATION: 7/17/09

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\_\_\_\_\_  
Name (Printed)

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date signed

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Mary Suzanne Johnston  
Name of study personnel

\_\_\_\_\_  
Study personnel Signature

\_\_\_\_\_  
Date signed

APPENDIX C: INTERVIEW GUIDE

## PART I

Date of Birth MM\_\_/DD\_\_ /YEAR\_\_\_\_\_

Education     High school Diploma  
 Community College Diploma \_\_\_\_\_  
 University Degree \_\_\_\_\_  
Highest grade completed in school? \_\_\_\_\_

Income Level  Less than \$10,000.00  
 \$10,000.00 – \$19,000.00  
 \$20,000.00 – \$29,000.00  
 \$30,000.00 – \$39,000.00  
 \$40,000.00 – \$49,000.00  
 Greater than \$50,000.00

Gender of teen     Female  Male

Birth date of teen \_\_\_\_\_

Does your teen attend school?  Yes  No Completed grade \_\_\_\_\_?

Does anyone in your immediate family have FASD?

- Yes, if yes, who? \_\_\_\_\_
- No
- Don't know

Have you been told that you have FASD? If yes, by whom? \_\_\_\_\_

- Yes
- No
- Don't know

Do or did either of your parents have FASD?

- Yes
- No
- Don't know

## PART II

I would like to ask you some questions about FASD and teenagers. Please remember that your responses are completely confidential and that you may indicate if there are any questions you do not wish to answer.

1. Where did you first hear about FASD?
2. How did you find out your child had FASD? What was that process like?
3. Can you tell me about some of your difficulties with your son/daughter? What did you do to manage these?

### PART III

I would like to ask you some further questions about the challenges you face in raising your teenagers. Please remember that your responses are completely confidential and that you may indicate if there are any questions you do not wish to answer.

1. What are some of the things you do to make sure your teen stays healthy? Can you describe any special activities that you carry out?
2. What are your traditional cultural beliefs about health?
3. Can you tell me about some of the ways you teach your teenager about your history and culture?

#### PART IV

I would like to ask you some further questions about the challenges you face in raising your teenagers. Please remember that your responses are completely confidential and that you may indicate if there are any questions you do not wish to answer.

1. Tell me about your average day with your teen.
2. What special challenges do you think you face raising a child with FASD?
3. Teens who are FASD often have a hard time thinking clearly or recognizing their symptoms. What is it like for you and your teen?
4. A teen with FASD might not be able to function at all in daily activities. Can you tell me about an instance that really stands out in your mind?
5. Suppose I was present with you when your teen had an angry outburst? What would I see going on at that time?
6. Tell me about a time when your teenager asked questions about sexual behaviors?

APPENDIX D: RECRUITMENT POSTER

Suzanne Johnston, MN, RN, is a nurse who is completing a research project for school. She is interested in interviewing mothers of teenagers who have Fetal Alcohol Spectrum Disorder (FASD) about how they use traditional and current cultural beliefs and practices to promote the well-being of their children.

If you are:

- Aboriginal
- Female
- English Speaking
- 30 – 45 years old
- Have at least one teenager with FASD

Please ask about being a part of the study.

The interviews can be done at the Center or in your own home.

If you would like to take part in this study please contact Suzanne Johnston 250 961 9805

THANK YOU

APPENDIX E: CODEBOOK

## Codebook

1. ABUSE Refers to instances where a mother describes history of abuse; this can be physical, emotional or sexual.
2. ACADACHIEV Refers to academic achievement and describes the educational experiences of adolescents.
3. ACCBEHAVIO Refers to acceptable behavior where something, such as drinking alcohol, becomes a norm or expectation of a group or members of a community. In this case, it is part of normal activity to drink while pregnant. It is not discouraged within a group.
4. ACTIVITIME Refers to the present day-activities that a mother carried out in the past, as well as in the here and now, to manage children's behaviors. This includes the moment when mothers learned (were told) of the diagnosis of FASD.
5. ADDADHD Refers to Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder and suggests a range of behaviors generally associated with such a disorder.
6. ADOLLEARN Refers to adolescent learning, where the mother describes how the adolescent learns, how they best comprehend subject matter in school, as well as how they learn and begin to understand how to carry out other activities, such as banking, grocery shopping, and budgeting.
7. ADOPTION Refers to the legal act of permanently placing a child with a parent or parents other than the birth (or "biological") parents.
8. AGGRESSION Refers to aggression, particularly in instances where the adolescents talk about losing their tempers and/or threatening to hurt someone. It also includes the mothers' perception of why that aggression manifests itself and of some of the triggers, such as the context of the school learning environment, relentless teasing, or overstimulation.
9. ALCOHOLISM Refers to alcoholism as the abuse of alcohol and/or dependency on alcohol.
10. ANIMALS Refers to the pets living within the family; can include both domestic and farm animals. In particular, it refers to relationships between these animals and the FASD adolescents.
11. BEABORIGIN Refers to being Aboriginal and how the beliefs that one has are derived from cultural experiences – these can be positive or negative. Includes

how these beliefs may have influenced a mother's approach to child rearing practices.

12. **BLAMING** Refers to considerations of blame placed on birth mothers for drinking alcohol during pregnancy.
13. **BULLYING** Refers to instances where someone upsets or creates a risk to another person's health and safety--either psychologically or physically--or their property, reputation or social acceptance, on more than one occasion. Often happens within the context of school as adolescents try to fit in with mainstream classmates.
14. **CHALLADL** Refers to the challenges for FASD adolescents that are inherent in carrying out the activities of daily living, such as include cleaning, cooking, hygiene, caring for oneself, and general household duties like cleaning a room and making a bed. The challenges arise as expectations to carry out these activities are placed upon them by others; these are not challenges the adolescents necessarily see.
15. **CHALLREAR** Refers to the challenges mothers face in childrearing. This code conjures up the whole realm of challenges from infancy onward. Transitions from child to adolescence are also included, as well as how mothers attempt to manage the numerous challenges that are brought to bear on their skills by adolescents with FASD.
16. **CHILDACCID** Refers to childhood accidents that normally befall children during growth and development. Sometimes these accidents and resultant injuries can be misconstrued by authorities as being related to potential abuse or poor mothering. Sometimes this results in fear of children being apprehended by authorities.
17. **CHILDACTIV** Refers to those childhood activities that a parent does with children, such as reading together, playing with pets, doing household chores, baking cookies, etc. These activities are often designed to lay the groundwork for the development of life skills. If a mother is affected by FASD, these activities take on additional meaning in that mothers with FASD often struggle with these activities themselves.
18. **CHILDHOEXP** Refers to the childhood experiences the mother has had in her own life, as far back as she can remember. Often these experiences are relived in the lives of their children and mothers reflect on these experiences as being similar to their own. Mothers have commented that there has been little to no exposure to strong mothering for them throughout their lives, due to a variety of circumstances, such as foster care).

19. COMMUNUCAT Refers to communication; specifically, the conversations that a parent has with a child in order to convey a message and to engage in dialogue around a particular topic area. This may encompass conversation about how a behavior might be expected in certain circumstances. Often it is directed to teaching socially acceptable behaviors.
20. COMPLEXRE Refers to how participants' relationships have a detrimental effect on their well-being and contribute to their further emotional injury. Relationships among family members are problems shared by all participants, but more importantly, the relationship between mother and child can be painful and can contribute to suffering for both.
21. CONSEQUENC Refers to the consequences that include actions or disciplines resulting from misbehavior on the part of an adolescent. Consequences can be delivered by the mother or teachers or other authority figures.
22. CONSISTENC Refers to consistency as a desired approach in developing interventions that parents utilize to promote the wellbeing of the child.
23. DEMOGINFO Refers to participant's demographic information.
24. DEPRESSINT Refers to the steps that a mother takes to help her to improve her well-being and mood when she is feeling depressed.
25. DEPRESSION Refers to feeling "down in the dumps," sad, loss of energy (not formally diagnosed).
26. DEPSYMPATOM Refers to descriptions of the signs and symptoms that a mother describes relating to her depression, and gives an idea of root causes.
27. DISABILITY Refers to disability resulting from FASD and the experience of qualifying for and receiving disability payment (a means of future financial support).
28. DISCIPLIN Refers to discipline activities undertaken by a parent(s) to correct a behavior that is not acceptable.
29. DRINKINGBE Refers to alcohol-drinking behaviors while pregnant.
30. EMPLOYMENT Refers to employment as the formal work the mother does to earn a living.

31. EXPECTATIO Refers to the expectation that is generally accepted within a community or group that it is more likely than not that a mother will have a child that has FASD; a norm.
32. FAMILYDYN Refers to family dynamics among and between family members. This includes relationships with siblings, parents, and step-relatives, and how those dynamics can promote the well-being of the mother, or be disabling and contribute to negative behaviors such as drinking alcohol or taking drugs.
33. FAMILYRELA Refers to family relationships that contribute to the overall effectiveness of the family unit in support of the mother of the FASD adolescent.
34. FAMILYSTRU Refers to the family structure and lays out “who’s who” in relationship to the mother of the adolescent affected by FASD.
35. FAMIVALUES Refers to family values as the set of moral beliefs present within the family.
36. FASCAUSE Refers to the cause of FASD and includes those behaviors that are thought to contribute to or cause FASD, such as drinking alcohol during pregnancy.
37. FASD Refers to Fetal Alcohol Spectrum Disorder and is the umbrella term that describes the full range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.
38. FIGHTING Refers to fighting between adolescents as a physical altercation resulting from loss of temper and likely the inability to problem-solve and understand consequences.
39. FORGIVESEL Refers to the belief that a mother must learn to forgive herself. However, does not provide any insights as to how that might be accomplished. Therefore, this could be considered a “wishful thinking” approach.
40. FOSTERCARE Refers to foster care as a legal process whereby children are removed from the home by child protection workers and placed into the safe custody of a foster parent(s) for an unspecified period of time.
41. FRIENDS Refers to friends as described by the mother, where she offers opinions of the nature of her teenager’s friendships, including opinions on their backgrounds, parents, childrearing, and so on; for example, whether the friendship is helpful, positive, negative, trustworthy, or destructive.

42. FRIENDSUPP Refers to the support that a mother might be able to expect from a circle of friends. This could include support such as taking a child overnight if a parent had to leave town unexpectedly, babysitting a child while a parent took another child to an appointment, etc. This does not speak to any support in the context of sharing feelings or emotions around parenting.
43. FRUSTRATIO Refers to frustrations experienced by a mother when she perceives difficulty in meeting the demands and expectations of others, such as expectations around parenting and running a household.
44. GENERATION Refers to the intergenerational patterns and appearance of FASD and speaks to the roots of historical trauma.
45. GENSELFMUT Refers to generational self-mutilation causing injury or other self-harm; that is, deliberate injury inflicted upon a person by themselves. This is the self-mutilation of the mother, and is manifested again with the adolescent.
46. GRANDMOTHE Refers to the knowledge a mother has about her own grandmother and the presence or absence of a relationship with the grandmother.
47. GUILTSHAME Refers to remorse and shame caused by feeling responsible for something that caused problems, but feeling powerless to change it. For example, drinking alcohol during pregnancy and knowing it is a cause of FASD.
48. HIDDENDISA Refers to hidden disability, as a mother describes how an adolescent looks normal and may not show the physical characteristics of FASD, but has a hidden disability.
49. HOPE Refers to hope for the future.
50. HOPELESS Refers to feelings study participants shared about their personal circumstances, including the guilt some participants expressed because of their drinking behavior. Also includes stories of abuse and describes the participant's view of having minimal or no self-worth.
51. INFANTILL Refers to illness or other difficulties experienced by the adolescent during infancy. (An infant is defined as someone up to one year in age.)
52. LEARNEXP Refers to the process mothers use to change some negative behaviors, through learning from experiences.
53. LEGAL Refers to the legal system, where the problematic behavior of adolescents can result in run-ins with the police or court system.

54. **MARITALSTA** Refers to the marital status of the mother (married, common-law, engaged, etc).
55. **MISINFORMA** Refers to misleading misinformation that given to mothers, particularly pre-pregnancy, by her peer group. This information will often be around issues that relate to the use of alcohol and/or drugs during pregnancy and the belief that a little bit will definitely not harm the baby.
56. **MOTHBEHAVI** Refers to behavior of the mother of the woman who has the adolescent with FASD. This behavior can be past, present, or future.
57. **MOTHERING** Refers to mothering (caring and nurturing, providing for and protecting) and describes the activities that are undertaken as women raise their children. This mothering behavior is individual and often spoken about in the context of what was not learned from their own mothers.
58. **NEIGHBOURH** Refers to the neighborhood in which a mother lives with her family. It describes the context of community, and incorporates issues of well-being and/or safety. Similarly, it encompasses elements of danger or risk.
59. **NEWBEGIN** Refers to new beginnings, a mother starting over, with a desire to change outcomes from past experiences. For example, beginning a new relationship, starting a new family and vowing to do things differently with child rearing to obtain different results. This is often expressed more as a desire or a wish, with no concrete plan.
60. **NORMALIZE** Refers to the way behaviors and ideas attain the status of normality through repetition, ideology, or cultural norms to the point where they are "natural" and have the appearance of being expected or taken for granted within a given context.
61. **OBSESSIVE** Refers to obsessive activities or behaviors where adolescents engage in persistent unwanted actions such as scratching.
62. **OVERSURVEY** Refers to over-surveillance of mothering skills and activities, often by authorities, but can also be initiated by family members, neighbors or others. This may occur as a result of children spending time in foster care or by virtue of stereotypical judgments made by others. Over- surveillance does not feel like as though it has a beginning and an end, but rather is an ongoing activity once it has been first experienced.
63. **PARENRESPO** Refers to parental response that is the beginning of establishing links between what parents observe and find out and what they do about it. For

example, if an adolescent starts drinking and getting into drugs, it is thought to be related to the rationale for their dropping out of school.

64. PARENTREL Refers to the relationship (if any) between parents of FASD adolescents and describes the characteristics of that relationship.
65. PARENTROLE Refers to the beliefs mothers have about the role of parents. It is the belief of mothers about how parents should behave, particularly around child-rearing practices.
66. POTPROBLEM Refers to potential problems and areas of development that might present a problem to mothering. This could include children's questioning a mother's commitment to parenting, questioning whether or not they are loved, and may result in unwanted activity such as running away or rebelling against authority figures.
67. PREJUDICE Refers to a negative attitude toward an entire category of people such as a racial or ethnic minority (in this case Aboriginal people), resulting in bias and stereotyping.
68. PROBTEENBE Refers to problematic teenage behavior or those things teenagers get into that may have less-than-desirable results: drugs, fighting, or other risky and dangerous behaviors.
69. PROFHELP Refers to professional help or assistance from nongovernmental agency workers, such as those found at the Center
70. PROMWELLBE Refers to the activities a mother undertakes and the strategies she uses to promote the well-being of her teenagers. This might include activities like connecting with teachers, school bus drivers and the like. This can also include activities carried out by a mother to ensure the adolescent is safe in relationships.
71. PROVIDING Refers to being able to provide for their children's well-being and safety. Includes aspects of worrying about the future.
72. RECOGFASD Refers to a mother's noticing the first signs and symptoms that something was not quite right with her child; includes when recognition of problems began, what the problems were, and maybe what the parental response was.
73. REGRETS Refers to the regrets and disappointment a mother may have from earlier years, pondering how things might have been different if she had behaved in a different fashion. The incidents sparking her regret could include drinking

behavior during pregnancy, life choices around her own education, or decisions about parenting as her children grew and matured.

74. REHAB Refers to rehabilitation for treatment of alcohol and drug use for adolescents.
75. RELIGION Refers to adherence to formal religious practices.
76. RELPHYSICI Refers to the relationship (positive or negative) that a parent has with their physician when it comes to seeking healthcare for FASD children.
77. REPETITION Refers to the act of repetition of commands and activities until children who are FASD-affected achieve learning. Despite knowing something today, the child will easily forget, so that repetition becomes necessary as part of trying to build knowledge and skills. This is often frustrating for parents and teachers.
78. RESIDENTIA Refers to the residential school experiences of some Aboriginal people.
79. ROLEMODEL Refers to the actions a parent takes to role-model desirable behavior for their adolescents. Includes some aspects of repetition.
80. ROLEPLAY Refers to an activity where mothers undertake to role-play and interact with children to teach life skills, mostly around stranger danger, e.g. being aware of stalkers, teaching children not to take candy from strangers. It is a component of teaching kids to be safe.
81. SETRULES Refers to rules as a set of standard behaviors expected in certain circumstances. For instance, how children are to act while shopping or at school.
82. SAFETY Refers to safety and the activities that parents undertake to ensure the well-being and safety of adolescents.
83. SECRECY Refers to maintaining silence on issues that are not openly discussed in the community or among family members. These issues include alcoholism, abuse, and FASD. Some participants expressed an opinion that secrecy perpetuates problems.
84. SELFCARE Refers to self-care as individual behavior when a person functions on his or her own behalf in health promotion.
85. SELF Worth Refers to feelings of self-worth manifested by behavior. Socialization, self-esteem, and self-image are all interrelated. Self-worth is

something that is experienced within, but often influenced by actions outside of the individual.

86. **SEXUALITY** Refers to discussions a mother has with her adolescents about sexuality and sexual behaviors; can include issues of promiscuity, practicing safe sex, being safe, understanding when “no means no”.
87. **SKILLDEV** Refers to the skills and abilities of mothers in caring, nurturing, and protecting their children. Also includes the initiative a mother undertakes to develop new skills to make improvements.
88. **SOCADVANCE** Refers to social advancement as the process whereby students who fail to meet academic standards for progression in school are advanced to the next grade level so they keep up with their peers. In addition, in circumstances of special learning classes, social advancement can be perceived by outsiders or mistaken for alternative learning methods.
89. **SOCIALNET** Refers to the social network that an adolescent with FASD might have and whether it is supportive or not of their well-being.
90. **SPANKING** Refers to spanking that includes striking the buttocks, usually as a physical punishment, usually with an open hand.
91. **STEALING** Refers to stealing: i.e., one person takes something from another without permission.
92. **STEREOTYPE** Refers to the perception a mother may have that her childrearing is less adequate than it should be, based on her own past experiences.
93. **STRESS** Refers to mothers who are trying to raise their FASD-affected children feeling stressed by events happening around them.
94. **SUCSTRATEG** Refers to the strategies learned by mothers, often through trial and error, and often based on intuitive knowing.
95. **TEACLIFSKL** Refers to strategies undertaken by mothers to teach life skills to their adolescents who have FASD.
96. **TEASING** Refers to teasing as the act of harassing someone playfully or maliciously (especially by ridicule); provoking someone with persistent annoyances.
97. **TESTCAREER** Refers to career testing that may take place to help an adolescent determine career interests.

98. **UNCERTAINT** Refers to the lack of confidence study participants have in their ability to raise their children and be competent mothers. Participants believed this uncertainty stems from within and from external causes.
99. **WORRYFUTUR** Refers the thoughts a parent expresses when describing potential fears, hopes and dreams for their children for the future. (Also relates to how activities today might influence that outcome). Also encompasses the fears, hopes and dreams a parent may have for themselves.

## REFERENCES

- Aday, L.A. (2001). *At risk in America*. (2<sup>nd</sup> ed.). San Francisco: Jossey-Bass.
- Anderson, J.M. (2004). Lessons from a postcolonial-feminist perspective: Suffering and a path to healing. *Nursing Inquiry*, 11(4), 238-246.
- Anderson, J.M. (2002). Toward a postcolonial feminist methodology in nursing research: Exploring the convergence of postcolonial and black feminist scholarship. *Nurse Researcher*, 9 (3), 7-27.
- Arendell, T. (2000). Mothering and motherhood: A decade in review. *Journal of Marriage and the Family*, 62(4), 1192-1207.
- Auditor General of British Columbia (2008). *Management of aboriginal child protection services*. ISBN 978-0-7726-5988-0. Victoria: BC.
- BC Stats. (1998). *Focus on BC Aboriginals: Aboriginal identity*. 1996 Census Fast Facts. Victoria, BC: Ministry of Management Services.
- Boas, F. (1963). *Kwakiutl ethnography*. Chicago: The University of Chicago Press.
- Boyle, J.S. (1994). Styles of ethnography. In J.M. Morse, (Ed.), *Critical issues in qualitative research methods*. Thousand Oaks, CA: Sage.
- Brascoupé, S., & Mann, H. (2001). *A community guide to protecting indigenous knowledge*. Ottawa, Ontario: Department of Indian Affairs and Northern Development.
- Braveheart, M.Y.H. (1999). Oyate Ptayela: Rebuilding the Lakota Nation through addressing historical trauma among Lakota parents. *Journal of Human Behavior in the Social Environment*, 2(1), 109-126.
- British Columbia. (2003). *Fetal alcohol spectrum disorder: A strategic plan for British Columbia*. Victoria, BC: Government of British Columbia & Children's and Women's Hospital.
- British Columbia. (2002). *Provincial Health Officer annual report 2001 – the health and well-being of Aboriginal people in British Columbia*. Victoria, BC: Ministry of Health Planning.
- Browne, A.J., & Fiske, J. (2001). First nations women's encounters with mainstream health care services. *Western Journal of Nursing Research*, 23(2), 126-147.
- Browne, A.J., & Smye, V. (2002). A postcolonial analysis of healthcare discourses addressing aboriginal women. *Nurse Researcher*, 9(3), 28-41.

- Browne, A.J., Smye, V. L., & Varcoe, C. (2005). The relevance of postcolonial theoretical perspectives to research in aboriginal health. *Canadian Journal of Nursing Research*, 37(4), 16-37.
- Caley, L.M. (2006). Identifying school nurses' knowledge of fetal alcohol syndrome, *Journal of FAS International*, 4. Retrieved November 11, 2007, from <http://www.motherisk.org/JFAS/econtent>.
- Caley, L.M., Kramer, C., & Robinson, L.K. (2005). Fetal alcohol spectrum disorder. *The Journal of School Nursing*, 21(3), 139-146.
- Canada. (1996). *Royal commission on Aboriginal People*. Ottawa: The Commission. Volume 2, Section 3.
- Canadian Institute of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (1998; amendments: 2000, 2002, 2005). *Tri-Council Policy Statement for Ethical Research Involving Humans*. Ottawa, ON: Author.
- Canadian Institute of Health Research. (2005). *CIHR guidelines for health research involving Aboriginal peoples*. Ottawa, ON: Author.
- Chamberlain, J.E. (2000). *From hand to mouth: the postcolonial politics of oral and written traditions*. In M. Battiste (Eds.). *Reclaiming Indigenous Voice and Vision*, (pp 125-141). Vancouver, BC: UBC Press.
- Chang, G., Goetz, M.A., Wilkins-Haug, L., & Berman, S. (2000). A brief intervention for prenatal alcohol use: An in-depth look. *Journal of Substance Abuse Treatment*, 18, 365-369.
- Chudley, A.E., Conry, J., Cook, J.L., Looock, C., Rosales, T. & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal*, 172, S1-S21.
- Claes, R. & Clifton, D. (1998). Needs and expectations for redress of victims of abuse at residential schools. Ottawa: Law Commission of Canada.
- Clark, E., Lutke, J., Minnes, P., & Ouellette-Kuntz, H. (2004). Secondary disabilities among adults with Fetal Alcohol Spectrum Disorder in British Columbia. *Journal of Fetal Alcohol Syndrome International*, 2(13), 1-12.
- Clarke, H.F. (1997). Research in nursing and cultural diversity: Working with First Nations people. *Canadian Journal of Nursing Research*, 29(2), 11-25.

- Clifford, J., & Marcus, G.E. (Eds.). (1986). *Writing culture: The poetics and politics of ethnography*. Berkeley, CA: University of California Press, Ltd.
- Coles, C.D. (2003). Individuals affected by Fetal Alcohol Spectrum Disorder (FASD) and their families: Prevention, intervention and support. In R.E. Tremblay, R.D. Peters, M. Boivin, & R.G. Barr (Eds.), *Encyclopedia on Early Childhood Development*, pp. 32-38. Montreal, Quebec: Center of Excellence for Early Childhood Development. Retrieved February 1, 2007, from <http://www.child-encyclopedia.com/pages/PDF/FASD.pdf>.
- Crockett, L.J. (1997). Cultural, historical, and subcultural context of adolescence: Implications for health and development. In J. Schulenburg, J. Maggs, & K. Hurrelmann (Eds.), *Health risks and developmental transitions during adolescence* (pp. 23-53). Cambridge, UK: Cambridge University Press.
- Denzin, N.K. (1997). *Interpretive ethnography: Ethnographic practices for the 21<sup>st</sup> century*. Thousand Oaks, CA: Sage.
- Denzin, N.K., & Lincoln, Y.S. (2005). Introduction: The discipline and practice of qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), *Qualitative Research* (3<sup>rd</sup> ed., pp. 1-32). Thousand Oaks, CA: Sage Publications.
- Denzin, N.K., & Lincoln, Y.S. (2005). *The sage handbook of qualitative research* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- DeSantis, L., & Ugarriza, D.N. (2000). The concept of theme as used in qualitative nursing research. *Western Journal of Nursing Research*, 22(3), 351-372.
- Dickson, G., & Green, K.L. (2001). Participatory action research: Lessons learned with Aboriginal grandmothers. *Health Care for Women International*, 22, 471-482.
- Dodgson, J.E. & Struthers, R. (2005). Indigenous women's voices: Marginalization and health. *Journal of Transcultural Nursing*, 16(4), 339-346.
- Dorazio-Migliore, M., Migliore, S., & Anderson, J. (2005). Crafting a praxis-oriented culture concept in the health disciplines: Conundrums and possibilities. *Health*, 9, 339-60.
- Etienne, M., & Leacock, E. (1980). *Women and colonization: Anthropological perspectives*. New York, NY: Praeger.
- Eustace, L.W., Kang, D.H., & Coombs, D. (2003). Fetal alcohol syndrome: A growing concern for health care professionals. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 32(2), 215-221.

- Ezenwa, M.O., Ameringer, S., Ward, S. E., & Serlin, R. C. (2006). Racial and ethnic disparities in pain management in the United States. *Journal of Nursing Scholarship, 38*(3), 225-233.
- Flaskerud, J.H., & Winslow, B.J. (1998). Conceptualizing vulnerable populations' health-related research. *Nursing Research, 47*(2), 69-78.
- Flaskerud, J.H., Lesser, J., Dixon, E., Anderson, N., Conde, F., Kim, S., et al. (2002). Health disparities among vulnerable populations. *Nursing Research, 51*(2), 74-84.
- Floyd, R.L., O'Connor, B.J., & Sokol, R. (2006). Reducing adverse outcomes from prenatal alcohol exposure: A clinical plan of action. *Alcoholism: Clinical and Experimental Research, 30*(8), 1271-1275.
- Gardner, J. (2000). Living with a child with fetal alcohol syndrome. *The American Journal of Maternal/Child Nursing, 25*(5), 252-257.
- Granitsas, J. (2004). Experiences of adoptive parents of children with fetal alcohol syndrome. *Clinical Excellence for Nurse Practitioners, 8*(1), 22-28.
- Greenwood, M. (2005). Children as citizens of First Nations: Linking indigenous health to early childhood development. *Pediatric Child Health, 10*(9), 553-555.
- Hall, J. M. (1999). Marginalization revisited: Critical, postmodern, and liberation perspectives. *Advances in Nursing Science, 22*(2), 88-102.
- Hall, J. M., Stevens, P.E., & Meleis, A.I. (1994). Marginalization: A guiding concept for valuing diversity in nursing knowledge development. *Advances in Nursing Science, 16*(4), 23-41.
- Hammersley, M. & Atkinson, P. (2005). *Ethnography: Principles in practice* (2<sup>nd</sup> ed.). New York: Routledge.
- Hartrick, G.A. (1997). Women who are mothers: The experience of defining self. *Health Care for Women International, 18*(3), 263-278.
- Health Canada. (2003). *A statistical profile on the health of First Nations in Canada*. Ottawa: Health Canada, First Nations and Inuit Branch.
- Hopkinson, J., Stephenson, P.H., & Turner, N.J. (1995). *Changing traditional diet and nutrition in Aboriginal peoples of coastal British Columbia*. In Stephenson, Elliott, Foster & Harris, A Persistent Spirit: Towards understanding Aboriginal health in British Columbia, (pp 129-1651). Victoria: Western Geographical Press.
- Hunter, L.M., Logan, J., Goulet, J.G., & Barton, S. (2006). Aboriginal healing: Regaining balance and culture. *Journal of Transcultural Nursing, 17*(1), 13-22.

- Johnston, M.S. (2005). Independent Study: Adolescent health. College of Public Health, University of Arizona.
- Johnston, M.S. (2006). Independent study: Concepts of vulnerability, mothering and marginalization. College of Nursing, University of Arizona.
- Kirkham, S.R., & Anderson, J.M. (2002). Postcolonial scholarship: From epistemology to method. *Advances in Nursing Science*, 24(1), 1-17.
- Kirmayer, L., Brass, G.M., & Tait, C. L. (2000). The mental health of Aboriginal peoples: Transformations of identity and community. *Canadian Journal of Psychiatry*, 45(7), 607-616.
- Kleinman A., (1980). *Patients and healers in the context of culture*. Berkeley: University of California Press.
- Krane, J., & Davies, L. (2007). Mothering under difficult circumstances: Challenges to working with battered women. *Affilia: Journal of Women and Social Work*, 22(1), 23-38.
- Krulwitch, C.J. (2005). Alcohol consumption during pregnancy. *Annual Review of Nursing Research*, 23, 101-134.
- Laenui, P. (2000). Processes of decolonization. In Marie Battiste (Ed.), *Reclaiming Indigenous Voice and Vision* (p. 16). Vancouver: UBC Press.
- Leight, S.B. (2003). The application of a vulnerable populations conceptual model to rural health. *Public Health Nursing*, 20(6), 440-448.
- Leininger, M. (1997). Overview of the theory of culture care with the ethnonursing research method. *Journal of Transcultural Nursing*, 8(2), 32-52.
- Leslie, M., & Roberts, G. (2001). *Enhancing fetal alcohol syndrome (FAS)-related intervention at the prenatal and early childhood stages in Canada*. Ottawa: Canadian Center on Substance Abuse.
- Loppie, C. (2007). Learning from grandmothers: Incorporating indigenous principles into qualitative research. *Qualitative Health Research*, 17(2), 276-284.
- Masotti, P., Szala-Meneok, K., Selby, P., Ranford, J., & Van Koughnett, A., (2003). Urban FASD interventions: Bridging the cultural gap between aboriginal women and primary care physicians. *Journal of FAS International*, 17. Retrieved November 11, 2007, from [www.motherisk.org/JFAS/econtent](http://www.motherisk.org/JFAS/econtent).
- May, K.M. (1997). Searching for normalcy: Mothers' caregiving for low birth weight infants. *Pediatric Nursing*, 23(1), 17-20.

- May, P.A., & Gossage, J.P. (2001). Estimating the prevalence of fetal alcohol syndrome: A summary. *Alcohol Research and Health*, 25(3), 157-167.
- Meleis, A.I., & Im, E.O. (1999). Transcending marginalization in knowledge development. *Nursing Inquiry*, 6(2), 94-102.
- Meleski, D.D. (2002). Families with chronically ill children. *American Journal of Nursing*, 102(5), 47-54.
- Mohammed, S.A. (2006). Moving beyond the exotic: Applying postcolonial theory in health research. *Advances in Nursing Science*, 29(2), 98-109.
- Morrisette, P.J. (1994). The holocaust of First Nation people: residual effects on parenting and treatment implications. *Contemporary Family Therapy*, 16(5), 381-392.
- Morse, J.M. (Ed.) (1991). *Qualitative nursing research: A contemporary dialogue*. Thousand Oaks, CA: Sage.
- Morse, J.M. (Ed.) (1994). *Critical issues in qualitative research methods*. Thousand Oaks, CA: Sage.
- Muckle, R.J. (2006). *The first nations of British Columbia*. Vancouver, BC: UBC Press.
- Munhall, P.L. (2001). *Nursing research: A qualitative approach* (3rd ed.). Mississauga, ON: Jones & Bartlett.
- Murphy-Brennan, M.G. & Oei, T.P. (1999). Is there evidence to show that fetal alcohol syndrome can be prevented? *Journal of Drug Education*, 29(1), 5-24.
- Nelms, T.P. (2000). The practices of mothering in caregiving an adult son with AIDS. *Advances in Nursing Science*, 22(3), 46-57.
- Nelms, T.P. (2005). Burden: The phenomenon of mothering with HIV. *Journal of the Association of Nurses in AIDS Care*, 16(4), 3-13.
- Nelson, A.N. (2002). A metasynthesis: Mothering other-than-normal children. *Qualitative Health Research*, 12(4), 515-530.
- Oregon State University (n.d.). Definitions of Anthropological Terms. Retrieved August 4, 2008 from <http://oregonstate.edu/instruct/anth370/gloss.html>.
- Olson, H.C., Streissguth, A.P., Sampson, P.D., Barr, H.M., Bookstein, F.L. & Thiede, K., (1997). Association of prenatal alcohol exposure with behavioral and learning problems in early adolescence. *Journal of the American Academy of Child & Adolescent Psychiatry*, 36(9), 1187 – 1194.

- Patton, M.Q. (2002). *Qualitative evaluation and research methods* (3<sup>rd</sup> ed.). Newbury Park, CA: Sage Publications.
- Public Health Agency of Canada. (2003). *Fetal alcohol spectrum disorder (FASD): A framework for action*. Ottawa, ON: Author.
- Prasad, P. (2005). *Crafting qualitative research: Working in the postpositivist traditions*. Armonk, NY: M. E. Sharpe.
- Premji, S., Benzies, K., Serrett, K., & Hayden, K.A. (2007). Research-based interventions for children and youth with a Fetal Alcohol Spectrum Disorder: revealing the gap. *Child: Care, Health and Development*, 33(4), 389-397.
- Reed, P.G. (1995). A treatise on nursing knowledge development for the 21<sup>st</sup> century: Beyond postmodernism. *Advances in Nursing Science*, 17(3), 70-84.
- Salmon, A. (2007). Walking the talk: How participatory interview methods can democratize research. *Qualitative Health Research*, 17(9), 982-993.
- Sawyer, L.M. (1999). Engaged mothering: The transition to motherhood for a group of African American women. *Journal of Transcultural Nursing*, 10(1), 14-21.
- Shambley-Ebron, D.Z., & Boyle, J.S. (2006). Self-care and mothering in African American women with HIV/AIDS. *Journal of Transcultural Nursing* (in press).
- Shi, L. (2001). The convergence of vulnerable characteristics and health insurance in the U.S. *Social Science & Medicine*, 53(4), 519-529.
- Smith, D., Varcoe, C., & Edwards, N. (2005). Turning around the intergenerational impact of residential schools on Aboriginal people: Implications for health policy and practice.
- Smith, D., Edwards, N., Varcoe, C., Marten, P.J., & Davies, B. (2006). Bringing safety and responsiveness into the forefront of care for pregnant and parenting Aboriginal people. *Advances in Nursing Science*, 29(2), E27-E44.
- Smye, V., & Browne, A.J. (2002). Cultural safety and the analysis of health policy affecting aboriginal people. *Nurse Researcher*, 9(3), 42-56.
- Spiers, J. (2000). New perspectives on vulnerability using emic and etic approaches. *Journal of Advanced Nursing*, 31(3), 715-721.
- Spradley, J.P. (1980). *Participant observation*. New York: Holt, Rinehart & Winston.
- Stade, B., Ungar, W.J., Stevens, B., Beyanne, J., & Koren, G. (2006). The burden of prenatal exposure to alcohol: Measurement of cost. *Journal of FAS International*, 4,

- Retrieved November 11, 2007, from <http://www.motherisk.org/women/index.jsp>.
- Statistics Canada (2008). Aboriginal peoples in Canada in 2006: Inuit, Metis, and First Nations, 2006 census. Catalogue no. 97-558-XIE, Ministry of Industry: Ottawa, Canada.
- Steckley, J.L., & Cummins, B. (2001). *Full circle: Canada's first nations*. Toronto: Prentice Hall.
- Streissguth, A.P., Brookstein, F.L., Barr, H.M., Sampson, P.D., O'Malley K., & Young, J.K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics*, 25(4), 228-238.
- Stout, M.D., Kipling, G.D., & Stout, R. (2001). *Aboriginal women's health research synthesis project final report*. Centres of Excellence for Women's Health. Retrieved November 11, 2007, from [www.cewh-cesf.ca](http://www.cewh-cesf.ca).
- Tait, C.L. (2003). *Fetal alcohol syndrome among aboriginal people in Canada: Review and analysis of intergenerational links to residential schools*. Ottawa, ON: Aboriginal Healing Foundation.
- Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, CA: Sage.
- Vasas, E.B. (2005). Examining the margins: A concept analysis of marginalization. *Advances in Nursing Science*, 28(3), 194-202.
- Walker, D.S., Darling-Fisher, C.S., Sherman, A., Wybrecht, B., & Kyndely, K. (2005). Fetal alcohol spectrum disorders prevention: An exploratory study of women's use of, attitudes toward, and knowledge of alcohol. *Journal of the American Academy of Nurse Practitioners*, 17(5), 187-193.
- Wilson, H.S. (1987). *Introducing research in nursing*. Menlo Park, CA: Addison Wesley.
- Wilson, K. & Rosenberg, M.W. (2002). Exploring the determinants of health for First Nations peoples in Canada: Can existing frameworks accommodate traditional activities? *Social Science & Medicine*, 55, 2017-2031.
- Wuest, J. (2000). Repatterning care: Women's proactive management of family caregiving demands. *Health Care for Women International*, 21, 393-411.
- Wuest, J. (2001). Precarious ordering: toward a formal theory of women's caring. *Health Care for Women International*, 22, 167-193.